

Autism Diagnosis in Low Resource Settings: Challenges and Opportunities to Enhance Research and Services Worldwide

Technical Meeting

Location: Johns Hopkins Bloomberg School of Public Health, Baltimore, MD
Date: October 15 & 16, 2014

Over the past decade, global awareness of autism has dramatically increased, leading to greater demands from individuals, families and other stakeholders for more research and services. These demands have escalated recently as a result of both the United Nations General Assembly (UNGA) and the World Health Organization (WHO) adopting new resolutions for autism, highlighting the condition as a global public health challenge. However, for most low and middle income countries, representing of 85% of individuals and families affected by autism through the world, progress is stymied by a lack of capacity and scientific evidence that could inform and support the development and implementation of feasible and sustainable policies and programs. Specifically, the lack of robust, public domain diagnostic instruments that are broadly endorsed by the research and clinical communities has emerged as a major barrier to enhancing autism research and services worldwide.

While the Autism Diagnostic Interview (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS), the “gold standard” diagnostic instruments, are available in numerous languages and settings, the adaptation process is time-consuming and requires expertise that is often rare to non-existent in low resource communities. In addition, the resulting version remains copyrighted, making the tools economically out of reach for a vast majority of the autism community. As a result, implementation is sparse and the evidence-base for best practices in autism diagnosis and intervention in low resource settings remains thin, with little prospect to support the surging needs of our global community affected by autism.

In order to better understand the state of the science and to identify opportunities and barriers to developing a public domain tool to advance autism research and enhance services worldwide, Autism Speaks and the Department of Mental Health at the Johns Hopkins Bloomberg School of Public Health (JHSPH), in collaboration with the International Society for Autism Research (INSAR), and with technical assistance from the WHO, have organized the technical meeting, “Autism Diagnosis in Low Resource Settings: Challenges and Opportunities to Enhance Research and Services Worldwide.”

The meeting will take place on October 15-16, 2014, and will convene international autism, developmental disability and child development experts to discuss challenges and offer solutions related, but not limited, to:

- (a) Benefits and drawbacks of adapting existing vs. developing new models;
- (b) Cross-cultural adaptation;
- (c) Feasibility, with a focus on developing a research *and* clinically relevant tool; and,
- (d) Research methodologies for the development and testing of an instrument.

The overall goal of the meeting will be to develop a consensus on the existing options and identify a process for future development of an open source diagnostic tool for autism. Additionally a small team of experts will be identified to lead the development effort. Autism Speaks and collaborators aim to leverage the information and guidance developed from this consultation to inform the design and implementation of international, multisite feasibility and validation trials for the potential instruments starting in 2015.