Thinking Globally: An International Perspective on Autism Research

This issue is all about diversity, whether in research or in career choices. To celebrate diversity in research, I want to spotlight international research experiences. Autism research in the Global South (outside North America and Europe, that is) faces many daunting obstacles, including the lack of prevalence data for autism and other developmental disorders. Another challenge is that, with the big burden of infectious diseases such as HIV and malaria—and now Zika—in these countries, there is a dire lack of funding for non-communicable and non-fatal diseases such as autism. These challenges mean that there is less government support for autism research and service delivery. Hopefully, obstacles such as these will foster creative research techniques. It will challenge the research community to create low-cost and relatively culturally unbiased assessment tools—tools that are fair regardless of education, language, or race. Everyone stands to gain from increased research coming from developing countries. For example, populations in the Global South are typically linguistically, culturally, and genetically diverse, which can improve our understanding of the behavioral presentation and genetics of autism. For instance, nearly all genetic research has been done on middle-income individuals from European descent, though this by no means represents the global population.

Clearly, more international and interdisciplinary collaborations are needed. Research groups often do well by partnering with non-profit groups to promote research and raise autism awareness at the same time. Partnerships with the technology industry may also hold promise for long-distance diagnosis and intervention. This may be particularly true in Africa, where people in rural areas sometimes have to travel for hours to access healthcare services, and where more people have a mobile phone than piped water or electricity at home. Collaborations are our best bet for moving towards research that includes low-income groups of diverse racial, linguistic and cultural backgrounds.

A challenge for international research is knowing when to follow standardized procedures originating from the Global North, and when to develop new techniques. Certainly, some problems will need to be approached differently in low-resource countries. For example, the ratio of professional healthcare providers to individuals seeking care is enormous in many countries in the Global South, and large-scale interventions delivered by specialized providers are unlikely to be sustainable. However, many cultures are very community-oriented—something researchers and healthcare providers can harness to provide intervention and safe spaces in areas where trained professionals are not available. Discussions between research groups facing similar problems can be helpful for fostering new ideas without reinventing the wheel.

It is promising that autism research coming from the Global South is increasing; it holds many challenges, but also great opportunity for improving the lives of countless people.

- Michelle Hoogenhout
INSAR STC Member, University of Cape Town, South Africa

Preview IMFAR 2017 Student/Trainee Events

Looking to get the most out of your experience at IMFAR as a student or trainee? Keep in mind these events when it comes time to register! Hope to see you there!

Early Career Pre-Conference Workshop

• This event occurs on the Wednesday before IMFAR (so plan your travel accordingly!). The workshop will allow early career researchers to hear about career trajectories from leaders in the field and participate in small group discussions with those experts. Be sure to pre-register!

Meet the Experts Luncheon

• This event gives students & trainees the opportunity to spend the lunch hour with leaders in the autism research community. Talk about research, get career advice; this is your time to ask all your questions. Be sure to pre-register as this event fills up quickly.

Student & Trainee Social

• Get to know other students & trainees who are interested in autism research! Attend the free social during IMFAR to connect with other early career researchers. This year you can enjoy free food and trivia at a local brewery while maybe even finding a future collaborator for a research project!

Attend a Special Interest Group (SIG)

• Check out the IMFAR program book before you go to see if there is a SIG that interests you! SIGs meet during IMFAR and are very welcoming to students & trainees.

Career Trajectories for Autism Researchers

The focus of the 2017 IMFAR Early Career Pre-Conference Workshop will be on the diverse career options in autism research. The workshop will offer individualized mentorship from colleagues in a variety of career trajectories.

Faculty: Academic careers at the university level could have either a research or teaching focus. Research-focused academic jobs will allow more time to securing external funding and conducting significant research. Teaching-focused academic jobs place less emphasis on the research aspect of the faculty position, carrying a heavier teaching load for preparing future practitioners, clinicians, or researchers.

Clinician: Clinicians have the opportunity to work hands-on with clients. Some clinicians also hold dual clinician/researcher posts at universities, where they can use their clinical work to inform research.

Government agency: Careers in government may focus on tracking prevalence rates, implementing local and national policies to improve the lives of people with autism, building infrastructure, and setting priorities for research. A benefit of working in this sector is the opportunity to make a tangible, large-scale impact.

Foundation: There are many nonprofit organizations that focus on research, improving science awareness, and promoting healthcare. Benefits of working for a foundation are having more flexibility in the workspace and working with a diverse set of passionate colleagues.

Industry: Careers in industry, such as in genetics or biotechnology, offer an alternate research path. Benefits of working in an industrial research lab include the availability of money and resources, and having time to focus on a particular problem.
Other factors, such as poor health tested my organization and project management skills to the limits. Managing the across several sessions. With the large sample involved in this study, that I spend approximately 12 physical and wellbeing measures, with a large sample. This means A: and is ongoing for the next 2 years at IMFAR. Geurts from the University of Amsterdam in the Netherlands who was with ASD: The consequences of aging adults (e.g. Howlin et al., 2004), and how we might greater cognitive difficulties in a significant sub group of autistic adults who are ageing with autism, there is so much work still to be done. research has helped to establish foundations for outcomes of adults who are ageing with autism, there is so much work still to be done. For example, I would like to further explore the factors that lead to greater cognitive difficulties in a significant sub-group of autistic adults (e.g. Howlin et al., 2004), and how we might be better able to support autistic adults in healthcare settings. A: I would like to continue this area of research whilst my current research has helped to establish foundations for outcomes of adults who are ageing with autism, there is so much work still to be done. Can you tell us about your experiences at IMFAR in the past? A: I have been fortunate to attend IMFAR since my Master’s year of study (2014), although then just as an observer which was a fantastic learning opportunity. I was invited to co-lead a SIG on Older adults with ASD: The consequences of aging, together with Prof. Dr Hilde Geurts from the University of Amsterdam in the Netherlands who was the SIG leader and mentor. This SIG was a great success in 2016, and is ongoing for the next 2 years at IMFAR. Q: What is a challenge you’ve faced in your research, and how have you overcome that? A: My study is really large and covers a broad range of cognitive, physical and wellbeing measures, with a large sample. This means that I spend approximately 12-14 hours with each person at Time 1, across several sessions. With the large sample involved in this study, managing the process needs a lot of planning (and time!). It has tested my organization and project management skills to the limits. Other factors, such as poor health of some individuals, have meant that some individuals are not able to participate in the research.

Amanda Roestorf is a 2nd year Psychology Doctoral student at City University of London

Q: Briefly, tell us about your research. A: The focus of my PhD research is to understand the effects of growing older with Autism Spectrum Disorder (ASD) on cognitive functioning and quality of life. This includes evaluating specific age-related difficulties associated with autism symptoms, mental health and co-occurring health conditions, and age-related cognitive changes in memory, executive function, language and intellectual ability, particularly for older autistic individuals in later life. Initial cross-sectional comparisons (Time 1) of younger and older adults with ASD (N=63) and a non-autistic control group from the general population (N=44), have extended to longitudinal follow-up (Time 2) of these individuals across the 4-year programme of work, which is nearing completion by March 2017. My research is funded by the Medical Research Council UK, in collaboration with the National Autistic Society UK.

Q: What are your future career goals/plans? A: I would like to continue this area of research whilst my current research has helped to establish foundations for outcomes of adults who are ageing with autism, there is so much work still to be done. For example, I would like to further explore the factors that lead to greater cognitive difficulties in a significant sub-group of autistic adults who are ageing with autism, there is so much work still to be done. I would like to continue this area of research whilst my current research has helped to establish foundations for outcomes of adults who are ageing with autism, there is so much work still to be done. I want to provide the foundation to my future students that will allow them to provide the proper techniques and tools to serve this population.

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Krystle Jalalian is a 4th year Applied Linguistics & Communication Doctoral student at the University of London, Birkbeck

Q: Briefly, tell us about your research. A: My research study is to investigate how social communication and behaviors in preschool-aged children with Autism Spectrum Disorder (ASD) and Typically Developing (TD) children ages 2-5, contribute to joint attention abilities and social-communication growth in the context of bilingual and monolingual home environments. The overall idea of my thesis is to explore the relationship between language environments, social skills, language ability, and behaviors in children ages 2-5 that have Autism Spectrum Disorders (ASD) or are Typically Developing (TD) and come from bilingual and monolingual households (environments).

Q: What are your future career goals/plans? A: My overall career goal is to be a Professor and teach future teachers and researchers who want to work with children with autism. I want to provide the foundation to my future students that will allow them to provide the proper techniques and tools to serve this population.

Q: Can you tell us about your experiences at IMFAR in the past? A: I had a wonderful time being able to hear the top researchers in the world discuss their research as well as attend events to enhance my knowledge. I really enjoyed the luncheon with an expert of choice, as it provided a personal connection and I was able to ask questions and hear their story. Additionally, the Early Career Workshop was helpful and insightful on outlooks for the future. Lastly, it was a life changing experience to present my research to my fellow researchers in the field and receive feedback and future ideas for my study.

Q: From a cultural and international standpoint, what do you think is the greatest need in autism research? A: From my experiences and research, I believe the aspects of cultural barriers within families and minority groups that have children with autism or associated with someone with autism needs to be addressed more heavily. These indirect influences affect the way people think and behave and interact with others. Language barriers and cultural stigma associated with autism hinder access to health services and also affect communication in ways that deter diagnostic decision-making. Many families from different countries and minority groups have cultural practices, value systems, and expectations that

Student & Trainee Research Spotlight

The Student & Trainee committee strives to highlight the innovative and significant contributions of early career autism researchers. The selection of our Student & Trainee spotlight was determined based on blinded submissions to the INSAR website and judged by the committee on clarity, significance, and diversity.

Are you conducting research right now that you would like to share with the INSAR community? Look for the submission opportunity for our next newsletter! This is your chance to let us know about the exciting work you are contributing to the autism research community.

Tell us what you think!
The Student & Trainee Committee is dedicated to helping to provide all our early researchers with what they need to know to be successful autism researchers. Do you have a suggestion for what you’d like to see in the next newsletter? We’d love to hear it! Send it to us at studentcommittee@autism-insar.org

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PLEASE SEND ANY QUESTIONS TO: studentcommittee@autism-insar.org