



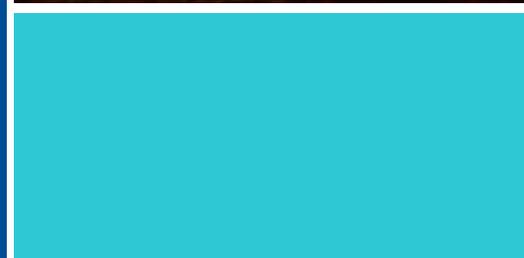
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Bridging Autism, Science and Society in the UK

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www.ioe.ac.uk



impact of the “new autism sciences”

guardian.co.uk

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Is autism screening close to reality?

Call for ethics debate as tests in womb could allow termination of pregnancies

Sarah Boseley, health editor
The Guardian, Monday 12 January 2009
[Article history](#)

New research published today will bring prenatal testing for [autism](#) significantly closer, prompting experts to call for a national debate about the consequences of screening for the disorder in the womb and allowing women to terminate babies with the condition.

The breakthrough study by Cambridge University's autism research centre has followed 235 children from birth to the age of eight. It found that high levels of testosterone in the amniotic fluid of pregnant women was linked to autistic traits, such as a lack of sociability and verbal skills, in their children by the time they are eight.



impact of the “new autism sciences”

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15-minute brain scan developed by British scientists could spot child autism earlier

By JENNY HOPE

Last updated at 9:55 AM on 11th August 2010

MRC

Medical
Research
Council

NEWS & PUBLICATIONS

Autism in adults diagnosed by quick, new brain scan

Tuesday 10 August, 2010

Scientists funded by the Medical Research Council (MRC) have developed a pioneering new method of diagnosing autism in adults. For the first time, a quick brain scan that takes just 15 minutes can identify adults with autism with over 90% accuracy. The method could lead to the screening for autism spectrum disorders in children in the future.

“

It could help to alleviate the need for the emotional, time consuming and expensive diagnostic process which ASD patients and families currently have to endure”

Dr Christine Ecker
Lead researcher



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Autism, Ethics and Society

10am – 5:30pm, 28th June 2010 · Anatomy J.Z. Young Lecture Theatre · University College London

<http://www.ucl.ac.uk/cpjh/autism>

public challenges to the “new autism sciences”

1. should we be pursuing a “cure for autism” and striving for a single “normal” developmental pathway?
2. does this have different implications for individuals who are so-called “high-functioning” and “low-functioning”?
3. who should be asked to make these decisions? scientists, parents, or autistic people?
4. is there any way of resolving disagreements?

who should get a say?

some researchers have suggested that clearly stating one's research goals at the outset should itself foster ethically responsible scientific pursuits ... **but claiming neutrality is not enough**

scientists must recognise that (a) science is not completely impartial, especially in the context of such highly charged issues; (b) the research they carry out and report has non-neutral implications for directly concerned parties; and (c) they must listen to, and learn from, non-scientists

who should get a say?

parents have a unique experience about the onset and development of their child ... and people with autism have direct experience of what it is like to be autistic → each has access to a “special kind of knowledge”

this “experience-based expertise” is vital but it needs to be combined with, rather than to replace, that of the scientific researcher

we need constructive dialogue

Three preconditions to engagement:

1. disagreement is inevitable and must be recognized
2. many concerned parties are currently excluded from decision-making or are dramatically under-represented
3. not all participants are equally affected by the impact of the new sciences of autism

three concrete suggestions from the UK conference

1. extensive quantitative and qualitative research is required on the attitudes of autistic people and parents and carers to the new sciences of autism and their application
2. proper participatory decision-making processes are required in all areas of research and policy on autism
3. researchers should recognise that such engagement as an essential part of the research process

conclusion

the new sciences of autism have generated much excitement both within and beyond the research community

... but this excitement is tempered by significant social and ethical concern

the way forward involves fostering “inter-dependence”, crafting new mechanisms of participation and dialogue to build a bridge between scientists and the broader autism community

many thanks to ...

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