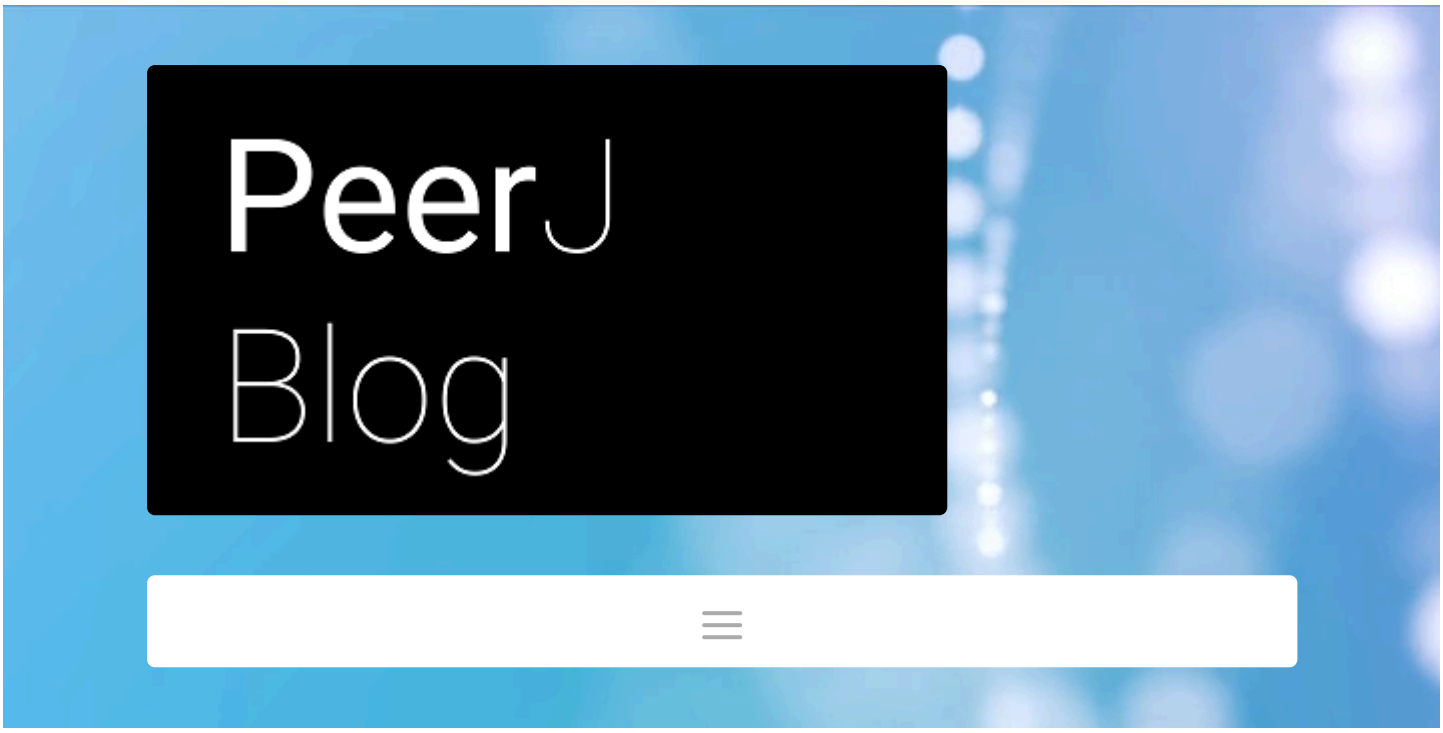
PeerJ
Blog

World Autism Awareness Day – Interview with Prof Baron-Cohen

by PeerJ Staff | Apr 2, 2014 | regular

In honor of the 7th annual World Autism Awareness Day (April 2nd), we invited Professor Simon Baron-Cohen, Academic Editor at PeerJ, to share his vision of autism.

Simon Baron-Cohen is Professor of Developmental Psychopathology at the University of Cambridge and Fellow at Trinity College, Cambridge. He is Director of the Autism Research Centre (ARC) in Cambridge.

What is your definition of autism?

Autism involves difficulties in socializing and communication, alongside unusually narrow interests and a strong need preference for predictability. It is a wide spectrum because it can be accompanied by other disabilities, such as learning difficulties or language delay of a moderate or severe nature; and because it can express itself so differently in different people.

For example, some people develop secondary (and in my view preventable) depression as a result of feeling socially excluded; many show extreme anxiety because their environment is not autism-friendly; some show self-injury perhaps because of the frustration of communication problems or to drown out sensory overload; in females the autism may result in anorexia because their narrow interest focuses on food and predictable body weight; and some people with autism may have medical conditions such as epilepsy or gastrointestinal issues, probably reflecting how the causes of autism do not just affect the mind and behaviour but also the rest of the body.

Note that my definition of autism is different to the formal definition in the American Psychiatric Association, in at least 3 ways. I don't mention "repetitive behaviour" even though I recognize this is often a key 'symptom', because I see this as a product of the unusually narrow interests that the person keeps returning to again and again, or as a sign of the person's need for predictability, which repeating actions allows.

Nor do I mention "obsessions" because this pathologizes what I see as a special learning style: that whilst most of us are content to have superficial knowledge of a wide number of topics (we are generalists), people with autism prefer to learn one topic at a time, in complete detail, thoroughly and deeply. They are specialists, not generalists. In an academic or professional context we would call this 'expertise' and we place a high value on it.

In a clinical context some doctors label this as an 'obsession' but this risks missing the potential of this learning style and how this can be harnessed to support the person to achieve their potential. In the bad old days, calling this behaviour an 'obsession' even led to the view

that such behaviour should be eradicated. Hopefully today we respect there is diversity in how people learn, and that we need to provide learning environments for both generalists (the majority of the population) and specialists (the minority of population, the extremes of whom might end up with a diagnosis on the autism spectrum).

Naturally, being a specialist in your learning style by itself doesn't mean you need a diagnosis, and nor does having a strong need for predictability. In the right environment these qualities need not interfere with your functioning and may even be an asset. But for some people these qualities bring them into difficulties in daily life. It may hold them back in their language or learning development or it may cause them extreme social confusion and social isolation, with all the negative consequences this can lead to. It is when these characteristics lead to an inability to cope that the person needs a diagnosis. This reminds us that diagnosis is as much about the "fit" between the individual and their environment as it is about the individual.

Finally, you might notice I don't use the term 'disorder' to describe autism. 'Disorder' has the connotations of something in the brain being 'broken', whereas all the scientific evidence I have read simply shows that the brain and mind in autism is different, not broken. I prefer the word 'condition' because this highlights that in some environments and in some individuals these differences result in disability where the individual needs support; and this word highlights that the disabling aspects of autism arise as a result of biomedical factors. Finally, the word 'condition' is less harsh and less stigmatizing: we all have conditions of one kind or another, in a transient or more permanent way. Few of us would want to be told we are 'disordered'.

I look forward to the American Psychiatric Association pulling itself into the 21st century by renaming the long list of diagnoses in the "Diagnostic and Statistical Manual (DSM)", to move away from the Victorian language of "Mental Disorders" to what could more neutrally be called "Neurodevelopmental and Psychiatric Conditions".

Can you tell us a little bit about your work at the Autism Research Center in Cambridge?

We study autism at multiple levels, from behaviour and cognition, through to the structure and function of the brain, to the ultimate causes of differences in the brain and mind that lie in genes and their interactions with epigenetic factors.

We also balance 'basic research' that aims to characterize the differences in and the causes of autism, with 'applied research' which aims to evaluate promising new interventions to ensure these are evidence-based, or to develop new tools for clinicians (e.g., in screening for early detection) or new tools for people with autism (e.g., educational software for people with autism to learn to recognize emotions in a more autism-friendly format).

Such multi-level research requires collaborations across different disciplines (for example psychology, neuroscience, genetics, molecular biology, endocrinology, pediatrics, and education) that make science both exciting (not being trapped within a discipline but learning about adjacent disciplines) and relevant (e.g., to social policy and changing the lives of people with autism).

Why is autism more common in males?

This is a big question that, for the first 50 years of autism research, was largely ignored. In the mid 1990s our group "woke up" to this big clue about the causes of autism that Nature was handing to us on a plate: that the cause of autism is likely to involve aspects of our sex-linked biology. Why otherwise would all population studies of autism show a sex ratio of at least 3 or 4 males to every female?

In the subgroup known as Asperger Syndrome (AS) reports suggest a sex ratio as high as 9 or 10 males to every females, and this may reflect under-diagnosis of AS in females (because they are more socially motivated – or find it easier – to hide their social and communication difficulties, from as soon as they start school), or mis-diagnosis of AS in females (it can express itself as anorexia, or social anxiety, or depression, or even Borderline Personality Disorder). But even when we are better at diagnosing autism in females, I suspect we will still find it is more common in males.

Our group has been testing the hormone testosterone during prenatal life, since animal research from the last half century shows this (and other sex steroid hormones like oestrogen) 'masculinize' the brain in permanent ways. The male foetus produces twice as much testosterone as the female foetus. Measuring prenatal sex steroid hormones in humans is very difficult but we have found a way to do this in an ethical way, via amniocentesis during pregnancy. It is crucial that we measure this hormone during the "critical period" of development (prenatally) because this is when it has its long-term effects on brain development.

Because amniocentesis itself is rare (in the UK it is only conducted in 6% of pregnancies and always only for clinical reasons) and autism is relatively rare (about 1% of pregnancies), we have collaborated with the Danish Biobank who had the foresight to collect and store all amniotic samples from the 1980s onwards. In their deep freezer in Copenhagen, they have 100,000 samples. Their national diagnostic register means we know which of these pregnancies resulted in the child developing autism.

We were therefore able to solve the scientific challenge of how to measure fetal testosterone and its precursor sex steroid hormones in children who go on to develop autism, to test the hypothesis that these hormones might be elevated in these children. The results will be published soon after Autism Awareness Month in 2014.

Professor Simon Baron-Cohen is author of several books including *Mindblindness* (MIT Press), *Autism and Asperger Syndrome: The Facts* (OUP), and *The Essential Difference* (Basic Books/Penguin UK).

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