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Studying autism genetics responsibly

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Autism and Asperger Syndrome are two subgroups on the autistic spectrum. They both share difficulties in social relationships and in communication, alongside the presence of unusually narrow interests and a strong preference for predictability. They are neurological and, as we now realise, strongly (though not 100 per cent) genetic. These two subgroups are differentiated by the presence of language delay and/or learning difficulties in autism, and by the absence of these in Asperger Syndrome.

Some people with Asperger Syndrome worry that research into the genetics of their condition will be misused to develop prenatal teststhat will lead to the eradication of the conditions. Their worries are not unfounded given that such prenatal testing is already possible and being used in this way in relation to other conditions (like Down Syndrome). And their worries raise the spectre of eugenics, which was fashionable within the medical profession in the first half of the 20th century in the US and in parts of Europe, but which turned into a horrific nightmare as it was integrated into the social policies of the Nazi government in Germany during WW2. The Nazis attempted to produce an Aryan race that was genetically pure even if it meant extermination of those who were different. This included those who were ethnically different, or different in their sexual orientation, or by virtue of having disabilities.

Genetic research into autism, the argument goes, can lead to such policies, if not as part of a eugenics program, then at least by making available a prenatal test that parents might use to make their choice as to whether to

continue or terminate a pregnancy. The latter scenario is based around the parent's perspective, rather than the perspective of the unborn child who may go on to develop autism. Clearly in this moral debate, we need to keep a keen eye on both perspectives. Note too that the perspective of the parent and the perspective of the unborn child are not invariably opposed, since some parents would be equally offended by the idea that autism should be eradicated.

I would argue that there *are* ways in which genetic research into autism can be conducted responsibly, so as to alleviate these otherwise well-founded worries. The first is to make clear why the research is being conducted. In our lab in Cambridge, for example, we have a clear statement on our website which declares that we wish to advance knowledge into the causes of autism and Asperger Syndrome, and that our agenda is not to eradicate autism. The second is to consider non-eugenic applications of such basic research. These might for example include early detection, so that families and their children are given the right support at an earlier point, instead of waiting for many years without support. A third might entail using genetic research to develop a medical treatment, though this may itself raise new ethical issues.

(In the best-case scenario, a medical treatment would alleviate any 'symptoms' that are causing suffering, whilst leaving those aspects of autism that are positive to flourish. Autism does involve positive as well as negative features, the positive ones including excellent attention to detail and the ability to focus for long periods on a narrow topic. New treatments therefore need extremely careful evaluation to consider their potential unwanted side-effects).

All of this means that, whilst genetics research is still a long way away from identifying which genes are necessary and sufficient for causing autism and Asperger syndrome with any specificity, it is key to have the debate way ahead of the research being in a state where it could be used or misused. Such debate might need to result in legislation and regulatory frameworks. And to pin my own colours to the mast, I for one am pro-diversity both socially and in terms of genetics; and believe that people with autism or Asperger Syndrome have