



2009 IACC Scientific Workshop:

Updating the Strategic Plan for
Autism Spectrum Disorder (ASD)
Research

September 30 - October 1, 2009

Bethesda, Maryland

Panel 5:

“Where can I turn for services?” (Question 5)
& “What does the future hold?” (Question 6)?

- Clinical Experts
 - *Tec Chapman, Cathy Pratt*
- Research Experts
 - *Peter Gerhardt, David Mandell*
- Family/Personal Experts
 - *Ann Gibbons, Marjorie Solomon*
- Coordinated by IACC Liaisons
 - *Ellen Blackwell, Christine McKee*

Panel 5 – Other Background Materials

- Panel Five reviewed other documents in addition to workshop materials provided by OARC

Question V – “Where Can I Turn for Services?”

- Key Issues

- The lag between development of efficacious interventions, services, and supports from research to community settings
- Increased emphasis on quality of life and across the ASD spectrum
- Access to services and supports across the lifespan
- Systems collaboration and new models for service coordination
- Principles of self-direction and self-determination

Question V – Aspirational Goal

Communities will **access and** implement **necessary** high quality, evidence-based services and supports **that maximize quality of life and health** across the lifespan for ***all*** people with ASD

Question V – Research Opportunities

- Annual “State of the State” review of policies, services and supports for people with ASD and their families. ✓
- **Development and** effective dissemination of evidence-based **community** practices for people with ASD **across the spectrum and lifespan.**
- **Comparative** effectiveness studies of interventions and services for people with ASD across the **spectrum and lifespan.**

Question V – Research Opportunities (Continued)

- Studies that characterize current ASD diagnostic and service utilization patterns in community settings, examine the relationship between the likelihood of a diagnosis and services availability for ASD, and evaluate services and intervention outcomes **across the spectrum and lifespan.**

Question V – New Proposed Research Opportunities

- Comprehensive descriptions of creative and innovative community-based ASD services and supports to stimulate change, generate ideas, and inspire the next generation of services innovations across the spectrum and lifespan.
- Development and evaluation of the effectiveness of a coordinated, integrated, and comprehensive community-based services and supports delivery system that is designed to enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and lifespan, and their families.

Question V – New Proposed Research Opportunities (Continued)

- Support a demonstration project to evaluate the effectiveness and outcomes of models for single case management across service delivery systems.
- Conduct a study to examine how self-directed services and supports impact children, youth, and adults with ASD across the spectrum.

Question V – New Proposed Research Opportunities (Continued)

- Researchers, people with autism across the spectrum, and the practitioners who work with them partnering to develop and test interventions, services and supports, using a community-based participatory research model

Question V – Short-Term Objectives

- Initiate a “State of the States” assessment of existing state programs and supports for people and families living with ASD by 2009. ✓
- Support studies that assess how variations and access to services affect family functioning in diverse populations, **including underserved populations**, by 2012.

Question V – New Proposed Short-Term Objectives

- Support promising practices briefs that describe innovative and successful services and supports being implemented in communities that benefit the full spectrum of people with ASD.
- Support a demonstration project to evaluate the effectiveness and outcomes of models for single case management across service delivery systems.
- Conduct a study to examine how self-directed services and supports impact children, youth and adults with ASD across the spectrum.

Question V – New Proposed Short-Term Objectives (Continued)

- Initiate demonstration projects that evaluate models of policy and practice-level coordination among state and local agencies to provide integrated and comprehensive community-based supports and services that enhance access to services and supports, self-determination, economic self-sufficiency, and quality of life for people with ASD across the spectrum and their families, with at least one project aimed at the needs of transitioning youth.

Question V – Long-Term Objectives

- Test the efficacy and cost-effectiveness of evidence-based services **and supports** for people with ASD **across the spectrum** and of all ages in living in community settings by 2015.
- Test methods to improve dissemination, **implementation, and sustainability of evidence-based interventions, services, and supports** in diverse community settings by 2013.

Question V – New Proposed Long-Term Objectives

- Develop, if necessary, and test service training strategies to increase skill levels in service providers, including direct support workers, education staff, and public service workers to benefit the spectrum of people with ASD.
- Fund a demonstration project that evaluates effectiveness and outcomes of person-centered models of single case management on self-advocacy, self-determination, economic self-sufficiency, and quality of life for persons across the spectrum with ASD, and their families.

Question VI – “What Does the Future Hold?”

Workgroup recommends the title of the Question be revised to reflect its intended focus on adults, and transitioning youth:

“What Does the Future Hold for the Spectrum of Adults with ASD?”

Question VI - Key Issues

- Include the full spectrum of adults with ASD
- Need to focus on principles of self-direction and self-determination
- Integrate programs for transitioning youth
- Focus on training
- Community integration
- Use of medications
- Access to adult services
- Individualized, quality care

For Discussion Purposes Only

Question VI – Aspirational Goal

- All adults on the autism spectrum will have the opportunity to lead self-determined lives in the community of their choice through work, community participation, satisfying relationships, and access to necessary and individualized services and supports

Question VI – Research Opportunities

- Longitudinal studies of **adults across the spectrum** with ASD and their families to **track factors** that account for **improved quality of life outcomes across the spectrum, including medical, vocational, community, and lifespan issues.**

Question VI – Research Opportunities (Continued)

- **Studies of the scope and impact of the spectrum of ASD in adults, including diagnosis of ASD in adulthood, needs during critical life transitions, and quality of life.**

Question VI – Research Opportunities (Continued)

- Use of existing administrative databases for information relevant to diagnosis, course, interventions, and long-term outcomes for **adults on the ASD spectrum**.

Question VI – New Proposed Research Opportunities

- Longitudinal studies that follow carefully characterized cohorts of the broad spectrum of adults with ASD and their families into adulthood in order to better understand their needs during critical life transitions, and to identify and track risk and protective factors that account for improved quality of life and health outcomes.

Question VI – New Proposed Research Opportunities (Continued)

- Support a series of promising practices briefs that describe innovative services and supports being implemented in communities that benefit the spectrum of adults with ASD.
- Optimize the use of existing State and Federal data to report information relevant to diagnosis, course, services and intervention utilization, medical and pharmaceutical utilization, and other factors that describe long-term outcomes for the spectrum of adults with ASD.

Question VI – New Proposed Research Opportunities (Continued)

- Evaluations of projects that increase coordination across State and local delivery systems to improve access to services and supports, particularly projects that focus on transitioning youth and adults on the ASD spectrum.
- Report on and develop, if necessary, accessible, affordable, and integrated housing options for adults with ASD that promote independence, choice, control, and privacy.

Question VI – Database Objectives Subsumed in New Long-Term Objective

- Develop and have available to the research community means by which to merge or link databases that allow for tracking the involvement of people in ASD research by 2010.
- Conduct a needs assessment to determine how to merge or link administrative and/or surveillance databases that allow for tracking the involvement of people living with ASD in health care, education, and social services by 2009.

Question VI – Database Objectives Subsumed in New Long-Term Objective (Continued)

- Develop and have available to the research community means by which to merge or link administrative databases that allow for tracking the involvement of people living with ASD research in health care, education, and social services by 2018.

Question VI – Short-Term Objectives

- Launch studies to assess and characterize variation **in the quality of life for adults on the ASD spectrum (e.g. integrated employment, community inclusion, self-determination, relationships, and access to health services and community-based services)** by 2011.

Question VI – Short-Term Objectives (Continued)

- Conduct **comparative effectiveness research that includes a cost-effectiveness component to examine interventions, services and supports to improve health outcomes and quality of life for adults on the ASD spectrum over age 21 by 2012.**

Question VI – New Proposed Short-Term Objectives

- Develop a method to identify adults across the ASD spectrum who may not be diagnosed, or are misdiagnosed.
- Conduct a study to measure and improve the quality of care being delivered in community settings to adults across the spectrum with ASD through provision of specialized training for direct care staff, including assessment and development of ASD-specific training, if necessary.

Question VI – New Proposed Short-Term Objectives (Continued)

- Initiate demonstration projects at the state and local level that evaluate models in which existing programs to assist people with disabilities (e.g. Social Security Administration, Rehabilitation Services Administration) are tailored to the needs of transitioning youth and adults with ASD.

Question VI – Long-Term Objectives

- Develop **individualized** community-based interventions **that improve quality of life or health outcomes for the spectrum of adults with ASD** by 2015.

Question VI – Long-Term Objectives (Continued)

The following proposed long-term initiative encompasses the three short and long-term data objectives referenced earlier:

- **Develop and have available to the research community means by which to merge or link administrative databases that allow for tracking adults with ASD involved in various service systems...**

Question VI – Long-Term Objectives (Continued)

...(e.g. state developmental disabilities agencies, vocational rehabilitation services agencies, state insurance commissions, state offices of children and family services, state educational agencies, state mental health agencies, state early intervention agencies, the Social Security Administration, local jurisdictions (city/county), state Medicaid agencies, state and local criminal justice systems and other entities).

Question VI – Long-Term Objectives (Continued)

- Conduct a **study that builds on carefully characterized cohorts of children and youth with ASD to determine how interventions, services, and supports delivered during childhood impact adult health and quality of life outcomes.**

Question VI – New Proposed Long-Term Objectives

- Develop a community-centered intervention that improves understanding of the strengths and challenges of the spectrum of adults with ASD, and increases opportunities for full community inclusion, including an assessment of benefits to communities, and adults with ASD.
- Conduct a study to evaluate current practices leading to the use of psychopharmaceutical medications and their effectiveness in the treatment of comorbid conditions or specific behavioral issues with adults across the autism spectrum.

Question VI – New Proposed Long-Term Objectives (Continued)

- Implement a demonstration to test the effective services and supports resulting from comparative effectiveness research that included a cost-effectiveness component to improve health outcomes and quality of life for adults on the ASD spectrum over age 21.

Other Comments from Panel 5

- The panel recommends in the future convening separate work groups for Questions V and VI
- The panel could have used additional discussion time (e.g. more than six hours)
- The panel appreciates OARC's work coordinating telephone meetings, sending e-mails, and providing materials
- The overall process was a great experience!

Summary and Discussion

- *Question V:* **“Where Can I Turn for Services?”**
- *Proposed Question VI:* **“What Does the Future Hold for the Spectrum of Adults with ASD?”**