



Ilina Singh.

## The listening project

Contrary to some expectations, young people are well able to discuss the ethical implications of neuroscience innovation and treatment of neuropsychiatric disorders.

Our ever-greater ability to influence the brain – for example, through pharmacological, electromagnetic and surgical interventions – is raising a host of philosophical and ethical questions. As an ethicist based in a department of psychiatry, **Ilina Singh** has an inside track on the application of brain-based approaches in medicine, and has a particular interest in how they are applied in young people.

This interest dates back to her PhD studies at Harvard, when she explored the explosive growth in the use of drugs such as Ritalin for attention deficit hyperactivity disorder (ADHD). “It was a time when more and more kids were being put on these meds, and nobody really understood what they were doing, on a neurochemical basis. But also no one had any real understanding of how parents were making decisions in moral terms about whether to put their kids on behaviour-modifying medications.”

A qualitative study with parents suggested that a key factor was the potential to shift responsibility for the condition: “There was this idea you could shift from ‘mother blame’ to ‘brain blame’ if you had a diagnosis for a child and chose medication, because the medication in a sense cemented the biological basis of the disorder.”

The obvious follow up was to find out what the children themselves thought about treatment. However, few attempts had been made to explore young people’s perspectives, and there was considerable scepticism that it was possible to discuss complex philosophical and ethical questions with such a group.

Nevertheless, Professor Singh secured support from the Wellcome Trust for a large study of children with ADHD in the UK and USA. “The idea in that study was to look at three ethical areas – authenticity, moral responsibility and moral agency,” says Professor Singh. The popular press was likening drugs to a ‘chemical cosh’ turning children into robots lacking personal autonomy, while ethicists were concerned that treatments were interfering with children’s ‘true’ or authentic nature.

By taking the unusual step of investigating children’s moral attitudes by talking to children, Professor Singh found that they were surprisingly dismissive of these concerns: “The interesting finding was that kids didn’t feel that those ethical areas were necessarily compromised.” In fact, children often felt that drugs actually gave them more control over their actions: “Medication actually fostered a sense of moral agency,” says Professor

Singh. “That was controversial, as you can imagine.” Controversy aside, the work had other important implications: “For me, one of the breakthroughs of that study was at the methodological level, because people didn’t think kids could talk about those kind of complex issues in a way that was valid.”

Following an interlude looking at some of the issues associated with pharmacological cognitive enhancement, Professor Singh is now exploring similar themes in studies funded through a Wellcome Investigator Award. A major focus is on prevention and early interventions in the field of child psychiatry, again with a view to finding out what young people themselves think of such efforts.

As well as children showing behavioural problems and symptoms of ADHD, Professor Singh and her team are working with young people with more severe mental health difficulties, including early signs of psychosis. Often, these young people have no clear diagnosis: “The NHS England Early Intervention in Psychosis (EIP) programme runs the danger of becoming a catch-all for kids with all kinds of problems, because we don’t have sufficient mental health services for children and adolescents.”

Although offered cognitive behavioural therapy and other support, the team’s preliminary analyses suggest that the EIP group value simple ‘interventions’ like care worker visits very highly: “When the kids talk about what is important to them, they talk about those visits, the fact that someone comes and sees them as a human being.” With much attention being given to the development of technological solutions in mental health, there is a risk that this basic human quality of relationship could be lost.

### Engaging young people

More generally, Professor Singh is keen to get young people engaged and involved in ethical questions in psychiatry and neuroscience. She and her colleagues have established a young people’s mental health advisory group, 50 children aged 13–18. “That’s been enormously successful for everyone involved,” she suggests. Her team has been exploring the everyday moral experiences of young people. The plan is to use these experiences to develop a range of digital tools that provide a conceptually robust and engaging way of investigating moral decision-making in health and medicine: “My great ambition is to move bioethics onto a digital platform so we can do empirical

research in ethics together with young people, at scale and globally.”

She welcomes the increasing attempts being made to engage young people, part of the growing trend towards greater patient and public involvement. However, she cautions, working with young people presents significant methodological challenges. Many researchers are going out to talk to young people, she suggests, “But they’re not thinking about it empirically in a systematic way.” She hopes her work will contribute to a set of replicable methods that provide a solid foundation for future work. Indeed, she extols the virtues of working with children: “Young people are compelling advocates for doing research with young people,” she suggests. Particular impact has come from short cartoons including the voices of young people with ADHD, which have been published on the web ([www.adhdvoices.com](http://www.adhdvoices.com)). These have been picked up by health workers in low-income settings, who typically have few resources for discussing ADHD with parents.

### Beyond young people

Professor Singh has also worked with groups such as military personnel, exploring their attitudes to neuro-experimentation, including neural implants, artificial intelligence and cognitive enhancement. Indeed, the impact of such neurotechnologies, and their implications for the conception of free will and personal responsibility, and even human identity, is an area she sees as of emerging importance.

There is also a strong international dimension to her work. With colleagues around the world, she has organised a conference, Our Brain, Ourselves, Our World ([www.o3brain.org](http://www.o3brain.org)), to discuss the desirability and possible nature of an international ethical framework for large-scale and global brain projects. She is also leading the Global Initiative in Neuropsychiatric GenEthics, part of a major international project in neuropsychiatric genomics led from the Stanley Centre at the Broad Institute of Harvard and MIT, which is collecting biological samples and data in partnership with researchers across Africa, East Asia, and other global sites.

Interdisciplinarity lies at the heart of Professor Singh’s work, and links between disciplines will be further enhanced through a new Wellcome Centre for Ethics and the Humanities, launching in 2017, for which she is one of four principal investigators. Professor Singh will be leading a strand of work examining developments in neuroscience, genomics and digital mental health, focused on where novel innovations might require re-thinking of traditional ethical concepts to ensure responsible and sustainable impacts on medicine and society.

These efforts, she suggests, critically depend on a strong relationship between science, medicine and ethics – in her case, bonds cemented by



Specially created cartoons have been used to convey the views of young people with ADHD.

her status as the only bioethicist embedded in a UK psychiatry department. “That’s been an extraordinary experience. I no longer have to start the conversation by convincing my colleagues that ethics matters. They’ve all bought into it.” This close collaboration has already resulted in papers examining the ethical issues surrounding therapies such as deep brain stimulation and ketamine as well as forensic applications of psychiatry.

Neuroscience may not yet have embraced ethics to the extent that genomics did during the Human Genome Project, but Professor Singh believes that there is an opportunity to learn from earlier experience and develop agendas better rooted in scientific realities. “Ethicists can’t do it without scientists sitting at the table telling us what is real and what isn’t,” she suggests.

Moreover, she adds, scientists stand to benefit from greater contemplation of the ethical aspects of their work, particularly if they are considering practical applications and translation. “We need to get better at demonstrating together that good ethics makes for better science, and it certainly makes for more successful implementation down the road.”

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