

Student research report

Mother blaming; or autism, gender and science

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Introduction

My PhD ‘Moving beyond love and luck; building right relationships and respecting lived experience in New Zealand autism policy’ suggests that good outcomes for autism are dependent on having family to advocate and luck that they will be able to find services and supportive people. But, we could improve autism policy if we worked with the experts, people with autism. My interest in this topic arose from having an autistic son who now has a job and a full social life, but he’s still autistic. When researching autism the meme of the ‘refrigerator mother’ and other mother blaming assumptions are difficult to avoid. Why is this?

Autism: contested meanings

Autism was named in 1943 (Kanner, 1943, p. 53). The latest descriptions in the psychiatrists’ bible the *DSM IV TR* (American Psychiatric Association, 2000) consider it to be a triad of impairments: in communication (none or inappropriate use of language), in understanding others (mind-blindness or lack of empathy) and imagination (replaced by obsessive special interests). It is now considered a wide spectrum from the non-verbal, intellectually impaired, cut-off person to the highly articulate and intelligent people such as Einstein (Attwood, 2009).

People with autism describe the condition differently. They often use the term neurotypical for non-autistic people and neurodiverse to encompass alternatives such as autism. They usually describe problems with understanding and predicting neurotypical peoples’ actions and behaviour, particularly their non-verbal cues, and often report sensory sensitivities to such things as sound, touch or taste. Many autistic people think very visually and literally. An instruction to ‘hop upstairs and get your coat’ could see an autistic child hopping upstairs on one leg and getting their coat but not coming down the stairs again as that was not part of the instruction.

In her video link address to the recent Autism New Zealand conference, Temple Grandin, US autism self-advocate and subject of a new movie, explained that when someone says church steeple she sees in her mind specific church steeples that she is familiar with, not a generic one, and her thought processes are like replaying a video.

Historical context

19th century

Autism wasn’t named until the 1940s but the context for such a condition had been developing for many decades. In the 19th century, particularly in Britain and Europe, poor people, people with infectious diseases or mental health issues were readily locked away in big institutions. This captive population provided a great opportunity for the medical profession to observe and theorise. The ‘medical model’ developed whereby people were seen as body parts which may

be diseased and could be cured. There were probably people in those institutions who would today be diagnosed with autism. But generally they were just part of the great 'other': the 'idiots', the 'feeble minded', the 'mentally defective', to use contemporary terms.

Throughout the 19th century scientific knowledge made major advances. The 1859 publication of Darwin's *On the origin of species* (Darwin, 1859) was influential as it showed humans were genetically linked rather than being here randomly or created by a divine power. Over the decades others developed his ideas about genetic heritability.

Eugenics

By the turn of the 20th century the white birth rate was dropping. The eugenics movement was developing, fuelled by a fear that certain undesirable groups were reproducing faster than more the more 'desirable' and thus diluting racial fitness. Some people linked intellectual impairment and physical impairments like epilepsy to moral degeneracy. In New Zealand these ideas were taken up enthusiastically by both liberals and conservatives. The 1911 Mental Defectives Act classified suspect groups into 'idiots, imbeciles and feeble minded'. New tools such as IQ testing were used to separate into those who could be trained as workers from those deemed less useful. In 1924 a NZ Committee of Inquiry into Mental Defectives and Sexual Offenders again linked intellectual impairment with moral degeneracy, and sought to separate suspect parents and children.

Childhood

From the early 20th century the new fields of psychiatry and psychology had developed in Europe and Britain as mental illness moved from something located in the body like a disease to something in the mind which could be treated by counselling or psychoanalysis (Grinker, 2007). Probably best known in this field was Sigmund Freud. Eugen Bleuler, a Swiss colleague of Freud's, treated young people with mental illness and named the diagnosis of schizophrenia about 1911 (Grinker, 2007). In describing its symptoms he used the word autismus, meaning self (Nadesan, 2005). So autism as a diagnostic description is 100 years old, although Bleuler didn't use it in the modern sense. Today, the previously common diagnosis of childhood schizophrenia is rarely used, while childhood autism has become increasingly common to describe that same population group.

Interest in the study of childhood continued into the 1920s with Swiss psychologist Piaget defining 'normal' developmental progress. So mothers anxiously observed their children to ensure they were developing normally (Nadesan, 2005). In New Zealand mothers also had to endure the prescriptive childrearing of Truby King and Plunket (Stace, 1998).

The 'refrigerator mother' theory

Into this context came Austrian born, German-educated pioneer child psychiatrist, Leo Kanner who by the 1930s was working in Baltimore in the US as the first ever specialist child psychiatrist. He first named autism as a separate condition in a 1943 article called 'Autistic disturbances of affective contact' about a group of children he had been working with (Frith, 1991; Grinker, 2007). He observed children who had an 'aloneness' and used the word 'autism'.

Meanwhile in Nazi dominated Vienna, and possibly unaware of Kanner's study, Austrian pediatrician Hans Asperger was working with his group of children, and seeing something similar, which he interpreted differently for his 1944 paper that would not become known to the English speaking world for decades. He described a more strengths based condition than Kanner possibly because disabled children were being sent to concentration camps at the time.

It took until 1981 for his work to be translated into English (Frith, 1991) and until 1994 for Asperger's syndrome to become an official diagnosis in the *DSM IV* (Grinker, 2007).

Kanner studied a small group of children of well-educated middle-class parents, and although he realised there was something genetic in their condition, he initially blamed parents, particularly mothers – he said parents kept their children ‘neatly in a refrigerator that did not defrost’ (Grinker, 2007, p. 72). Apparently he later regretted saying this as the idea was taken up with enthusiasm by Bruno Bettelheim, of the ‘refrigerator mother’ theory, in his 1967 book *The empty fortress: Infantile autism and the birth of the self* (Bettelheim, 1967). This idea of mother blaming persisted for many decades, and remains problematic. Kanner also suggested that autism is a middle class condition and that idea has also persisted.

Bettelheim was a holocaust survivor (who was freed from a concentration camp on Hitler's birthday in 1939 and then migrated to the US) not qualified in psychoanalysis, but managed to find employment as the Director of the residential Orthogenic School for children with mental illness at the University of Chicago. He suggested autistic children suffered from ‘extreme situations’ similar to being in the holocaust but caused by maternal deprivation. He advocated what he called ‘milieu therapy’, a psychoanalytic approach to reaching the inner child, which unfortunately ‘will always, to some degree, mean a descent to one's own hell’ (Severson, Aune, & Jodlowski, 2008, p. 71). But rather than being regarded as eccentric unqualified therapist, Bettelheim developed a following among a mainstream American audience as a popular writer for publications such as the *Ladies Home Journal*, *Scientific American* and *Playboy*. A recent assessment claims his ‘career benefited from his ability to construct an ethos that appealed to an audience beyond the scientific community. His status as a European intellectual propelled him to fame with an American mass audience’ (Severson, et al., 2008, p. 76). So when his book *The empty fortress* was published in 1987 it was to a ready made audience.

Bettelheim's research was based on a few supposedly autistic children at his residential school. His theories have since been shown to be false and after his death by suicide in 1990 aged 89, some of his former child patients reported emotional and physical abuse. But he is important in the construction of autism in that his work represents ‘a little-studied phenomenon in the rhetoric of science: the persistence of false beliefs in an ostensibly scientific community’ (Severson, et al., 2008, p. 66).

The empty fortress's ‘refrigerator mother’ motif was a useful tool in that by blaming parents, particularly mothers, it challenged the authority and expertise of mothers. Some call this the ‘autism conversion narrative’ involving ‘visionary therapists who rescued children from toxic parents and the hostile culture threatening sensitive young people in post-war America’ (Severson, et al., 2008).

The Kanner/Bettelheim influence in blaming mothers for their child's autism is significant because mothers have been fighting it ever since. One of the ways many middle class mothers have fought back against such views is by becoming experts on child development themselves – as their mothers and grandmothers had earlier done under the influence of the male child rearing ‘experts’ of their eras. Mothers learn what is ‘normal’ and from surveillance of their children's development become alert to any supposed ‘deviance’. In this narrative a diagnosis of autism is devastating. After the ‘tragedy’ of an autism diagnosis, they become experts on autism and may pursue various ‘treatments’ in an attempt to return their child to normality (Nadesan, 2005). The autistic child has been constructed in the public mind over the decades as locked inside, a non-fitting jigsaw piece, the child poisoned by immunisation, a suffering child in need of rescuing or curing, both heroic and tragic. Some parents deny autism is a life-long genetic condition, instead seeing it as a temporary condition caused by an adverse event such as exposure to toxins. I suggest that many parents hold these views partly as a reaction to the

widespread views that parents have caused their child's autism.

This inevitably leads to conflicts such as in the UK in 2007 when Jane Asher launched the National Autism Society's campaign 'Thinking differently about autism' which encouraged acceptance of autism as just another way of being. She was immediately attacked by a parents' lobby group which did not want autism to be seen as normal but instead wanted to have access to the latest treatments (Murray, 2008).

Immunisations

The theory that immunisations, particularly the MMR vaccine, caused autism was perpetrated by British doctor Andrew Wakefield in a 1998 *Lancet* article and he has had considerable influence particularly on 'middle class' parents ever since (Wakefield, 1998). His theory provided parents of autistic children something apart from genetics or parenting (ie themselves) to blame for their child's autism. After Wakefield's work was found to be unethical and unscientific by the British General Medical Council earlier this year (General Medical Council. Fitness to Practise Panel, 2010), it could be expected that parents would accept these findings and start immunising again. However, there remains considerable support for Dr Wakefield and his theories among many parents.

Autism cultural wars

As if this isn't enough, we also need to consider the 'Autism cultural wars'.

The Autism Self-Advocacy Movement, based in the United States, is run by and for people with autism and has neurotypical people as allies. It has flourished with the growth of the internet which is a communication method particularly suited to autistic people as they tend to be a very wired sector of the population. President Obama recently appointed the 21-year-old coordinator of the self advocates, Ari Ne'eman, to his national disability committee (Silberman, 2010). However the appointment needed congressional approval and the 'cure' autism lobby fought against his appointment and his message of normalising autism as a natural human variant.

A long time autism advocate is engineer Temple Grandin, who has famously said that without people with autism humans would still be living in caves. Temple Grandin's early life is the feature of a new movie *Temple Grandin*. (Incidentally, she is full of praise for her mother.)

This division between those who see autism as fascinating, positive, and even part of cultural identity, versus those who see it as personal tragedy and seek intervention and cure, also occurs in New Zealand, and it is a complicating factor in formulating policy approaches to autism.

Latest prevalence estimates are that more than 1:100 people are on the autism spectrum, a huge increase in the last 20 years. Psychologist Tony Attwood, who has studied autism for almost 40 years, half-jested in a recent Wellington talk that all humans are on a continuum, with those with autism clustered more towards one end (Attwood, 2009). All this illustrates that our understanding of autism is constantly evolving and prediction of where we will be in 20 years time is difficult to make.

In 2010 we have a *United Nations Convention on the Rights of Persons with Disabilities* (United Nations, 2007) and a *New Zealand Disability Strategy* (Ministry of Health, 2001) based on the social model of disability whereby people have impairments but disability is a process imposed by an ableist society. But there is still little support for people with autism to live a good life in the community. Yet internationally there is big money in research on genetics, brain development, biomedical and psychological interventions and 'cures'.

In conclusion, I'm not trying to make light of parenting a child with autism. It's a challenge but not a tragedy to have a child who is different. Parents, particularly mothers, can be very stressed and exhausted, but autism is not about fault, blame or guilt. Scientists, and those professing to be scientific, such as Bettelheim, have not helped. I think the key is a more scientifically literate population, so parents can more confidently critique the condition of autism, and interventions. Good support and services would help too.

Footnote

Reporters for the *Atlantic* magazine have recently tracked down the first child diagnosed with autism by Kanner: Donald, Case No 1 (Donvan & Zucker, 2010). Donald Triplett is living an independent life at 77. He didn't seem too adversely affected by his parenting, in fact his mother was instrumental in ensuring he has had a good life.

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