

2013 IACC Strategic Plan Update - Question 6 Draft

“What does the future hold, particularly for adults?” - Volunteer drafters – Paul Shattuck & Anne Roux

Introduction

The aspirational goal for question 6 is that “all people with ASD will have the opportunity to lead self-determined lives in the community of their choice through school, work, community participation, meaningful relationships, and access to necessary and individualized services and supports.”¹ Positive, early childhood experiences can help increase the likelihood of better outcomes in adulthood. However, gains that were hard-won in childhood are at risk of losing traction during the period of new challenges associated with the transition to adulthood. The nature and availability of supportive services change dramatically as youth age out of eligibility for special education^{2,3}. Families and adults on the autism spectrum need to navigate an entirely new terrain of services. The social-ecological context of development, which encompasses how individuals interact with the communities and systems around them, also changes radically upon leaving secondary school.

Adulthood brings new challenges related to the attainment and performance of social roles, shifts in family roles and relationships as parents age, and coping with the accumulation of a lifetime of financial and psychological stressors. Co-occurring mental health conditions also present an area of great challenge for many adults on the autism spectrum^{4,5}. For some, adulthood may also introduce new abilities, declining impairment severity, discovery of new ways to participate and contribute in communities, and new opportunities for achieving health and well-being. For others, particularly those with significant intellectual impairment, severe behavioral and communication challenges persist into adulthood often with additional complications like epilepsy.⁶ As in other stages of life, there must be a wide spectrum of approaches available to adults to reflect the wide diversity of challenges found in home and community contexts and to support improved outcomes for people across the entire autism spectrum.

The 2009 IACC Strategic Plan emphasized the need for research on individual-level interventions to improve outcomes for adults with ASD. This remains an important area for research, and some progress has been made. However, there have been important changes in thinking over the past few years about how best to support the success of adults on the autism spectrum. There have been calls for research performed in real world settings that focuses on outcomes related to quality of life, and interventions that target the social environment and not just the individual. There also has been a growing recognition of the need for building an evidence base in partnership with promising innovations being developed in community agencies and businesses rather than in academic research settings.

Progress Toward Strategic Plan Objectives

The 2009 Strategic Plan, including revisions in 2010 and 2011, called for eight objectives within Question 6 that the Committee viewed as gap areas. Under this question there are four short-term objectives and four long-term objectives that highlight the need for research about transitioning youth, adult diagnosis, and adult interventions. The total recommended budget was \$53.8M across all eight objectives for this question.

Of the eight objectives under Question 6, three objectives address the impact on quality of life for adults utilizing various services, including aspects of the service delivery system such as educational and health services, specialized training for direct care providers, and interventions and services received during childhood. The recommended number of projects was fulfilled for these objectives and the recommended budgets were partially met. Two objectives regarding the evaluation of existing disability programs for their effectiveness in meeting the needs of transitioning youth and adults and the development of community-based interventions partially met the recommended budget levels and had active projects underway to accomplish the objective. Another two objectives, with projects to develop a method to service undiagnosed or misdiagnosed adults and conduct implementation research of services for adults, were far below the recommended budget and number of projects. Finally, one objective to conduct comparative effectiveness research to examine community-based interventions, services, and supports for adults has had only 2 projects in the past 5 years, and in the most recent two years did not have any funding or projects. The Committee raised the question of whether there are yet enough empirically solid adult interventions to make it possible to do comparative effectiveness. The Committee noted that an overarching issue in the current organization of the Strategic Plan objectives was that grouping of several distinct topics into each objective made it challenging to assess progress, and that future iterations might potentially benefit from further division into discrete topics like community housing, life transitions, employment, and services/supports for older adults.

There have been several notable advances in research in this area over the past five years. A number of studies have begun describing young adult outcomes⁷, service needs and access⁸, and service program models³. Systematic reviews have examined extant research on services and interventions⁹. Examples of community-based participatory research have also emerged, such as adaptation of surveys to allow for more active participation of adults with ASD in reporting on health care experiences.¹⁰

Despite these advances, the rate of production of scientific knowledge about the experience of autism in adulthood remains very low. The generalizability of findings from many of these studies is limited by small sample sizes, lack of information about the socioeconomic and ethnic-racial characteristics of study subjects, and problems with research design and methodology.^{9,11,12} The quality of studies conducted through 2011 regarding vocational programming,¹³ pharmacology,¹⁴ social skills interventions,¹¹ and psychosocial interventions,¹⁵ remains in an emergent state.

The growing number of adults with autism due to increased awareness and diagnosis as well as the transition of children and adolescents into adulthood has reinforced the sense of urgency around research that can guide national policy recommendations for supports and models of employment, community living, and continued education. Much growth in ASD program innovations is occurring outside of the traditional academic realm,¹⁶ and this body of practice-based knowledge should be incorporated along with more traditional research efforts as an important driver of future investigations.

Progress Toward the Aspirational Goal

Longitudinal data on life course pathways and outcomes; evaluation of service innovations in partnership with community agencies; understanding the positive contributions people on the autism spectrum can make to society; financial impacts on families; and improved ability to measure outcomes at the population level are all areas of research where work is required to continue progress toward the aspirational goal. The majority of a typical lifespan is spent in adulthood. However, this is the stage of

This document is for discussion purposes only and does not reflect the decisions of the IACC

life that is still the least understood in ASD. In recent years, awareness of the needs of adults on the autism spectrum has increased to some extent, and more data on services gaps and outcomes have become available. More research focus should be directed, however, toward understanding how ASD unfolds across the lifespan by conducting longitudinal studies that extend into adulthood. Longitudinal studies have paid dividends in basic science knowledge for other developmental disorders like Fragile X syndrome and Down syndrome and have the potential to yield similar benefits for autism. In addition, more detailed studies of the needs of adults on the spectrum are required to better understand the nature of these needs and to determine which services will best support individuals across the lifespan with the greatest return on investment for society.

Several seminal studies have been published that provide basic epidemiological description of the prevalence and correlates of various outcomes of the transition into early adulthood, along with risks and protective factors. Through these, we are learning more about the high prevalence of co-occurring health and psychiatric disabilities in adults,^{5,17} and the lack of physicians trained to specifically care for adults with an ASD.⁸ Exploration of state developmental disability services data found the rate of self-injurious and destructive behaviors was twice as high in middle-aged adults with ASD and intellectual impairment compared to those with only intellectual disability, signaling the urgency of treatment and policy to address severe behavior problems.¹⁸ A follow-up to a 1980s statewide autism prevalence study in Utah to investigate mortality among individuals with autism spectrum disorders (ASD) found that elevated mortality risk associated with ASD appeared to be related to the presence of co-occurring medical conditions and intellectual disability rather than ASD itself, suggesting the importance of access throughout life to coordinated medical care for this high risk sub-population¹⁹.

Cohort studies have revealed a high rate of complete disconnection of young adults from any work or education during the first several years after high school – greater than 50% during the first two years after exiting high school.²⁰ The rate of disconnection was higher compared to youth with other disabilities even after adjusting for correlates. The latest research data indicate that outcomes are particularly poor for young adults from socially disadvantaged families and for those who have greater levels of impairment.^{20–22}

Employment has been a particular area of research focus. The rate of ever having a paid job in the first eight years after high school is about 50% - much lower than among youth with other types of disability.²² Types of jobs are limited in range, and average rate of pay does not support independent living. However, even the most severely impaired do find work. Those who engage in work and have greater vocational independence are more likely to have fewer maladaptive behaviors and improved activities of daily living skills five years later.²³ Vocational outcomes are better for individuals who were not in sheltered work settings prior to participating in supported employment.²⁴ Suggested vocational indexes will allow us to better track the types of jobs that people with an ASD hold.²⁵

More is also known on the social and mental health issues faced by adults on the autism spectrum. The experience of social isolation is more pronounced in young adults with ASD than those with other types of disabilities.^{26,27} Increased levels of loneliness appear to have a negative effect on mental well-being.²⁸ In regard to residential status, young adults on the autism spectrum were more likely to have lived at home, to never have lived elsewhere on their own, and to have required supervision compared to adults with other disability types.²¹

In the arenas of intervention and services research, which are more thoroughly addressed in Questions 4 and 5 of the *2013 IACC Strategic Plan Update*, much research has focused on psychosocial interventions with noted improvement with use of methods like applied behavior analysis and social cognition training.^{15,29} Development and adaptation of social skills interventions for people with severe intellectual disability is a continuing need.¹¹

What Gaps Have Emerged in the Past Two Years?

Several gaps – and opportunities – have become clear in the past two years. Using the World Health Organization’s biopsychosocial framework for understanding disability, several areas for further ASD adults services research efforts can be defined.³⁰ Overall, currently there is a limited knowledge base regarding the needs of adults on the autism spectrum as they relate to severity of impairment at all levels. The Committee noted particular urgency for increasing research attention on those at the more severely-affected end of the autism spectrum, and for the development of services approaches and service delivery models that will improve quality of life for adults with severe disability. These include approaches to address issues of employment, housing, health, social life, recreation and other issues that influence how a person with ASD integrates into adult society.

Research gaps within the medical/health arena (the “biological” level of analysis in the WHO framework) include a limited understanding of the course of co-occurring health conditions through adulthood, little study of neurological development into later stages of life, and limited studies of the long-term outcomes associated with use of various types of interventions. Programs of research addressing questions about the maturation and aging process in disability conditions such as fragile X syndrome and Down syndrome may represent opportunities for asking similar scientific question about the process of aging in ASD.

Gaps in the mental and behavioral health arenas (the “psychological and behavioral” level of analysis) include continued difficulty describing the heterogeneity of the autism spectrum in ways that are informative for treatment planning and policy making. Developing strategies for intervening in complex cases with both severe developmental and mental health challenges remains an area where the knowledge base needs to be expanded. With increasing awareness of co-occurring conditions that affect people with ASD and recent data suggesting that co-occurring conditions such as epilepsy can be a cause of elevated mortality, it is important to understand the pattern of emergence of these conditions in order to anticipate and work toward prevention of the secondary effects of these added challenges. There is a strong need for more studies that characterize the heterogeneity of development and outcomes in ASD in middle and later stages of adulthood.

There also continue to be major gaps in knowledge at the “social and population health” levels of analysis. There is limited knowledge of the ways people on the autism spectrum contribute to communities and society. Strategies being examined in health and mental health services research, such as peer mentoring and navigation, may represent opportunities for adaptation. A growing autism self-advocacy movement increases opportunities for collaborative research partnerships. With respect to adults who remain dependent on their families for care, very little is known about the needs of these individuals and what approaches will provide the greatest help to families planning for the transition when parents are no longer able to care for their dependent adult child.

Identification and surveillance of autism in adults, and development of screening and diagnostic tools for use in adult populations remain important needs. There is an ongoing study to adapt the ADOS modules 1 and 2 for use in adults, but multiple projects testing different approaches would be optimal. It is important that these tools be efficient so they can be readily employed in large, community based settings. There is also a need for screening and diagnostic tools to be adaptable to different settings and cultural contexts, including international settings. A study conducted in 2012 illuminated the need for adaptation of diagnostic tools for Latino populations.^{31a} Along with the development of screening and diagnostic tools, attention needs to be focused on ensuring that there is an available network of services available for those who receive a diagnosis and that diagnosis does not inadvertently result in a loss of services and supports.

Outcome measures are needed for quality of life in adults with ASD. It is important to understand what outcomes are meaningful to adults with ASD and their families. Person-centered outcomes strategies and measures should be developed. Achieving validity and reliability of such measures across the lifespan and full range of the autism spectrum remains a big challenge.

ASD affects multiple domains and many adults are simultaneously involved in different types of services and interventions. Research is needed to better understand the challenges entailed in navigating the service system and how family finances are impacted over the lifespan. Most research remains focused on one intervention at a time, not taking into account the complexity of systems of care in real-world settings. There is little understanding of how nonprofit and government service providers and systems are adapting to the growing number of adults on the spectrum. Advances in conceptualizing and measuring social return on investment and patient preferences could be adapted to build a stronger basis to study the population-level benefits of societal investment in adult services.

As mentioned under Question 5, NIH has recently launched a series of three initiatives to support research on services implementation across the lifespan, with the goals of addressing the challenges of improving outcomes for people with ASD across the lifespan. Of relevance to Question 6, one of the initiatives focuses on models to assist adolescents ASD to transition to adult supports and services while preventing lapses in services and supports, enhances functioning across settings, and maintaining or improving ASD symptoms, general health, safety, and quality of life^{31b}. Another addresses development of adult ASD service strategies that address areas of employment and training, social relationships, physical and mental health, and independent functioning including community housing and safety, alone or in combination, with the ultimate goal of improving behavioral, functional and health outcomes^{31c}. Awards are expected in 2014.

There are some exciting developments in other sectors and fields that may hold promise for adapting and examining in ASD research. Much growth in ASD program innovation is occurring outside of the traditional academic realm, highlighting a need for funding community-based research and examination of promising practices. There is growing interest in social networks and health outcomes, especially because of the concerns of many parents about what will happen to their child after they are gone. There have been significant research advances in other fields for investigating complex systems, social networks, and factors related to successful knowledge translation and program implementation. Much could be gained by fostering transdisciplinary research to leverage advances in other fields. The field of continuous quality improvement is receiving a lot of attention in health services research. The corresponding potential for building practice-based evidence remains largely untapped in ASD.

A number of states now have dedicated autism agencies or bureaus and state-level advisory commissions. There is a growing interest among these stakeholders in improving systems for collecting data about services and outcomes. Combined with technological advances in data aggregation and mining, there is an opportunity to pilot test methods for community-, state-, and national level population indicators of unmet needs, services access, and outcomes.

Summary and Recommendations

Since the release of the IACC Strategic Plan in 2009, the adult services research field has made some important advances, including gathering of new data on the services available across the states, information about how adults are interacting with the service system, and data on the service needs of adults on the autism spectrum. Data have shown tremendous gaps in the service system that need to be addressed by innovative services approaches that are cost-effective and can be adapted to use in a broad variety of settings. While recent systematic reviews about adult interventions and services have noted the need to increase the evidence base to support access to services¹⁵, the research field is beginning to yield promising randomized controlled trial results^{32,33} that have already influenced service provision in many states and service providers and businesses have been rolling out innovative promising practices. Moving forward, partnerships between academic researchers and state, local and private service providers will play an important role in building a body of practice-based evidence that can support effective service provision strategies. This work may also be helpful in filling the gap in effective methods for measuring population level outcomes that can indicate whether efforts implemented at agency and community levels are translating to improvements in the well-being of the population. While adult services remain a major frontier in autism research, increased investment in this area holds great potential to strengthen the service system with approaches and practices grounded in a strong evidence base, with the ultimate goal of providing all people with ASD with access to the services and supports they need to maximize their health, fully participate in community life, and live self-determined lives.

References

1. Interagency Autism Coordinating Committee. *2011 IACC strategic plan for autism spectrum disorder research*. (U.S. Department of Health and Human Services, 2011).
2. Shattuck, P. T., Wagner, M., Narendorf, S., Sterzing, P. & Hensley, M. Post-High School Service Use Among Young Adults With an Autism Spectrum Disorder. *Arch. Pediatr. Adolesc. Med.* **165**, (2011).
3. Smith, L. E., Greenberg, J. S. & Mailick, M. R. Adults with Autism: Outcomes, Family Effects, and the Multi-Family Group Psychoeducation Model. *Curr. Psychiatry Rep.* **14**, 732–738 (2012).
4. Tsakanikos, E., Sturmey, P., Costello, H., Holt, G. & Bouras, N. Referral trends in mental health services for adults with intellectual disability and autism spectrum disorders. *Autism Int. J. Res. Pract.* **11**, 9–17 (2007).
5. Joshi, G. *et al.* Psychiatric Comorbidity and Functioning in a Clinically Referred Population of Adults with Autism Spectrum Disorders: A Comparative Study. *J. Autism Dev. Disord.* **43**, 1314–1325 (2012).
6. Howlin, P., Savage, S., Moss, P., Tempier, A. & Rutter, M. Cognitive and language skills in adults with autism: a 40-year follow-up. *J. Child Psychol. Psychiatry* **55**, 49–58 (2014).
7. Anderson, D. K., Liang, J. W. & Lord, C. Predicting young adult outcome among more and less cognitively able individuals with autism spectrum disorders. *J. Child Psychol. Psychiatry* (2013). doi:10.1111/jcpp.12178

8. Bruder, M. B., Kerins, G., Mazzarella, C., Sims, J. & Stein, N. Brief Report: The Medical Care of Adults with Autism Spectrum Disorders: Identifying the Needs. *J. Autism Dev. Disord.* **42**, 2498–2504 (2012).
9. Shattuck, P. T. *et al.* Services for adults with an autism spectrum disorder. *Can. J. Psychiatry* **57**, 284–291 (2012).
10. Nicolaidis, C. *et al.* Comparison of Healthcare Experiences in Autistic and Non-Autistic Adults: A Cross-Sectional Online Survey Facilitated by an Academic-Community Partnership. *J. Gen. Intern. Med.* **28**, 761–769 (2012).
11. Walton, K. M. & Ingersoll, B. R. Improving Social Skills in Adolescents and Adults with Autism and Severe to Profound Intellectual Disability: A Review of the Literature. *J. Autism Dev. Disord.* **43**, 594–615 (2012).
12. Warren, Z., Taylor, J. L., McPheeters, M. L., Worley, K. & Veenstra-Vander Weele, J. *Future Research Needs: Interventions for Adolescents and Young Adults With Autism Spectrum Disorders: Identification of Future Research Needs From Comparative Effectiveness Review No. 65.* (Agency for Healthcare Research and Quality (US), 2012). at <<http://www.ncbi.nlm.nih.gov/books/NBK121979/>>
13. Taylor, J. L. *et al.* A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics* **130**, 531–538 (2012).
14. Dove, D. *et al.* Medications for Adolescents and Young Adults With Autism Spectrum Disorders: A Systematic Review. *PEDIATRICS* **130**, 717–726 (2012).
15. Bishop-Fitzpatrick, L., Minshew, N. J. & Eack, S. M. A systematic review of psychosocial interventions for adults with autism spectrum disorders. *J. Autism Dev. Disord.* 1–8 doi:10.1007/s10803-012-1615-8
16. Autism Speaks. *Employment Think Tank Report.* (2012). at <http://www.autismspeaks.org/sites/default/files/as_think_tank_exec_summary_web1.pdf>
17. Kohane, I. S. *et al.* The Co-Morbidity Burden of Children and Young Adults with Autism Spectrum Disorders. *PLoS ONE* **7**, e33224 (2012).
18. Kats, D., Payne, L., Parlier, M. & Piven, J. Prevalence of selected clinical problems in older adults with autism and intellectual disability. *J. Neurodev. Disord.* **5**, 27 (2013).
19. Bilder, D. *et al.* 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**, 1196–1204 (2012).
20. Shattuck, P. T. *et al.* Postsecondary education and employment among youth with an autism spectrum disorder. *Pediatrics* **129**, 1042–1049 (2012).
21. Anderson, K. A., Shattuck, P. T., Cooper, B. P., Roux, A. M. & Wagner, M. Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder. *Autism* (2013). doi:10.1177/1362361313481860
22. Roux, A. M. *et al.* Postsecondary employment experiences among young adults with an autism spectrum disorder. *J. Am. Acad. Child Adolesc. Psychiatry* **52**, 931–939 (2013).
23. Taylor, J. L., Smith, L. E. & Mailick, M. R. Engagement in Vocational Activities Promotes Behavioral Development for Adults with Autism Spectrum Disorders. *J. Autism Dev. Disord.* (2013). doi:10.1007/s10803-013-2010-9
24. Cimera, R. E. & Burgess, S. Do adults with autism benefit monetarily from working in their communities? *J. Vocat. Rehabil.* **34**, 173–180 (2011).
25. Taylor, J. L. & Seltzer, M. M. Developing a vocational index for adults with Autism Spectrum Disorders. *J. Autism Dev. Disord.* **42**, 2669–2679 (2012).
26. Orsmond, G. I., Shattuck, P. T., Cooper, B. P., Sterzing, P. R. & Anderson, K. A. Social Participation Among Young Adults with an Autism Spectrum Disorder. *J. Autism Dev. Disord.* **43**, 2710–2719 (2013).

27. Shattuck, P. T., Orsmond, G. I., Wagner, M. & Cooper, B. P. Participation in social activities among adolescents with an autism spectrum disorder. *PLoS One* **6**, e27176 (2011).
28. Mazurek, M. O. Loneliness, friendship, and well-being in adults with autism spectrum disorders. *Autism Int. J. Res. Pract.* (2013). doi:10.1177/1362361312474121
29. Kandalaf, M. R., Didehbani, N., Krawczyk, D. C., Allen, T. T. & Chapman, S. B. Virtual Reality Social Cognition Training for Young Adults with High-Functioning Autism. *J. Autism Dev. Disord.* **43**, 34–44 (2012).
30. World Health Organization. *International classification of functioning, disability and health (ICF)*. (2001).
- 31a. Magaña, S. & Smith, L. E. The Use of the Autism Diagnostic Interview-Revised with a Latino Population of Adolescents and Adults with Autism. *J. Autism Dev. Disord.* **43**, 1098–1105 (2012).
- 31b. National Institute of Mental Health 2013 Services Research for Autism Spectrum Disorder across the Lifespan (ServASD): Pilot Research on Services for Transition-Age Youth (R34)
<http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-14-101.html>
- 31c. National Institute of Mental Health 2013 Services Research for Autism Spectrum Disorders across the Lifespan (ServASD): Pilot Studies of Services Strategies for Adults with ASD (R34)
<http://grants.nih.gov/grants/guide/rfa-files/RFA-MH-14-102.html>
32. Landa, R. J., Holman, K. C., O’Neill, A. H. & Stuart, E. A. Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial: RCT of social intervention for toddlers with ASD. *J. Child Psychol. Psychiatry* **52**, 13–21 (2011).