

Book

Does autism need a cure?

Earlier this year, I called for an ethical debate about how biomarkers for autism research should be used (*Community Care*, Jan 14, 2009). Almost every month a new genetic study of autism is published, but what are we going to do with all this brave new science? One scenario—embodied in the mission statements of American autism charities like Defeat Autism Now! (DAN) or Cure Autism Now (CAN, which has now merged with the charity Autism Speaks)—is that we should use such science to “cure” or “prevent” autism.

My own view is that I would not want to see biomedical autism research being used to prevent autism in the eugenic sense of the word, because people with disabilities have as equal a right to life as anyone else. Nor would I want to see autism research being used to cure autism in the normalising sense of the word, because I value and respect diversity and don't think we all need to be given treatment to conform to the majority. In addition, autism and Asperger's syndrome often (perhaps invariably) involve areas of strength—such as remarkable attention to detail, the ability to focus on a small topic for long periods, and to see repeating patterns—and these human qualities are not in need of treatment. For sure, there are other aspects of autism that would benefit from treatment—such as severe language delay or learning disability, epilepsy (when it occurs), gut problems, and social difficulties—but that is a far cry from saying we should “cure” autism itself.

So I was delighted to discover Deborah Barnbaum's *The Ethics of Autism* because it provides a serious examination of the moral and ethical issues surrounding autism and Asperger's syndrome. Although there are many books about autism, in the 66 years since the condition was

first described none has tackled the ethics of autism head on in the way that Barnbaum does. This book kick-starts the ethical debate that I think we need.

Barnbaum is a philosopher and so is well placed to consider the ethical issues surrounding autism. She starts from the idea that, for neurological reasons, people with autism are

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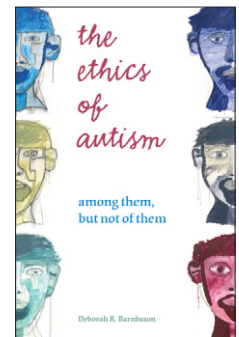
“mental solipsists”—ie, that they think about their own view of the world rather than other people's. This is the idea that people with autism have difficulties in developing a “theory of mind”, that is, attributing mental states to others. As a result, social interaction and communication is confusing for them to make sense of, whereas for a typical person it is effortless. Mental solipsism is much clearer in cases of severe autism, but Barnbaum points out the related difficulties with empathy even in adults with high-functioning autism or Asperger's syndrome. For example, she quotes Gunilla Gerland, who has autism and describes how she was unperturbed by the death of her father, comparing his loss to a bowl of fruit that was on the table one day and gone the next. But Gerland says “On the other hand, it greatly disturbed me when they moved the furniture.”

Barnbaum explores the consequences of this mental solipsism for people with autism. Does this leave them without the ability to be moral? 18th-century philosopher David Hume

argued “a feeling of sympathy is required for morality”. So Hume would have had to conclude that, if they do not spontaneously empathise, people with autism must lack a moral sense. By contrast, another 18th-century philosopher Immanuel Kant argued that to develop a personal morality, “feelings of empathy are not necessary”. For Kant, all that is needed is a sense of duty, expressed as imperatives. So, Kant would have argued that, if a person with autism can understand rules (eg, treat people with respect and dignity), that is sufficient for them to be moral.

My own experience of people with high-functioning autism or Asperger's syndrome is that they are certainly not just capable of morality, but may even be hyper-moral, wanting all of us to follow the rules in a precise way and to the nth degree. Some become the whistle-blowers when they spot the rules being broken. While many “neurotypical” people arrive at their morality via a very visceral empathic route, responding emotionally to another person's distress, other people (and this includes many with Asperger's syndrome) arrive at their moral code through a logical route based on rules (systemising). “Treat others as you would have them treat you” is an example of a moral code that is rule-based and can be arrived at by appreciating its logic and that it works. In this way morality can be like mathematics: Pythagoras' theorem that $a^2 + b^2 = c^2$ has a logic that works for any right-angled triangle. Barnbaum's conclusion is that because people with autism are concerned to be good, they can therefore be moral (unlike psychopaths).

But in a shocking section of the book she highlights how some moral philosophers, such as Martha Nussbaum, have argued that if a person lacks the capacity for



The Ethics of Autism: Among Them, but Not of Them
Deborah R. Barnbaum.
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relationships with other people, "such a life is not a life worthy of human dignity". Barnbaum also quotes Tavistock Clinic psychiatrist Peter Hobson who argues "the autistic person is outside the moral community, biologically human but not a person in the moral sense". That is because, for Hobson, to be a person assumes not just an ability to have what philosopher Martin Buber calls "I-It" relationships, but also "I-thou" relationships—the ability to relate to people as well as things.

But Barnbaum is uncomfortable with Nussbaum and Hobson's idea of putting people with autism "outside the moral community". She reminds us that in history, placing people outside the moral community led to the horrors of Nazi Germany, when Jews, gypsies, homosexual people, psychiatric patients, and those with learning disabilities were slaughtered because they were judged not to merit full moral human rights. And she reminds us of the eugenics

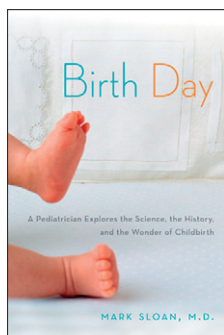
programmes in the USA when tens of thousands of people were forcibly sterilised because of their learning disabilities, doctors (presumably within the moral community) making decisions to deny people their autonomy, in some sense treating them as subhuman. She is clear where she stands on this: "Agents compromise their own moral standing, their own claim to membership in the moral community, when they disqualify others."

She then turns to the ethical issue: should people with autism be cured? Barnbaum quotes another woman with high-functioning autism, Temple Grandin, who says: "If I could snap my fingers and be non-autistic, I would not—because then I wouldn't be me. Autism is part of who I am." Grandin says that she "thinks in pictures" and that "I would never want to become so normal that I would lose those skills". Barnbaum also quotes a teenager with autism as saying "We don't have a disease,

so we can't be 'cured'. This is just the way we are."

For some, Barnbaum's book will be hard going in places, since she writes more for her academic colleagues than for practitioners, parents, policy-makers, or people with a diagnosis. But this book is invaluable since it starts a much-needed ethical debate. Despite her attempt not to take sides and to present the arguments with clarity, to enable others to make up their own minds, my sense is that Barnbaum believes in what she calls "autistic integrity": the idea that people with autism are "leading a life that is different—in some ways incomprehensibly different—from the life led by those who are not autistic". Her view is one I have long shared: that people with autism deserve the same respect as any other person, with the same rights to be different, and to be themselves.

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Birth Day: A Pediatrician Explores the Science, the History, and the Wonder of Childbirth
Mark Sloan. Ballantine Books, 2009. Pp 384. US\$25.00. ISBN 978-0-345-50286-5.

In brief

Book Witness to birth days

Birth Day begins in the Chicago hospital ward where Mark Sloan started his obstetrics rotation, as Tonya, "the first woman I had ever touched with medical intent", labours to deliver her third child. As the baby's head appears and Sloan desperately wonders what to do next, his senior resident steps in, yanks the infant out "like a rabbit pulled from a magician's hat", clamps and cuts the cord, and passes the "big, squalling, slippery boy" to his mother. Soaked in sweat, his socks and shoes bloodied, Sloan remembers, "I just sat on the stool with my mouth hanging open, dumbstruck."

Sloan deftly traces the evolutionary, historical, political, and scientific forces that have made childbirth what it is today. A paediatrician, he

has witnessed about 3000 births—including those of his two now-teenaged children. Sloan's spark and wit keep us entertained while allowing us to share in the fascination and awe he clearly still feels, three decades after the birth of Tonya's son.

His discussion of childbirth anaesthesia is the freshest and most agenda-free analysis of this topic I've seen. He provides an historical perspective, and takes a critical look at what midwife Judith Rooks has dubbed "the evolving epidural monoculture" in the USA. According to Sloan, too often American women awaiting labour seem to be faced with two choices: "the challenge of climbing a drug-free Mount Everest" or an epidural, with the goal of complete elimination of pain. Sloan advocates the concept of "good

enough" labour pain relief where women are offered nitrous oxide and a host of non-pharmacological pain relief options.

At the close of the book, Sloan describes his most recent night on call. An obstetrician pages him to the when a fetus's heart rate becomes irregular, but by the time he arrives, the baby is doing fine "cradled in her mother's arms, her bewildered "what just happened here?" eyes slowly coming to focus on her mother's face". Now anticipating retirement from his hospital duties, Sloan imagines that if this call night is his last, "I'll have gone out more or less the way I came in: a witness to a normal birth." A quiet observer, still full of wonder.

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