



AUTSCAPE

2011 "Owning Autism"

22 – 25 August 2011 Ackworth School, Pontefract, Yorkshire, UK

Part 2: Programme

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1. Presentations

Everything at Autescape 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.

Please note that although breaks for meals are 1.5 hours total, you can only get food **during the first half hour**.

Monday, 22 August

14:30-17:00 Registration (Information Area)

See part 1 for details of what to do. Spend this time relaxing and settling in - personalise your name badge or folder if you like. Some sensory items and games will be available.

17:30-18:00 Orientation (Music Centre)

Orientation will explain a few things about how things work at Autescape. There may be new information, so please come along even if you have attended Autescape before. Attendance is *strongly recommended* for all participants.

18:00-19:30 Supper (service until 18:30; Dining Room)

19:30-22:00 Evening Activities (various locations)

In the evening there will be a variety of casual and semi-structured activities including discussions, films and games. Lists of exactly what's on and when will be available at Autescape.

Tuesday, 23 August

08:00-09:30 Breakfast (service until 8:30; Dining Room)

09:30-10:15 Owning autism research – Kalen (Music Centre)

Autistic people may be involved in autism research as participants, consumers, advisers, scientists and critics. As members of a group that is currently a hot topic for research, an understanding of the research process is particularly important for autistic people. This presentation will introduce participants to research ethics, methods, and results. Through this, we will explore the scope and limits of participants' rights and what research is really telling us about autism. Finally, we will discuss ways in which we can communicate our interests so researchers can better focus their efforts in ways that will benefit us. Through an understanding of the research process, passive subjects can become active participants and collaborators, and uncritical recipients of media reports can become critical consumers of study results. Participants will leave this presentation with knowledge that will help to empower them to take active ownership of autism research whatever their involvement.

10:15-11:00 *Pitfalls in autism diagnosis and support: reflections from an autistic doctor – Ava-Ruth Baker (Music Centre)*

There is a vast range of methods and quality in attempts to provide autism diagnosis and support, but largely based on 'outsider' views. The presenter, who trained under autism professionals from both sides of the world, will share some of her own observations, experience and ideas from two decades working in this field, both before and after her place on the autism spectrum was formally confirmed. She will include examples of the shortcomings of current 'outsider' approaches to autism diagnosis, counselling and support, and allude to the personal struggles of working as an 'insider' in this field, amid feedback ranging from professional hostility to client appreciation for 'insider' insight.

11:00-11:30 Break (drinks and snacks will be in the Dining Room)

11:30-12:30 *Discussion of "Owning autism research" (Music Centre)*

12:30-14:00 Lunch (service until 13:00; Dining Room)

14:00-15:00 *Leisure (various locations)*

In parallel with the leisure times on Tuesday afternoon people can visit SpaceKraft. See <http://www.autscape.org/spacekraft> for more details.

15:00-16:30 *Leisure/Art (Coram House Art Room)*

16:30-17:00 Break (drinks and snacks will be in the dining room)

17:00-18:00 *Owning the languages of autism – Martijn Dekker (Music Centre)*

Words have not just a literal meaning but also a connotation. Connotations hiding in words like "empathy", "happy", "behaviour", "repetitive", "epidemic" may be used to influence your personal life as well as the position of the autistic community in society. This workshop will start with a presentation outlining currently used autism-related expressions and turns of phrase in European languages, and on how these influence the situation of autistic people in the corresponding countries. This is meant to inspire a moderated participant discussion on topics including:

- How a different choice of words might make you more effective in advocating for yourself, e.g. when it comes to disclosing your own condition.
- How autistics can "read between the lines" to understand the agenda behind a text or speech.
- How to take control of the public discourse surrounding autism to be more effective in public self-advocacy.

18:00-19:30 Supper (service until 18:30; Dining Room)

19:30-20:30 *Discussion of "Pitfalls in autism diagnosis and support"*

19:30-22:00 *Evening Activities*

Wednesday, 24 August

08:00-09:30 Breakfast (service until 8:30; Dining Room)

09:30-10:15 *Owning our support: personalisation - theory and reality – Yo (Music Centre)*

This session will provide participants with an overview of the policies which are currently being implemented in social care services in the UK and how those policies are working in practice. Although the presentation will focus on the UK, this will also have some relevance to those from other countries, as similar systems of personal budgets operate in many other countries, including France, Germany, the Czech Republic and the Netherlands. As well as the national picture, the presentation will offer examples of individual experiences of the current programme of personalisation. This will enable participants to relate their personal experiences to a wider context which may help them to make more informed choices about how and whether to own their own support. This session will provide participants with an overview of the policies which.

10:15-11:00 *An insider's critique of the dominant psychological models of autism – Damian Milton (Music Centre)*

This paper critically reflects upon the most recent attempts to build a psychological explanatory model of autistic spectrum conditions, from the viewpoint of an 'insider'. This paper contains an overview and critique of the three dominant theories of more recent times: 'theory of mind' deficit, executive dysfunction, and weak coherence theory, followed by a critique comparing and contrasting two of the most recent models: empathising-systemising theory and monotropism theory. A major criticism of the majority of these models that is highlighted in this paper, is that they are formed from a perspective of a cognitive paradigm overly restricted by its total adherence to scientific method, often blind to sociological issues, and restrictive of the 'autistic voice' being heard. It is argued in this paper that the inconsistencies of these models need to be critiqued, in order to subvert the dominance they enjoy in defining what it is to be autistic.

11:00-11:30 Break (drinks and snacks will be in the Dining Room)

11:30-12:30 *Concurrent discussion of "Owning our support" and "An insider's critique" (locations to be announced)*

12:30-14:00 Lunch (service until 13:00; Dining Room)

14:00-15:00 Leisure

15:00-15:45 *Use it or lose it. How autism has been owned, and how to claim it for ourselves – Larry (Music Centre)*

This presentation intends to ground the concept of owning autism historically and build upon that to give a historical perspective to where we are currently at in terms of self advocacy, and to give a very pragmatic basis in the various ways, both large and small that an individual can bring the focus of "ownership" back to the people who live with and have to deal with the consequences of the way autism is currently understood and controlled in terms of the way the diagnosis is given and services provided. Larry considers that taking ownership of autism is a very important tool in self advocacy and one which can be asserted in many ways at many levels. His

presentation is definitively not a part of his research role but wholly of his advocacy role and comes from his background in a lot of disability movements.

15:45-16:30 *Specialisterne Scotland: passion for details – Alastair Cooper (Music Centre)*

Specialisterne is a non-profit company originally set up in Denmark by Thorkil Sonne after his young son was diagnosed with autism. He set it up with a vision of enabling people with autism to make positive use of their differences in the field of information technology, specifically software testing, having found that many of these perceived disabilities were extremely beneficial in this area. Specialisterne Scotland is the first overseas expansion of Specialisterne, based in Glasgow. It currently employs several people with autism in the field of software testing and runs an on-going recruitment and training cycle. Alastair will discuss the operation of Specialisterne Scotland, and the opportunity it has presented to him personally as a person with high-functioning autism and some computing background. He will also talk about the recruitment process for Specialisterne, and how the training programme might be of interest to Autescape attendees.

16:30-17:00 Break (drinks and snacks will be in the Dining Room)

17:00-18:00 *Concurrent discussion of “Use it or lose it” and “Specialisterne Scotland” (locations to be announced)*

18:00-19:30 Supper (service until 18:30; Dining Room)

19:30-22:00 *Evening Activities*

Thursday, 25 August

08:00-09:30 Breakfast (service until 8:30; dining room)

09:00-09:30 Packing (please vacate your room at this time)

09:30-11:00 *Annual General Meeting (AGM; Music Centre)*

All Autescape members have the opportunity to vote on issues related to the running of The Autescape Organisation. If you wish to become a member (£5 per year) please contact registrar@autescape.org. Membership helps to support Autescape, allows you to vote at the AGM and, in the coming year we hope to offer more benefits for members.

11:00-11:30 Break (drinks and snacks will be in the dining room)

11:30-12:30 *Panel discussion on the theme of “Owning autism” - various presenters (Music Centre)*

12:30-14:00 Lunch (service until 13:00; Dining Room)

2. Presenters' Bios

Larry Arnold

Presenting: Use it or lose it. How autism has been owned, and how to claim it for ourselves

Larry has played a pivotal role in the Autism Rights movement in the UK, serving on the board of the NAS and facilitating a local neurodiversity group amongst other things. He comes from a background of disability rights and specialise in video, this being the topic of his research in Autism and Education at the University of Birmingham. He claims the right to be called neuro-diverse by virtue of more than one neurological diagnosis; however, autism is one he is happy to use as a positive affirmation of who and what he is.

Ava-Ruth Baker

Presenting: Pitfalls in autism diagnosis and support: reflections from an autistic doctor

Ava-Ruth was diagnosed autistic in adulthood. A gifted but 'odd' child, she was obsessed with other cultures and languages, resolved to be an interpreter but trained in medicine and mental health, and after a circuitous life journey, found her current niche interpreting between different autism perspectives (insider versus outsider), different medical paradigms (orthodox versus holistic), and providing autism diagnosis and support. She has contributed to two autism books, co-founded ASK (support for and by autistic adults in NZ), serves on the 'expert advisory group' for implementing the New Zealand ASD Guidelines, and has presented at previous conferences including Autscape 2009.

Alastair Cooper

Presenting: Specialisterne Scotland: passion for details

Alastair Cooper has high-functioning autism and has been involved with Specialisterne Scotland since November 2010, having graduated with Distinction from the University of St Andrews in June of that year. He has derived immense value from the opportunity presented by Specialisterne and is keen to spread awareness. Alastair has a keen interest in computers which he channels through his work and enjoys watching, but not playing, tennis. He is also interested in politics and current affairs.

Martijn Dekker

Presenting: Owning the languages of autism

Martijn Dekker, from the Netherlands, has a diagnosis of high functioning autism and has been internationally active in the autistic community since 1996. The online support group he started in that year was recognised in the New York Times. He has presented at autism conferences in four languages in countries across Europe and in the US. In his private life he has an active interest in European languages and translation.

Kalen

Presenting: Owing autism research

Kalen has gained an understanding of autism research as both participant and researcher. Her undergraduate studies in neuroscience and psychology included rigorous education in research design and analysis. Following this, postgraduate studies in medical ethics included a detailed look at research ethics. Kalen has been involved with Autescape since its inception. She has given presentations for autistic and other audiences including several at Autescape which were well received. Currently on maternity leave from her studies, she is the busy mother of four children who, despite the odds, are not autistic (yet).

Damian Milton

Presenting: An insider's critique of the dominant psychological models of autism

Damian is a doctoral researcher with the University of Birmingham, and holds a number of academic qualifications in Sociology, Psychology, and Education, with experience as a lecturer in Further and Higher Education, and presenting at academic conferences. Damian has a diagnosis of Asperger's, and is a single father to his young son who has a diagnosis of autism.

Yo

Presenting: Owing our support: personalisation - theory and reality

Yo was diagnosed (Asperger Syndrome) 10 years ago and has two children who are both also autistic. She has extensive experience of personalisation, both through her own experience and her work as an advocate for other autistics interacting with social care services around the country. She has a PhD in policy analysis and is familiar with the national policy climate in the area of social care.

3. Timetable

	Monday	Tuesday	Wednesday	Thursday	
08:00		Breakfast			
09:00		Break		Packing	
10:00		Owning autism research <i>Kalen</i>	Owning our support <i>Yo</i>	AGM	
		Pitfalls in autism diagnosis and support <i>Ava-Ruth Baker</i>	The dominant psychological models of autism <i>Damian Milton</i>		
11:00		Break			
12:00		Discussion of 09:30 lecture	Concurrent discussion of 09:30 and 10:15 lectures	Panel	
		Lunch			
13:00		Lunch			
14:00		Registration	Leisure		
15:00			Leisure/Art	How autism has been owned, and how to claim it for ourselves <i>Larry Arnold</i>	
	Specialisterne Scotland - Passion for Details <i>Alastair Cooper</i>				
16:00	Break				
17:00	Break	Owning the languages of autism <i>Martijn Dekker</i>	Concurrent discussion of 15:00 and 15:45 lectures		
	Orientation				
18:00	Supper				
19:00					
20:00	Discussion of 10:15 Lecture		Evening Activities		