

Oral Public Comments

**IACC Full Committee
Meeting**

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My name is Dr. Christina Nicolaidis and I am commenting today in my role as the Editor-in-Chief of a new journal to be published by Mary Ann Liebert, Inc., called *Autism in Adulthood*.

For those of you who don't know me, I am an internal medicine physician, a Professor at Portland State University, an Adjunct Associate Professor at Oregon Health & Science University, and the parent of a transition-aged autistic son. I Co-Founded and Co-Direct the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), a long-standing, NIH-funded, national, academic-community partnership that conducts participatory research to improve the health and wellbeing of autistic adults.

As you all know, there has historically been *far* too little attention to issues affecting the lives of autistic adults. In the eleven years since we founded AASPIRE, I have noticed significant progress. I am pleased that the IACC has recognized the importance of autism across the lifespan and that the NIH and other funders are starting to focus more funding on research about autistic adults. I have been thrilled to see a burgeoning recognition of the importance of authentically including autistic adults in research and policy about autism. And I have been excited to see widespread growing attention to "transition" issues for autistic youth. As a clinician, researcher, parent, and friend, I know that we have a long, *long* way to go, but I am optimistic that the field is moving in the right direction, and I thank all of you who have contributed to these changes.

Given this context, when Mary Ann Liebert approached me with the idea of becoming Editor-in-Chief of their new journal, I just couldn't say no. I believe that this is the perfect time for a journal focused specifically on autism in adulthood and am honored to play a role in shaping the journal.

I envision the journal becoming *the home* for research and scholarship on autism in adulthood. The journal will bring together academic, practitioner, and autistic voices to advance our understanding. We plan to include original research, in-depth analysis, and multi-disciplinary dialogue on the most pressing issues affecting adults on the autism spectrum. The goal is to provide new insights and evidence that will promote practice, system, and policy change.

Given my joint appointments in Medicine, Public Health, and Social Work, I appreciate how different norms can be in different fields. Yet, to truly address the issues most important to autistic adults, we need clinicians and researchers from a multitude of disciplines. I am committed to ensuring that the journal is multidisciplinary in nature and welcoming to authors from a wide range of personal and professional backgrounds.

And of course, if we are ever going to make a true impact on the field, we need to include autistic adults themselves. The one thing I am most excited about is having the opportunity to build a new type of journal that truly integrates autistic individuals into the academic literature. My long-time collaborator, Dr. Dora Raymaker, will serve as the Associate Editor. Dr. Raymaker brings a dual perspective, both as an autistic adult and as a new, NIH-funded autism researcher. We intend to include other autistic individuals - both from within and outside of academia - in multiple roles: as some members of the Editorial Board, authors, commentators, and as part of the peer review process.

Finally, the journal will always remember that autism does not exist in a vacuum. In addition to basic science, clinical, and services research, we aim to include work addressing the intersectionality of autism

and race, ethnicity, gender identity, sexual orientation, disability, class, trauma, discrimination, and other social determinants of health.

The journal will start publishing papers in 2018. It will be an international, subscription-based, print and online journal, with an open-access option. I am excited about the great potential our new journal has to impact the field of autism in adulthood, but I need your help. Please contact me if you are interested in potentially playing a role with the journal. We are looking for more Editorial Board members, Deputy Editors, peer-reviewers, authors, and commentators. And please pass the word along to other researchers, clinicians, autistic adults, family members, policymakers, or anyone else who may be interested in helping shape our new journal.

With your help, I believe the journal can play an important role in supporting the goals of the IACC and advancing knowledge, practice, and policy on autism in adulthood.

Thank you to the IACC for the opportunity to share the work we have been doing to increase access to best-practice care for underserved children with autism and their families.

Children with autism and their families face significant barriers to accessing high-quality evidence-based care in their communities. Even though parents may notice early signs of autism in the first years of life, many children are not diagnosed until several years after the first onset of symptoms. This leads to delays in accessing intervention and worse long-term outcomes. Children with autism also have trouble accessing family-centered, coordinated, and comprehensive medical care. As a result, significant co-occurring medical and psychiatric conditions often go untreated, leading to poor health and well-being.

There are many reasons for these health care gaps. One of the biggest barriers to access is the significant nationwide shortage of health care professionals with training in autism. Families are often required to travel long distances to access autism services, and those from rural or remote areas or with limited financial resources are often unable to get there. Even for families who live near autism specialists, waitlists can be months or even years. Our vision is to improve the system of care so that children with autism and their families can have ready access to best-practice care in their home communities.

Over the past 2 ½ years, our team has been developing and testing a new model for enhancing capacity for high-quality autism care in rural and underserved communities. Based on the innovative Project ECHO model originally designed for hepatitis C by Dr. Sanjeev Arora at the University of New Mexico, our tele-mentoring program trains community-based primary care providers in best-practice screening and medical management of autism. The ECHO Autism program uses high-quality videoconferencing technology to connect local primary care providers to an interdisciplinary team of autism experts through bi-monthly ECHO Autism Clinics. Through a combination of didactics, case-based learning, and guided practice, participants learn and implement best-practice techniques in their own practices. Our initial pilot study showed significant improvement in provider self-efficacy and in autism screening practices. This model has the potential to spread specialty knowledge exponentially - building local expertise and reducing healthcare disparities for rural and underserved families.

Thanks to funding from HRSA through the Autism Intervention Research Network on Physical Health (AIR-P), we are currently conducting a large multi-site cluster randomized study to test the model in 10 sites across North America, training 150 primary care providers who care for underserved children. We are directly measuring change in provider practices through chart review, and are testing provider knowledge and self-efficacy in autism screening and medical management.

The results of this work will directly guide our ongoing efforts to improve systems of care and to eliminate healthcare disparities for children with autism and their families. We would like to encourage other researchers, clinicians, and policy-makers to consider the potential benefits and applications of ECHO and similar training models for disseminating knowledge, closing the research-to-practice gap, and increasing local capacity for autism care in underserved communities.

References:

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