

Report of the Advisory Committee of Adults on the Spectrum Meeting of May 1, 2008 ASD Research: What Adults living with an ASD Think....

Introduction:

On May 1st 2008, the Advisory Committee of Adults living with an ASD of Autism Society Canada met to discuss the topic of **ASD Research**. The committee members began their discussion with general subjects; research priorities, ways to make research more available/accessible to people with ASD, and areas requiring more study. Specific topics, such as genetic links and predisposition to autism, links between environmental contaminants/toxins and autism were also proposed as potential future research topics.

Inclusion:

A key theme of the committee meeting was the concept of inclusion: people living with an ASD should be included and involved in all aspects of research by defining research priorities, providing validation/peer-review throughout the research process and being invited to join researchers at conferences and symposiums. **The exclusion of individuals with an ASD from the research process continues to marginalize individuals and present them to society as “less capable”**. This is often not the case at all. Excluding individuals living with an ASD from research about their own conditions simply reinforces society’s stigmas about ASDs. This is not acceptable.

Research Priorities:

The Committee determined that research priorities for ASDs must remain focused on the basic and practical needs of people living with an ASD: housing, finance, transportation, self-help, overall mental health and well-being, sensory issues, sexuality, coping with stress and anxiety. Also, an analysis of supports that currently exist in schools and post-secondary institutions, along with research into psycho-social factors contributing to mental health problems (stigma, isolation and exclusion) might shed some light into what role society’s perception about autism plays into the ASD condition itself. A third proposed research area was the topic of mental health: depression and anxiety in adulthood, bi-polar, TS, ADHD, psychosis and over-medication relating to misdiagnosed health problems were all subjects that the committee felt were candidates for further research. The fourth and final research subject discussed was the lack of professionals and researchers in the field of ASDs. How do we attract them?

Child Focused Research: Street Smarts vs. Book Smarts

There is genuine concern by the committee that current ASD research is very child-focused, resulting in a gap in research for those adults who are diagnosed later in life. This particular group requires *street smarts as opposed to book smarts* and feels like they missed out on such basic skills as being an adolescent, making friends, and other coping skills. Soft skills are key for this group of individuals; learning insight, awareness, being able to read other people’s intentions, understanding predators and assessing risky situations are practical skills that would greatly benefit these individuals as they grow older. As these individuals mature we will also need to address the needs of seniors living with Autism.

Future Topics:

Other topics that were presented but not discussed due to time constraints included: how involved adults with an ASD are in defining a Canadian agenda for research, what kind of suggestions individuals would have for researchers when requesting involvement from individuals with an ASD in research projects and finally, the importance of research and access to research when making day-to-day decisions about life and treatment services for individuals living with an ASD.