

**Working Group 6 – Conference Call #2 Summary
October 3, 2016; 12:00pm EDT**

Welcome and Introductions

Working Group Members in Attendance:

Brian Parnell – Co-Chair
Julie Lounds Taylor – Co-Chair
Samantha Crane
Amy Goodman
Kevin Pelphrey
Edlyn Pena
Scott Badesch
Sommer Bishop
Leslie Caplan
Nancy Cheak-Zamora
Laura Klinger
JaLynn Prince
Susan White

Working Group Members Absent:

David Mandell
Robyn Schulhof
Alison Singer
Vanessa Hus Bal
Ophelia McLain
Paul Shattuck
Nancy Spencer

Discussion of Public Comments received through Request for Information

- Working group members noticed there were a substantial amount of comments about the greater need to support caregivers of individuals with ASD. Members agreed there needs to be a greater emphasis on research focusing on how to better support the needs of caregivers as well as understand the implications when a caregiver is no longer able to provide support to the person with ASD.
- There was a discussion on the lack of comments surrounding aging for a person with ASD. A reason there might not have been many comments about this topic could be due to the small number of caregivers that provide for individuals that are 60+ years old with ASD. Since many public comments are provided by caregivers, this subpopulation might not have a voice represented in the public comments.
- The lack of adult services was mentioned in the public comments, and was mentioned in the last Strategic Plan, however working group members agree there is an inadequacy in funding and availability of adult services to meet the needs of this population.
- Some working group members mentioned the lack of feedback from the public about interventions for the adult population. However, this topic will need to be coordinated with the working group members in Question 4 (Treatments and Interventions) to see where this fits best.

Discussion of Research Progress

Topics may include: Transition to adulthood, Secondary Education, Vocational Services and Employment, Financial Planning, Housing, Community Integration, Social and recreational opportunities, Inclusion, Long term supports, Health/healthcare (prevention, mental health, physical health, aging, co-occurring conditions), Safety (wandering, self-harm, criminal justice issues, victimization), Adult diagnosis

1. What are the most notable areas of recent progress in this Question's field of research? What new opportunities have emerged?
 - The National Autism Indicators Reports from the Life Course Outcomes Program at Drexel University's Autism Institute have provided baseline outcomes that are useful for assessing the quality of life outcomes for adults with ASD.
 - There have also been a number of cohort studies that have defined the majority of difficulties faced by adults with ASD. This has been helpful in defining the problem in a way for us to understand what is the most impactful research that needs to be done to help adults with ASD. It is important for us to now push beyond describing the problem to understand the research impact.
 - A number of studies have been published on socioeconomic and demographic differences for individuals with ASD and their families. The next step would be understanding how people in different situations might need different services.
 - Studies have started to include autistic perspectives in the development of the study's methodology, however it is necessary to continue and increase collaboration with individuals with ASD in the design of studies.
 - It was also mentioned there has been some research focused on driving and virtual reality for transition-age youth and adults with ASD.
 - There have been new opportunities in research based on technology that would impact services research. Some programs that would be promising for more independent living based on technology research. NIH has been funding studies that involve positive reinforcement and triggers for behavior. Through technology there have been opportunities in telehealth for families in rural areas, telehealth could also be beneficial to adults that do not have a lot of resources. Smart cars are also being developed which can be helpful for individuals with ASD.
2. What progress has been made in translating research into practice?
 - Overall for adults with ASD, there have been baseline indicators for life course outcomes. At this point it is being used in policy and
3. What are the most significant barriers to progress in this field?
 - There is a need to define good measures across the variety of topics represented in quality of life outcomes. To be able to define measures and indicators that are valuable to adults with ASD it is important to include their input.
 - There is a lack of medical research on adults with autism. Understanding the medical complications for this population is important in understanding the implications on their finances and daily living needs.
4. What are the most pressing needs or evidence gaps that can be addressed through research?

- When discussing the quality of life for adults with ASD, it is important to address physical health as well as emotional well-being, mental health and suicide. Quality of life should focus on having happy and meaningful lives as individuals with autism would define it.
 - Many of the studies in this area use cross-sectional data, there is a need to fund cohort studies that can track upward trajectories over time.
 - Future studies need to look at outcomes for individuals with ASD as a spectrum of services and outcomes that parallels the spectrum of ASD. A single outcome will not work for all individuals with ASD, instead there will be multiple outcomes that will be better suited depending on where an individual lies on the autism spectrum.
 - There is a need to build new infrastructure to support the studies needed to make research advances in lifespan issues. There is some opportunities to combine existing cohort studies, however it will be necessary to build new cohorts for individuals that have been diagnosed with ASD in the past 10 years since their trajectories will look much different than the trajectories of adults with ASD at this present time.
 - Adult diagnosis was an important topic addressed by the working group members. Many believe a diagnosis in adulthood gives many adults the closure and sense of relief of knowing the reason for many of their questions. It is also beneficial with government benefits such as the ABLE act. A diagnosis opens up the ability to access services. However, there are barriers with the measures used to diagnosis adults. It is very difficult to receive a diagnosis for adults when the diagnosis instruments rely heavily on third party reporters (such as parents). There is a limited number of providers who have experience diagnosing adults. Also, if someone made it to adulthood without a diagnosis, there are many explanations and barriers as to why they did not receive a diagnosis in childhood.
 - While there are many benefits for an individual to be diagnosed with ASD in adulthood, there are some negative impacts such as: employment opportunities, custody cases, military and pilot opportunities, religious participation. Working group members agreed the benefits of a diagnosis in adulthood do outweigh the costs, but the field of research needs to help with those costs.
 - There is also a need to understand typical life outcomes for individuals with ASD. As individuals age, many want the same measures of independence as everyone else. Housing, marriage, sexual identity, among other life outcomes are areas that have never been researched or understood in this population.
5. Are there emerging areas of research that need additional support?
- Safety, and in particular wandering, studies are in need of additional support. The current data on wandering is not a quality representation of true wandering statistics. There is a need to do more thorough studies on wandering to understand what is considered the definition of wandering, what are the baseline statistics, how often is wandering associated with a negative outcome, and then why it is happening and what interventions can be provided.
 - Working group members discussed the growing concern of individuals with ASD interacting with the legal system. It would be helpful to perform studies on why individuals with ASD are being targeted by police, the negative outcomes that could be putting individuals in jeopardy of interactions with the police, and practices in the court system involving individuals with ASD.

Discussion of Services and Policy Changes

1. Are there any innovative programs or recent policy changes that have addressed some of the gaps or interests of this Question's research area? Is there new research evidence that can inform the policy agenda? Are there opportunities for practice to be more actively informing research?
 - The government spends a significant amount of funding on adult services, however we are still not seeing positive or successful outcomes for adults with ASD. There is little to no research for ASD specifically on where money should increase or be reduced in certain services areas, or if there should be an emphasis on targeted groups of people to more efficiently use the funding available for services.
2. What are the most significant services needs or gaps that are not being addressed by current policies and programs?
 - The working group members had a discussion on the distinction between interventions and services. For a child, an intervention is considered a technique or device that helps an individual in their home, however for an adult we consider that a service. While not all services for adults would be considered interventions, there are many services and supports for adults that are interventions. It would be beneficial to understand what are the interventions that adults with ASD need in the service system.
 - The service delivery system is very inefficient, we need data rather than assumptions to really understand the spectrum of services people with ASD need.

Discussion of Aspirational Goal

Based on the state of the field, is the **Question6 Aspirational Goal** still appropriate?

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.

- The group discussed changing the word "necessary" to appropriate.

Also, is the title of the chapter still appropriate?

"What does the future hold, particularly for Adults?"

- *No major comments on the title.*

Wrap up and preview of next call

- On the next call the working group will discuss new objectives for Question 1 that capture the key ways the field can move forward in screening and diagnosis.