# OCAUTSCAPE 2017 Autism in context

8 - 11 August 2017 King's Park Conference Centre, Northampton, UK

# PROGRAMME

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# INTRODUCTION

The first thing you need to know is that everything at Autscape is completely optional. You are not obliged to attend anything, speak to anyone (unless you are a parent or carer), or participate in any way. If you are interested in doing things, there is plenty going on throughout the day – serious, fun, structured and unstructured.

This document includes a schedule telling you when and where everything is happening at Autscape and descriptions for each session. But first, there is an overview of some of the activities happening at Autscape (see the schedule for the times).

# ACTIVITIES

### **Entertainment evening**

The entertainment evening has become a regular feature at Autscape. We have had various acts, musical and otherwise. If you are interested in performing this year, please sign up on the list at the Information Centre. In an attempt to ensure the evening does not last too long, we are asking that people limit performances to 5 minutes. It's on at Thursday, 21:00-22:30. Location: Courteenhall.

## **Evening** activities

There are a number of planned and unplanned activities in the evenings. There is a separate schedule for these on the website and at the Information Centre at Autscape. Others may also be announced at the Information Centre last minute.

We'll run a cold drink and snack bar in the lounge, but we will not sell alcohol. **Due to restrictions imposed by the venue, it is also** *not* **allowed to bring your own alcohol.** 

### Home groups

Are you looking for some help with meeting new people? Home groups have been created to help people, especially those who are new, feel comfortable at Autscape and get the best out of the experience by providing a small group that they can get to know a bit better. The daily home group meetings are scheduled in the programme just after the evening meal (A) or first thing in the morning (B). If you're interested in joining a home group, please sign yourself up to one using the signup sheets at the Information Centre and then write the number of your home group in the top right corner of your name badge.

### Leisure activities

A lot goes on during leisure time, some of it decided during Autscape itself. Go to the Information Centre to see what's on. You could organise an activity of your own, such as a board game or a discussion. You could also use this time to socialise, do something on your own or rest.

#### Sensory room

We have a small sensory room set up for participants to explore and enjoy equipment at their leisure. This is open throughout the day, although it will occasionally be used for scheduled activities (including one of the Home Groups) or silent times. Please treat all equipment with due care!

#### Autscape 2017

## Singing rounds

It is traditional at Autscape for small groups to gather in the garden to sing simple songs such as rounds. Meet after lunch in the Lounge. Rounds singing may spontaneously occur at other times as well. Feel free to join in, everyone is welcome.

### Disco

There will be a less loud, autism-friendly disco on Wednesday the 9th from 20:00 to 22:00 in John Kirkham Hall. Come and dance with the rest of us or by yourself, or just sit and enjoy the atmosphere — it's all good. **Warning:** this will include flashing lights.

### **Retro computers**

The retro-nerds among us will find their paradise on Wednesday the 9th from 09:30 to 17:00 in John Kirkham Hall. Twenty retro gaming consoles and 8-bit home computers, kept alive by love, will be available for your enjoyment courtesy of the Retro Computer Museum in Leicester. Come and play!

# Sparklies in the Dark

This is one of Autscape's traditions! Time to share enjoyment with light up toys and glow sticks. Meet on Tuesday evening at 21:00 in John Kirkham Hall. Autscape will provide one glow stick per person. More sparklies can be purchased at the time.

# Crèche hours

Childcare takes place in John Kirkham Hall from 09:15-12:45 and from 16:00-18:15.

Some of the leisure activities happening from 14:00 to 16:00 will be suitable for children and young people to attend with their carers. Childcare staff will be on hand to help children access leisure activities.

# SCHEDULE

# Tuesday, 8 August

- 14:30-17:00 Registration (Lounge)
- 14:30-17:00 Drop-in activities during registration

#### 17:15-18:00 Orientation (Courteenhall)

Orientation will explain a few things about how things work at Autscape. Attendance is *strongly recommended* for all new participants.

#### 17:30-18:00 Refresher orientation (Teeton)

If you have attended Autscape before and don't need the full orientation, please attend this refresher instead, which will focus on what has changed this year.

18:00-18:30 Volunteers meeting

18:30-19:30 Evening meal

19:30-20:00 Home groups A

20:30- Sparklies in the Dark (John Kirkham)

# Wednesday, 9 August

- 08:00-08:30 Home groups B
- 08:30-09:30 Breakfast
- 09:30-17:00 Retro computer gaming (John Kirkham)

#### 09:30-10:30 Yo: The other half

In this presentation I will set out key issues in current law and policy (primarily in England, but with some pan-European content) on Mental Capacity, Deprivation of Liberty, Guardianship, Adult Safeguarding and "Challenging Behaviour". These issues affect substantial numbers of Autistic adults, primarily those who are less verbal and who may also have an Intellectual Disability. That population is not well represented amongst those who attend Autscape and their voice is rarely heard within Autistic communities. As a result, these issues are all too often excluded from discussion of "Autism policy", when, in fact, they massively affect the autonomy, liberty and rights of large number of Autistic adults.

I will passionately argue that Autistic adults who are not ourselves affected by these issues should, nevertheless, educate ourselves and become involved in advocacy and campaigning work around these issues.

#### **10:30-11:00** Dr. Louise Beattie: *Autism and psychosis: the role of social interactions?*

Psychosis is typically defined as a difficulty with reality-checking, and autism and psychosis frequently co-occur. 'Atypical' psychosis has been recently reported to be more common in those with autism, and this may be defined as a pronounced change in personality or alterations in functioning.

Autism and psychosis additionally share phenomenological similarities: they are both linked to difficulties in understanding others (and may share sensory processing alterations as well). Shared issues may be in social network size, loneliness, social behaviours, and social skills difficulties; stigma and discrimination likely exacerbate these and contribute towards experienced distress.

We aim to discuss the interactions of psychosis and autism, summarising the literature about what is known regarding social interactions in both, and present a new model which we have developed for discussion.

11:00-11:30 Break

#### 11:30-12:45 Concurrent discussion sessions

The other half (Courteenhall)

Autism and psychosis (Teeton)

13:00-14:00 Lunch

14:00-16:00 Various leisure activities (TBA)

#### 14:10-16:00 Lyte: Humpty Dumpty and the right mask

#### Lecture: 14:10-14:30 (Courteenhall); hands-on workshop: 14:30-16:00 (Teeton)

Mask Making – this workshop will commence with an introductory illustrated presentation (slides, imagery, metaphor and story) looking at the possibility of 'hidden' aspects of ourselves and then bringing them back to life through a hands-on mask-making activity. We will use found materials and some 'craft' materials.

This is an opportunity to explore who we may be in different contexts and areas of our lives - which are far more varied and complex than in previous generations. This can be a tremendous strain on any autistic / neurodivergent person.

This workshop offers the opportunity to explore some aspect of yourself, and make your own Mask out of materials provided or gathered, to represent this.

As a participant you will be given opportunity to then move around wearing your mask and responding to others. You are invited to bring some light cloth or shawl to Autscape for this. No prior experience is needed.

#### 16:00-16:30 Break

#### 16:30-17:15 Martijn Dekker: *Pick a side: the dilemma of being an autistic parent*

For decades two activist camps have been frequently opposite and opposed: parents of autistic children and autistic people. Those who are both autistic and a parent find themselves at a rather awkward intersection, not fitting in well with either or even rejected by both.

This lecture is an attempt to reach out. It will describe our experience and challenges and summarise coping strategies and solutions, drawing from the life experience of several different autistic parents. The dual aim is on the one hand to increase understanding between autistic people and parents, and on the other to raise awareness of the position of those who are both.

#### 17:15-18:00 Heta Pukki: Autistic identity and initiatives in four European countries

This workshop will introduce current issues that are central to autistic communities in four European countries: Finland, Sweden, Estonia and the Czech Republic. Autistic activists from each country have been interviewed about their views regarding autistic people's needs, the advocacy they are currently engaged in, and their perceptions of autistic identity.

One uniting theme for these countries is concern for autistic adults' employment situations and financial survival. This theme has been approached in a variety of ways. An ongoing service programme, a survey study, a public campaign, a recently completed project and an initiative to start a new project will be discussed.

Many English-language sources give an impression of talking about a homogeneous, global autistic culture. In the light of the examples, the participants will be invited to question such assumptions, and to discuss potential ways to learn more from initiatives and discourses generated in different cultural contexts.

19:30-20:00 Home groups A

20:00-21:00 Concurrent discussion sessions

*Identity and initiatives in European countries* (Courteenhall) *The dilemma of being an autistic parent* (Teeton)

20:00-22:00 Disco (John Kirkham)

# Thursday, 10 August

08:00-08:30 Home groups B

08:30-09:30 Breakfast

#### 09:30-10:30 John Binns: Are you high- or low-functioning? Who says, and does it matter?

Clinicians and others use 'functioning' labels to describe how well they think autistic people function in everyday (neurotypical) life, but this reflects a value judgement, and neglects context. This workshop explores what those value judgements are about and how context can have an effect, for instance for someone who functions well at home but less so at work (or vice versa). It is an opportunity to explore how such labels might be effectively repurposed so as to reflect the reality of autistic people's experience and needs, including what 'functioning' might mean from the subjective point of view of the autistic person him- or herself, and the reasons why autistic people can function better (to their own satisfaction) in some environments than others.

#### 10:30-11:00 Hannah Ebben: Autism in a historical context in our neoliberal times

The term 'autism' has meant different things for different people throughout history, ever since it was formulated for the first time by therapists. Even though it has functioned to give people the help they need, it also has a legacy of institutionalised and normalised everyday violence against Disabled people; think of the 'refrigerator theory' and the Lovaas method with its 'punishments'. Even though the autism rights moment and the principle of neurodiversity have offered alternatives, I am interested in traces of the past in the present. In my talk, I will talk about how I think about the past and the changeability of the term 'autism' with a link to the oppression of Autistic people in contemporary neoliberalism. This stands for the assessment of human value on the basis of economical worth. I then would like to discuss how we could resist the historical and neoliberal context of autism.

11:00-11:30 Break

#### 11:30-12:45 Concurrent discussion sessions

Are you high- or low- functioning? (Courteenhall)

#### Autism in a historical context in our neoliberal times (Teeton)

13:00-14:00 Lunch

14:00-16:00 Various leisure activities (TBA)

#### 14:15-16:00 James Pelham: Choral workshop

An informal rehearsal aimed at autistic adults, but mature teenagers/children would also benefit. A small selection of accessible pieces, e.g. rounds/canons to enjoy, while incorporating some basic vocal techniques to keep interest. Possibility of preparing for a performance in the entertainment event on the last night of Autscape (optional for participants.) Pieces chosen will recognise that the balance of parts may not be constant (i.e. simple 2-part songs will be preferred.) Non-singing observers will be welcome, and no minimum standard will be required.

#### 16:00-16:30 Break

# **16:30-17:15** Daniel Bendelman: *Being autistic in a non autistic world: politics and performativity of passing*

I propose to present a paper on the politics of what it means for us as both the collective autism community, and also for each individual on the spectrum, to pass within a NT world.

Drawing on both scholars of Disability critical theory, post modern thinkers such as Michel Foucault and prolific scholars on the spectrum, it will be my aim to give a broad understanding for a both a layman audience and academics in the audience, a critical reading of the impact of what passing might have within a sociopolitical context for both ourselves and NTs.

In doing so I hope that the lecture will both serve to empower and offer new ways of thinking about our every day involvement in the NT world.

#### 17:30-18:00 Annual General Meeting (AGM)

- 18:30-19:30 Evening meal
- 19:30-20:00 Home groups A
- 20:00-21:00 Discussion

Being autistic in a non-autistic world (Courteenhall)

21:00-22:30 Entertainment evening (Courteenhall)

# Friday, 11 August

- 08:00-08:30 Home groups B
- 08:30-09:30 Breakfast
- 09:30-10:00 Vacate rooms by 10:00

# **10:15-11:00** David Hartley: *Finding a better approach to autism fiction... and using fantasy to get there*

Representations of autism in works of fiction continue to be problematic. Autistic characters are still too often cliched, simplified or placed in narratives just to act as tragic metaphors for their neurotypical counterparts. It's hard to find well-rounded autistic characters who have agency in a story and show the full depth and complexity of the condition.

I am writing a contemporary fantasy novel which tries to approach autism in a whole new way. I'm using the tricks and freedoms of the fantasy genre to help avoid the lure of cliches and to give autism a fresh representation which incorporates as wide a range of experiences as possible.

My talk will be a unique insight into a work-in-progress as I attempt to chart some of the challenges I have faced and the ways I'm using fantasy, "the literature of subversion", to defeat them...

11:00-11:30 Break

#### 11:30-12:15 Panel discussion

The presenters sit down for a final discussion on the theme of this conference together with the audience.

12:15-12:30 Event feedback

13:00-14:00 Lunch

# PRESENTERS' BIOS

# Daniel Bendelman

# Presenting: *Being autistic in a non autistic world: politics and performativity of passing* (Thu. 16:30)

Daniel Bendelman trained at The Royal Central School of Speech and Drama, and has both a honours degree and research Masters, having specialised in Live Art research and Autism Representation. Daniel is a freelance academic and Installation Artist with a focus on the politics of Autism Representation.

Daniel is also a prospective PhD student for Kent University, where he will undertake research into the political aesthetics of Installation Art, in relation to a post modern critical reading of Autism Representation.

# David Hartley

# Presenting: *Finding a Better Approach to Autism Fiction... and using fantasy to get there* (Fri. 10:15)

David Hartley is a writer, performer and PhD student at The University of Manchester studying Creative Writing. He is writing a fantasy novel for his PhD based on his childhood as the sibling to an autistic older sister. The novel aims to explode apart the cliches of autism representation. His PhD has been fully funded by the Arts and Humanities Research Council.

Hartley's works of fiction have been published in many literary magazines including Ambit, Black Static and Structo. He tweets at @DHartleyWriter and regularly performs at spoken word nights in Manchester and beyond.

# Hannah Ebben

#### Presenting: *Thinking about autism in a historical context in our neoliberal times* (Thu. 10:30)

Hannah Ebben is a Dutch Autistic second-year PhD student at the Autism Centre at Sheffield Hallam University. She studies the use of the word 'autism' in films and visual personal accounts. Before her university course in the UK, she contributed to a Dutch Disability Studies research group. She has spoken at several conferences before, including her presentations at Autscape in 2015 and 2016. Having had her diagnosis of Asperger's Syndrome in 2006, she always tries to include a critical perspective in her work in order to enable activism from within the Autistic community.

# Heta Pukki

#### Presenting: Autistic identity and initiatives in four European countries (Wed. 17:15)

Heta Pukki has been involved in organising and developing autistic peer support and advocacy in Finland since the late 1990's. She has a long-term interest in exploring differences between autistic communities in other countries, and in creating international connections. She has an M.Sc. in biology (University of Helsinki) and an M.Ed. in special education for autistic adults (University of Birmingham). Her work experience includes project work, training, translating, writing and publishing educational materials about autism, and working as a personal assistant for autistic children and adults.

### James Pelham

#### Presenting: *Choral workshop* (Thu. 14:15)

James is a seasoned performer, his skills including solo performance, vocal accompaniment and choral direction. He has also had some of his compositions/arrangements performed in a professional setting. Although he sets a very high standard for himself, he is keen to encourage people of all abilities to experience and enjoy music in any setting. Being autistic himself, James is aware of the importance of clear communication in unambiguous terms, and enjoys helping people reach their full potential in their chosen area.

### John Binns

#### Presenting: Are you high- or low-functioning? Who says, and does it matter? (Thu. 09:30)

John Binns is a partner in a London law firm, specialising in 'white collar' criminal defence. In that context he frequently gives oral and written presentations to clients and peers, and attends social gatherings of lawyers and other such marketing opportunities. At home, he is a husband and a father of two children (aged 9 and 7), and regularly struggles with sensory and emotional overloads. He was diagnosed in 2014 at the age of 40.

## Dr. Louise Beattie

#### Presenting: *Autism and psychosis: what may be the role of social interactions?* (Wed. 10:30)

Towards the end of her PhD, and about to relocate to start a new job, Louise experienced her first psychotic episode. She was then referred on to the local Early Intervention in Psychosis (EIP) service, ESTEEM, and from there received an Autism Spectrum Disorder (ASD) diagnosis. She is currently conducting research into autism and psychosis, and their ramifications for social interactions and relationships.

#### Lyte

#### Presenting: *Humpty Dumpty and the right mask* (Wed. 14:10)

Lyte is a qualified, practicing artist and experienced teacher in H.E and F.E. Lyte is neurodivergent. This discovery finally shed some light on why the struggles to be 'normal' and to fit into 'mainstream' had led to turmoil and deep self-alienation. However, it also led to the finding of Autscape, community and a general re-direction into more academic work, writing, presenting and developing creative workshops to explore neurodivergence and liberation.

Lyte is motivated by a need for freedom and a longing to contribute towards the evolution of a different kind of society in which all beings can be true to themselves and each other. Eclectic, creative, with interests that have ranged from motorbike mechanics to animal communication and much besides, Lyte is a 'galaxy thinker' with particular ability to synthesise and make unexpected connections that inevitably lead to further puzzling about life, the universe and everything. They hope one day they will be comfortable with just 'not knowing'!

Lyte's neurodivergent nature is reflected in their presenting style and their 'combination workshops' which include visual images, references to fairy tales, and the inclusion of 'non-academic' and academic sources. This provides context and stimulus for participants to then explore with materials and making.

Presentations include Autscape, TAP (Theorising Autism Project: Birmingham, London), NAS Conference, 'Normalcy' (Bristol) and elsewhere. Publications include Autonomy Journal and GAP, amongst others.

# Martijn Dekker

#### Presenting: Pick a side: the dilemma of being an autistic parent (Wed. 16:30)

Martijn is a 43 year old father of three who divides his life between the Netherlands and the UK. He was diagnosed autistic in 1995 at age 21 and was actively present in online autistic space from then on. In July 1996, he started running the first entirely self-hosted online autistic community on the internet: InLv (Independent Living on the Autistic Spectrum), which lived until 2012-ish. He has also done many conference presentations on autism and autistic community themes in various countries over the years. He served on the board of Autscape in various capacities, including chair, programme coordinator and technical manager, between 2006 and 2015 and from 2016 until now.

### Yo

#### Presenting: The other half (Wed. 09:30)

Yo is Autistic. She is a trainer and consultant who works across the public sector (primarily in social care and education) with specialisms in autism and law. She creates and delivers high level training on the legal framework of adult social care (Care Act; safeguarding; Mental Capacity law; DOLS; SEND law) and specialist autism courses for education and social care professionals in many English local authorities and other clients. She has a thorough and up to date working knowledge of public law and public sector practice issues affecting autistics both with and without intellectual disabilities.