

## Inside Out Conference: Speaker biographies and talk abstracts

**#InsideOutAutism #PlayingApart**

**Friday 5<sup>th</sup> July**

**10:30 – 11:30 Aphra Theatre**

**Welcome and Presentations**

**Dr Will Mandy and Dr Catriona Stewart**

*Chaired by Professor Julie Beadle-Brown*

Dr Will Mandy

**Twitter:** @willclinpsy

Will Mandy is a clinical psychologist and associate professor at University College London (UCL). His work aims to improve the recognition of autism, and to develop new interventions to help autistic people. He has a particular research interest in improving the identification and care of females on the autism spectrum, who are currently at high risk of going unnoticed and unhelped by clinical and educational services. He also studies sub-diagnostic autistic traits in non-clinical populations, and the role these can play in the development of a range of common childhood, adolescent and adult mental health problems. With colleagues at Great Ormond Street Hospital's National Centre for High-Functioning Autism he has developed and trialled interventions to help children with autism transition from primary to secondary school, and to teach children about their autism diagnosis, with an emphasis on fostering their sense of self-worth and pride.

*Girls and women on the autism spectrum*

Autism is more commonly diagnosed in males than in females. This partially reflects an underestimation of the true prevalence of autism in girls and women, arising from systematic biases in diagnostic criteria and clinical services. As a result, autistic females are less likely to receive an accurate and timely diagnosis, which reduces their chances of benefiting from appropriately targeted health care and educational resources.

This talk will consider why so many autistic women fly under the diagnostic radar. This will include the proposal that there is a female autism phenotype that is not well captured by current diagnostic criteria, which were largely based on male cases. In addition, initial evidence for environment contributions to under-diagnosis of females will be presented.

Dr Catriona Stewart

**Twitter:** @CatrionaSScot

Founder of SWAN: Scottish Women's Autism Network which since 2012, has grown to run regular peer support groups across Scotland, including 'Young Swans' aged 15-17 and groundbreaking learning events. SWAN won a Social Services Scotland Award 2018. Catriona's PhD focussed on the experiences of anxiety for Asperger girls.

Employed by Scottish Autism initially to develop the Right Click online resource, Catriona conceived, designed and managed recent SWAN/Scottish Autism Under Our Wing peer mentoring project, funded by Scottish Government. Evaluation of this pilot is in process.

Catriona was an 'expert' and advisor to the National Autism Project, is a PARC Convenor and advisor to the current review of the Mental Health Act, Scotland. SWAN is member of the parliamentary Cross Party Group. Catriona was a contributor to "Spectrum Women" published 2018. Described by Steve Silberman as a 'Rosetta Stone' for autistic women, the book was listed by the Independent as their #1 Best Buy book on autism.

*Shared visions of inclusion: gender, identity, and peer-support.*

Created initially in response to the, sometimes tense, dialogue within 2nd Wave feminism between groups of people with different theoretical paradigms, and differing lived experiences, Kimberley Crenshaw's model of Intersectionality describes the different strands of power - or disempowerment - that may come together in any one person; it's a model that perhaps raises as many questions as answers. As autistic women, autistic people, professionals, academics, allies, how do we locate - if we do - ourselves within those intersections. Quotes from peer support co-ordinators of 'SWAN' (Scottish Women's Autism Network): "Forming a positive autistic identity is crucial to well-being. I feel empowered through peer support...transformational" "When we feel better about ourselves, we are better able to contribute to society: we need to know who we are"

**12:00 – 12:30 Aphra Theatre**  
**Practice Research Perspectives**  
**Leni Van Goidsenhoven, Amanda McDowell and Annette Foster**  
*Facilitated by Dr Helen Kara*

### Leni Van Goidsenhoven

Leni Van Goidsenhoven is a postdoctoral researcher at the University of Antwerp (Philosophy) and KU Leuven (Literary and Cultural Studies). Her book *Autism in Plural: the potential of life writing for alternative forms of subjectivity* is forthcoming with Garant (in Dutch).

In this short talk I will present my role within the interdisciplinary research project NeuroEpigenEthics – an ERC funded project investigating entanglements of human biology, responsibility and experience. Working on the intersection of disability studies, new feminist materialism, cultural studies and literary theory, my main focus is on integrating life experiences of young people (and their parents) living with diverse diagnoses by using arts-based research methods and by working with and rethinking the possibilities of qualitative research methods. To make it more concrete, I will introduce you to The Creative Reading Club. This is one of the four specific projects I'm developing and it focuses on acknowledging the ethico-onto-epistemology of disabled people, and especially how it is mediated through intra-

actions with images and texts. The Creative Reading Club is a reading club of five autistic women living in and out of psychiatric hospitals who gather every five weeks for one year. We use a diffractive methodology to intra-act with the graphic novels chosen for this reading group (Barad 200, Bozalek and Zembylas 2016). We not only read and discuss our 'companion texts' (Ahmed 2017), we are also journaling about our reading process (cf. reparative and resurgent reading, Sedwick 2003) and do writing and sound exercises in group based on the books we've read and discussed (Swinnen 2017, Savarese 2018).

### Amanda McDowell

Amanda McDowell, AHRC Chase PhD candidate, SMFA University of Kent

As part of my practice based PhD I have been working with sound from a British Library video archive to create a multichannel soundpiece exploring women's experiences of psychiatric treatment in the UK in the second half of the twentieth century. My research is primarily concerned with transgenerational haunting and listening, and is a response to the historic, and, ongoing failure of listening within the psychiatric institution. The work reassembles five women's voices from The Mental Health Testimony Project Archives, enabling them to speak beyond the isolation of the archive in dialogue with each other and an audience. The work speaks of trauma, abuse and survival and is driven by an ethics of entanglement.

### Annette Foster

**Twitter:** @annettepfoster

Annette Foster has been a practicing multidisciplinary performance artist and lecturer for the past 21 years. She has exhibited internationally and been commissioned by The Arnolfini, Bristol; The [Green Room](#), Manchester; The Arches and The National Review of Live Art, Glasgow; The Phoenix Art Museum in Arizona; and Dieppe Scène Nationale, France. She was a Forward-Thinking Fellow (Artist Residence) at The Bonington Gallery at Nottingham Trent University (2002-2005).

Annette's autobiographical work has been informed by feminism, identity, gender, sexuality, and difference.

Annette is dyslexic and dyspraxic and was diagnosed as autistic eight years ago. This has led her to become an autistic self-advocate and to undertake a funded Practice as Research (PaR) PhD at the University of Kent starting in 2016 articulating the experiences of women's, non-binary and trans peoples experience of being autistic through visual and performance art.

Annette has created a solo performance titled Adventures of Super Autie Girl about her experience of a being autistic that premiered at the Autism Art Festival, Canterbury and the Invisible Festival in London.

Annette is currently carrying out creative workshops with other women, nonbinary and trans people on the spectrum that looks at expressing their experience in sensorial forms using visual and performance art. Annette's ambition is to collaboratively explore creative autistic self-advocacy by producing art with the

workshop participants that aims to dispel the stereotypes, in order to make autistic women, nonbinary and trans people more visible.

She recently premiered a spin off show titled Adventures of Super Autie Gang which was made in collaboration with five autistic workshop participants and premiered at the Autism Art Festival, Canterbury April 2019.

**14:00 – 15:00 Aphra Theatre**  
**Panel Discussion: Gender and Identities**  
**Ruth Moyle, Felicity Sedgwick, Sarah Hampton, Sharmin Faruque and**  
**Venessa Bob**  
*Led by Helen Kara*

Ruth Moyle

Ruth Moyle is a PhD student at the University of Reading, researching why a growing number of adolescent autistic girls stop attending mainstream secondary schools. Her background is in education, training initially as a primary teacher and working in schools for 10 years, in this country and abroad. Ruth's interest in autism and education began when her daughter was diagnosed as autistic at the age of five. Struggling to find information on the experiences of autistic girls in school, and how best to support them, she decided to do some research herself. She combines her skills for the Berkshire charity, Parenting Special Children, writing and delivering workshops for the parents and carers of autistic girls and the professionals working with them, and holding events for the girls themselves. Along the way she was also diagnosed as autistic, and flies mainly under the radar as @mum2aspergirl.

Ruth's current research seeks to understand why a growing number of autistic adolescent girls stop attending mainstream secondary schools in England. Little is known about why this is happening or what needs to change. The historical underdiagnosis of girls has meant their stories have been absent from research into autism and into the ways in which they are excluded from education. Ruth's study positions the voices of these missing girls as central to understanding their lack of access to education, engaging them as participants and co-collaborators in knowledge production.

Felicity Sedgwick

**Twitter:** @SedgewickF

Dr Sedgwick is a Lecturer in Psychology of Education at the University of Bristol, having completed her PhD at the UCL Institute of Education in 2017. Her PhD examined the friendships of autistic girls and women in contrast to those of autistic boys and non-autistic women. Between these two roles, she held a post-doc at King's College London working on a project looking at the potential links between autism and anorexia. Her current research focusses on the relationships and mental health of women, girls, and non-binary people on the autism spectrum, and what we can do to support positive and safe relationships.

Felicity's research focusses on the relationships of autistic girls and women, both friendships and romantic relationships. She will talk about her PhD research on these topics, work she has done since then looking at the relationship experiences of autistic non-binary people, and the links between positive social relationships and good mental health for those on the spectrum.

### Sarah Hampton

**Twitter:** @SarahCHampton

Sarah is currently completing a PhD in Psychiatry at the University of Cambridge. Her PhD research explores autistic people's experiences of parenthood. This research particularly focuses on the experience of pregnancy and childbirth, both in terms of the physical and sensory aspects as well as interactions with health professionals. Sarah's research involves a mix of qualitative and quantitative methods, including semi-structured interviews, focus groups, surveys and questionnaires. The aim of the research is to understand how autistic parents can be better supported, including identifying any areas where adjustments to services would be beneficial. Before starting her PhD, Sarah was a research assistant at the University of Edinburgh and completed a master's degree in cognitive neuroscience and an undergraduate degree in philosophy.

There is currently very little research aimed at understanding how autistic people experience pregnancy, childbirth and being a parent to young baby. This talk outlines findings from a qualitative study in which autistic people took part in semi-structured interviews about their experiences, once during pregnancy and again after giving birth. The talk gives an overview of the main themes that emerged from these interviews and the implications of these findings for how autistic parents can be better supported.

### Sharmin Faruque

**Twitter:** @FaruqueSharmin

Sharmin Faruque is a Masters Student at the Tizard Centre, University of Kent. She is currently researching social enterprise as employment for autistic people as part of her dissertation. She is also interested in the impact of Autism in South Asian communities and the stigmas surrounding an autism diagnosis and how this impacts quality of life. She currently supports ethnic minority parents of autistic children and has helped to devise a parent forum to offer support and advice. Sharmin was also diagnosed autistic at the age of 33 and has an 11-year-old autistic son.

#### *The concept of Autism in South Asian Communities*

I will be talking about the stigma of autism in south Asian communities and how this translates to mental health. I will also be discussing how this impacts issues such as forced marriage.

## Venessa Bobb

**Twitter:** @BobbVenessa

Venessa Bobb, mother of 3 - ages 18, 16 and 13, the two youngest diagnosed with Autism and ADHD. The youngest also diagnosed with Epilepsy. Her oldest daughter diagnosed with Moderate Language Difficulties, pending an ASC diagnosis.

Founder of A2ndvoice, she also volunteers as Branch Officer for NAS Lambeth Branch and Member of the Advisory Group for the All Party Parliamentary Group on Autism. She is also a videographer and co-author to "Girls and Autism" edited by Professor Barry Carpenter et al.

Her journey with her daughters being late diagnosed has shown the taboos and myths around the challenges BAME girls face.

Supported by Cassandra Centre a charity supporting young people who have experienced domestic abuse. Soapbox offers a range of activities supporting youths, mentoring, working with schools and street safety. The Lifespan Learning and Sleep Laboratory at present, working with individuals with Autism Spectrum Disorders (ASD), Down Syndrome, William Syndrome.

Getting an autism diagnosis for many affects all communities the same, but for the many issues the BAME girls face is overlooked. Overshadowed by prejudice, stereotypes and taboos, BAME girls will struggle to get a diagnosis of autism in their early years. For those who do get an early diagnosis, may experience lack of representation, language barriers and cultural differences that hinders BAME families in seeking for help or not aware of the help they are entitled too.

Autism is not recognised in many countries and for service providers and professionals they need to take into consideration when offering advice and information to service users, we have to be aware of many factors that is not offered, once the diagnosis is given from the offset. Not everyone will understand the dynamics many BAME families face, unless they live it.

**15:30 – 16: 15 Aphra Theatre**  
**Serious Play: Practical Perspectives on the Playing A/Part Project**  
**Sonia Boué and Professor Nicola Shaughnessy**

## Sonia Boué

**Twitter:** @SoniaBoue

Sonia Boué is an Anglo-Spanish multiform artist, with a focus on themes of exile and displacement, including object work, painting, installation, video and performance

She develops and lead creative projects, such as the Arts Council funded Through An Artist's Eye, recent works includes a film collaboration with Tate Britain about the British artist Felicia Browne.

Other recent work includes the BBC Radio 4 programme *The Art of Now: Return to Catalonia*. Her film work includes a commission for the Bodleian Library, Oxford, and forms part of the Arturo Barea archive.

Her most recent project has been the Arts Council funded, Museum for Object Research, which includes a professional development initiative for autistic project leadership and an inclusive exhibition for autistic and non-autistic artists.

Sonia also works as an advocate, creative mentor, and consultant.

[www.soniaboue.co.uk](http://www.soniaboue.co.uk)

### Professor Nicola Shaughnessy

**Twitter:** @nshaughnessy1

Nicola Shaughnessy is Professor of Performance at the University of Kent. Throughout her career she has researched the potential of theatre and performance to investigate identities and experiences that have been hidden, articulating the untold stories of underrepresented or marginalised groups. Her MA and PhD focused on feminist theatre and autobiography before a teacher training course led to her interest in using drama in education and health settings. After her son's autism diagnosis in 2002, her interests in neurodiversity and ethnography led to interdisciplinary work. Since then she has collaborated with neuroscientists and cognitive psychologists to inform her ongoing use of creative practices to investigate different ways of being in the world.

She was Principal Investigator for the AHRC funded project 'Imagining Autism' and is currently leading the AHRC project 'Playing A/Part', exploring the experiences of autistic girls through participatory arts. She is the author of *Applying Performance: Live Art, Socially Engaged Theatre and Affective Practice* (Palgrave, 2012) and the edited collection *Affective Performance and Cognitive Science: Body, Brain and Being* (Methuen, 2013). She is series editor (with Professor John Lutterbie) for Methuen's Performance and Science volumes for which she has recently published a new collection (co-edited with Philip Barnard): *Performing Psychologies: Imagination, Creativity and Dramas of the Mind* (2018).

[n.shaughnessy@kent.ac.uk](mailto:n.shaughnessy@kent.ac.uk)

[www.imaginingautism.org](http://www.imaginingautism.org)

[www.playingapartautisticgirls.org](http://www.playingapartautisticgirls.org)

