

## 2017 annual report

Exploring Diagnosis (Ex Dx) is on track, working steadily through the research questions and public engagement strategy outlined in the original applications to meet our objectives. Research questions have been adapted by the team members responsible for each area, and fall under three broad themes: diagnosis, treatment, and neurodiversity.

### Highlights:

#### 1. *Diagnosis theme:*

- 2 PhD Theses (ongoing)

We have two excellent PhD candidates supported through the award, Jennie Hayes (JH) and Thomas Lister (TL), a social psychologist and sociologist, respectively. TL was appointed in Feb 2017; JH is now in her second year and successfully passed her PhD upgrade in December. JH's PhD on *Social Process in Autism Diagnosis* uses observational methods on multidisciplinary teams in clinical diagnostic practice to establish how decisions are negotiated and made. TL is looking to develop key concepts in medical sociology such as medicalisation, ways of knowing and labelling through examining the function and impact of diagnosis, and particularly self-diagnosis for autistic adults.

- 1 encyclopaedia entry (in press)

For the encyclopaedia *Disability in American Life* Steven Kapp (SK) collaborated with Jennifer Sarrett of Emory University, US on *Self-Identification and Self-Diagnosis in the Autistic Community*.

- 3 'Debates'

The Ex Dx website [www.ex.ac.uk/exdx](http://www.ex.ac.uk/exdx) is a platform for academic and cultural debates aimed at audiences of parents, clinicians, academics and autistic adults. Our first debate features an autistic academic/activist and a psychiatrist discussing whether autism has an essential nature, the second gives parent/academic insights on diagnosis and its consequences, and in the third two clinicians consider social issues in diagnosis.

- Ex Dx was commended for its excellent work by the Power Threat Meaning Framework (PTMF), a new network of clinicians and patients seeking to develop an alternative approach to treating mental health than through diagnosis. We have subsequently joined.

## 2. *Treatment theme:*

- Academic journal articles (1 published and 3 in press).

The published article is an examination of selective patient and public involvement using autistic adults' perspectives on drug treatment, published in *Health Expectations* (Russell et al. 2017), and is a collaboration with Ilina Singh at Oxford.

We also produced an associated short film that puts the questions of autistic adults to biomedical researchers, co-hosted by our website and the EU-AIMS project, a pan-European biomedical consortium that was working towards developing drug treatments for autism.

The articles in press are *Social Support, Well-Being, and Social Support among Individuals on the Autism Spectrum*, in the top US Journal *Pediatrics*, led by SK and *Dilemmas of Dementia Diagnosis in International Journal of Care and Caring* by the PI Ginny Russell (GR) and a systematic review. 2 further articles were submitted in 2017.

## 3. *Neurodiversity theme:*

- Book contract

Provisionally titled *Autistic Activism and the Neurodiversity Movement: Stories from the Frontline*, the contract is for a monograph with Palgrave Macmillan led by SK. The book will provide an overview of the neurodiversity movement, describing the key actions of autistic activists in the movement in their own words, covering how these actions have influenced how we understand autism in more social terms of civil rights and identity rather than as a medical collection of deficits and symptoms. Such a historical overview has never been attempted. The book will also provide a critical space, led by GR, looking at activists' responses to various academic critiques that have been made of neurodiversity.

- Book Chapter (in press)

This examines parallels between the Neurodiversity Movement and other consumer-survivor movements of the 20<sup>th</sup> Century by GR in collaboration with historian Erika Dyck at University of Saskatchewan, Canada, for 'Healthy Minds in the Twentieth Century' commissioned by Palgrave Macmillan Social Histories of Medicine Series.

## *Public engagement*

- 10,000 neurodiversity leaflets.

Last year, we were asked by a psychiatrist collaborator at our local Child and Adolescent Mental Health Service to provide information about the Neurodiversity Movement so we created a leaflet in consultation with parents, autistic adults and clinicians as an additional resource for newly diagnosed people. 100 UK NHS diagnostic services have received it, found it useful and informative (and requested more).

- Film workshops for autistic adults.

We have run five animation workshops with our film partners, Calling the Shots. Our website hosts resulting film clips and the associated blog. These workshops, held at the National Autistic Society's Lynx Centre, St Marks Centre, and Stallcombe House, have taught animation skills to over 50 adults with autism. We achieved inclusive participation across the spectrum which was a major ambition, and aided us in involving autistic adults in the wider research projects. In 2017 the Trust awarded us a PPE award to support our public engagement activities in film.

Our ongoing research and planned PPE activity includes:

- Systematic review of guidelines for diagnosis in UK, led by JH.
- Re-evaluation of autistic symptoms (repetitive behaviours known as stimming) as having functional and adaptive purpose: collaboration with Centre for Research in Autism and Education at UCL, with SK and GR.
- Mapping the autistic advantage: reporting autistic adults' self-reported strengths led by GR.
- Neurodiversity and treatment for autism: perspectives from autistic adults, led by Ruth Gwernan-Jones who has been working part-time as a research fellow.
- Functions of the diagnostic label for adults who self-identify as autistic, led by TL.
- Examination of diagnostic tools –who has access to them and how they work, led by GR.
- How disclosure of diagnostic labels affect children's perceptions of a classmate, involving GR, SK and JH.
- A fourth debate is planned between autistic activists about the prospects for an independent autistic state.
- Autism voices project in collaboration with Wellcome centre in Oxford.
- Discussion and podcast on PTMF/diagnosis in collaboration with Wellcome centre at Exeter.
- Animation workshops for autistic adults at National Autistic Society's Lynx Centre
- We are currently recruiting, interviewing and commissioning autistic activists and artists for our three short films

### *Challenges*

The most challenging aspects for the PI have been management -handling her own and others' expectations, balancing administration, engagement and research work, and staff retention and recruitment. We have benefitted enormously from the advice of the advisory board and senior Exeter academics. A key strength has been insider involvement of autistic researchers. Bi-weekly team meetings, annual advisory meetings and occasional social events have fostered team support for individuals' differing working rhythms.