NIHR CLAHRC for Cambridgeshire & Peterborough

Collaborations for Leadership in Applied Health Research and Care



Applied research in autism in the CLAHRC CP

Briefing paper, November 2012

Cambridgeshire and Peterborough CLAHRC (CLAHRC CP) is a collaboration between the University of Cambridge and the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), in partnership with other organisations. It is funded by the National Institute for Health Research.

What is autism?

Autism and Asperger Syndrome are part of a range of developmental conditions known as autism spectrum conditions (ASC). They affect how a person communicates with others and how they make sense of the world around them. Individuals with ASC have difficulties in social interaction and adapting to change, alongside unusually narrow interests and strongly repetitive behaviour.



A pplied research aims to deliver practical improvements to patient care within a relatively short timeframe. Autism research at the CLAHRC CP is led by Professor Simon Baron-Cohen at the University of Cambridge Autism Research Centre (ARC) and focuses on:

- creating practical tools for detecting autism;
- creating special educational materials for teaching social skills;
- improving local services for adults with

autism; and

creating a new clinical centre of excellence for autism.

The 'Red Flags' project

ASC can be difficult to diagnose. Symptoms can be hard to detect and assess in very young children and there is often a delay in receiving an assessment and a diagnosis.

The Red Flags are 4 brief checklists (one for each of 4 age groups: toddlers, children, adolescents, and adults). Each of these was tested with 1,000 patients. Results showed that all 4 checklists accurately predicted cases of autism. The checklists provide a quick and accurate tool to help both parents and healthcare professionals decide whether there is a need for a specialist assessment to diagnose possible autism.

To make all 4 Red Flags easily accessible to front line professionals (including social workers), parents, and adults with suspected autism, the Red Flags will be available online at www.redflagsforautism.com in 2013.

The 'Teaching Emotions' Project

Prior to the CLAHRC the Autism Research Centre (ARC) developed two educational DVDs to teach people how to recognise emotions:

'**The Transporters' DVD** (www.thetransporters. com) is aimed at young children with autism. It was developed in collaboration with Culture Online to help children with autism aged 5-10 years old. It is an animation that uses vehicles with emotional faces grafted on, because young children with autism love to watch movies of vehicles moving in predictable ways along tracks. In this way they are learning valuable social skills that they otherwise miss out on.

The 'Mindreading' DVD (www.jkp.com/ mindreading) is a comprehensive electronic encyclopaedia of emotional expressions. It contains over 5000 video and audio files of actors expressing every human emotion, aimed at people with autism age 4 years up to adulthood to learn to recognize emotions.



CLAHRC CP has gathered feedback about these two interventions, and with European Union funding we are now adapting them to make them available as online interactive special educational resources.

The 'Autism Pathways' Project

Adults with Asperger Syndrome (a subgroup on the autistic spectrum) have been overlooked by the NHS and Social Care in the past. In recognition of this the UK Government produced the Autism Act (2009) and the Autism Strategy (2010). CLAHRC CP is represented on the Autism Program Board at the Department of Health.

Locally we work collaboratively with patients, the NHS, the National Autistic Society and local agencies to improve the way adults with autism are supported in Cambridgeshire and Peterborough. The CLASS (Cambridge Lifespan Asperger Syndrome Service) clinic has pioneered methods for the diagnosis of autism and Asperger Syndrome in adults and diagnosed over 700 patients who otherwise were overlooked. The CLASS clinic was set up in 1999 by Professor Baron-Cohen with charitable funding from the Three Guineas Trust and since 2011 it has been part of Cambridge and Peterborough Foundation Trust (CPFT). For more information about the CLASS clinic for adults see www.cpft.nhs.uk/services/class-clinic. html.

The 'National Autism Clinical Centre' Project

The National Autism Clinical Centre is a collaboration between two charities (the National Autistic Society and the Autism Research Trust) as well as CPFT and Cambridge University. Its aim is to provide a model service for people with autism. It will be based in Fulbourn Hospital and is expected to open in September 2013. Initial plans have been drawn up and people with autism will be involved in the design of the building and the planning of services.

How we engage with the public in our work

The ARC has a database of 30,000 individuals with a diagnosis of ASC or a relative with ASC who have registered as volunteers. As well as participating in studies, volunteers have the opportunity to feed back about their experiences of taking part in research and often put forward ideas for new research.

We involve people with autism and parents in every stage of our research projects to make sure the research is relevant to them. For example, we hold focus groups to discuss possible research ideas, and we involve them in the advisory groups that oversee the research projects.

Further information

To find out more look on our website and join our mailing list: www.clahrc-cp.nihr.ac.uk or contact Professor Simon Baron-Cohen at the Autism Research Centre; sb205@cam.ac.uk

To join the Autism Research Centre volunteer database visit www.autismresearchcentre.com/ register.