

Autism and prenatal screening

December 2 2013, by Andrew Whitehouse

The internet was ablaze last week with the news that health authorities in Western Australia (WA) have given approval for IVF clinics to 'screen' embryos to reduce the chances of a couple having a child with autism.

The [Reproductive Technology Council](#) will now allow certain women undergoing IVF treatment to be selectively implanted with female embryos only. The rationale for this practice is that [autism](#) is more likely to affect males than females (approximately 4 males for every 1 female), and by selecting female embryos, the chances of this child developing autism are reduced.

The West Australian [reported](#) that: "only families at high risk of having a child with autism, such as families who already have two boys with severe autism, would be considered for embryo screening".

The reaction to this report was swift and furious, and came from all corners of the globe.

Some were concerned about the science underpinning this approach, and pointed to [recent evidence](#) that autism may be under-diagnosed in females, and that the gender imbalance in autism may not be as skewed towards males as we once thought. These critics argue that the selective implantation of female embryos may not actually reduce the chances of a child developing autism.

Others opted for a more extreme attack on health professionals and families, branding the developments as eugenicist - a scientific discipline

that advocates practises that are aimed at improving a population's gene pool. The connotation of this label is a deeply negative one, and will be forever linked to Nazi regime, who used eugenics as a justification for the genocide of Jews, Gypies, homosexuals and others during World War II.

Prenatal screening for autism

This is an extraordinarily sensitive topic and the arguments on both sides of the debate are impassioned.

The concern about the current state of the science is valid. It is a very blunt technique to 'screen' embryos for autism based on sex alone. Autism is likely to be caused by dozens of gene sets, perhaps in interaction with the environment. It is also quite possible, perhaps probable, that the genetic causes of autism are quite different between individuals. There is absolutely a link between an individual's sex and their chances of developing autism, but this is only one factor amongst a constellation of others – many of which remain unknown to us.

To a certain extent, the concern about the validity of the current science is a moot point. Despite constant hype in the recent years, there is currently no genetic test for autism. Importantly, however, this won't always be the case.

The extraordinary developments in genetic technology in the recent past and the immediate future will undoubtedly lead us to a point, not too far from now, where we have the techniques and information to identify whether a person has autism by their genetic make-up alone.

Science is moving fast and this is a debate that needs to be had.

Pre-implantation genetic diagnosis/screening

And this is where we come to the argument about eugenics. Informed opinions are vital here, and it is important that we understand very clearly the exact technology that has been approved.

Pre-implantation genetic diagnosis/screening (PGD) is an IVF technique that occurs at the embryo stage prior to implantation. An egg from a woman and a sperm from a man are combined outside of the body (i.e., in a petri dish) to create an embryo (a fertilized egg). That embryo can then be 'screened' to determine whether its genetic make-up increases risk for a given disorder. If an individual embryo is found to contain a genetic risk factor for this disorder, then it would not be implanted into the woman's womb. This technique is used in many countries around the world to identify embryos that contain a gene mutation known to definitively cause a disorder, such as cystic fibrosis, haemophilia A and Huntington's disease.

PGD is not the abortion of a developing baby in the womb. It is the screening of fertilized eggs prior to being implanted in the womb.

Two sides of the debate

Understandably, PGD is a technique that causes concern within certain parts of the autism community. Some autism advocates argue that PGD will eventually be used to select autism out of the [gene pool](#).

This is certainly something I would not want. I have forged dozens of friendships with autistic people and their families, and have seen first-hand the skills, talents, smiles and diversity these individuals bring to the lives of those around them. The world is immeasurably improved by their presence in it.

I also imagine how I would feel if I were a person with autism and I heard a discussion about [prenatal screening](#) for 'me'. I imagine how I would feel if the 'all clear' had been given to screen embryos for short-sightedness or for extraversion, both of which are part of who I am.

Angry, outraged, and certainly more than a little unwanted.

The flip-side of the debate is that autism sometimes associated with significant disability that can affect quality of life.

It is without question that a person's life would be improved if they were free from intellectual disability, if they had the facility to communicate more freely, and if they had the capacity to live independently.

To want a person to live without disability does not diminish in any way our love for people in these circumstances, nor their irreplaceable importance in our lives.

Only a minority of our community know the challenges (and joys) of raising a child with significant disability. It is just plain wrong for people who have never been in this position to judge the wants and desires of those who have.

A debate that needs to be had

The discussion about PGD for autism and other developmental disabilities is an important moment in the intersecting paths of science and society. It is a debate that requires considerable thought, a debate that needs to remain respectful, and a debate that must include autistic people and their families.

But the science is coming fast, and so above all, it is a debate that needs to be had.

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