



The unfinished body: The medical and social reshaping of disabled young bodies



Janice McLaughlin^{a,*}, Edmund Coleman-Fountain^b

^a Newcastle University, UK

^b York University, UK

ARTICLE INFO

Article history:

Received 2 January 2014

Received in revised form

3 September 2014

Accepted 4 September 2014

Available online 6 September 2014

Keywords:

United Kingdom

Disability

Children

Young people

Medical intervention

ABSTRACT

Stories about disability are heavily shaped by the narratives offered by medicine and society. Those narratives enact an 'anomalous' body that is constructed as distant from the norm and therefore 'damaged' but also fixable. In this paper we explore how such narratives, and the practices they encompass, influence the stories disabled young people tell about their bodies and impairment. We do so by drawing on narrative qualitative interviews and visual practices carried out with seventeen disabled young people in a project funded by the Economic and Social Research Council that took place between 2011 and 2012 in the North East of England. The findings discussed here focus on how medical and societal responses to bodily difference become part of the stories disabled young people tell about their bodies, and influence the way they work with the body as something which remains 'unfinished' and therefore both fixable and flawed. Our conclusion is that a narrative of an unfinished body is produced, as young people manage their bodies as something that is integral to their emerging identity, but also as a potential threat that could undermine and give away their labour in making an 'ordinary' functioning body and life. The paper contributes to medical sociology and sociology of the body by producing new knowledge about how disabled embodiment is lived and framed by disabled young people in the context of ongoing attempts to change the body.

© 2014 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/3.0/>).

1. Introduction

Disability in childhood 'contributes to the disintegration of expected narratives' about both children and their futures (McLaughlin et al., 2008: 53). A disabled child is 'read as out of place with the "normal"', as the presumption of an 'ordinary' childhood is suspended and replaced by 'regulative stories of childhood identity and potential that are assumed to be less than those of other "normal" children' (McLaughlin et al., 2008: 53). We speak of the 'disabled child' to reflect the UK disability movement argument that impairment is of the body, while disability reflects the social dynamics that are built around impairment. Elsewhere we have written about how that distinction is more complex than it implies (Coleman-Fountain and McLaughlin, 2013), but here retain the language of disabled child, rather than child with a disability to reflect the socially embedded nature of the relationship between

disability and the body. Disability can, but does not always, produce a different kind of child's body, different in ability and appearance. The dominant view of such bodies is that they are 'lacking' (Corker and Davis, 2002: 75) and in need of repair if a 'good' life is to be made possible (Phillips, 1990). The most common route to 'overcoming' such damage is through medical intervention. Some interventions may be about alleviating pain and improving life expectancy, most however are about attempting to ensure the disabled child is a better fit with norms of embodiment, for example physiotherapy and surgery to improve mobility; speech and language therapy to aid speech; or facial surgery to normalise appearance. The child's body is monitored, worked on, and reshaped in line with norms of how bodies should be. Yet across childhood and into adulthood the body remains open to repair – both because interventions do not reach their goal and also because bodies change and age creating new issues to resolve. This leaves the body always *unfinished*.

Drawing on data from an Economic and Social Research Council (ESRC) funded study of the narratives of young people with cerebral palsy, the focus of this paper is how medical imperatives to fix, guided by narratives of damage, repair, progress and control, influence disabled young people's experience and use of the body.

* Corresponding author. Policy, Ethics and Life Sciences Research Centre, School of Geography, Politics and Sociology, Claremont Bridge Building, Newcastle University, Newcastle upon Tyne NE1 7RT, UK.

E-mail address: janice.mclaughlin@ncl.ac.uk (J. McLaughlin).

This indicates a concern with the relationship between stories and practices, and between matter and the discursive, including the entanglement of disabled bodies in fixing narratives, the ways of seeing bodies those narratives produce, and the things done to disabled young bodies by society and disabled individuals. In this paper we look at how notions and practices of *fixing*, embedded in medical narratives, influence the stories that disabled young people tell over time. Our curiosity lies in considering how disabled young people refer to, make use of, or refute, notions of fixing in their own stories, and how that informs the relationships they have with their bodies, and other bodies considered working and *normal*. This includes looking at the social as well as medical sources of fixing narratives, in particular the significance of disabled young people's aspirations for the future for how they attend to their bodies.

The paper starts by highlighting the significance of medicine to the production of categories of disability and normality and evolving frameworks for understanding how such categories are produced. Following an account of the study on which this paper is based, the paper explores disabled children and young people's visual and oral narratives. It looks first at reflections on childhood surgery, and perceptions of the body as damaged, before exploring how disabled youth engage with the body as something that continues to be problematic. Throughout this we reflect on the materiality of the body, showing that cerebral palsy does not stay the same. The way the body is framed as 'not right' changes as the body changes and as disabled young people themselves age and grow, giving disability a temporal character and goals of normality fragility.

1.1. Fixing normality

Medical sociology (Stiker, 2000) and disability studies (Barnes and Mercer, 2010; Illich, 1977) have detailed medicine's authority in informing the belief that certain body types and persons fall outside measures of normality, categorizing 'different' bodies as disabled and undesirable and offering up treatments for their difference. Foucault (1990) meticulously highlighted the politics of and processes involved in the establishment of 'normal bodies' through medicine's categorisation of bodies considered outside of the normal. Foucault (1975, 1977), and those who have drawn upon his work (Conrad, 1992; Conrad and Schneider, 1980), proposes that medicine does more than identify and help us understand the sources of normal and abnormal function and capacity. Instead it has been productive in shaping the types of bodies drawn into the protection of being defined as 'normal' and those positioned as abnormal and in need of treatment. This occurs at a discursive level through the diagnostic categories of medicine and materially through the interventions that follow. In doing so, as Davis has argued, medicine produced the 'concept of the disabled body' (1995: 30). Over time the medical gaze has produced a disciplining dynamic both at the level of state intervention through institutions of welfare, law and education, and at the level of the self as people have sought to monitor and manage their bodies against medical norms. Therefore, while the understandings of normality produced by medicine are 'fictional', they are also 'real' in their effects through how '[i]ndividuals regulate themselves in relation to the norms that circulate' (original emphasis, Holt et al., 2012: 2194). This disciplining of the self and body has been linked by Rose (2000, 2006) to the growth of health promotion as a mechanism of control and surveillance and to neoliberal biopolitical requirements that individuals take responsibility for being healthy, productive citizens.

Understandings of the dynamics embedded in the medicalization of different embodiment have changed over time, both to acknowledge changes in how medical power is said to operate and

also reflecting new theoretical understandings of the relationships between medical organisations and actors and those that fall under their 'gaze'. For example, contemporary feminist work on medicine has moved away from earlier work that saw medical practices as primarily objectifying women (Birke, 1999; Hubbard, 1989). While still concerned with medicine's ability 'to define appropriate humanness' (Asberg and Lum, 2009: 333), this new work, influenced by science and technology studies (Braidotti, 2002), explores how medical technologies can become significant cultural artefacts incorporated into women's personhood practices (Draper, 2002; Nishizaka, 2011; Roberts, 2012). Likewise critical disability studies has raised similar arguments to produce a different account of the relationship between medicine, bodily difference and normality (Goodley, 2011; Goodley and Runswick Cole, 2013). Of crucial importance here is the work of Shildrick (2002) who has long sought to problematize how the body is subject to normalising medical practices and to produce new imaginaries for embracing bodily ambiguity and difference. Her work asks why society is so uneasy with 'anomalous' bodies (Shildrick, 2005a) and the response is that such bodies display a 'disruptive excess' that speaks to the fiction of autonomous self-hood as possible for anyone (Shildrick, 2005b). The self-evidently 'normal' body is undermined via the presence of what it can and will become. That bodies are forms of 'always already unstable corpus' (Shildrick, 1999: 77) is hidden behind modernist fantasies that 'imperfect' bodies can be 'put right'. We can think of disability as a core category in establishing the normality of persons and practices. It is not so much normality that establishes disability; rather the normal is established through identifying what is considered strange and ill-fitting. Therefore, who sits within the category of the normal and the abnormal or pathological are always in relationship with each other, co-defining the meaning each exists within (Canguilhem, 1989; Lester and Paulus, 2012). For those whose bodies are categorised as outside normality, the requirement is that they work towards appearing normal in order to be socially valued. Taking this back into the context of medical therapies for children with diagnoses like cerebral palsy we can think of such therapies as emerging from a desire, institutionally and discursively validated, to minimize impairment and make the bodies of disabled children look and/or function 'normally'.

Much of the critique of normal embodiment within medical sociology and critical disability studies has not included a concern with childhood. We would argue that it is important to reflect on childhood, not just as a different site of empirical investigation, but also to consider the distinctive regulatory practices and discourses that occur around children and young people (James and James, 2004; James et al., 1998). Various childhood studies writers argue that childhood is increasingly regulated (Prout, 2000). The sources of such regulation are multiple, but medicine has, unsurprisingly been central (Turmel, 2008). Childhood historians argue that the medical gaze emerging in the 19th century identified by Foucault and Davis quickly turned on children, linking their successful development to the future progress of the modern state (Aries, 1962). What was put in place, and has grown over time, is the regular and routine measurement of child development against norms in areas such as body height and weight, cognitive capacity and moral reasoning (Honig, 2009; Kelle, 2010). From well before an infant is born, it is the target of continual measuring and monitoring, its bodily attributes, growth and development noted and compared against pre-established norms. Infants are expected to conform to certain markers of 'age-appropriate', 'normal' development. If they do not, they are typically drawn into a network of expert intervention to ensure that they do not 'fall behind' (Lupton, 2013).

Download English Version:

<https://daneshyari.com/en/article/7334489>

Download Persian Version:

<https://daneshyari.com/article/7334489>

[Daneshyari.com](https://daneshyari.com)