

## Speaker biographies and Abstracts:

“Ethical Ethics” by Dr Dinah Murray

It is part of every parent's job to help their babies become civilised adults who can cope with life. In autism, the notion of helping the child grow easily turns into a mission to modify the young person, however unreceptive, specifically by changing the child's behaviours with a strong emphasis on compliance and social modelling. Yet a child with a typically autistic pattern of interests is notably more capable of learning and communicating when it is based on their own interests and passions. An ethical perspective dictates deep questioning about the goals of intervention. This talk will focus on what we can and should do to change the world, rather than the individual, and what we can't. It will argue that in order to give autistic people the best possible chance in life, we need to make sure we live in a world where there is time and space for soul-fulfilment. Achieving that will not occur through compliance, typical behaviours, or reputation management skills, yet achieving it would benefit everyone. An ethical perspective shows that this is an issue beyond autism and beyond disability, which calls for widespread solidarity, determination and passion.

Short Biography:

Dinah has a PhD in linguistics and was a tutor on Birmingham University's Distance Education Autism Adults course from 1996 to 2013. She's spent thousands of hours working one to one with non-speaking autistic adults. She's been assessed as on the autism spectrum herself and has written, researched and published about it extensively.. Since late 2011 she has been involved in Ask Autism, the NAS project to develop and deliver autistic led training about autism. She is also currently involved in developing the Autistic Space Kit app, funded by the 3 Guineas Trust.

“Doing ethics the university way, is it enough?”

By Larry Arnold

“Nothing about us without us” without us has long been a slogan of the disability movement with respect to policy decisions and service provision, but what of research.

University researchers, who work with so called “vulnerable groups” will be familiar with the process of “doing ethics” that is getting ethical clearance for a project in order to ensure that the participants have given their consent and understand their position. It is also important that the process of volunteering does not produce harmful and traumatic results.

But what of the research itself, does ethical clearance mean that the project is ethical, or are there other considerations that ought to be made. In this paper, which forms the background and ethical position behind my research I suggest that the traditional ethics process is not enough, and that there are other issues to be considered, particularly for students whose disabilities have traditionally constructed them as having a diminished moral agency.

This paper introduces concepts such as the emancipatory paradigm, and Kathy Charmaz’ constructivist grounded theory as alternatives to the traditional research that separates observer and participant into “watertight compartments”

Short Biography:

“Larry Arnold has been a disability activist since the 1980s with a special interest in research and communications, being involved with a number of projects in association with local organisations and charities since those times.

He was the first person with an autism spectrum diagnosis to be elected onto the board of trustees of the NAS, having recently retired after 9 years of service.

Larry is currently researching a PhD in video as an educational tool for autistic adults at the Autism Centre for Educational Research, Birmingham University

He has been a regular presenter at conferences on topics varying from disability studies and Normalcy, to research ethics, the revisions to DSM as well as presenting his early research findings currently in write up.

He has also lectured on the social model of disability and autistic culture at Birmingham University and elsewhere.

Most recently he has written a chapter on the concept of need, for an introduction to disability studies published in 2013

## “Meaningful involvement in organising our own support – ethical issues”.

By Dr. Yo Dunn

Person centred approaches to formal support services are now widespread (Boxall et al., 2009; Martin, 2009). At the same time, continuing cuts to services have increased the difficulty of maintaining levels of support or even accessing formal support at all (Kendall & Cameron, 2013; West, 2013). This presentation will consider:

- the extent to which these approaches are effective in accommodating autistic communication differences and recognising the 'double empathy problem' (Milton, 2012);
- the autistic accessibility of person centred approaches as they are currently implemented, including approaches aimed at promoting participation where the person receiving support is non-verbal, less verbal or there are issues of capacity (such as 'Involve Me', Mencap);
- whether person centred approaches are really delivering the meaningful involvement of autistic people in organising our own support;
- the challenges of making autistic involvement in organising support meaningful when it may be a struggle to obtain support at all;
- how person centred approaches as they are currently implemented might be made more accessible to autistic people;
- what else might need to change in order to achieve more meaningful forms of involvement of autistic people in organising our own support.

The presentation will seek to highlight less obvious barriers to meaningful involvement and provide practical proposals for change.

Using illustrations from practical situations, conference attendees will be invited to consider the ethics of autistic involvement in organising our own support. The presentation will seek to challenge tokenistic approaches which provide superficial 'choice', 'participation' or 'voice' and encourage movement towards a deeper consideration of the ethics of the organisation of support services and a goal of genuinely maximising the autonomy of autistic people receiving support.

Short biography:

Yo has extensive experience of organising her own support and support for her autistic children. She has employed her own team of support workers through direct payments and disabled students allowance for over 10 years. For more than 5 years she has provided advocacy services to autistic adults and parents of autistic children to assist them in obtaining and managing formal support, gaining a broad overview of experiences across the UK in the process. She has a PhD in educational research, which included a substantial element of policy analysis across educational and other social policy fields.

“Autism spectrum conditions (ASC), ethics and issues of gender”.

By Wen Lawson

Autism spectrum conditions (ASC) are commonly thought to occur more frequently in males than in females (e.g. 4 to 1). But, is this more a case of professionals not seeing something because they are not looking for it? Females with ASC present differently in their behaviour than the males, but, again is this recognised or is it passed over as ‘just a female issue’.

Ethically, females need to be recognised and their specific needs accommodated. As Professionals, we must not dismiss this population but be checking for ASC just as we do in Males. Therefore, this presentation explores possible ways that ASC presents in females, as being different and yet the same, as in males. It also looks at what this will mean as we prepare for being senior adults living with ASC who happen to be female.

Short Biography:

Psychologist and author, being on the autism spectrum, Dr. Lawson is passionate about the rights of those who so often cannot speak for themselves. The parent of four children, one of whom is now an adult on the spectrum, and grandparent to two gorgeous little girls, also on the spectrum, Wen is committed to creating a world where individual’s on the spectrum can thrive in safety and in peace. ‘There has never been a better time to be autistic. I’m excited with the current technological advances helping us connect to and understand the world we all share.’

“So what exactly are autism interventions intervening with?”

By Damian Milton

A cursory look on an internet search engine regarding autism will soon have the viewer coming across the notion of intervention, and in particular a narrative of early intervention to help the development of autistic people. Today, the Research Autism website lists over one-thousand named interventions in the field of autism, along with indications of the amount of research evidence there is to support the claims they make. Yet, with so many on the market, it is quite obvious that they are not all trying to achieve the same goals. With discussions regarding ‘intervention’, what is often left out, is: What is it all for? What is one trying to achieve and why? Are there ethical issues regarding these purposes, or the means by which one tries to achieve them?

This presentation will uncover the dubious history of ‘intervention’ in the field of disability and mental health, before discussing the spectrum of ideology underlying current debates in the field, and the tensions that exist between different viewpoints. Such a spectrum ranges from practices aiming to eradicate autism, to those that are radically against any such notion. The presentation will use a number of research studies in the area to highlight these tensions in the field, and why they exist, will review a number of currently popular practices (e.g. ABA, RDI, Intensive Interaction), and will offer some suggestions as to a way forward that is open about such disputes rather than trying to build a false consensus between them.

Short Biography:

Damian is currently studying for a doctorate with the the University of Birmingham, a member of the programme board for the Autism Education Trust, and a member of the scientific and advisory committee for Research Autism. Damian also works for the NAS as lead consultant for the ‘Ask Autism’ project. Damian has a number of years of experience as a lecturer in both FE and HE. Damian’s interest in autism began when his son was diagnosed in 2005 as autistic at the age of two. Damian was also diagnosed with Asperger’s in 2009 at the age of thirty-six.

The conference will be chaired by Kabie Brook from ARGH and Mark Lever, CEO of the National Autistic Society.

## **Kabie Brook**

Autistic and with Autistic family members and 25 years experience working paid & unpaid with and for Autistic people of all ages.

I have specialised in supporting people labelled as having 'challenging behaviour' and am passionate about educating people to understand the communication styles and self advocacy attempts that can often be ignored and labelled as 'challenging'.

Cofounder and the current chairperson of ARGH, I sit on the Autism Reference Group, the Scottish Government advisory group responsible for implementation of the autism strategy, and as such I work in partnership through ARGH, to directly effect policy in Scotland.

As ARGH chair I am also a member of the Highland Autism Improvement Group: a multidisciplinary, multiagency group chaired by NHS Highland and also on the steering group for the AI One Stop Shop in Highland, a service that ARGH was instrumental in bringing to the area through lobbying and collective representations to the Scottish Government.

I am involved with other national & local organizations, including the Autism Network Scotland steering group, ASK (Autistic Space Kit app), the Inverness Access Panel, and as a community advisor locally, for Police Scotland.

I also have experience of organising and speaking at events, including conferences and training workshops for parents and practitioner audiences and was involved in writing material for the NAS e-learning project Ask Autism.

I am particularly interested in pandisability engagement, intersectionality, 'Autistic' as political identity and Autistic rights as a standalone and as a component of the wider disability rights movement.

## **Mark Lever**

Mark Lever joined the National Autistic Society (NAS) as Chief Executive in March 2008. During this time he has led the organisation through a period of significant strategic change.

The NAS is the UK's leading organisation for people affected by autism. The NAS runs 6 independent autism specific schools and delivers thousands of packages of community based support for adults affected by autism.

The NAS is a highly effective campaigning organisation and champions the rights and interests of all people with autism. It aims to provide individuals with autism and their families help, support and services that they can access, trust and rely upon and which can help them lead the life they choose.

Mark is a member of the National Autism Programme Board in England which oversees the implementation of the strategy for adults with autism in England.

As a founder member and Chief Executive of the NAS Academies Trust he has led the development of the organisation's autism specific free school plans. The first, Thames Valley School in Reading, opened in September 2013. Two more, one in the London Borough of Lambeth and one in Cheshire are due to open in early 2015.

Prior to the NAS he worked for 12 years at the Women's Royal Voluntary Service (WRVS), holding a range of roles, including, Director of Strategic Development and Operations and then CEO. He was previously a partner at accountancy firm Kidsons (now Baker Tilly). He is a Cranfield MBA, a member of the Institute of Chartered Accountants and the Chartered Institutes of Personnel and development, and Marketing.

When he is not negotiating peace settlements and behavior related pay awards with his four boys he relaxes by cooking, drinking wine with his wife, long distance cycling, running a disco for charity and regularly losing at tennis and golf.