



Abstracts for the Workshop “Participatory Autism Research”

on 6 March, 2018
at the Center for Advanced Studies, LMU Munich

Sue Fletcher-Watson (University of Edinburgh)

Researchers and the autistic community in partnership: a beginners guide

During her talk Sue will describe how researchers and people in the autistic community can work together to deliver results that benefit people on the spectrum. She will provide key justifications for such ‘participatory research’ practices, illustrated with examples from her own work, and address a few common questions for the field.

James Cusack (Autistica, London)

Discover Involvement: catalysing involvement between researchers and autistic people

Autistica is the UK’s autism research charity. We believe that the most effective way to give autistic people the opportunity to live a long, happy, healthy life is to focus on their research priorities and ensure that autistic people are meaningfully involved as partners throughout the research process. In this talk, James will focus on how Autistica came to understand the priorities of autistic people and their allies through a James Lind Alliance Priority Setting Partnership. He will then discuss how Autistica has developed an Involvement Promise. This is a strategy for including autistic people in the whole research process underpinned by Autistica’s recent launch UK’s first autism research network: Discover.

Leonhard Schilbach (MPI of Psychiatry, Munich)

Studying participation in social interaction rather than social observation in autism spectrum disorder

Research into the mechanisms of autism spectrum disorder has focused on how individuals with ASD observe others rather than how they participate in social interaction with them. In his talk Leonhard Schilbach will focus on a recent paradigm shift in social neuroscience, which suggests that social abilities and their underlying neural mechanisms should be investigated in ecologically valid situations. This development is likely to be relevant for our understanding of ASD and for the development of support and therapeutic strategies for individuals with ASD.

Isabel Dziobek and Silke Lipinski (HU Berlin)

Performing research that matters to autistic people: Insights from 10 years of work of the Autism Research Cooperation (AFK)

The Autism Research Cooperation (AFK) is a project that brings together adults on the autism spectrum and scientists. The goal of the AFK, which was launched in 2007, is to jointly design and conduct research projects that the autism community finds relevant. Study results are moreover disseminated in science and general societal contexts with the aim of contributing to a better quality of life for autistic people. In this presentation, Silke Lipinski and Isabel Dziobek will provide an overview of the projects and project realization of the past ten years. Insights into challenges and achievements from this experience and an outlook on goals for the future will be given.

Sander Begeer (VU Amsterdam)

The Netherlands Autism Register

The Netherlands Autism Register (NAR, www.nederlandsautismeregister.nl/english) is a longitudinal online cohort monitoring a sample of 2000 individuals with Autism Spectrum Disorders (ASD). About half of our participants are adults who provide self reports. The other participants are parents reporting on their minor children, or representatives of adults with ASD who are unable to report themselves. We started collecting data in 2013, and are currently analyzing our 5th wave of data. Research topics are decided upon in close collaboration with individuals with ASD. We collect data using internationally validated questionnaires, but using questions provided to us directly by the autism community. Every year, we publish easy to read factsheets, in addition to our scientific publications. We also provide automatic individual reports, with unique scores of each participant in relation to the norm group of individuals with autism, segregated for age and gender. These reports are valuable to our participants in contact with care professionals or other organizations. The translational nature of the NAR allows for close collaboration between scientist, people on the spectrum and their loved ones. We continue to be extremely inspired by this collaboration.

Tobias Schuwerk (LMU Munich)

A forum for participatory autism research

Traditional autism research focused on the investigation of the etiological basis of this condition in well-controllable lab settings. To date, we have little systematic knowledge about the impact of autistic symptoms on the everyday life of people with autism and their families. Further, people with autism had only few opportunities so far to actively shape research programs. Tobias Schuwerk presents a project that aims to face these challenges. In close collaboration with people with autism and their families a research platform is developed that allows for large-scaled autism research that is both theoretically significant and of practical relevance for everyday life with autism.