



Broadening the Bioethics Perspective Through Disabled Dance A Policy Brief for Ethics Educators and Practitioners

Introduction

InVisible Difference: Disability, Dance and Law is an AHRC-funded project that seeks to extend thinking and alter practice around the making, status, ownership, and value of work by contemporary disabled dance choreographers, specifically disabled ones. Questions associated with the functioning of bioethics might seem remote from such a project, but they arose when it became clear that a bioethics perspective was not welcomed by our participants within the context of considering matters of ‘normality’ and ‘normativity’. Evidence generated by *InVisible Difference* confirms a sense of invisibility within the medical and bioethics frame. This policy brief addresses that reality and makes recommendations for its alleviation.

Project Overview

Running from January 2013 to December 2015, ours is an interdisciplinary partnership between academics in Higher Education and artists working in the creative industry. Members of the project are: Professor Sarah Whatley, Coventry University; Professor Charlotte Waelde, University of Exeter; Dr Abbe Brown, University of Aberdeen; Dr Shawn Harmon, University of Edinburgh; Dr Karen Wood and Hannah Donaldson, research assistants; Mathilde Pavis and Kate Marsh, Doctoral candidates and dance artist Caroline Bowditch. During the course of our research we are conducting qualitative research with disabled choreographers and dancers, including Caroline Bowditch, Claire Cunningham, Marc Brew, Chisato Minamimura, and others. We also have strong links with Candoco dance company and other independent disabled dancers.

The Problem

Ethics should be a vehicle for casting acts ‘in a different light’ so we can better critique them. A fundamental question that ethics asks is: ‘How should we live?’ Those in bioethics seem to have answered this question across a range of clinical circumstances and technology deployments as, ‘With dignity.’¹ This is an oversimplification but the majority of substantive bioethical assessments will either explicitly or implicitly begin from this proposition. While we do not reject the proposition, the frequent absence of analysis is disheartening, particularly when one considers that an ethical assessment must surely be one of the most suitable places to problematize this question.

A driving factor for this trend is the converge of law and ethics; bioethics is increasingly entangled with legal principles and rules, specifically those emergent from human rights law.² Legal instruments have become the key shapers of bioethical thought and practice,³ diminishing the scope of the bioethics inquiry and imagination.⁴ The result is that bioethics concerns itself primarily with instrumental issues relating to

¹ If pressed to elaborate, a stock answer is: “We should live independently and autonomously, without coercion or interference, with few imposed duties and little sense of obligation, free to avoid risk and to vigorously protect our physical and emotional integrity against state organs, private entities, and individuals.”

² For more, see S Harmon, ‘The Invisibility of Disability: Using Dance to Shake from Bioethics the Idea of ‘Broken Bodies’’, forthcoming in *Bioethics*.

³ See Convention on Human Rights and Biomedicine (1997), Universal Declaration of the Human Genome and Human Rights (1997), Declaration of Helsinki (2000), CIOMS International Ethical Guidelines for Biomedical Research Involving Human Subjects of the (2002), Universal Declaration on Bioethics and Human Rights (2005), and more.

⁴ T Koch, ‘Bioethics as Ideology: Conditional and Unconditional Values’ (2006) 31 *J Med & Philosophy* 251-267; R Amundson and S Tresky, ‘Bioethics and Disability Rights: Conflicting Values and Perspectives’ (2008) 5 *Bioethical Inquiry* 111-123.





questions of moral agency and the allocation of responsibility and control.⁵ Assessments and decisions are too often divorced from the lived experience of patients.⁶ This has resulted in increasingly ‘depersonalised’ norms and principles which serve to disembodify and disempower the person.⁷ Both the lived experience and the particularities of individual bodies have been rendered invisible.

This invisibility can have profound impacts on disabled people, because it permits them to be viewed as ‘others’ based on the form and functionality of their physiology.⁸ This ‘othering’ has led to the construction of a rather narrow understanding of what a normal, desirable, acceptable, or passably healthy body is, and has given rise to a social repugnance toward the different or divergent body, encouraging misunderstandings such as that they are necessarily weak, painful, homogenous, and non-sexual.⁹

An Empirical Response

Respondents in *InVisible Difference* report: complying with the medical paradigm; learning how to speak to doctors using the “medical language”; being “put on display” from an early age; and never being engaged by healthcare professionals over their lived experience.¹⁰ They thus confirm existing evidence that medicine often reduces the person to the biological without acknowledging everything that is salient to wellbeing.¹¹ *InVisible Difference* demonstrates that disabled bodies can be remarkably robust, and not as ‘other’ as typically constructed; they are not ‘uncivilised bodies’ with unusual boundaries and uncanny characteristics which require concealment and prosthetic masking.¹²

By exposing themselves through dance, respondents in *InVisible Difference* affirm themselves as *subjects* entitled to respect and the full enjoyment of rights and opportunities, and as uniquely abled individuals with particular and valuable talents. Dance is valued because it allows them to present themselves in ways that the medical gaze has been incapable of acknowledging. It exposes the idea that disabled bodies are not ‘broken bodies’ as commonly constructed, but rather richly diverse embodiments of humanity that offer a voice through which individuals can speak. It offers a sense of what disabled individuals experience and how their body is both like and unlike ours, and reaffirms that we need to give special moral value to all bodies.

Conclusions

The bioethics undertaking would benefit from a wider view permitting deeper deliberations about health and illness in their broader and experiential contexts. This wider view can be encouraged by the injection of more empirical evidence from interested communities, including the disabled community.¹³ The enlightenment on offer needs to be better captured in medical and bioethics training and practice.

⁵ S Lash, ‘Introduction to the Ethics and Difference Debate’ (1996) 13 *Theory, Culture & Society* 75-77; R Martensen, ‘The History of Bioethics: An Essay Review’ (2001) 56 *J Hist Med Allied Services* 168-175.

⁶ M MacDonald, ‘Health, Health Care and Culture: Diverse Meanings, Shared Agendas’ in H Coward and P Ratanakul (eds.), *A Cross-Cultural Dialogue on Health Care Ethics* (Wilfred Laurier Press, 1999) 92-112.

⁷ D Leder, *The Absent Body* (Chicago U Press, 1990); D Reeve, ‘Negotiating Psycho-emotional Dimensions of Disability and their Influence on Identity Construction’ (2002) 17 *Disability & Society* 493-508; A Campbell, *The Body in Bioethics* (Routledge 2009).

⁸ A Finger, *Past Due: A Story of Disability, Pregnancy and Birth* (Seal Press, 1990); S Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (Routledge, 1996); S Linton, *My Body Politic* (U Michigan Press, 2006).

⁹ N Begum, ‘Disabled Women and the Feminist Agenda’ (1992) 40 *Fem Rev* 70-84; A Smith, ‘Persons with Disabilities as a Social and Economic Underclass’ (2003) 12 *Kan LJ & Pub Pol* 13-68.

¹⁰ One reported: “They never quite appreciated the experience of my bones, and those bones and my condition informs my dance in many ways.”

¹¹ G Canguilhem, *The Normal and the Pathological* (Zone Books, 1990); L Davis, *Enforcing Normalcy: Disability, Deafness and the Body* (Verso, 1995); R Thompson, ‘Feminist Theory, the Body and the Disabled Figure’ in L Davis (ed.), *The Disabilities Studies Reader* (Routledge, 1997) 279-306.

¹² S Snyder and D Mitchell, ‘Re-engaging the Body: Disability Studies and the Resistance to Embodiment’ (2001) 13 *Public Culture* 367-389.

¹³ Rich evidence around disability is generated within disability studies but has been little noticed in bioethics: M Kuczewski, ‘Disability: An Agenda for Bioethics’ (2001) 1 *Am J Bioethics* 36-44.





Recommendations

1. Bioethics practitioners need to better engage with the question: ‘How should we live?’ In doing so, they need to loosen their conceptual grip on the idea of the ‘broken body’, more accurately and sensitively locate individuals in their diverse physiological and social contexts, and refine the core values on which bioethics relies.
2. To truly become a site of social collaboration, bioethics practitioners and institutions need to be supported in developing more systematised connections with stakeholders like the disabled community, interacting with them not only in the medical context but the lived context that arts practices represent.
3. Though this has cost and curriculum repercussions, the teaching of medical ethics needs to move beyond the lecture hall and into the wider world, interacting with (medically and socially) marginalised groups in settings where they are not disempowered (such as in the dance studio). This will allow them to understand such groups ‘in a different light’.

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