

## **‘Super Kids’: Regulating the Use of Cognitive and Psychological Enhancements in Children**

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### INTRODUCTION

With headlines such as, ‘Get smart drugs out of the closet, scientists urge’ and ‘Smart drugs for straight As’,<sup>1</sup> discussions about individuals taking psychopharmaceutical drugs to enhance their cognitive performance<sup>2</sup> are increasingly in the public domain. In the US, drugs such as Modafinil are being used by university students because they provide a more targeted, powerful mental ‘sharpening’ than traditional stimulants such as caffeine

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<sup>1</sup> Lucy Bannerman, ‘Get smart drugs out of the closet, scientists urge’ *The Times* (London 27 February 2010) and Peta Bee, ‘Smart drugs for straight As’ *The Times* (London 14 May 2007); see, also Alexandra Frean and Patrick Foster, ‘Cheating students turn to “smart drug” for edge in exams’ *The Times* (London 23 June, 2007).

<sup>2</sup> Martha J Farah, Judy Illes, Robert Cook-Degan, Howard Gardner, Eric Kandel, Patricia King, Barbara Sahakian and Paul Root Wolpe, ‘Neurocognitive enhancement: what can we do and what should we do?’ (2004) *5 Nature Reviews Neuroscience* 421.

in its various forms.<sup>3</sup> Such drugs are readily available on the Internet<sup>4</sup> and the US experience is reflected in the UK.<sup>5</sup> There have been calls from a former governmental Chief Scientific Officer to make ‘smart’ pills available for all.<sup>6</sup> His report noted scientists’ calls for the removal of restrictions from cognitive enhancers that have been dubbed ‘cosmetic neurology’ and ‘nip and tuck’ for the mind.<sup>7</sup> It is perhaps unsurprising that many of these drugs are already being used ‘off-label’, whereby an approved drug may be used in ways not specifically sanctioned although it is likely to be supported with scientific evidence.<sup>8</sup> The prospect for older individuals to avoid debilitating conditions such as Alzheimer’s disease is exciting and the popular perception is that there are no obvious short-term harmful effects.<sup>9</sup> However, these psychopharmacological drugs do have side-effects and have the potential to become addictive.<sup>10</sup> In addition, they target

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<sup>3</sup> Simon M Outram, ‘The use of methylphenidate among students: the future of enhancement?’ (2010) 36(4) *Journal of Medical Ethics* 198-202; Quinton Babcock and Tom Byrne, ‘Student perceptions of methylphenidate abuse at a public liberal arts college’ (2000) 49 *Journal of American College Health* 143.

<sup>4</sup> N 1.

<sup>5</sup> Alexandra Frean, ‘Let students take drugs to boost brainpower, says leading academic’ *The Times*, 1 January 2009.

<sup>6</sup> The *Brain Science, Addiction and Drugs* project led by Sir David King, Director of the Office of Science and Technology and Chief Scientific Adviser to Government until 2007 <[www.foresight.gov.uk](http://www.foresight.gov.uk)> accessed 14 March 2011.

<sup>7</sup> *Ibid.*

<sup>8</sup> This is often the case with children’s medication: Peter Hill, ‘Off licence and off label prescribing in children: litigation fears for physicians’ (2005) 90 *Archives of Disease in Childhood* 17.

<sup>9</sup> N 1.

<sup>10</sup> Outram (n 3).

molecular events underlying cognition and emotion,<sup>11</sup> and there is a concern that there may be long-term consequences such as cognitive decline, even when taken by the young.<sup>12</sup> Enhancement of psychological traits, such as personality or cognitive ability, has particular ethical, legal and social implications when applied to children. Of particular concern are the potential effects on personal identity, which is a core aspect of the self.<sup>13</sup> There are also ethical concerns of widening the gap between those able to afford the drugs and those who cannot, but a *detailed* examination of this is beyond the scope of this paper.<sup>14</sup>

Cognitive enhancing drugs are widely available on the Internet and include those available through a prescription but are more likely to be off-label. They may possibly be counterfeit,<sup>15</sup> as well as technically illegal because their supply outside of the jurisdiction

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<sup>11</sup> Paul Root Wolpe, 'Treatment, enhancement, and the ethics of neurotherapeutics' (2002) 50 *Brain and Cognition* 387.

<sup>12</sup> British Medical Association (BMA), *Boosting your brainpower: ethical aspects of cognitive enhancement* (London 29 November 2007) 7; Farah et al (n 2) and Danielle C Turner and Barbara J Sahakian, 'Neuroethics of Cognitive Enhancement' (2006) 1 *Biosocieties* 113.

<sup>13</sup> Anthony Giddens, *Modernity and Self-Identity* (Polity Press, 1991).

<sup>14</sup> For a discussion on some of the implications for society see Michael J Selgelid, 'An Argument against Arguments for Enhancement' (2007) 1(1) *Studies in Ethics, Law and Technology* 1.

<sup>15</sup> See World Health Organisation, *Medicines: counterfeit medicines* 2010 for the claim that up to 10 per cent of all medication is fake or substandard (25 per cent in developing countries)

<<http://www.who.int/mediacentre/factsheets/fs275/en/>> accessed 14 May 2011.

breaches national regulations.<sup>16</sup> This accessibility may require its own approaches. Many will prefer to use traditional routes to access these drugs and this will be the focus here: there will be concern about the sale of fraudulent drugs on the Internet, about potential interaction with drugs already being taken and because many patients want the reassurance of what they will perceive to be balanced advice from their doctors.<sup>17</sup> There will be those who doubt that parents would even consider giving their children cognitive enhancement with unknown side effects, but evidence suggests that many would.<sup>18</sup>

Part I of this paper sets out what is meant by cognitive enhancement. Part II provides key arguments both opposing and supporting its use. We wish to contribute to the current debate by setting out how decisions should be made about the use of cognitive enhancement in children. Part III explores the rationale for involving children as much as possible in personal decision-making and policy-making processes. The main proposal here is that legally competent children should decide whether to use cognitive enhancement, not their parents. Even if not legally competent, children should be as fully involved in the decision-making process as possible. With this in mind, Part IV sets out proposals for a regulatory framework that embraces principles of good practice. No

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See also Sam Lister, ‘Treat medicine counterfeiters like traffickers, says Glaxo chief’ *The Times* (London 2 October 2010) for a call to impose harsher sentences on those involved in the manufacture and supply of counterfeit drugs.

<sup>16</sup> Jonathan Richards, ‘Online drugs “put patients at risk”’ *The Times* (London 20 August 2007).

<sup>17</sup> Wendy Levinson, Audiey Kao, Alma Kuby and .Roanald A Thisted, ‘Not All Patients Want to Participate in Decision Making’ (2005) 20(6) *Journal of General Internal Medicine* 531.

<sup>18</sup> See discussion at n 102ff .

assumptions will be made about the benefits or otherwise of cognitive enhancement. Decisions will have to be taken at a societal level about the provision of enhancement generally and cognitive enhancement specifically. Responsible development and use of enhancing technologies<sup>19</sup> should be carried out in accordance with Brownsword's demand that this respect rights and preserve the conditions necessary for a prospering moral community.<sup>20</sup> This would address the recent call for appropriate risk and ethical assessments to be undertaken in parallel.<sup>21</sup> If cognitive enhancement is made available through legitimate mechanisms, then, provided a balanced picture of its use is presented, we advocate choice over rather more nebulous safety concerns.

## I. WHAT IS COGNITIVE ENHANCEMENT?

Cognitive enhancement is defined as 'internal methods of enhancement by members of the population who do not have a specific medical condition or recognised health impairment',<sup>22</sup> that is, for improving the psychological function of individuals who are

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<sup>19</sup> As advocated by Henry Greely, Barbara Sahakian, John Harris, Ronald C Kessler, Michael Gazzaniga, Philip Campbell and Martha J Farah, 'Towards Responsible Use of Cognitive-Enhancing Drugs by the Healthy' (2008) *Nature* (7 December) 702.

<sup>20</sup> Roger Brownsword, 'Regulating Human Enhancement: Things Can Only Get Better?' (2009) 1(1) *Law, Innovation and Technology* 125, 151

<sup>21</sup> The Royal Society, *Brain Waves. Module 2: Neuroscience: implications for education and lifelong learning*, February 2011, 15.

<sup>22</sup> BMA (n 12).

not ill.<sup>23</sup> A more refined definition suggests that cognitive enhancement occurs where cognitive and/or behavioural functioning is not impaired at clinically significant levels in a particular context.<sup>24</sup> Methylphenidate (hereafter, Ritalin) is an example of a neurotechnology that could be used as a cognitive enhancement. Ritalin has cognitive enhancing properties and has been available since the 1960s.<sup>25</sup> When it is used in people with no diagnosed condition of Attention Deficit Hyperactivity Disorder (ADHD), performance improves significantly because of a heightened ability to concentrate. Turner describes how many of the brain's executive functions, such as attention, problem-solving and adapting behaviour, are susceptible to the influence of pharmacological agents such as Ritalin.<sup>26</sup> Perhaps not surprisingly in the highly competitive culture of the US, it appears that many parents are seeking ADHD diagnoses

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<sup>23</sup> Farah et al (n 1). For a comprehensive survey of the ethical and policy questions that arise from biotechnological advances see the President's Council on Bioethics, *Beyond Therapy: Biotechnology and the Pursuit of Happiness* (Regan Books, Harper Collins, 2003) passim.

<sup>24</sup> Ilina Singh and Kelly J Kelleher, 'Neuroenhancement in Young People: Proposal for Research, Policy, and Clinical Management' (2010) 1(1) *AJOB Neuroscience* 3.

<sup>25</sup> Even the practice of Ritalin prescribing for treatment of ADHD itself is controversial. It has been argued that the condition is a US-inspired fad, an excuse for bad parenting, a quick and easy diagnosis for overburdened doctors or 'disease-mongering' by pharmaceutical companies keen to sell more drugs. Fukuyama argued that parents and teachers use Ritalin as a 'medical shortcut' to enhancement: Francis Fukuyama, *Our posthuman future: Consequences of the biotechnology revolution* (Profile Books, 2003) 49.

<sup>26</sup> Turner and Sahakian (n 12). Drugs newer to the market are also viable as cognitive enhancers. Turner's research showed that Modafinil (originally intended to treat narcolepsy) improves working memory in healthy, young volunteers, adults with ADHD and patients with schizophrenia with minimal side effects.

so that they obtain Ritalin for their offspring to improve their life chances.<sup>27</sup> Ritalin is currently only available in the UK legitimately with a prescription.<sup>28</sup>

Except in cases of severe intellectual disability, typically defined as an IQ below 70,<sup>29</sup> attempting to improve the cognitive function of children with below average levels of ability (IQ 70 to 100) is enhancement, not treatment. Although children with low cognitive ability are relatively disadvantaged, they are within the normal and able range of functioning. Those with below average levels of intelligence are still ‘intellectually intact’, to use Whitehouse et al’s<sup>30</sup> term. Exceptions occur when ability has been affected adversely by a factor in the external environment. For example, consider a case where lead poisoning lowered a child’s IQ from 100 to 85, raising it back would count as a

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<sup>27</sup> Anjan Chatterjee, ‘The promise and predicament of cosmetic neurology’, (2006) 32(2) *Journal of Medical Ethics* 110. The drug was re-classified in the US as a Class II drug in 1971. A Class II classification is warranted where the drug or other substance has a high potential for abuse but does have a currently accepted medical use in treatment or a currently accepted medical use with severe restrictions. In addition, abuse of the drug or other substances may lead to severe psychological or physical dependence: Larry H. Diller, ‘The run on Ritalin. Attention deficit disorder and stimulant treatment in the 1990s’ (1996) 26 *Hastings Center Report* 26, 12-18; Root Wolpe (n 11). A US study in 2000 showed that up to 20 per cent of health college students reported Ritalin use there: Babcock and Byrne (n 3).

<sup>28</sup> Such application is equally plausible in the British context: BMA (n 12); Farah et al (n 2); Turner and Sahakian (n 12) and Freat (n 5).

<sup>29</sup> World Health Organisation. *The ICD–10 Classification of Mental and Behavioural Disorders: Clinical Descriptions and Diagnostic Guidelines* 1992.

<sup>30</sup> Peter J Whitehouse, Eric Juengst, Maxwell Mehlman and Thomas H Murray, ‘Enhancing cognition in the intellectually intact’ (1997) 27(3) *Hastings Center Report* 14.

treatment.<sup>31</sup> If there was no toxin, but medication raised it from 85 to 100, this would count as an enhancement. The nature of individual differences in cognitive ability is that half of children have below average ability by definition.<sup>32</sup>

Treatment can be distinguished from enhancement by reflecting on the purpose of medical and educational provision. Medical treatment is intended to restore ‘proper functioning’,<sup>33</sup> i.e. species-typical functioning,<sup>34</sup> where ‘there is a malfunctioning part’ and is intended to improve health outcomes.<sup>35</sup> This includes preventive medicine, where there is an attempt to prevent disease before it occurs, at the population level. For Daniels,<sup>36</sup> the role of medicine is to allow patients to experience the normal range of opportunity. This is why parents may encourage a balanced diet and immunisation for their children. The term ‘range’ is important: it acknowledges that health outcomes are

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<sup>31</sup> Peter H Schwartz, ‘Defending the distinction between treatment and enhancement’, (2005) 5 *American Journal of Bioethics* 17.

<sup>32</sup> Charles Murray, *Real Education: Four Simple Truths for Bringing America's Schools Back to Reality* (Crown New York:Forum, 2008).

<sup>33</sup> Norman Daniels, ‘A Lifespan Approach to Health Care’ in Nancy Jecker (ed), *Ageing and Ethics* (Humanities Press, 1991).

<sup>34</sup> John Harris commenting on the work of Christopher Boorse, ‘On the distinction between disease and illness in Marshall Cohen, Thomas Nagel and Thomas Scanlon (eds), *Medicine and Moral Philosophy* (Princeton University Press, 1981) 49-68 and Norman Daniels, *Justice and Justification* (Cambridge University Press, 1996) 185 in ‘Enhancements are a moral obligation’ (2005) *WellcomeScience* 18.

<sup>35</sup> Whitehouse et al (n 30) 14-22.

<sup>36</sup> John Harris, ‘One principle and three fallacies of disability studies’ (2001) 27 *Journal of Medical Ethics* 383.

distributed unequally in society. Similarly, one of the purposes of education is to provide equality of educational opportunity, but with the expectation that these educational outcomes differ, are graded, ranked and unequal. The role of healthcare and education is ‘to produce “normal competitors” but not necessarily equal competitors’:<sup>37</sup> put another way, medical care and education are provided as treatments, not enhancements because they ‘level the playing field’<sup>38</sup> within a normal range which is generally considered typical for a society. In contrast, cognitive enhancements are attempts to improve upon species-typical parameters.<sup>39</sup> Daniels disagrees that education is comparable to treatment. For him, education is already an enhancement technology, merely another of the ‘ways that our uniquely innovative species tries to improve itself’.<sup>40</sup> This invokes an alternative definition of enhancement, a movement beyond species (rather than individual) limits.

The opportunities for self-enhancement and for parents to enhance their children may prove to be irresistible given its superficial attractiveness and its availability on the Internet.<sup>41</sup> People already self-medicate to improve performance in many domains,<sup>42</sup> and

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<sup>37</sup> Norman Daniels, ‘Normal functioning and the treatment-enhancement distinction’ (2000) 9(3) *Cambridge Quarterly of Healthcare Ethics* 309.

<sup>38</sup> *Ibid* 322.

<sup>39</sup> Eric T Juengst, ‘What does *enhancement* mean?’ in Erik Parens (ed), *Enhancing Human Traits* (Georgetown University Press, 1998).

<sup>40</sup> Greely et al (n 19), 702.

<sup>41</sup> <<http://www.parliament.uk/documents/upload/postpn285.pdf>> accessed 14 March 2011.

<sup>42</sup> Eg using caffeine, herbal stimulants, tonics and other over-the-counter remedies: Turner and Sahakian (n 12).

if cognitive enhancement can be shown to have minimal risks and reliable benefits, several commentators argue that their usage should be encouraged subject to ‘appropriate research and evolved regulation’.<sup>43</sup> Potential for side effects and adverse events associated with cognitive enhancers, (whether existing now or brought to the market in the future), need to be considered carefully.<sup>44</sup> If risks from cognitive enhancement are demonstrated, these risks need to be managed and regulated in the same way as other controlled substances.<sup>45</sup> As we have seen, there is also concern that the drugs may be counterfeit<sup>46</sup> which increases the risk of harm if they are toxic, inherently or because of chemical reaction with other drugs that may be taken at the same time. It is not surprising then that commentators have already noted that the Internet should be more closely regulated for this reason<sup>47</sup> and that global threats require a global approach.<sup>48</sup> The

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<sup>43</sup> Greely et al (n 19) 702.

<sup>44</sup> Farah et al (n 2).

<sup>45</sup> Turner and Sahakian (n 12) and Danielle C Turner and Barbara J Sahakian, ‘Ethical questions in functional neuroimaging and cognitive enhancement’ (2006) 4 *Poiesis Prax* 81. See also Shaheen E Lakhan and Gareth E Hagger-Johnson, ‘The impact of prescribed psychotropics on youth’ (2007) 3 *Clinical Practice and Epidemiology in Mental Health* 21.

<sup>46</sup> Richards (n 16).

<sup>47</sup> Sorrel Downer, ‘The perils of self prescription’ *Financial Times* (London 6 May 2006) 1. It is clear from events in Pakistan that more can be done where there is a will even though we may not approve of such draconian measures: Jeremy Page, ‘YouTube cut off over offensive cartoons’ *The Times* (London 25 February 2008). Such an approach may prove to be difficult in the European context: see the discussion below at n 206ff and <<http://www.ehfcn.org/eu-corner/eu-policy/counterfeit-medicines/>> accessed 14 March 2011 which outlines the current European position.

European Parliament has proposed new legislation that will allow the possibility for tough sanctions to be imposed on counterfeiters.<sup>49</sup> It will be some time before this becomes effective and is unlikely to completely resolve the problem.

Having set out what is meant by cognitive enhancement, the following section highlights the specific issues it raises for children.<sup>50</sup>

## II. COGNITIVE ENHANCEMENT: AN OBLIGATION, A RIGHT OR A STEP TOO FAR?

Safety concerns about cognitive enhancements can be found elsewhere<sup>51</sup> and justify arguments for further research<sup>52</sup> and regulation. Knowledge about risks may increase as the evidence base improves,<sup>53</sup> but as it currently stands, the risks and benefits are not clear. The problems associated with equal access to cognitive enhancements are not the

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<sup>48</sup> Carlisle E George, 'Internet Pharmacies: Global threat requires a global approach to regulation' (2006) 4(1) *Hertfordshire Law Journal* 12.

<[http://www.herts.ac.uk/fms/documents/schools/law/HLJ\\_V4I1\\_George.pdf](http://www.herts.ac.uk/fms/documents/schools/law/HLJ_V4I1_George.pdf)> accessed 14 March 2011.

<sup>49</sup> <<http://www.europarl.europa.eu/en/pressroom/content/20110215IPR13734/html/Fake-medicines-Parliament-approves-new-rules-to-protect-patients-better>> accessed 14 March 2011.

<sup>50</sup> For a detailed discussion of ethical perspectives on enhancement more generally, see Brownsword (n 20).

<sup>51</sup> See, for example, BMA (n 12) 11 and 17 which provides an overview of some of these concerns.

<sup>52</sup> Dimitris Repantis, Peter Schlattmann, Oona Laisney and Isabella Heuser, (2010). 'Modafinil and methylphenidate for neuroenhancement in healthy individuals: A systematic review'. (2010) 62(3) *Pharmacological Research* 187.

<sup>53</sup> Chatterjee (n 27).

focus of this paper but are clearly important if cognitive enhancers become regulated. We largely ‘tolerate’ inequalities in access to health care<sup>54</sup> but these issues do raise concerns about society’s vision and the type of citizens it wishes to have.<sup>55</sup> Unregulated access to cognitive enhancers can also result in the ‘red queen’ effect, in which attempts to improve children’s cognitive ability reap no net benefit<sup>56</sup> and average levels of ability, and normal levels of cognitive functions such as attention span, could become pathologised.<sup>57</sup> Our paper largely concerns the interplay between the effects of cognitive enhancement on children’s character and respect for their autonomous interests.

Enhancement of cognition, mood and/or emotion raises concerns about possible dubious effects on character which may be seen as inauthentic if children’s right to self-creation, sense of personal responsibility and experience of an unmedicated self are threatened.<sup>58</sup> Drugs can change the way we feel about and represent ourselves<sup>59</sup> and how others see us. Externally focused ‘shortcuts to excellence’ are accepted in many

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<sup>54</sup> Chatterjee (n 27) and Farah et al (n 2). Cf G Horn, J Barnes, R Brownsword, JFW Deakin, I Gilmore, M Hickman, L Iversen, T Robbins, E Taylor and J Wolff, *Brain science addiction and drugs* (Academy of Medical Sciences, 2008).

<sup>55</sup> See Derek Beyleveld and Roger Brownsword, *Human Dignity in Bioethics and Biolaw* (Oxford University Press, 2001), Chapter 2.

<sup>56</sup> *Ibid.*

<sup>57</sup> Schwartz (n 31). See also An Ravelingien, Johan Braeckman, Luc Crevits, Dirk De Ridder and Eric Mortier, ‘“Cosmetic Neurology” and the Moral Complicity Argument’ (2009) 2(3) *Neurethics* 151.

<sup>58</sup> Singh and Kelleher (n 24) 8.

<sup>59</sup> Paul Martin and Richard Ashcroft, *Neuroscience, Ethics and Society: a review of the field*. Background paper prepared for the 2005 Wellcome Trust Summer School on ‘neuroethics’.

domains,<sup>60</sup> and there can be an increased sense of agency on the part of young people.<sup>61</sup> However, others suggest that internally focused cognitive enhancement ‘break[s] some unwritten rules’<sup>62</sup> and involves cheating thus giving children the right to refuse it because it seems unfair. Even young children understand morals<sup>63</sup> and the ethical implications of cheating.<sup>64</sup> If enhancement is *not* regarded as cheating, children may regret being enhanced in later life: ‘cognitive performances are not only valued as such, but are also valued for the manner in which they are achieved’.<sup>65</sup> When cognitive enhancement divorces performance from effort, the risk is that the individual can become de-humanised<sup>66</sup> and their dignity compromised.<sup>67</sup>

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<sup>60</sup> Nick Bostrom and Anders Sandberg, ‘Cognitive Enhancement: Methods, Ethics, Regulatory Challenges’ (2009) 15(3) *Science and Engineering Ethics* 311.

<sup>61</sup> Singh and Kelleher (n 24) 8.

<sup>62</sup> See eg Maartje Schermer, ‘On the argument that enhancement is “cheating”’, (2008) 34(2) *Journal of Medical Ethics* 85.

<sup>63</sup> Judith Dunn, Jane Brown and Mary Maguire, ‘The development of children’s moral sensibility: Individual differences and emotion understanding’ (1995) 31 *Developmental Psychology* 649 and Nicholas Lake, Sophie Lane and Paul L Harris, ‘The expectation of guilt and resistance to temptation’ (1995) 4 *Early Development and Parenting* 63.

<sup>64</sup> Lake et al *ibid* and Matt Woolgar, Howard Steele, Miriam Steele, Susan Yabsley and Peter Fonagy ‘Children’s play narrative responses to hypothetical dilemmas and their awareness of moral emotions’ (2001) 19(1) *British Journal of Developmental Psychology* 115.

<sup>65</sup> Schermer (n 62) 87.

<sup>66</sup> Leon R Kass, *Life, Liberty and the Defense of Dignity: The Challenge for Bioethics* (Encounter Books: 2002) at 12 in particular.

Enhancement could also ‘undermine senses of identity and what gives meaning to our lives’<sup>68</sup> given personality traits and cognitive abilities are strong determinants of individual character. They refer to ‘. . . those characteristics of the person that account for consistent patterns of thinking, feeling and behaving.’<sup>69</sup> Traits have become a dominant model in psychology because they are core aspects of the person and show impressive stability across the lifespan.<sup>70</sup> A range of personality traits and other individual differences are part of species-typical functioning.<sup>71</sup> Changing this variation could be hazardous. Natural selection may have favoured a balance between different personality traits, some helpful and some harmful, depending on the environment and situation. Cognitive enhancement may attempt to target a narrow range of traits, removing important individual differences from the population. Even ‘undesirable’ traits, such as low cognitive ability, may have adaptive features which have evolved over time<sup>72</sup> and

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<sup>67</sup> Dignity is variously conceptualised in the medico-legal field. Beyleveld and Brownsword’s ‘dignity as constraint’ incorporates the idea that it is as wrong to compromise one’s own dignity as much as that of others is apposite. Beyleveld and Brownsword (n 55) Chapter 1.

<sup>68</sup> Chatterjee (n 27) 111.

<sup>69</sup> Lawrence Pervine, Daniel Cervine and Oliver John, *Personality: Theory and Research* (Wiley, 9<sup>th</sup> edn 2004) 6.

<sup>70</sup> Stephen Soldz and George E Vaillant, ‘The Big Five personality traits and the life course: A 45-year longitudinal study’ (1999) 33 *Journal of Research in Personality* 208.

<sup>71</sup> BMA (n 12) 24.

<sup>72</sup> Nicholas B Allen and Paul BT Badcock, ‘Darwinian models of depression: A review of evolutionary accounts of mood and mood disorders’ (2006) 30(5) *Progress in Neuro-Psychopharmacology and Biological Psychiatry* 815.

eliminating them may have unintended consequences. Highly intelligent individuals may possess maladaptive personality traits, for example: [a]n individual with brilliant intellectual skills may not necessarily be happy and could still be prejudiced, intolerant or socially inept' ... '[society does] not need only very highly intelligent people'.<sup>73</sup> There are probably benefits for the population from having a mixture of traits between individuals even if we do not fully understand the evolutionary reasons for this.

There are particular concerns about the potential for cognitive enhancements to be used as 'techniques of exercising control over children, since parents are more likely to desire to help their children fit the mold and conform to the conventional pattern than to seek social conformity for themselves'.<sup>74</sup> Unprecedented opportunities to make children conform to conventional standards could also reduce mankind's receptiveness to a range of human dispositions, thwarting the potential for children's individuality to a more dramatic extent than has hitherto been possible.

As Turner argues, the brain deserves ethical consideration because '. . . we primarily define and distinguish ourselves as individuals by our behaviour and personality.'<sup>75</sup> Cognitive abilities and personality traits are 'fragile, fragmented and embedded' concepts.<sup>76</sup> Modifying these changes people, so enhancing the cognition of

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<sup>73</sup> BMA (n 12) 18-19.

<sup>74</sup> President's Council (n 23) 90.

<sup>75</sup> Turner and Sahakian (n 12) 116.

<sup>76</sup> Iina Singh, 'Will the "real boy" please behave: dosing dilemmas for parents of boys with ADHD' (2005) 5 *American Journal of Bioethics* 34.

children need to be evaluated in terms of possible violations of the principles of autonomy, dignity and respect for the individual. It could be perceived as improving control of cognitive abilities. However, cognition is ‘intrinsically linked with our personality and individuality’<sup>77</sup> so decisions to enhance cognition in children may infringe their identity and there is established evidence that young people have a clear sense of their unique, distinctive features.<sup>78</sup>

While there is unease about safety, the preceding discussion highlights how the benefits and risks of taking cognitive enhancement will become more apparent. Here, the main concern is in relation to the effect they may have on the character and personal identity of children. If the risks are shown to be minimal, there is at least an argument that cognitive enhancement could have positive outcomes for children.

It has been argued that concerns about cognitive enhancements outlined above are simply ‘spectres’<sup>79</sup> and commentators such as Harris<sup>80</sup> propose that there is a moral obligation to pursue optimal enhancement and confer even small benefits when these become known: this is the purpose of conducting medical research to discover

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<sup>77</sup> BMA (n12) 3.

<sup>78</sup> Marjorie Rutter and Michael Rutter, *Developing Minds: Challenge and Continuity across the Life Span* (Penguin, 1993) 253-254.

<sup>79</sup> Editorial, ‘Enhancing, not cheating’. (2007) 450(7168) *Nature* 320.

<sup>80</sup> John Harris, *Wonderwoman and Superman*, (Oxford University Press, 1992), John Harris, ‘Is there a coherent social conception of disability?’ (2006) 26(2) *Journal of Medical Ethics* 95 and Harris (n 36) *passim*

treatments.<sup>81</sup> He emphasises that such opportunities must undergo a risk assessment but avoid the use of the precautionary principle so prevalent in current debate.<sup>82</sup> Opposition to enhancement, taken to its logical conclusion, would mean that diseases of old age will no longer be addressed.<sup>83</sup> For him, the moral imperative in using technology to improve people's life chances includes cognitively enhancing intellectual performance:<sup>84</sup> the only discussion should be about the level of risk that is acceptable for both individuals and society.

Hopkins<sup>85</sup> proposes a means by which cognitive enhancement can be viewed as a human right. He rejects pure, content-free autonomy claims as immature and 'vapidly libertine'<sup>86</sup> in preference for a version that is both rational and practical.<sup>87</sup> Hopkins

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<sup>81</sup> *Ibid.*

<sup>82</sup> For adherents of a more precautionary approach, see Ingmar Persson and Julian Savulescu, 'The perils of cognitive enhancement and the urgent imperative to enhance the moral character of humanity' (2010)

*Journal of Applied Philosophy*(forthcoming):

<[http://www.practicaethics.ox.ac.uk/Pubs/Savulescu/moral\\_enhancement.pdf](http://www.practicaethics.ox.ac.uk/Pubs/Savulescu/moral_enhancement.pdf)> accessed 14 March 2011.

See also Turner and Sahakian (2006) (n 45) and Farah et al (n 2) who advocate a more precautionary stance.

<sup>83</sup> Harris (n 34) and Daniels (n 33).

<sup>84</sup> John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* (Princeton University Press, 2007) *passim*.

<sup>85</sup> Patrick D Hopkins, 'Is enhancement worthy of being a right?' (2008) 18(1) *Journal of Evolution and Technology* 1.

<sup>86</sup> *Ibid* 2. See also John Coggon, 'Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?' (2007) 15(3) *Health Care Analysis* 235.

believes that an appeal to important, worthwhile and reasonable interests is more grounded, serving to realise the potential goodness of our lives. The pursuit of knowledge (as represented by cognitive enhancement) is a legitimate claim, and one that is aligned with the classic values of natural law. It is worth re-iterating his note of caution that to be recognised as a right, cognitive enhancement must *be* worthwhile, dignified and noble, not merely perceived as such.<sup>88</sup> We must be more rigorous if we wish to defend cognitive enhancement and avoid the shorthand of (shallow) autonomy claims, but it is a useful starting point given its legal recognition in cases affecting adults and children.<sup>89</sup>

Our intention is not to raise a new ‘spectre’. We believe neurotechnologies could affect children’s dignity and autonomy, not simply because of their possible implications but also because of the potential lack of involvement in decision-making. The decision to enhance has implications for safety, inequality, character and autonomy, and this is why legal clarification on the extent to which children should be involved is essential. Part of any deliberations about the use of cognitive enhancement must note the difficulties associated with the unintended side-effects, and that some affected personality traits, while commonly perceived to have negative qualities, may prove to have adaptive functions in the longer term. Perhaps this potential should preclude the possible gains to the individual in the short term. If we agree with advocates for cognitive enhancement,

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<sup>87</sup> Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press, 1988) 6 where he lists the broad range of meanings attributed to autonomy and Coggon *ibid*.

<sup>88</sup> Hopkins (n 85) 6.

<sup>89</sup> Eg *Re B (Adult: refusal of medical treatment)* [2002] 2 FCR1 and *Mabon v Mabon et al* [2005] 3 WLR 460 where Thorpe LJ commented that there should be increased recognition of children’s autonomy.

should parents be permitted to enhance their children at will? The important issue for us, regardless of eventual outcomes, is that decisions to use cognitive enhancement requires a more robust approach than is currently the case. The following section explores briefly the rationale for involving children as much as possible in the decision-making process.

### III. CHILDREN'S INVOLVEMENT IN DECISION-MAKING

#### **A. Children and Personal Decision-making**

In the case of younger children who lack legal competency,<sup>90</sup> the decision to give them cognitive enhancement is likely to be made by parents. The fact that parents should act in a child's best interests is a well-established legal principle.<sup>91</sup> On this basis, making children eat their greens, do their homework and receive treatments for psychological and physical illnesses would be acceptable.<sup>92</sup> Attempts to give children a competitive edge are considered customary,<sup>93</sup> though the pressures from these are not always in the child's

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<sup>90</sup> Ie do not satisfy the *Gillick* test as having 'sufficient understanding and intelligence' to make a decision: *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112, 189.

<sup>91</sup> *Ibid* 184 per Lord Scarman.

<sup>92</sup> See the discussion of best interests in Lynn Hagger, 'Parental Responsibility and Children's Health Care Treatment' in Rebecca Probert, Stephen Gilmore and Jonathan Herring (eds), *Responsible Parents and Parental Responsibility* (Hart, 2009).

<sup>93</sup> As Chatterjee notes, it is not unusual for professionals to work 80 or 90 hours a week, while their children enrol in several sports and after school music programmes .to ensure they can make competitive applications to colleges: Chatterjee (n 27) 111.

best interests<sup>94</sup> and they may reflect the interests of the parents.<sup>95</sup> Potential adverse side effects of cognitive enhancement have yet to be given the oxygen of wide publicity,<sup>96</sup> so parents could view it as providing a positive benefit to their children or at least a risk worth taking all things being equal. It is also arguable that all that a parent is required by the law to do is act in a way which is not against a child's best interests.<sup>97</sup> This could be seen as a dilution of the welfare principle<sup>98</sup> and could render non-therapeutic interventions lawful provided they do not cause significant harm.<sup>99</sup> This means that even if portraying cognitive enhancement as a *clearly* beneficial intervention presents

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<sup>94</sup> Deborah A Phillips, 'Socialization of Perceived Academic Competence among Highly Competent Children' (1987) 58(5) *Child Development* 1308.

<sup>95</sup> See e.g. Meir Statman and Jessica A Weng, 'Investments across Cultures: Financial Attitudes of Chinese Americans', (2010) 11(1) *The Journal of Investment Consulting* 38 and <<http://genxfinance.com/love-and-money-between-parents-and-children/>> accessed 14 March 2011 for an example of different cultural expectations.

<sup>96</sup> Anjan Chatterjee, 'Is it acceptable for people to take methylphenidate to enhance performance? No' (2009) 338 *British Medical Journal* b1956 where she discusses evidence of abuse and dependence, sudden death, cardiovascular adverse events and cardiac arrhythmia in older people.

<sup>97</sup> See *S v S* [1972] AC 24 where it was considered that to allow paternity testing against the mother's wishes would not be against the child's interests and was justifiable in the general public interest.

<sup>98</sup> Marie Fox and Jean McHale, 'In Whose Best Interests?' (1997) 60 *Modern Law Review* 700.

<sup>99</sup> Shaun D Pattinson, *Medical Law and Ethics* (Sweet and Maxwell, 2006) 65. One example of where parents may consent to a non-therapeutic intervention can be found in ritual circumcision where there is no clinical need for the operation. See John M Hutson, 'Circumcision: A Surgeon's Perspective' (2003) 30 *Journal of Medical Ethics* 238 who discusses the possible protective effects of circumcision and their alternatives and further exploration of the issue in Lynn Hagger, *The Child as Vulnerable Patient: Protection and Empowerment* (Ashgate, 2009), Chapter 3.

difficulties, the lack of evidence of longer term substantial harm is likely to be seen as legally permissible.

We should not be too hasty to depart from the view that parents have a fundamental interest in their children's welfare, although, clearly, parents do sometimes harm their children.<sup>100</sup> Generally, they have a stake in the child's well-being and possess unique, detailed knowledge of their child as well as high levels of empathy.<sup>101</sup> It may be thought that the idea that parents would consider giving their children cognitive enhancement with both known and unknown side effects is far-fetched. However, these doubts can be dispelled.<sup>102</sup> Salvemini<sup>103</sup> discusses the risks of children taking growth hormone and notes that 42 percent of prescriptions are off-label in the US which indicates that parents are willing to take these risks. She describes parents' aesthetic preferences for taller children,<sup>104</sup> even where their children are only two standard deviations below the mean for height, but still part of the normal distribution of height.<sup>105</sup> They are prepared to give these drugs to their children even though they carry significant risks

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<sup>100</sup> David P Southall, Michael C Plunkett, Martin W Banks, Adrian F Falkov and Martin P Samuels, 'Covert Video recordings of Life-Threatening Child Abuse' (1997) 100 *Paediatrics* 735.

<sup>101</sup> See the discussion in *An NHS Trust v MB* [2006] 2 FCR 319 discussed further in Hagger (n 99).

<sup>102</sup> Singh and Kelleher (n 24) 9.

<sup>103</sup> Vita M Salvemini, 'Idiopathic Short Stature or Just Plain Short: Why the Federal government Should regulate the Administration of Human Growth Hormone to healthy Children' (2003) 38 *Georgia Law Review* 1105.

<sup>104</sup> *Ibid* 1109.

<sup>105</sup> *Ibid* 1113.

such as kidney failure.<sup>106</sup> The evidence of increasing use that is fuelled by parental requests has led to a call for ethical approval for such uses.<sup>107</sup> Given that parents are willing to enhance their offspring in this way, despite the possibility of dangerous side effects, it follows that many would be willing to cognitively enhance.

Diaz<sup>108</sup> notes the increasing use of Prozac in the US, which is not approved for use in children but is prescribed off-label, so parents should have been informed that the risks of taking this drug in a young, growing body and developing brain are yet to be definitively determined. There is some evidence that it does little to relieve childhood depression and can precipitate ‘psychotic panic’ in seriously troubled children.<sup>109</sup> Powers echoes some of these concerns when noting parents’ role in the ‘race for perfection’ and the influence of parents’ ideals.<sup>110</sup> In striving to optimise their child’s life-chances as they see it, parents will go to great lengths: Chiumino describes a case where parents campaigned against a nurse’s refusal to prescribe Ritalin despite the known and unknown side effects.<sup>111</sup> This echoes Albright’s concern about parents making poor choices in

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<sup>106</sup> *Ibid* 1130.

<sup>107</sup> *Ibid* 1143.

<sup>108</sup> Letitia M Diaz, ‘Regulating the Administration of Mood-Altering Drugs to Juveniles: Are We Legally Drugging Our Children?’ (2001) 25 *Seton Hall Legislative Journal* 83, 103.

<sup>109</sup> *Ibid* 105.

<sup>110</sup> Therese Powers, ‘Race for Perfection: Children’s Rights and Enhancement Drugs’ (1998) 13 *Journal of Law and Health* 141, 152.

<sup>111</sup> Ann Chiumino, ‘Class Action Suits Prompt Governmental Action to Examine Ritalin Use and Regulation’ (2001) 13(4) *Loyola Consumer Review* 380, 391.

relation to the use of psychotropic drugs in their children to improve their academic success.<sup>112</sup>

It is not hard to imagine that doctors can just as easily succumb to parental pressure in the UK and be willing to prescribe cognitive enhancing drugs.<sup>113</sup> Some doctors will have concerns about long-term risks and/or have doubts about the ethical justification for their use while others will be persuaded by arguments that support their use. Although the NHS is unlikely to fund drugs that are not clinically indicated, private prescriptions could be readily available.

Where there are disputes about whether parents are acting in the child's best interests, the courts will be the final arbiter. For cases decided under the Children Act 1989, section 1(3) provides a checklist to guide the court in assessing what course of action would be in the child's best interests: in medical cases this is seen as synonymous with the welfare of the child.<sup>114</sup> A wide range of factors should be taken into account as a matter of good practice<sup>115</sup> adopting the formulation of best interests as it is applied to incompetent adults with respect to medical treatment.<sup>116</sup> Here we see a broad reading of

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<sup>112</sup> Jennifer Albright, 'Free Your Mind: The Right of Minors in New York to Choose Whether or Not to be Treated with Psychotropic Drugs' (2006) 16 *Albany Law Journal of Science & Technology* 169, 188-193.

<sup>113</sup> Singh and Kelleher (n 24) 12.

<sup>114</sup> *Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480, 512.

<sup>115</sup> *Re J* [1999] 2 FCR 345 (circumcision) and *Re C* [2003] EWCA Civ 1148 (immunisation).

<sup>116</sup> *Wyatt and another v Portsmouth Hospital NHS Trust and another* [2005] EWCA Civ 1181, para 79.

the best interests' principle encompassing medical, emotional and other welfare factors<sup>117</sup> including the psychological and social benefit to the individual.<sup>118</sup> The potential effects of cognitive enhancement incorporate all these aspects and would need to be given serious consideration.

The court must have regard to the wishes and feelings of the child concerned as far as they can be ascertained according to their age and understanding.<sup>119</sup> This should help to inform about their needs,<sup>120</sup> their particular characteristics<sup>121</sup> as well as the likely effect of any proposed intervention.<sup>122</sup> Decision-making needs to be more structured in relation to cognitive enhancement. It carries more significant implications than other decisions parents take to improve children's life chances. Music lessons and private education are not of the same order:<sup>123</sup> [t]he new forms of neuroenhancement can nonetheless be distinguished in terms of proximity to the neural level and the more direct, immediate and long-term effects on the brain they will likely have.'<sup>124</sup> Participatory decision-making can be used with very young children, even where they are deemed to

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<sup>117</sup> *Re A (Male Sterilisation)* [2000] 1 FLR 549 per Dame Butler-Sloss P, 555.

<sup>118</sup> *Re Y* [1997] 2 WLR 556, 562. Latterly, the courts have been enthusiastic about adopting a balance sheet approach whereby a list is drawn up of benefits and burdens of proposed courses of action: see, for example, *Wyatt* (n 116).

<sup>119</sup> S 3(1) (a).

<sup>120</sup> S 3(1) (b).

<sup>121</sup> S 3(1) (d).

<sup>122</sup> S 1 (3) (c).

<sup>123</sup> Cf BMA (n 12) 23.

<sup>124</sup> Ravelingien et al (n 57) 152.

be legally incompetent because they still bear interests that should be taken into account<sup>125</sup> and empirical evidence suggest that children can make significant decisions even at a very young age.<sup>126</sup>

A note of caution seems apposite here. It should not be assumed that the guiding light of the welfare principle provided by the Children Act 1989 will necessarily lead to the correct decision. The welfare principle can be seen as unpredictable, lacking in substance, susceptible to bias, and can mean a child's interests are insufficiently acknowledged.<sup>127</sup> As James has pointed out,<sup>128</sup> the courts can be only too ready to 'deny children's ability to behave and decide responsibly and to set aside their wishes and feelings, it also demonstrates the power of the language of welfare and how it can be used to deny children's agency.'<sup>129</sup>

As far as older, potentially competent children are concerned, interfering with their decision to take cognitive enhancement (or to impose it upon them) interferes with

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<sup>125</sup> See Jane Fortin, *Children's Rights and the Developing Law* (Butterworths, 2<sup>nd</sup> edn 2003) for a useful survey of the development of the notion of children's rights, particularly Chapter 1.

<sup>126</sup> Discussed further in Hagger (n 99), Chapter 2.

<sup>127</sup> Helen Reece, 'The Paramountcy Principle: Consensus of Construct?' (1996) 49 *Current Legal Problems* 267, 303.

<sup>128</sup> Adrian James, 'Responsibility, Children and Childhood' in Jo Bridgeman, Heather Keating and Craig Lind (eds) *Responsibility, Law and the Family* (Ashgate, 2008) discussing *Re W (Contact: Joining Child as Party* [2001] EWCA Civ 1830.

<sup>129</sup> *Ibid* 153.

their autonomy.<sup>130</sup> It may seem unlikely that parents will impose cognitive enhancement on older children but coercion takes many forms and we have seen the US evidence that parents will take risks with respect to the medication of their children.<sup>131</sup> There is no reason to believe that parents in the UK are not prepared to undertake similar risks. Duress or other interference in such decision-making may not only violate children's autonomy, but prevent them from 'owning' their own educational success and maintain their cognitive abilities and personality traits. This gives children a particularly strong case to be involved in decisions about whether they should take cognitive enhancers or not. The call for mature children to make their own decisions has many proponents, because there is persuasive empirical evidence that children are more capable than is generally thought to be the case: they can understand the implications of what they are deciding.<sup>132</sup> This plea has a particular force where the intervention is not clinically necessary, as in the case of cognitive enhancement.

The capacity of anyone over 16 is now determined under the empowering Mental Capacity Act 2005 (MCA).<sup>133</sup> There is a rebuttable presumption of capacity under the

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<sup>130</sup> For a discussion of children's right to autonomy and its scope see Hagger (n 99), Chapter 2.

<sup>131</sup> See n 102ff.

<sup>132</sup> See eg Priscilla Alderson, *Children's Consent to Surgery* (OUP, 1993); Christine Eiser, 'Changes in understanding of illness as the child grows' (1985) 60 *Archives of Disease in Childhood* 489-492 and Katy Sutcliffe, Priscilla Alderson and Katherine Curtis, *Children as Partners in Their Diabetes Care* (Institute of Education, University of London, 2004) <[http://eppi.ioe.ac.uk/ssru\\_docs/DiabetesReportFinal.pdf](http://eppi.ioe.ac.uk/ssru_docs/DiabetesReportFinal.pdf)> accessed 14 March 2011 and Hagger (n 99), Ch 2.

<sup>133</sup> S 2(5).

MCA<sup>134</sup> and a requirement to take all practicable steps to help the individual make that decision,<sup>135</sup> which may be significant.<sup>136</sup> *Gillick*<sup>137</sup> provided a precedent for furthering the interests of children under 16, because it established their right to consent to medical interventions provided they have ‘sufficient understanding and intelligence to enable him or her to understand fully what is proposed’ even in the face of parental opposition.<sup>138</sup> Subsequent cases retracted from this empowering decision by not allowing competent children to refuse treatment.<sup>139</sup> The Human Rights Act 1998 (HRA) has begun to emphasise the importance of children’s autonomy. By largely incorporating the provisions of the European Convention on Human Rights (ECHR), the HRA provides an opportunity to challenge traditional notions of children’s ability to make decisions.<sup>140</sup> Articles 3 and 8 have particular relevance in relation to cognitive enhancement.

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<sup>134</sup> S 1(2).

<sup>135</sup> S 1(3).

<sup>136</sup> Discussed in Hagger (n 99). There are onerous requirements contained in Part 2, Chapter 3 of the Code of Practice in some detail as to what might be expected including appropriate settings and the use of aids. Additionally, a person is not to be assumed to lack capacity merely because of their age or appearance (s. 2(3)), or because others believe they have made an unwise decision (s. 1(4)) thus capturing the common law approach in *Re W* [2002] EWHC 901) for example.

<sup>137</sup> *Gillick* (n 90) 127 and discussed further in Hagger (n 99).

<sup>138</sup> *Gillick* *ibid* per Lord Lord Scarman, 189.

<sup>139</sup> Eg *Re R (A Minor) (Wardship: Consent to Medical Treatment)* [1991] 4 All ER 177.

<sup>140</sup> See Hagger (n 99) for further discussion on this point.

Dignity is protected by Article 3 of the ECHR. This prohibits the infliction of inhuman and degrading treatment but is likely to be infringed only in extreme cases.<sup>141</sup> Currently, a failure to assess competence accurately is unlikely to constitute a breach, but if this is followed by very significant medical intervention, then it could be regarded as a form of harm. Generally, therapeutically *necessary* treatment without consent would not constitute inhuman and degrading treatment.<sup>142</sup> Conversely, the imposition of enhancement (by definition an intervention that is not clinically indicated and one that potentially interferes with identity), without appropriate consultation with the child and/or without sufficient risk information, could easily fall foul of Article 3. This is even more likely to be the case if there is any element of compulsion.<sup>143</sup> Of course, many might assert that the practical reality is that parents and/or doctors are unlikely to force young people to take cognitive enhancing drugs against their will when life is not at risk, but there is a need to be alert to different levels of coercion. Pushing children to excel can be subtle or overt as can be seen from the US evidence.<sup>144</sup>

The focus here is on Article 8(1), which requires respect for private and family life. This would be at the centre of any claim now made by the mature minor who

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<sup>141</sup> See eg *D v United Kingdom* (1997) 24 EHRR 423 and *Z v UK* [2001] 2 FLR 612.

<sup>142</sup> *Herczegfalvy v Austria* (1992) 15 EHRR 437.

<sup>143</sup> Case law under the Mental Health Act 1983 illustrates how the HRA adds a further protection to existing barriers to compulsory treatment in cases where patients resist it. See eg *R (on the application of PS) v G (RMO) and W (SOAD)* [2003] EWHC 2335 (Fam) regarding unnecessary compulsory treatment and *Keenan v UK* (2001) EHRR 38 with respect to unreasonable physical force.

<sup>144</sup> N 102ff.

believes their autonomy has received insufficient recognition: there may have been a failure to consult them on their views or they may wish to argue that their refusal of enhancement should not be overridden by the court and/or their parents. Not only is Article 8(1) particularly important because it can support a child's autonomy, but also because it protects the right to dignity<sup>145</sup> which may be affected by cognitive enhancement. If we accept that personality traits are a core aspect of identity<sup>146</sup> which may be altered by cognitive enhancement intentionally or otherwise, this can be seen as an infringement of dignity. A person's psychological integrity may be disrupted by changing the way they feel and represent themselves<sup>147</sup> and traits may be removed that have important values that may not yet be discovered.<sup>148</sup> As the Strasbourg court said in *Pretty v United Kingdom*:<sup>149</sup> [t]he very essence of the Convention is respect for human dignity and human freedom.<sup>150</sup> Commenting on the 'physical and psychological integrity' point raised in *Botta v Italy*,<sup>151</sup> Munby J in *R (on application of A, B, X, & Y) v East Sussex County Council (No. 2)*,<sup>152</sup> took the view that this, *inter alia*, embraced the concepts of human dignity. Thus dignity has clear protection under the law. The broad

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<sup>145</sup> See the discussion at n 67ff on how this may be conceived.

<sup>146</sup> Soldz and Vaillant (n 70).

<sup>147</sup> Martin and Ashcroft (n 59).

<sup>148</sup> Eg Paul J Watson and Paul W Andrews, 'Toward a revised evolutionary adaptationist analysis of depression: the social navigation hypothesis' (2002) 72(1) *Journal of Affective Disorders* 1.

<sup>149</sup> (2002) 35 EHRR 1.

<sup>150</sup> At para 65.

<sup>151</sup> *Botta v Italy* (1998) 26 EHRR 241.

<sup>152</sup> [2003] EWHC 167 (Admin).

reading given to Article 8(1) includes ‘attacks on his physical or mental integrity or his moral or intellectual freedom’.<sup>153</sup> In the context of children, this is relevant because the imposition of cognitive enhancement can undermine their right to make such a decision for themselves.

The judiciary has begun to adopt a stance towards the mature minor’s autonomy that is more aligned to the liberal interpretation of *Gillick*. In *R (Axon) v Secretary of State for Health (Family Planning Association intervening)*,<sup>154</sup> *Gillick* was revisited in the light of Mrs Axon’s right to family life under Article 8(1) of the HRA<sup>155</sup> in that she wished to be informed if either of her daughters, then aged 12 and 15, sought an abortion. Silber J indicated that the international instruments illustrate: ‘. . . that the right of young people to make decisions about their own lives by themselves at the expense of the views of their parents has now become an increasingly important and accepted feature of family life.’<sup>156</sup>

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<sup>153</sup> Jacques Velu , ‘The European Convention on Human Rights and Right to Respect for Private Life, the Home and Communications’ in Arthur H Robertson (ed), *Privacy and Human Rights* (Manchester University Press, 1973) 12, 92.

<sup>154</sup> *R (Axon) v Secretary of State for Health (Family Planning Association intervening)* [2006] EWHC 37 (Admin).

<sup>155</sup> In relation to Guidance for Doctors and other Health Professionals on the Provision of Advice and Treatment to Young People under 16 on Contraception, Sexual and Reproductive Health (29 July 2004), Gateway Reference No 3382. Relevant parts of the Guidance are set out at [2006] EWHC 37 (Admin), at paras 22 - 24.

<sup>156</sup> *Axon* (n 154) citing Articles 16(1) and 12(1) of the United Nations Convention on the Rights of the Child 1989 (UNCRC) and the judgment of Thorpe LJ in *Mabon v Mabon* (n 89).

More recently, in *Re P*,<sup>157</sup> Johnson J was prepared to acknowledge that there *might* be cases where older children would be permitted to refuse to receive blood products. Further cases decided less unequivocally would encourage a further shift in attitudes because these cases, which purportedly protect child autonomy, also have a strong focus on child welfare.<sup>158</sup> In addition, Silber J's judgment in *Axon*<sup>159</sup> suggests that the Fraser guidelines for assessing competence<sup>160</sup> require a very high level of understanding of the decision to be made, and that the decision is in the child's best interests if it is made without parental knowledge or consent.

Using *Gillick* cautiously in determining children's competence is dubious. Using age<sup>161</sup> and traditional measures of general intelligence alone is a poor measure of a child's capacity to understand and meaningfully engage with medical information.<sup>162</sup>

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<sup>157</sup> *Bro Morgannwg NHS Trust v 'P' and others* [2003] EWHC 2327 (Fam) (*Re P*).

<sup>158</sup> *Mabon* (n 89) para 29.

<sup>159</sup> *Axon* (n 154).

<sup>160</sup> Laid down in *Gillick* (n 90). As Lord Fraser explained, '[s]ocial customs change, and the law ought to, and does in fact, have regard to such changes when they are of major importance' and, explaining current perceptions of the parent/child relationship, he said that 'most wise parents relax their control gradually as the child develops and encourage him or her to become increasingly independent' and 'the degree of parental control actually exercised over a particular child does in practice vary considerably according to his understanding and intelligence', at 171F and 171 D-F respectively.

<sup>161</sup> As suggested by s 1(3)(a) CA.

<sup>162</sup> Priscilla Alderson and Jonathan Montgomery, *Health Care Choices: Making Decisions with Children* (IPPR, 1996) discovered this to be the case based on a 1993 research project generally.

Notwithstanding the emphasis the judiciary places on understanding the implications of a decision in cases concerning mature minor's competence to consent, the evidence is that using age to determine capacity continues even in institutions that purport to focus on the individual child's rights.<sup>163</sup> Such a position fails to acknowledge the importance of contextual factors in cognitive development including any particular perspective a child may have gained.<sup>164</sup> Evidence suggests that experience of illness, disability and treatment is a more indicative factor in assessing competency than age.<sup>165</sup> Cognitive maturity is often related directly to age but this provides a very general indicator of a child's cognitive competence because children develop at different rates across a range of situations.<sup>166</sup> Research<sup>167</sup> highlights how young children's cognition appears to be 'hardwired' enabling them to process and interpret the demands of their world at a very early age. Psychologists, who adopt contemporary mainstream thinking in this area, prefer to assess profiles of children's cognitive competencies in both broad and specific abilities.<sup>168</sup>

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<sup>163</sup> BMA working party on children's consent < <http://www.bma.org.uk/ap.nsf/Content/consentk2>> accessed 14 March 2011. This seems to be the case even in specialist children's settings: see Healthcare Commission's *State of Healthcare*, 2007, 71.

<sup>164</sup> Alderson (n 132) 123.

<sup>165</sup> Louise Hammond, *Children's Decisions in Health Care and Research* (Institute of Education, 1993).

<sup>166</sup> John H Flavell, 'Stage-related properties of cognitive development' (1971) 2(4) *Cognitive Psychology* 421..

<sup>167</sup> See eg Jean M Mandler, 'A new perspective on cognitive development in infancy' (1990) 78 *American Scientist* 236 and Stephen Pinker, *The Blank Slate: The Modern Denial of Human Nature* (Penguin Books, 2002).

<sup>168</sup> *Ibid.*

There is anecdotal and other evidence that where parents and health professionals agree with a child who does not wish to receive even life-saving treatment, the child's decision is allowed to stand<sup>169</sup> but practice is inconsistent.<sup>170</sup> Of course, notwithstanding the support for children's involvement in decision-making preferred here, there will always be those who adopt a more protectionist stance. Some commentators believe that encouraging children to make mature decisions unnecessarily redraws the boundary between childhood and adulthood and that the focus should be on the child in the present.<sup>171</sup> Similarly, Feinberg argues that intervening in the lives of children for the sake of the child's future autonomy, their 'right to an open future',<sup>172</sup> where a child's decision

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<sup>169</sup> One of the authors has had wide contact with a range of health professionals across the UK over the last 22 years. See also 'Tributes paid as Joanne, 19, dies after refusing double transplant', *Northern Echo* (Darlington 5 March 2007) which publicises how Joanne Vincent was allowed to refuse a life-saving heart-lung transplant at the age of 12 years because she wished to enjoy the time she had left with her family. This is supported by the comments in Emily Jackson, *Medical Law: Texts, Cases and Materials* (Oxford University Press, 2006) 247. Of course, agreement amongst all those involved means that the matter does not need judicial resolution but may give a more balanced picture of actual practice. However the autonomy of the mature minor is not always this protected. What is needed is *consistent* protection where the necessary conditions for autonomy are present.

<sup>170</sup> Alderson, and Montgomery (n 162); BMA and Healthcare Commission (n 163) and personal communication from Dr. Jerry Wales, Consultant Paediatrician, Sheffield Children's NHS Foundation Trust.

<sup>171</sup> Tom Campbell, 'The Rights of the Minor' in Philip Alston, Stephen Parker and John Seymour (eds), *Children, Rights and the Law* (Clarendon Press, 1992).

<sup>172</sup> Joel Feinberg, *Freedom and Fulfilment: Philosophical Essays* (Princeton University Press, 1992) 76-98.

or behaviour is such that it threatens her own future is justified. Mental ability is demonstrably affected by cognitive enhancement and other commentators have proposed a more precautionary approach for its use with children more specifically.<sup>173</sup>

The paternalistic arguments outlined above fail to convince. There will always be a need to strike a balance between a child's need for protection vis-à-vis the importance of promoting their capacity for self-determination.<sup>174</sup> Account must always be taken of the physical and mental differences between children and adults, but these are not always accurately assessed.<sup>175</sup> The argument here is that a child's autonomy should be respected where the child has demonstrated that they clearly meets the legal standard for establishing capacity and that the process for doing so takes account of the broad range of factors affecting cognitive maturity alluded to here. Sophisticated measures of cognitive social maturity<sup>176</sup> can introduce a welcome element of objectivity into any assessment of whether a child can satisfy a requirement to be able not only to understand information, but to weigh it up when reaching a decision. Given decisions about cognitive

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<sup>173</sup> Turner and Sahakian (2006) (n 45) and Farah et al (n 2).

<sup>174</sup> See Michael Freeman, *The Rights and Wrongs of Children* (Pinter, 1983) Chapter 2 and Hagger (n 99) for an outline of what may constitute a child's right to autonomy.

<sup>175</sup> Mary Donnelly, 'Capacity assessment under the Mental Capacity Act 2005: Delivering on the functional approach?' (2009) 29(3) *Legal Studies* 464.

<sup>176</sup> Eg Carolyn E Levers-Landis, Rachel N Greenley, Chris Burantand Elaine Borawski, 'Cognitive Social Maturity, Life Change Events, and Health Risk Behaviors among Adolescents: Development of a Structural Equation Model' (2006) 13(2) *Journal of Clinical Psychology in Medical Settings* 111.

enhancement involves calculations about future risk-benefit ratios, levels of competence will need to be suitably high.<sup>177</sup>

Putting pressure on a mature minor to accept cognitive enhancement or preventing them from taking it is an irrevocable step that cannot be ameliorated by allowing them to take such decisions on their own in the future. Any sense of violation of their autonomous interests may not subside and makes no logical sense because they will not become more legally competent in the future.

As well as ensuring children and young people are as involved as possible in personal decisions about taking cognitive enhancement, opportunities should be provided to be engaged in policy formulation about its use more generally.<sup>178</sup> Not only do they have the ability to be meaningfully involved at this level, any resulting policies are likely to be more pertinent to this age group. More importantly, children's views about health and health services differ from those of their parents and professionals with whom they are in contact.<sup>179</sup> Therefore adopting their perspective will lead to more appropriate healthcare as perceived by *them*.

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<sup>177</sup> Singh and Kelleher (n 24) 7.

<sup>178</sup> Allison James, Chris Jenks and Alan Prout, *Theorising Childhood* (Polity Press, 1999).

<sup>179</sup> For a discussion of the evidence see Hagger (n 99), Chapter 8.

## **B. Children and Policy-Making**

In the light of evidence that children are competent social actors, there should be more concerted efforts to involve them in policy making. The United Nations Convention on the Rights of the Child 1989 (UNCRC) is seen as pivotal in relation to the call for greater recognition of children and young people to not only express their views but also to have these acted upon.<sup>180</sup>

The Convention underpins the United Kingdom's approach to children but some of its key Articles are not reflected fully in law, policy and practice, in common with most other jurisdictions.<sup>181</sup> Some changes in the representation of young people in the policy arena have taken place and this should be replicated in policy formulation with respect to cognitive enhancement. At this level, as scientific discoveries about the brain are made, medical practice, legal interpretations and health and social policy should be addressed from a wide perspective, along with full involvement by those directly affected. Decision-making is improved when a breadth of opinion is taken into account

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<sup>180</sup> Articles 12 and 13 in particular.

<sup>181</sup> Lothar Krappmann, 'The weight of the child's view (Article 12 of the Convention on the Rights of the Child)', (2010) 18(4) *International Journal of Children's Rights* 501. Children's Rights Alliance for England, *Convention on the Rights of the Child: Review of UK Government Action on 2003 Concluding Observations of the UN Committee on the Rights of the Child*. Children's Rights Alliance for England: London and see Allison James and Adrian L James, *Constructing Childhood: Theory, Policy and Social Practice* (Palgrave: Macmillan, 2004), Chapter 4 *passim*.

by drawing on different areas of expertise.<sup>182</sup> The proposal here is that the child should be a central part of the policy-making process to ensure their interests are fully protected.<sup>183</sup>

There is a growing recognition of a need for participation where health care services are provided for young people in the context of enhanced user involvement more generally,<sup>184</sup> the rights agenda<sup>185</sup> and the growing acknowledgement that children are competent social actors.<sup>186</sup> Young people should also be consulted on issues that concern everyone, not just those that affect them. We need an approach that is child-centred rather than just child-focused, so that children are valued, respected, treated as individuals, accorded the same rights as everyone else and whose engagement is seen as part of a jointly negotiated process.

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<sup>182</sup> See eg, Gillian Brook, 'Children's competency to consent: a framework for practice' (2000) 12(5) *Paediatric Nursing* 31 in which she discusses how such a framework of practice was established at the Liver Unit, Birmingham Children's Hospital NHS Trust and Y Murray, 'Integrated Care Pathways for Paediatrics: a guide for nurses', Paediatrics 2000 Conference, Olympia, London.

<sup>183</sup> See Lynn Hagger 'Foundation Trusts and Children's Participation' (2007) 8(4) *Medical Law International* 325 for the rationale for this type of involvement and for examples of where this has been done successfully.

<sup>184</sup> See eg Department of Health, *A stronger local voice: a framework for creating a stronger local voice in the development of health and social care services*, 2006 that establishes a range of new arrangements to enhance citizen empowerment and engagement in developing services.

<sup>185</sup> UNCRC.

<sup>186</sup> James and James (n 181).

Jasanoff<sup>187</sup> argues that the most powerful argument for wider lay participation in decision-making is the public's 'critical supervision':

[E]xpertise is constituted within institutions, and powerful institutions can perpetuate unjust and unfounded ways of looking at the world unless they are continually put before the gaze of laypersons who will declare when the emperor has no clothes'.<sup>188</sup>

Some organisations have developed a track record in working with participants who are not expected to cope with traditional, formal approaches. To hear the voice of young people presents even greater challenges but there are a number of participation 'frameworks' and benchmarking tools for working with children and young people.<sup>189</sup> The specific engagement of children in the citizenship agenda has been encouraged because it prepares them for the appropriate exercise of adult rights, rather than to empower them to exercise political influence in their own right.<sup>190</sup> Young people do care about policies as they affect them and even quite young children can articulate their

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<sup>187</sup> Sheila Jasanoff, 'Breaking the waves in science studies: comment on H.M. Collind and R. Evans "The Third Wave of Science Studies"' (2003) 33 *Social Studies of Science* 389.

<sup>188</sup> *Ibid*, 398.

<sup>189</sup> Eg Hart's Ladder of Youth Participation used by UNICEF: Roger Hart, *From Tokenism to Citizenship* (UNICEF Innocenti Research Centre, 1992).

<sup>190</sup> Malcolm Hill, John Davis, Alan Prout and Kay Tisdall, 'Moving the Participation Agenda Forward' (2004) 18 *Children and Society* 77. See also Department of Health, *Our health, our care, our say*, 2006 published after a significant consultation exercise with the public on the direction they wished health services to go.

views.<sup>191</sup> They can develop to the point where they also care about issues where they are less directly affected<sup>192</sup> so they must be seen as full partners listened to as they are now and not merely because of the person they will become. Examples of organisations that have begun to use children and young people effectively include the Carnegie Young People Initiative which aims to increase the breadth of young people's participation in public decision-making and improve its quality.<sup>193</sup> The establishment of a Children and Young People's Unit in 2001 within the Department of Education and Skills, which advises the Government on the development of policies for children and young people, has been welcomed as providing a key impetus for their involvement in policy, service design and delivery. Funky Dragon's (the Welsh Youth Council and the Children and Young People's Assembly for Wales)<sup>194</sup> main task is to make sure that the views of children and young people are heard, particularly by the Welsh Assembly Government. It has been quoted as an exemplar by the previous Children's Commissioner for England.<sup>195</sup>

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<sup>191</sup> See eg Moira Borland, Ann Laybourn, Malcolm Hill and Jane Brown, *Middle Childhood* (Jessica Kingsley, 1998).

<sup>192</sup> Donna Koller, "'Making a Difference": Youth Participation in Education and Health Care' presentation at the University of Sheffield, Centre for the Study of Childhood and Youth: 'Childhood and Youth: Choice and Participation International Conference, 2006 highlighting the Children's Council of the Toronto Hospital for Sick Children where 10 to 18-year-old children are involved in aspects of service delivery and are seen as a resource for staff.

<sup>193</sup> The Carnegie United Kingdom Trust, *Measuring the Magic? Evaluating and researching young people's participation in public decision-making*, 2002, 2.

<sup>194</sup> Funky Dragon Annual Report and Accounts, 2008-9.

<sup>195</sup> Personal communication from Sir Al Aynsley Green, England's first Children's Commissioner.

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Public involvement in the health agenda specifically, apart from the limited participation within National Institute for Health and Clinical Effectiveness,<sup>196</sup> takes place mainly at a local level. The Care Quality Commission's regional teams are building networks of community-based groups and groups led by users through their recent consultation process so that they can engage with local people on issues that concern them.<sup>197</sup> This will increase children and young people's involvement in the healthcare agenda, as will their role as associate governors in foundation trusts, but they need more presence at a national level.

The law needs to establish very clear principles about access to cognitive enhancement. Whatever form this takes, it must take cognisance of the increasing recognition of children's autonomy: in international instruments, empirical evidence of their existing cognitive abilities, developing case law and their involvement in policy-making discussed here. The final section of this paper explores a range of approaches that could be adopted to address access to cognitive enhancement by children.

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<sup>196</sup> Keith Syrett, 'Nice Work? Rationing, Review and the 'Legitimacy Problem' in the New NHS' (2002) 10 *Medical Law Review* 1.

<sup>197</sup> Care Quality Commission, *Engaging Patients and the Public*, 2010.

<http://www.cqc.org.uk/guidanceforprofessionals/nhstrusts/specialreviews/2008/09/patientandpublicengagement.cfm> accessed 14 March 2011.

IV. APPROPRIATE DECISION-MAKING: TO COGNITIVELY ENHANCE OR NOT?

While not wishing to diminish the importance of the ethical debates surrounding cognitive enhancement, especially in relation to children, the focus here is on the process by which decisions are reached. The discussion that follows examines a range of regulatory approaches that could be used to govern access to cognitive enhancement in children.

Conventional law and economics adhere to notions of what Jolls, Sunstein and Thaler<sup>198</sup> term ‘consumer sovereignty’, whereby citizens are seen as the best judges of what is in their interests with the important caveat that they need reasonable access to relevant information. This could include whether to take cognitive enhancement. However, they note that decisions may be impaired as a result of cognitive and motivational difficulties, such as underestimation of risks even with the provision of adequate information.<sup>199</sup> Further behavioral research has indicated that people’s assessment of future experience can be mistaken.<sup>200</sup> In addition, to leave the availability of cognitive enhancement to market forces would offer no means of protecting children’s interests, nor would there be any guarantee that sufficient information on possible risks would be provided. Actors, particularly children, do not have equal power.<sup>201</sup> This may

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<sup>198</sup> Christine Jolls, Cass R Sunstein and Richard Thaler, ‘A Behavioral Approach to Law and Economics’, (1998) 50 *Stanford Law Review* 1471, 1541.

<sup>199</sup> *Ibid*, 1541 - 2.

<sup>200</sup> *Ibid*, 1542.

<sup>201</sup> James and James (n 181) *passim*.

be an example of where the community may be prepared to allow some form of regulation for all of these reasons, although it cannot be assumed that government agencies will not have their capabilities similarly impaired albeit to a lesser extent if wide-ranging, relevant views are taken into account.<sup>202</sup>

Coteanu<sup>203</sup> argues that new approaches are required for what she terms 'cyber consumer protection'. This has particular relevance here because of the prevalence of cognitive enhancing drugs advertised on the Internet. Consumer transactions take place in a global marketplace and there needs to be a means of safeguarding reasonable consumer expectations in this context. We agree that there needs to be regulation in this area, but maintain that cognitive enhancing drugs will continue to be sought through other sources not least because concern is increasing about the fraudulent supply of drugs more generally on the Internet.<sup>204</sup> Regulating access to enhancing drugs through the Internet is a possibility and the European Court of Justice is poised to address the issue of international Internet jurisdiction.<sup>205</sup> Problems may nonetheless remain as the tobacco

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<sup>202</sup> Jolls et al (n 198) 1541-1546.

<sup>203</sup> Christina Coteanu, *Cyber Consumer Law and Unfair Trading Practices (Markets and the Law)* (Ashgate, 2005) and George (n 48).

<sup>204</sup> See, for example, Lauren Thompson, 'Fraud alert over fake diet and viagra pills' *The Times* (London 30 January, 2010). WHO has responded to the challenge by creating an international coalition of stakeholders (International Medical Products Anti-Counterfeiting Taskforce) in 2006 to seek solutions to this global challenge and in raising awareness of the dangers of counterfeit medical products:

<<http://www.who.int/impact/en/index.html>> accessed 14 March 2011.

<sup>205</sup> Christian Mensching, 'Limitless or Limited International Internet Jurisdiction within the European Union?' (2010) (21)7 *Entertainment Law Review* 281 and Downer (n 47).

advertising example outlined below illustrates and, in the case of cognitive enhancement, the risks are not as clearly established as those in relation to tobacco consumption.

It might have been thought that the use of cognitive enhancement could be regulated by the European Union (EU) given its broad reach. However, Mossialos, Permanand, Baeten and Hervey<sup>206</sup> note that there is no legislative basis in the EU for a common approach to such public health measures.<sup>207</sup> Any provisions with this goal in mind have been achieved through internal market law, soft law, and also through the use of EU-funded projects to create and disseminate information that is subsequently used in legislative processes to promote public health. Market bans are only effective where they are the result of interest group lobbying that is sufficiently powerful to overcome the converse pressure from the industry. This is proven in the case of tobacco, where bans on advertising failed to have an impact on the industry, because it did not have the effect of reducing market access.<sup>208</sup> Some comfort may be derived from the Council non-binding recommendation<sup>209</sup> that Member States adopt measures to restrict methods of tobacco advertising that have no cross-border effects. Such soft law can sometimes be a precursor

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<sup>206</sup> Elias Mossialos, Govin Permanand, Rita Baeten and Tamara K Hervey, *Health Systems Governance in Europe: the Role of EU Law and Policy* (Cambridge University Press, 2010), Chapter 5.

<sup>207</sup> Article 129 (now 152) of the EC Treaty expressly excludes the ability to take harmonizing measures for public health purposes.

<sup>208</sup> ASPECT Consortium, *Tobacco or Health in the European Union: past, present and future*, The ASPECT Report (European Communities, 2004) and Jolls et al (n 198) 1516.

<sup>209</sup> Council Recommendation on the prevention of smoking and on initiatives to improve tobacco control, OJ [2003] L 22/31.

to future hard law measures, when the legal and political climate allows;<sup>210</sup> this approach could be deployed with respect to the regulation of cognitive enhancement. In addition, EU governing institutions have achieved some measure of success to achieve public health goals through the judicious use of limited resources in carefully targeted areas. These have sometimes led to larger scale, more integrated sets of policy-making tools and institutions, supported by a long-term financial framework. The EU exercises influence through information collection, dissemination, development of best practice and networking with key stakeholders.<sup>211</sup> If relevant EU institutions decide to focus on cognitive enhancement in such a way and influence some of the UK's organisations discussed below, they may be similarly successful in ensuring a greater likelihood for its appropriate use. Some form of regulation of cognitive enhancement seems desirable at least to ensure that only products from bona fide sources are advertised to deal with concerns about their origins and thus their authenticity.

It is also worth noting that notwithstanding the promising rhetoric arising from the Treaty of Lisbon 2009 where it was stated that the protection of the rights of the child was a core objective of the EU, there is a distinct lack of legal and practical competence in this area.<sup>212</sup> Encouraging the participation of children in policy formulation using the

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<sup>210</sup> Mossialos et al (n 206). They provide the example in the health field of the 'Blood Safety' Directive 2002/98/EC, which refers to a Commission communication and three Council resolutions in its preamble.

<sup>211</sup> *Ibid* Chapter 5.

<sup>212</sup> Helen Stalford and Eleanor Drywood, 'Coming of Age?: Children's rights in the European Union' (2009) 46(1) *Common Market Law Review* 143.

soft law approaches outlined above and supported by the European Commission's Strategy on the Rights of the Child may help in this regard.<sup>213</sup>

In the current absence of EU regulation, can the UK adopt a regime that protects children when decisions are being taken about cognitive enhancement? One proposal might be to ban enhancement drugs, but policing illicit drug use already creates huge resourcing difficulties<sup>214</sup> and these drugs are less clearly harmful. Such a ban seems impracticable because access is so easily available on the Internet<sup>215</sup> and there seems to be little appetite for control,<sup>216</sup> notwithstanding calls for global regulation.<sup>217</sup> Nevertheless, many people may prefer a more reliable route to obtain these drugs. If, as has been advocated earlier, parents are not best placed to decide whether children should receive cognitive enhancement, should doctors make the decision?

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<sup>213</sup> [http://ec.europa.eu/justice/policies/children/policies\\_children\\_intro\\_en.htm](http://ec.europa.eu/justice/policies/children/policies_children_intro_en.htm) accessed 14 March 2011.

<sup>214</sup> <http://www.ic.nhs.uk/pubs/drugmisuse07> accessed 14 March 2011.

<sup>215</sup> Bee and Freaan and Foster (n 1).

<sup>216</sup> Stephanie Y Crawford, 'Internet Pharmacy: Issues of Access, Quality, Costs, and Regulation' (2003) 27(1) *Journal of Medical Systems* 57. See also John McConnell, 'Internet Subverts European drug regulation' (1998) 352(9141) *The Lancet* 1690; WHO has responded to the challenge by creating an international coalition of stakeholders (International Medical Products Anti-Counterfeiting Taskforce) in 2006 to seek solutions to this global challenge and in raising awareness of the dangers of counterfeit medical products: < <http://www.who.int/impact/en/>> accessed 14 March 2011.

<sup>217</sup> George (n 48).

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Doctors already regulate access to drugs<sup>218</sup> and patients cannot demand treatment against their clinical judgment.<sup>219</sup> Doctors are likely to become ever more cost-conscious as the purchasing power of services within the NHS shifts to them.<sup>220</sup> Cognitive enhancement could be offered by doctors if a broad view is taken of the need to promote patients' quality of life. Their medical knowledge will be invaluable about the long-term impact of enhancement drugs, as such information becomes more available. They may also have an established relationship of trust with their patient. However, leaving the decision-making to doctors alone is problematic because of concerns that doctors already over-prescribe<sup>221</sup> or under-prescribe<sup>222</sup> certain drugs and, more importantly, this is as paternalistic as leaving this to parents. For incompetent children, there is no reason to assume doctors have the skills and knowledge required to make more than a clinical assessment as to what an appropriate intervention might be. The wider factors to be considered in determining best interests require, arguably, a range of views. As

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<sup>218</sup> Medicines Act 1968, Medicines (Standard Provisions for Licences and Certificates) Regulations 1971 SI 1971/972 and the National Health Service (General Medical Services) Regulations 1992. London: HMSO, 1992: sched 2, para 43. (SI 1992, No 635.)

<sup>219</sup> *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930.

<sup>220</sup> [http://www.dh.gov.uk/en/Aboutus/Features/DH\\_122384](http://www.dh.gov.uk/en/Aboutus/Features/DH_122384) accessed 14 March 2011.

<sup>221</sup> Nigel Hawkes, 'Doctors doing more harm than good "by misusing antibiotics"' *The Times* (London 26 July 2007).

<sup>222</sup> 'The true incidence of ADHD in children cannot be determined from prescription stimulant use alone, since, for all of the noted reasons, it is highly likely that Ritalin and similar drugs are both over-prescribed and under-prescribed': President's Council (n 23) 81.

Ravelingien et al point out,<sup>223</sup> the idea that cognitive enhancement is as morally suspect as cosmetic surgery is not clear cut so should not necessarily be resisted by doctors as they act as gatekeepers,. Some may prefer not to carry out this function because of concerns about the ethics of cognitive enhancement or a lack of expertise. Conscientious objection should be available for them. Equally, some may be strongly in support of cognitive enhancement. It should not be within their gift to decide whether cognitive enhancement is a social harm.<sup>224</sup> It is advocated here that only doctors providing the service along the lines discussed below should be accredited to provide the service. The final decision would be for the patient or their parent(s) ideally following a discussion exploring the broad implications of taking cognitive enhancement for themselves and others.<sup>225</sup> Of course, if the doctor has a veto on what is offered, then they are clearly in a dominant position and patients can always refuse treatment a doctor thinks is appropriate.

If we accept that there will inevitably be medical involvement in decision-making about enhancement,<sup>226</sup> we would support the robust approach advocated by Alderson and Montgomery. They call for legislation supported by a code of practice covering all

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<sup>223</sup> Ravelingien et al (n 57) and Margaret O Little, 'Cosmetic surgery, suspect norms, and effects of complicity'.in Erik Parens (ed), *Enhancing human traits: ethical and social implications* ( Georgetown University Press, 1998).

<sup>224</sup> Ravelingien et al (n 57) 158.

<sup>225</sup> *Ibid* 159.

<sup>226</sup> Anjan Chatterjee, 'Cosmetic neurology and cosmetic surgery: predictions and challenges' (2007) 16(2) *Cambridge Quarterly of Healthcare Ethics* 129.

aspects of children's healthcare decision-making.<sup>227</sup> The code could be drafted after consultation with those involved with children and the children themselves.<sup>228</sup> The basic principles would be contained in the framework legislation, with the code providing the more detailed guidance and checklists of appropriate issues particularly in difficult cases. It would require procedures and policies in place to deal with potential problems. Any departure from the standards of good practice in the code could provide evidence of a breach in a negligence action where harm can be demonstrated, unless this could be justified in the individual case. This approach would be supplemented by the usual internal complaints procedures, professional disciplinary action and be overseen by the courts. Most importantly, central to their proposals is the participation of the child in the decision-making process which can be supported by empirical evidence of children's abilities and the trajectory of their human rights.

Alderson and Montgomery's proposals for legislation may seem unlikely given the failure to include children under 16 within the remit of the MCA. This would have provided an ideal opportunity to ensure as robust an approach to decision-making to this group as to older children.<sup>229</sup> Nevertheless, much of the guidance envisaged in their suggestion for a code of practice could be adopted within suitably invigorated existing regulatory structures. The Medicines and Healthcare products Regulatory Agency (MHpRA) could more closely follow the model provided by the licensing and inspection

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<sup>227</sup> Alderson and Montgomery (n 162).

<sup>228</sup> *Ibid* 66-71. Further evidence that children are capable of contributing to policy making may be found in Hagger (n 183).

<sup>229</sup> Hagger (n 99).

regime under the Human Fertilisation and Embryology Act 1990 as amended.<sup>230</sup> This may be seen as disproportionate to the issues raised by cognitive enhancement, but the 1990 Act's provisions and the guidance offered in its evolving Code of Practice is an instructive model<sup>231</sup> nonetheless. One of the Human Fertilisation and Embryology's Authority's<sup>232</sup> key strengths lies in its range of expertise, including lay members' opinions, when developing policies.<sup>233</sup> In the approach suggested here, this should include children. The MHPRA could license enhancement drugs only to those doctors in the NHS or private sector who can demonstrate good decision-making practice that optimises children's involvement by providing evidence of the information that will be provided, to whom and how the decision will be reached. The approach would, of course, be supplemented by the possibility of using alternative grievance procedures. At the policy-making level, the Agency could employ the participatory tools developed to help with the engagement of children and young people adopting the points of good practice from the models where this has been used to good effect. It is worth emphasising that the approach should be child-centred not merely child-focused, so that children and

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<sup>230</sup> By the Human Fertilization and Embryology Act 2008.

<sup>231</sup> Ss 9-22.

<sup>232</sup> Established by s 5 of the Human Fertilization and Embryology Act 1990 although, at the time of writing, the current Government is planning to subsume its remit within another regulatory organisation as yet not clearly identified: Department of Health, *Review of arm's length bodies to cut bureaucracy*, 26 July 2010: [http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH\\_117844](http://www.dh.gov.uk/en/MediaCentre/Pressreleases/DH_117844) accessed 14 March 2011.

<sup>233</sup> For an assessment of this model of regulation see Lynn E Hagger, 'The Role of the Human Fertilisation and Embryology Authority' (1997) 3(1) *Medical Law International* 1.

young people can comment on issues that concern everyone and enjoy the same rights as adults.

To bolster the regulatory approach outlined above, guidance should be adopted that uses rights-based language when discussing children while at the same time nurturing a sense of responsibility. The use of rights discourse is important because language can be seen as an important instrument of social change:<sup>234</sup> the more we talk about children's rights, the more society will attend to their interests in an appropriate manner. Guidance should be consistent across the NHS so that whether it is issued by the Department of Health, the National Centre for Health and Clinical Excellence, health professional bodies, such as the General Medical Council or British Medical Association, and/or the Royal Colleges who set standards of practice for the various specialisms, the message will be the same. There are attractions in this proposal, because guidance can easily reach the large numbers of prescribing health professionals in the public and private sector, but there may be concerns as to adherence. There would be significant reliance on patients and colleagues alerting relevant professional bodies in the event of

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<sup>234</sup> Selected writings of Benjamin L Whorf in John B Carroll (ed), *Language , thought and reality* (MIT Press, 1956) 252. Whorf was the most prominent, modern proponent of the idea that patterns of the language we use affects the configuration of our thought and thus our culture: our view of the world is determined by language. 'Weak determinism' whereby the influence of language on thought is recognised, remains persuasive: see eg Izchak M Schlesinger, 'The wax and wane of Whorfian views' in Robert L Cooper and Bernard Spolsky (eds.), *The Influence of Language on Culture and Thought* (Mouton de Gruyter, 1991) 19-29. The British Institute for Human Rights, *The Human Rights Act: Changing Lives*, 2007 demonstrates how the use of rights-based language and ideas can help to change cultures.

non-compliance. This is not always forthcoming. Should a matter be referred however, strong disciplinary action could foster an appropriate culture of compliance.<sup>235</sup> Improved appraisal through the revalidation of doctors in both the public and private sectors due to commence in 2012 will provide another important tool to encourage appropriate intervention with patients.<sup>236</sup> More importantly, clinical governance structures within organisations are paying increasing attention to quality as well as safety standards and this can act as an important lever. The Operating Framework for the NHS in England<sup>237</sup> requires each NHS trust to obtain feedback from patients about their experience of care. Part of the Care Quality Commission's remit is to regulate healthcare wherever it is provided and it uses data from its ongoing programme of patient surveys to calculate this indicator.<sup>238</sup> This revitalised<sup>239</sup> focus on patient experience will include methods of engagement with patients.<sup>240</sup>

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<sup>235</sup> One of the authors has a long association with the NHS and it is clear that decisions and recommendations from bodies such as the GMC become widely known within and without organisations. This can result in more rigorous compliance by affected individuals and the issue gains a focus through clinical governance mechanisms.

<sup>236</sup> Licence to Practice and Revalidation for doctors', GMC publications, April 2003 and Revalidation: A Statement of Intent, 2010:  
<[http://www.gmc-uk.org/Revalidation\\_A\\_Statement\\_of\\_Intent\\_October\\_2010\\_Final\\_version\\_\\_web\\_version\\_.pdf\\_35982397.pdf\\_36401645.pdf](http://www.gmc-uk.org/Revalidation_A_Statement_of_Intent_October_2010_Final_version__web_version_.pdf_35982397.pdf_36401645.pdf)> accessed 14 March 2011.

<sup>237</sup> Department of Health, Operating Framework for the NHS in England, 2011/2012.

<sup>238</sup> <<http://www.cqc.org.uk/periodicreview/nationalcommitmentsandpriorities2009/10/primarycaretrusts/nationalpriorities/patientexperience.cfm>> accessed 14 March 2011.

Taken as a whole, the proposals set out above should *guarantee* a place for children to be at the heart of decision-making generally and specifically where cognitive enhancement is concerned. Our argument builds on Turner and Sahakian's call that:

. . . healthcare professionals should be encouraged to acquire the skills to analyze scenarios on a case-by-case basis, bringing together an understanding of science and public policy in collaboration with social scientists, legislators, insurance companies, employers and educational authorities.<sup>241</sup>

People have a right to make informed decisions<sup>242</sup> and we should not underestimate people's ability to do so.<sup>243</sup> The risk for children is that parents who want to give their child the edge at school opt for enhancement under the influence of forces such as advertising, the views of other parents, teachers and other social forces. When parents are potentially in control of these decisions, an appropriate decision-making structure (supported by the HRA in particular), would help to ensure they do not succumb to these

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<sup>239</sup> As a result of the scandalous treatment of patients at the Mid Staffordshire NHS Foundation Trust: *Francis Report: Independent inquiry into care provided by Mid Staffordshire NHS Foundation Trust January 2005 - March 2009*, 2010.

<sup>240</sup> Primary care trust patient experience methodology, 2010:  
[http://www.cqc.org.uk/\\_db/\\_documents/PCT\\_patient\\_experience\\_methodology.pdf](http://www.cqc.org.uk/_db/_documents/PCT_patient_experience_methodology.pdf) accessed 14 March 2011.

<sup>241</sup> Turner and Sahakian (n 12) 119.

<sup>242</sup> *Chester v Afshar* [2004] 4 All ER 587.

<sup>243</sup> *Ibid.*

pressures too easily and that they allow children to be thoroughly engaged in the process. Such a framework can protect competent children by allowing them to choose or refuse to enhance and ensure that appropriate determination of incompetent children's best interests is undertaken. This could work alongside other regulation which would consider safety issues and population-wide risks. We believe a multi-pronged approach that involves children and young people in personal decision-making and policy formulation within a robust licensing and accreditation system would be appropriate because many parents and children may prefer to make decisions after receiving medical or other advice. We also believe that political decisions should be made about whether or not cognitive enhancers should be made available and to whom. This would help to address the concerns about equity and the fostering of an individualistic and competitive society.

## CONCLUSION

As more information becomes available about cognitive enhancement, concerns about safety may be quelled. If risks are shown to be minimal, there is at least an argument that cognitive enhancement could have positive outcomes for children. It can be argued that there is a moral imperative to use technology to improve people's life chances generally and this will include cognitive enhancement to improve human functioning. It has also been proposed that cognitive enhancement can be viewed as a human right in that it is a rational and practical autonomy claim in the pursuit of knowledge. However, cognitive enhancement may have unintended or unknown side effects such as personality, identity

and mental ability change that have implications for society and individuals. For the latter, their right to develop their character and sense of personal responsibility in an unmedicated state may be threatened. Children's dignity has also been shown to be at stake and further jeopardised if they are not involved in making decisions about whether to take cognitive enhancement to the maximum extent possible.

If we assume that neurotechnologies should be made available for enhancement purposes, for principled or pragmatic reasons, it is the contention of this work that appropriate regulation should be in place to ensure children and young people are properly empowered and protected. Concerns about cognitive enhancements are not simply 'spectres'.<sup>244</sup> There are substantive legal issues concerning aspects of human functioning that should be protected by law. Provided different perspectives of cognitive enhancement and potential effects are presented to legally competent children, the decision of whether to take it, or not, is one for them. This standpoint can be supported through the use of human rights instruments and empirical evidence of children's abilities which may also be used to contend that they should be fully involved in policy formulation as well as personal decision-making. Human rights discourse allows for a balanced consideration of the child's interests vis-à-vis those of their family or society more generally. The broad reading of Article 8(1) of the ECHR in particular, embracing such notions as autonomy, development of the personality and identity, means that the HRA could be an important vehicle for underpinning regulation and the ongoing discussion about appropriate intervention.

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<sup>244</sup> Editorial, 'Enhancing, not cheating'. (2007) 450(7168) *Nature* 320.

Where children are not legally competent, caution should be exercised in allowing parents to decide whether they should take cognitive enhancement because of the evidence that their view of best interests may be suspect. The preference here is for a statutory body to regulate access to cognitive enhancement through a licensing and inspection system supplemented by clear guidance and other clinical governance arrangements. Licences should only be issued where there is assurance that children and young people are fully involved in the decision-making process with rights of appeal. The body's policy and guidance should also be informed by children and young people by utilising participatory tools developed to optimise their engagement. Adopting these suggestions would take children's healthcare decision-making to an unprecedented level and one that is long overdue in light of their capacities and the international trajectory of their interests.