



2006 OAR Applied Research Convocation

First Impressions Report

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On June 5 and 6, the Organization for Autism Research (OAR) hosted its first Autism Research Convocation. The idea behind the Convocation Program is to bring people with the best minds together with professionals and people with practical and personal expertise every two years to illuminate topics and priorities for research. The ultimate purpose is simple: To improve the quality of life of learners with autism and their families by providing a comprehensive review and summary of the current state of ASD related research on one specific topic and, subsequently, to offer recommendations in terms of best practices in that particular area and identify future research priorities. By all accounts, this first step in the process was an unprecedented success.

In the course of the just completed Autism Research Convocation a select group of prominent researchers and service providers along with professionals, parents and individuals with an autism spectrum disorder diagnosis from both the U.S. and Canada, examined *Evidence-based Interventions in Support of Adolescents and Adults with Autism*. In each of the 14 presentations, the participants followed a structured format to review the research, openly discuss the relevant implications, and offer their recommendations. It concluded with a Consumer Panel, in which a parent, a person on the autism spectrum, and a service provider shared their perspectives on the issues presented.

In addition to this vital, core group of participants, OAR was honored by the participation of key leaders from the federal government, specifically from the Department of Education and the National Institutes of Health, and two of the leading groups in the autism community. On the federal side, Dr. Louis Danielson, Director of the Research to Practice Division of Office of Special Education Programs (OSEP), Dr. Celia Rosenquist of the National Center for Special Education Research (NCSER), Mr. Steven Tingus, Director of the National Institute on Disability and Rehabilitation Research (NIDRR) and Dr. Audrey Thurm of the National Institutes of Mental Health (NIMH) spoke to the assembled group. Bringing additional research and community perspective to the forum were Dr. Alycia Halladay, Associate Director of Research and Programs for Autism Speaks/NAAR and Dr. Lisa Glow, Executive Director of the Southwest Autism Research and Research Center (SAARC). The participation of these guests was much to the benefit of the overall process.

While the process of synthesizing all the information from this initial meeting, writing papers, providing commentary, and publishing a comprehensive *Proceedings* has begun, it will be several months before it is complete. Nonetheless, a number of critically important points of consensus emerged. Perhaps the most significant are:

- The research in support of older learners with autism is scarce and, when available, is often more than a little dated.
- Areas of support and intervention for older learners in which there are significant gaps in our understanding include (not in any order of priority):
 - the mental and physical health assessment and intervention;
 - the experience of parenting an older learner;
 - promoting effective communicative competencies;
 - sexuality instruction and community safety;
 - functional behavior assessment and intervention beyond childhood, and;
 - self advocacy/self determination.
- The valid research that does exist generally does not get translated into effective practice.
- All of these issues are inter-related and future research, therefore, needs to take into account measures beyond generalization and maintenance to include assessments of “broader” change including quality of life.

This meeting is just a first step as the OAR Applied Research Convocation is best thought of a process rather than a product. Every presenter has agreed to now “write the chapter” based on his or her presentation. Participants who did not present will be able to offer commentary on the chapters (from the point of view of a parent, a provider, or a person with an ASD). The completed chapters and their commentaries will allow OAR to formulate a research agenda for the next decade specifically targeting the needs of older learners. This entire document will be published and made available to the public.

OAR will host the next Autism Research Convocation in June 2008 on the topic of *Asperger Syndrome* and continue subsequent meetings on a new topic of high research interest to the autism community every other year until 2018, when the cycle of topics is to begin again, and OAR will reconvene and reexamine the topic, *Evidence-based Interventions in Support of Adolescents and Adults*, in order to assess progress relative to the 2006 Research Agenda and to identify new or emerging priorities in this area for the next decade.

Our thanks go out to all of the Convocation participants for their willingness to join us in this critically important first venture, the spirit in which they took on the task, and the passion, professionalism, and thought they bring to each day. This was a significant first step. Together, we can change lives.