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ADHD, education and culture: an interview with Ilina Singh (Part I)

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Here is the first in a series of three interviews[c] with Ilina Singh that, as a whole, will explore aspects of her wide academic production on Attention deficit hyperactivity disorder (ADHD). We prioritize some of the shifts operated along her trajectory of research, the movements and contingencies that led her to undertake certain types of research, and the importance of considering the biosocial understanding of ADHD. In the second part, we will explore some questions about the psychostimulant use possibilities (such as Ritalin) with enhancement purposes and will discuss the issue of ADHD in the context of globalization or "global mental health". The third part will consider some discussions that enables us to think in terms of a political, ethical, medical, social and educational agenda to deal with ADHD.

[c] Interview (previously authorized by Professor Ilina Singh) made by Luís Henrique Sacchi dos Santos, with questions made by both authors, at the Department of Social Sciences, Health and Medicine (SSHM) of King's College - London/UK, in 10th December of 2014. Resources obtained by the first author through "Short Scientific Mission" by Pró-Reitoria de Pesquisa da Universidade Federal do Rio Grande do Sul (PROPESQ/UFRGS). We would like to thank to Maria Isabel Edelweiss Bujes, Jonathan Henriques do Amaral and Fabiana de Amorim Marcello for their comments over the manuscript. We also would like to thank Dr. Nikolas Rose, head of SSHM, for all permissions, and to Irene Boston, from IB Secretarial Services, Norfolk/UK, for the transcription.

ILINA SINGH

Ilina Singh, Doctor of Education by Harvard University (2000), was Professor of Science, Ethics & Society in the Department of Social Science Health and Medicine of Kings College – London/United Kingdom (UK), and was cross-appointed to the Institute of Psychiatry until December 2014. Since January 2015, she is Professor of Neuroscience and Society at Oxford University, in a joint appointment between the Department of Psychiatry and the Vehiro Centre for Practical Ethics. Her work examines the psychosocial and ethical implications of advances in biomedicine and neuroscience for young people and families. Her research has several goals: a) to investigate the benefits and risks of biomedical and neuroscience technologies for children; b) to enable evidence-based policy-making in child health and education; c) and to bring social theory and ethical insights into better alignment with children's social, emotional and behavioral capacities. Current projects include the VOICES project (Voices on Identity, Childhood, Ethics & Stimulants: Children join the debate – funded by the Wellcome Trust); SNAPBY (Survey of neuroenhancement attitudes & practices among British young people – funded by STICERD); and an edited volume on bio-prediction published in 2013 by Oxford University Press. Future work includes a major project on character and children's moral education.

BRIEF BACKGROUND ABOUT ADHD IN BRAZIL

Dear Professor Ilina, before any question, we think it is necessary to introduce you briefly to the Brazilian context of ADHD and use of Ritalin, which changed rapidly in recent years. This is important because the main objective of this interview is to explore some important points of your work analyzing the contexts of this topic in USA and UK, published between 2002 and 2013. We would like to do this interview in order to bring some of the ethical, political and academic contributions of your work to problematize the Brazilian context, mostly in terms of education.

A significant number of children have been identified as hyperactive In Brazilian schools from 1990's. They are usually identified by teachers ("as legitimate primary diagnosticians of children's cognitive and emotional problems"[1,2]), with any or limited expertise about the topic, who are forwarding children of all ages to medical offices with "suspicious" of having ADHD. Ritalin (*methylphenidate*) is the drug most consumed in Brazil when the diagnoses of ADHD is announced[3]. Anecdotal data suggests that to appoint some children with ADHD is a current practice to explain any problem at schools. Also, this "diagnoses" has been occupying a frequent and varied space in media in general, including newspapers, magazines and television programs.

It can say that such a diagnoses is reaching epidemic levels, extending quickly and reaching a burgeoning number of children. There is some novelty in reporting on children described as having ADHD. If the medical literature is capable of explaining a trajectory of (what today we call) ADHD as long as a hundred years ago, the emergence of this explanation on schools is much more recent. In the first decades of the 20th Century we observed the hygienic and eugenic discourses in the Brazilian education[4-7], but now we have a new investiture of medical discourses over schools and students. In some contexts, like in the city of Porto Alegre (RS-Brazil), some teachers in public schools are receiving training (offered by health experts[(c)]) to become capable of identifying mental disorders among students and to forward them to health experts (the idea is that they could be

[(c)] As a community extramural activity, PRODAH (Programa de Transtornos de Déficit de Atenção/Hiperatividade) offers a basic program of training teachers for the recognition and management of ADHD. This program is available only for public schools in the city of Porto Alegre/RS-Brazil. Lectures and case discussions are held at the school. The program serves a limited number of schools each year. The coordination of this activity is in charge of Dr. Silvia Martins and further information can be obtained in the following site address - http://www.ufrgs.br/prodah/teacher-training/.

helping to identify children who possibly are suffering of clinical and diagnosable pathologies). The medical diagnoses is still very important to the usually lay diagnoses that schools' discourses are producing over children and any discussion about the topics of hyperactivity and ADHD, or even a similar possible condition, cannot ignore what has been researched in the fields of neurology, genetics and psychiatry. In other words, schools are calling medicine and giving to this field the authority to legislate over problems or questions that would be seen as schools' or social's problems, in a clear process of medicalization. We believe that schools are letting a pedagogical empty space in their practices, or, as you say in *A framework to understanding trends…* schools support the medicalization of behavior in children and opt out of their pedagogical commitments. We also believe that schools would accept their commitments with children in another political and ethical level, sometimes questioning the medical truths and trying to find non-medical ways to deal with their public.

Considering this context, we have the following objectives in this interview: a) to introduce your work to a larger Brazilian audience; b) to explore your research's trajectory in order to offer some possible ways to better explore topics about ADHD, hyperactivity, Ritalin and enhancement in Brazil; c) to detach some of the main concepts and methodologies (like that employed to work with children) you have operated in these texts, specially their articulation with the field of education; d) and to listen from you, based on your trajectory of research, teaching and in public political positions to delineate a possible political, ethical and academic agenda to explore the issues over ADHD, Ritalin, enhancement and other related topics in the Brazilian context.

Recently, we offered a seminar for graduate students to explore your texts from 2002 to 2013. We observed that since 2002 – or even before – you have employed the understanding that it is not productive to fight in favour of the biomedical or socio-cultural approach to understand ADHD. Instead, you have been signalizing the necessity to comprehend it as an effect of a multifactorial process. In Brazil, despite this comprehension based in the Diagnostic and Statistical Manual (DSM) (of a multidisciplinary evaluation), the "real practice" has been that of medicalisation (prescription of pills) made by doctors frequently following the complaints from schools over other factors. In this year of 2014, in São Paulo – Brazil, for example, there was an important movement of a group of different professionals and institutions (the *Medicalisation Forum*) fighting to stablish the multifactorial evaluation in legal terms to the diagnoses and treatment of ADHD. In other words, they are simply following what is written in the consensus about ADHD in the DSM IV or V. This movement is challenging the medical and pharmaceutical supremacy and is having important effects in the diagnoses and treatment of ADHD. On the other side, doctors in general are complaining that this movement is possibly damaging children, specially the poor ones – taking off their rights of/to diagnoses. How this multifactorial process has been considered in UK, both in terms of how schools are considering it and the forwarding of their students to medical professionals? Alternatively, as you said, "How does one try to gain multiple perspectives on the problematics of ADHD as a researcher?"

In the United Kingdom, it varies. There are school systems where the child with ADHD in the UK we've found tends to be a child who has often got a lot of externalising behaviour; so they tend to be quite aggressive and angry and

troublemakers and what we call in the UK a naughty child. Therefore, from a teacher's point of view, these children are challenging kids and then they sometimes have associated learning difficulties so they tend to be challenging in the school system. It really depends on whether the school system is equipped to manage a child like this and sometimes they have very good learning services; most often, they do not.

Therefore, I think the clinic gets pulled in really at the point where the school feels it can't cope and when the clinic is pulled in, most clinics in the UK will still ask for evidence from teachers and parents. I have seen clinics where entire families are brought into the clinic as part of the diagnostic evaluation to talk about various perspectives on the child. In the best possible sense, you have the child, the parents, the grandparents, all in a room talking about what is happening with this child and a very long developmental history is taken.

I have seen rigorous good evaluations happening. They tend to take two sessions and they are very time consuming, they are very resource intensive and then I think the child walks away with a very good multifactorial diagnosis. I do not think that happens everywhere but some psychiatrists insist on that process. I think in other services where there is more pressure on time and you have psychiatrists who are oriented differently or trained differently, you get less of that very careful holistic look at who this child is and what can be done to help the child.

Therefore, I think it varies. Despite this, UK is still much better than America because in the UK you have to go to a specialist service to get an ADHD diagnosis; you have to see a psychiatrist, unless you go to the private sector where I think a paediatrician can diagnose ADHD. Here, in the public sector, General Practitioners (GPs) will refer to the psychiatric service. Therefore, you should get very good specialist diagnoses that are done in this very careful multifactorial way.

As we see more pressure on services coming with more and more children entering for a diagnosis, there is some talk about returning the diagnosis to the GPs. I think that is where problems would arise: as in America, where you get GPs who don't know very much about the diagnosis, who don't take this holistic view, who don't do assessments that look at how the child is at school and home and it's just 15 minutes and you walk about with some Ritalin.

We also observed that in your last papers you are more preoccupied to explore the role of medical professionals (especially paediatrics) concerning the ADHD context[8-10]. In your former papers, like *A framing for understanding trends ...*[1], you say, for example, "*I examine social, cultural and political aspects of this context in order to illustrate the layered complexities that reveal themselves when considering the school as a mediating context for US ADHD diagnoses and treatment strategies. I argue that such an analysis raises challenging questions about the validity of ADHD diagnoses and supports the importance of further investigation of macro- and micro-level variations... "* (p. 440). Are this preoccupation or addressing related to a shift in the comprehension of "the nature" of ADHD or it is simply related to the journal's audiences? What is ADHD today and how much the comprehension about it has changed since 2000?

I found this an interesting question because it led me to reflect on my own journey through this. I think what happened, early on I interviewed parents and I did the historical work and I was always sitting in clinics watching clinical evaluations, both in America and in the UK, but my interest and my emphasis I suppose was much more on these cultural systemic dynamics. Once I had finished that work, the question people kept asking me was "why haven't you spoken to children?" There were actually complicated reasons for that which I can go into in another question.

When I finally did get funded to talk to children, it had to be from a bioethics point of view because the funder was interested in ethics. Therefore, what happens when you move from a sociological approach to an ethical approach is that you shift, at least temporarily from attending to a macro-structural dynamic to attending to a much more individualised understanding of what is happening for a child in the context of this diagnosis. I wanted to hear from children themselves what mattered most to them. I wanted to better understand, particularly, the relationship between ADHD diagnosis and treatment on concepts that are strong within the bioethical critique of ADHD:

authenticity, moral agency, and personal responsibility. Bioethicists had framed drug treatment of ADHD in particular as potential threats to these 'goods.' I wanted children to help me understand the nature of those threats, if they did indeed exist. Of course, what we discovered was that the picture is more complicated than it appears; that in some senses, there are threats to authenticity, but in others – and this was a strong finding of the ADHD Voices study – children reported that drug treatment helped protect their moral agency.

To go back to your earlier question about the role of professionals in the ADHD context: Children also talked about their teachers and the health professionals they met. When you look at the ADHD Voices videos[d], there is material on teachers and doctors. Some of that material has been problematic for teachers. They argue that you have to observe the classroom dynamic in order to understand how the child is making sense of what the teacher is doing, and the children with ADHD were just extremely negative about the teacher.

[d] Access through the following link: http://www.adhdvoices.com/adhdvideos.shtml

I thought that that was fair; that we need a study where someone is sitting in those classrooms, or someone is able to observe those classrooms, to really understand: "what are the dynamics and how much does a child (who is already always in trouble and labelled as being naughty and difficult) perceive the teacher to be negative when perhaps the teacher is trying to be helpful?". We do not know.

Now a PhD student of mine is doing some of this work: Sebastian Rojas Navarro[e] from Chile. He is conducting observational research in the Chilean school system. I should also say that I think doing that kind of work; certainly, you cannot do it in the US now. He was able to negotiate fantastic access to schools in Chile. From a pragmatic point of view, access can be a real barrier to research in schools, and countries vary a lot in how much access they will allow researchers, particularly given the controversies over ADHD.

[e] For further information, see: http://www.kcl.ac.uk/sspp/departments/sshm/people/PhDStudents/sebastianrojasnavarro.aspx

In terms of clinicians, I had spent enough time sitting in clinics and waiting rooms to understand how children could come to feel alienated from the processes of evaluation, diagnosis and treatment. As I said before, clinical practices vary; some children and families are cared for really well; but many others felt disconnected from the clinical process. I do not think this is an issue of the clinical view on ADHD changing so much as it is a pressure on services that are overwhelmed with waiting lists. But certainly as ADHD becomes more widely known and viewed as more legitimate, more families are going to consider diagnosis as a potential way of framing the challenges a particular child is having. This is particularly true – of course – if a child's school cannot manage him or her. So clinical services are going to feel that pressure.

You have defended the integration of biomedical and sociocultural approaches at least from the beginning of 2000. How do you see this perspective today? Especially if we consider [despite the arguments of Nikolas Rose[11], b) and the fact that, despite the burgeoning of knowledge, the integration of these two perspectives - biomedical and sociocultural] that still there is a strong hegemony of the biomedical truth regarding ADHD (despite the lack of biomarkers) diagnoses and treatment.

This problem of the hegemony of the biological is with us this day. I do not imagine that we will see a shift back to the hegemony of the social. I think it is very instructive to look to see what are the most powerful funders funding at the moment and, as we know, the National Institutes of Health (NIH) is now moving to a focus on biomarkers. I think funders in many countries will go that direction as well.

But ironically, I also think there is more interest in the social than there has ever been, and that is partly because of epigenetic theories and it is partly because people are beginning to understand that the social, or the environment, mediates and moderates all the developmental psychiatric diagnoses. But it is a difficult empirical challenge to find out exactly how that works, and to establish causality rather than correlation. We can take a theoretical position that says that the biological and the social are entangled from the start, and then from a sociological point of view, we can go forward to better understand that entanglement. There is terrific work on this within science technology studies (STS) and sociology going on right now. However, if we were scientists, looking to test how independent factors produce certain outcomes, and which of those factors is most important, then the concept of 'biosocial entanglement' seriously complicates a scientific research protocol. Certainly the mechanisms of that entanglement are still poorly understood, which is why there is a tendency to focus on the few mechanisms that have been researched, such as methylation and histone formation in epigenetics research.

It is also worth noting that in the health services delivery side of psychiatry, or we might say the care side, the social is most of what health practitioners care about most. I think it is generally recognised that treatment outcomes, for example, are not just products of biological effects of treatment, but are also bound up in the resources and contributions of the social care environment.

I have been using an ecological model in my work for many years – the one by Urie Bronfenbrenner. It is very well known and widely cited, even though it is so general as to be useful mainly as a heuristic. However, the model is better than other models that I have seen in the literature because it helps us understand the developmental context of a child (who sits in the centre of that model), moving from micro-level influences, to meso-level and then to macro-level influences. Bronfenbrenner argued that the dynamic of influences within the model was bidirectional, such that the child was influenced by factors across these systems, but also exerted influence on them. At a very high level, it seems to be an early model of biosocial entanglement,

That is why I found that ecological niche idea so powerful. Social theorists, such as Ian Hacking and Bruno Latour, have elaborated more complex models of biosocial entanglements, but without the attendant emphasis on the contribution of biology. In my opinion, the strongest example of social theory in this respect is Margaret Lock's famous work[f] in Japan, showing the embodiment of social forces in women's reproductive cycles. We are all talking about similar sorts of things, but our interests and emphases differ. For me, the interests are "how does a child's behaviour represent that intertwining of the biological and the social? How does understanding of that biosocial dynamic help us understand where we can make good interventions to help children cope better with challenges?

[f] The interviewee is possibly referring to the book Encounters with Aging: Mythologies of Menopause in Japan and North America (University of California Press, 1995).

Another one of your questions, is ADHD a valid disorder? I have met diagnosed children with a wide range of cognitive and behavioural capacities, and a wide range of impairments. ADHD is not a categorical disorder – it is dimensional. We can argue about whether children who are on the low end of the distribution should be medicated and diagnosed, and probably the answer is if there were more supportive school environments and more family resources, then children might not need a medical solution to their difficulties; they and the adult caregivers in their lives would learn to cope in different ways. That is different to kids who are at that more extreme end. However, across that spectrum, what I heard "again and again" from children was what they struggled with was self-control.

Therefore, we come to the idea that Russell Barkley[1] put forward years ago: that ADHD is a disorder of self-control. I always thought was a terrible construct because it was so narrow and so focused on executive functions. Barkley argues that this is precisely why ADHD diagnosis is not a *moral* issue; from the point of view of moral philosophy of course, self-control is all about ethics, or the capacity to act according to the high-level principles and values that operate in a society. In any event, difficulty with self-control is what you hear from kids, who tell all sorts of stories about it. Nevertheless, it is abundantly clear when you ask children to describe their behaviours in the classroom, in the playground, at home, how much biosocial dynamic there is moving in these spaces. Self-control is not just a biological issue although there is a biological contribution, of course, to any behavioural capacity.

The example I like to give to show these biosocial dynamics is the UK playground. The playground is a terrible place for a child who has self-control problems, because children get bullied, teased, wound up. I have tried to show this in the 2011 publication in Social Science and Medicine[12] – the ways in which self-control is an embodied response to environmental challenges. I would argue that, on the basis of my research, a primary intervention space in the UK context is the playground. In addition, I would go further to say that the playground culture should change *before* one starts trying to change individual biology. However, here I am making a claim about causality, and I have to admit it's not proven yet.

According to our point of view, it is very clear in your academic production, between 2002 and 2013, a kind of research program (maybe organized in three broadly phases – a) discussing more historical aspects, the schools and schooling process, and the mother-children relationship on medical, psychological and lay discourses related to ADHD and Ritalin; b) the VOICES Project (*Voices on Identity, Childhood, Ethics and Stimulants: children join the debate* - http://www.adhdvoices.com/) and the political, ethical and academic eliciting of children agency; c) and the contribution to the discussion over enhancement and the necessity of establishing ways to research, to deal with it in juridical, medical, public policies terms, etc.). Besides your contribution over the theme of ADHD, we are also interested in listening from you about some aspects of this research program. Was this program designed in broad terms in the beginning of 2000 years or even previously? How the field evidences, the research's contingences, and the context of each time constituted a pathway that (looking back) seems to be very well designed in your research trajectory. Or simply, would you talk a little bit about how do you see your own research's trajectory concerning ADHD?

I am glad you see coherence! Of course, the reality is different. I was an unmotivated student for a long time, but when I got to my second year of university, some flame was lit, and I fell in love with academic life – specifically, at first, with literature. I ended up starting work on a PhD in English Literature when I was twenty, having finished my undergraduate studies early. About a year into that, I thought: "I don't know if I even want to do a PhD in English, so why don't I take some time away?"

I taught English in a secondary school, and it was just the time when a lot of children in America began moving out of the learning disability office and going to their paediatrician and coming back to school with this diagnosis called ADHD

-- and with medication. I was tremendously sceptical, and I thought this would be very interesting for me to study. I looked around for programmes, in education actually, and I found them all to be unsatisfying.

But Harvard had a doctorate in a field called Human Development and Psychology, which was a place that held faculty who had come from another programme at Harvard that had been closed. This former programme had been a wonderful interdisciplinary space for anthropologists, sociologists and some psychologists, but it ended because the world of disciplinary thinking had taken over. A few years after I graduated from the Human Development and Psychology programme it also was closed – or re-named. You may find this ironic: it is now called the Mind, Brain and Education programme!

I went there, and I was supervised by Professor Carol Gilligan, whose seminal work on girls' moral development argued against classic developmental stage theory, which viewed girls and women as inferior in their achievement of moral maturity, as compared to men. I was lucky enough also to become a McArthur Foundation Mind, Brain, Behaviour Fellow, which allowed me to spend a lot of time in the History and Philosophy of Science department with Professor Anne Harrington, who had done a lot of work on the history of neuroscience and psychiatry. That is where I got my education in philosophy and sociology.

So, I had this great, rich doctoral experience, and I tried to bring it together in my doctoral thesis. My central questions were still about ADHD. I wasn't a parent at the time, and I kept coming back to a basic concern: Why would parents bring a child who is not behaving into a clinical setting, and then agree to give them medication? It felt extraordinary to me that that would be a possibility. So I began to sit in clinical settings watching a group of neuropsychologists work with these kids.

Then I started interviewing the children's parents, and what I realised almost immediately is that the ADHD critique can wrongly make it sound as though there is a simple answer to the problem of ADHD: bad parents. In actuality it is enormously complicated; there is suffering really all around, within individual parents, in the marital relationship and in the parent-child relationship. Mothers came in particularly for blame, and felt terribly guilty about what was going on with their (usually) sons[13-15]. To understand this, Ire-read a lot of the feminist literature I had first encountered in my doctoral studies in English literature, which tended to include a psychoanalytic view of gender dynamics. To frame the broader context, I read social theory and then added historical research on Ritalin and ADHD to the mix. What a jumble! Each individual thesis chapter was eventually published as a separate article between 2002 and 2004 after I graduated.

After I moved back to Europe I found myself in the Centre for Family Research, at the University of Cambridge, working with Professor Martin Richards. He was trained originally as a zoologist! But he moved into developmental psychology. He was, and is, a fantastic supporter of thinking across disciplinary lines. Later, when I met Nik Rose, I began to read much more sociology than I'd ever read before, and I began to really think about this problem of docility and disciplinary power; and how that might exert itself on the child.

But I never forgot those many experiences I had sitting in the clinic and listening to the challenges that children and parents face. Very often real people's dilemmas did not map onto social theory terribly well. When you looked at the complexity of lives lived, you very often felt that social theory was an inadequate explanation of that complexity, although it might illuminate some aspects of it, and it certainly might illuminate some of the structural concerns that we might have. Those theoretical influences helped me frame what might be going on in a disciplinary sense, but I did not know what to do with my developmental understanding that the socialisation of the child is a parental and indeed, a societal obligation. So the question is: where can you actually exert a critique in a way that does not leave the child then at the mercy of the critique? For me, this was a very live question.

Between 2000 and 2004, I had my own children, so I was a very part time academic. I began to look around for funding to do the research with children to understand their experiences of the ethical threats associated with ADHD diagnosis and drug treatment. I must have applied to five or six funders and they all said the same thing; how can you talk to children about these sorts of issues? Children cannot tell you anything, they are unreliable, and they will just tell you what their parents have told them. So it became clear that, in addition to lots of entrenched ways of thinking about the docility of

children and their apparently inherent lack of agency, there was also a methodological hole. Nobody had developed tools to talk to children about these sorts of issues.

So, a lot of my work leading up to the Wellcome Voices project was to try to develop those methodologies in a way that respected some of the sociological questions and factors that I knew were valuable, but also respected the developmental psychology that I knew, that children are capable of reasoning and reflective thought and that we all reflect, to some extent, social norms and so do children, you just have to find ways to engage them in ways that challenge those norms as well.

When I applied to the Wellcome Trust for the Voices project, I applied to the Biomedical Ethics Programme. They were looking for people to do empirical work in bioethics, which was, and still is, a methodological challenge, because we are not sure quite how to combine empirical research and normative analysis. I came along at the right time, with the right combination of interests and skills, and they funded me generously and enthusiastically.

That is how I become someone who is thought of as a bioethicist! I think sometimes sociologists feel as though my work with the children from this bioethics point of view has, in a sense, abandoned some of the sociological values that I held dear. But it's just a temporary shift in emphasis.

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