

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.” (2011 Plan) 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 being diminished during the 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. Families and adults on the autism spectrum need to navigate an entirely new terrain of services. The social-ecological context of development also changes radically upon leaving secondary school.

Adulthood also brings new challenges related to the attainment and performance of social roles, shifts in family ecological context 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. For some, adulthood may also introduce new abilities, diminishing impairment severity, discovery of new ways to participate and contribute in communities, and new opportunities for achieving health and well-being.

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 a focus on ecologically valid 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.

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. Failure to understand how ASD unfolds across the lifespan represents a scientific opportunity cost. Following cohorts of people into later adulthood has paid dividends for basic science in other developmental disorders like Fragile X syndrome and Down syndrome.

The majority of a typical lifespan is spent in adulthood. However, this is the stage of life we still know least about. In recent years, awareness of the needs of adults on the autism spectrum has increased some and more data are available on services gaps and outcomes. Much work is still needed 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.

Progress towards 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, both long-term and short-term, under Question 6, three objectives address the impact on quality of life for adults of 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 that 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. Additionally, 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.

There have been several notable advances in this area over the past five years. A number of studies have begun describing young adult outcomes, service needs and access, and service program models. Systematic reviews have examined extant research on services and interventions. Examples of 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. (Nicolaidis 2013 – Oreg Health & Science Univ)

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 studies is limited by small sample sizes and lack of demographic characteristics of study participants. The growing number of adults on the autism spectrum creates an urgent need for model programs and policies. 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. (Shattuck 2012, Walton 2013, Taylor AHRQ- 2012) The quality of studies conducted through 2011 regarding vocational programming (Taylor 2012), pharmacology (Dove 2012) social skill interventions (Walton 2013), and psychosocial interventions (Bishop-Fitzpatrick, 2013) remains in an emergent state.

The growing number of adults with autism 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 [cite AS employment think tank], and this body of practice-based knowledge should be incorporated along with more traditional research efforts as an important driver of future investigations.

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Progress towards aspirational goal

What is new in the understanding of individuals with autism and how their lives unfold?

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 comorbid health and psychiatric disabilities in adults (Kohane, 2012; Wozniak 2013), and the lack of physicians trained to specifically care for adults with an ASD. (Bruder, 2012) Exploration of state DD 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. (Kats 2013 – Piven’s group)

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.[Shattuck et al 2012] The rate of disconnection was higher compared to youth with other disabilities even after adjusting for correlates. We now know that outcomes are particularly poor for young adults from socially disadvantaged families and for those who have greater levels of impairment [cite].

Employment has been a particular area of research focus. We now know that 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. (Roux 2013) 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 5 years later. (Taylor 2013 – engagement in voc). Vocational outcomes are better for individuals who were not in sheltered work settings prior to participating in supported employment [Cimera, 2013]. New thinking about vocational indexes will allow us to better track the types of jobs that people with an ASD hold. (Taylor, 2012)

The experience of social isolation is more pronounced in young adults with autism than those with other types of disabilities. (Shattuck 2013) Increased levels of loneliness appear to have a negative effect on mental well-being. (Mazurek 2013) 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. (Anderson 2013)

What is new in the understanding of effective interventions and services?

Much research has focused on psychosocial interventions with noted improvement with use of methods like applied behavior analysis and social cognition training (Bishop-Fitzpatrick, 2013; Kandaloft, 2013) Development and adaptation of social skills interventions for people with severe intellectual disability is a continuing need. (Walton 2013).

What Gaps Have Emerged in the Past Two Years?

Several gaps – and opportunities – have become clear in the past two years. This review is organized using the World Health Organization’s biopsychosocial framework for understanding disability (ICF).

Gaps at the biological level of analysis include a weak understanding of the course of comorbid health issues through adulthood, little study of neurological development into later stages of life, and no studies of the long-term consequences of psychopharmacological interventions. Programs of research resulting in advances in understanding changes in biological systems for conditions like fragile X syndrome and Down syndrome may represent opportunities for thinking about matching basic scientific questions with studies of aging in ASD.

Gaps at 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 important work remains. With increasing awareness of co-morbidities, it is important to understand how different psychiatric comorbidities tend to emerge at different ages, in order to work toward prevention of the secondary effects of these added challenges. Very few studies in the history of ASD research have characterized development and outcomes in middle and later stages of adulthood.

There continue to be major gaps in knowledge at the social and population health levels of analysis. There is little known of ways people on the autism spectrum contribute to communities and society. Peer mentoring and navigation, strategies being examined in mental health services research, are ideas that may represent opportunities for adaptation. A growing autism self-advocacy movement increases opportunities for collaborative research partnerships.

Little advancement has been made in the identification and surveillance of autism in adults. One study illuminated the need for adaptation of diagnostic tools for Latino populations (Magana & Smith, 2013)

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

We still know very little about service navigation challenges and family financial impacts as they unfold over the lifespan. ASD affects multiple domains and many adults are simultaneously involved in different types of services and interventions. Most research remains focused on one intervention at a time, ignoring 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.

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 [cite AS employment think tank], highlighting a need for funding community-based research and examination of promising practices. There is growing interest in social networks and

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health outcomes, especially because many parents are concerned about what will happen to their child when they die. 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, some advances have been made in understanding the needs of adults on the autism spectrum. Recent systematic reviews about adult interventions and services have noted how disappointing and thin the evidence base is for developing guidelines. Nonetheless, service providers and businesses have been rolling out innovative promising practices. Partnering with these efforts to build practice-based evidence is a promising direction for future work. Developing effective methods for measuring changes in outcomes at the population level is needed to understand whether efforts implemented at agency and community levels are translating to improvements in the well-being of the population.