



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

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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.

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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).

Procedures for monitoring children have adapted over time, as the priorities of measurement have sought to match shifting notions of the 'good' citizen (Roberts, 2011). Prout argues that young people now are under a contemporary requirement to 'self realise' their transition to adult citizenship in a context of transformations in work, consumption and intimate life (Holland et al., 2000). While several childhood and youth studies writers point out the influence of factors such as gender, race and ethnicity and class in how transitions occur and whether they are judged as successful or not (Holdsworth and Morgan, 2005; McDowell, 2000), far less consideration has been given to the significance of disability to the monitoring of young people's bodies and lives and the possibilities of transition that exist. This is surprising as disabled young people have not been excluded from this focus on encouraging young people to work towards norms of good development. A variety of narratives now exist emphasising that disabled young people should be motivated to 'overcome' disability. One of the strongest imaginaries stressing this goal is seen around para-athletics, and terms such as 'super-humans' that are used to describe disabled athletes as 'inspirational' (Silva and Howe, 2012).

Embedded in cycles of intervention that may have started at birth, one might suppose that disabled young people incorporate such practices without question. However, understanding young people's relationship to medical imperatives in this way is risky. It treats young people as passive recipients incapable of questioning what is happening to them. Instead, as childhood studies teaches us, it is important to think about how young people as 'experiencing agents' (Kelly, 2005) situate medical practices within their social worlds. Our paper explores how young people who have grown up in a context of medical therapies trying to normalise their bodies respond as they enter adolescence. Through their narratives and practices we enquire how the medical imperatives of fixing are drawn into the personhood the young people are shaping and enacting. How do they work with and against medical practices that define their bodies as lacking and in need of repair? How are their approaches influenced by their thoughts on the future and aspirations for adulthood?

2. Methods

The paper draws on data from an ESRC¹ funded study of disabled young embodiments which builds on a mainly statistical study of participation and quality of life among disabled children: Study of Participation of Children with Cerebral Palsy Living in Europe (SPARCLE). The research aimed to return to a group of young people who, as children, had been part of a small qualitative study within SPARCLE. As this group was small, we invited young people from the project who were not part of that qualitative work to join. In total, seventeen disabled young people participated: eleven from the original group, two from the wider study and four from a local school for disabled young people. The young people recruited through SPARCLE were written to as the first point of contact. The young people recruited through the school were introduced to the project by a teacher, who provided them with information about the project (as were the others) and invited them to come forward if they were interested in taking part. Each had the opportunity to ask questions to the researcher before deciding to participate. Before interviews began (which were undertaken at home for those recruited through SPARCLE and at school for those recruited through that route) the researcher (for all participants) discussed

again the purpose of the research and what was involved and whether they still wished to take part. At this point written consent was taken and was then subsequently confirmed before any other interaction with the project and the researcher. For those under 16 consent was also obtained from parents before the first interview was undertaken. The sample included ten young men and seven young women aged fourteen to twenty who lived in and around the North-East of England. Each participant had a diagnosis of cerebral palsy and all had physical impairments which affected them in varied ways. Ethics approval for the project was granted by the regional Local Research Ethics Committee of the National Health Service.

Our intention on working with this group was to let them expand on themes that emerged in the previous qualitative work, including the management of disabled, painful bodies. We wanted to understand what had been happening to their bodies since the last interview and what kinds of stories would get told now about bodies that had, in the past, been presented as troublesome. To do this, we felt it was appropriate to adopt a range of non-clinical methods that let the young people convey their thoughts as 'capable, social actors' (O'Kane, 2008: 133). Consequently, we used face-to-face narrative interviews, photography, photo-elicitation and craft-making – methods shown to be particularly effective in research with children and young people (Morrow, 2001). Multi-method designs can make participation in research more interesting for children and young people by giving greater flexibility in how data is produced, and can enable different yet complementary insights into the meanings they make of their worlds (Bagnoli, 2011; Darbyshire et al., 2005). By having participants produce images or objects that spoke to their own experiences, whilst holding on to more traditional narrative modes of interviewing, we aimed to allow the participants to piece together narratives that disrupted medical ways of explaining bodies and impairments (Rich and Chalfen, 1999).

Much of this echoes what has been said in the methodology literature, and much of what we did followed the principal of giving the young people freedom and flexibility in how they conveyed information. The point was not to follow a strict protocol, but to provide the option of doing something different (Kullman, 2012). Thus we allowed the young people to decide on the extent of their participation, and how and what they used to take part, for instance in creating or gathering images or physical objects. Interestingly, despite the range of methods we employed, most opted to be part of a one off face-to-face narrative interview only. Time was a consideration, particularly in light of the demands of school work and exams, and some preferred brevity to a more extended involvement. Seventeen took part in those interviews, with eight doing the visual work, six of whom participated in a photo-elicitation interview. Three participated in the craft making workshops. In this paper we draw from across the data produced via these methods. The analysis process was guided by an exploration of the narratives contained within text, image and representational artefact (Garland-Thomson, 2007). Drawing from our theoretical interest in embodied practices and narratives, we first analysed the interviews to identify patterns within the ways in which the body was spoken of in the past and present tense and the types of activities and interventions being undertaken or reflected on. We each did this process separately and then worked together to compare the patterns each of us found and agreed a set of common narrative themes. The images produced then became both prompts to explore those themes further in the second interview, and also a site of analysis. We think of imagery and the objects some of the young people made as both artefacts that are made meaningful through narrative, and also through which it becomes possible to tell certain narratives. In examining the narratives we identified in

¹ ESRC Grant 'Embodied Selves in Transition: Disabled Young Bodies', the full team: Professor Janice McLaughlin, Dr Edmund-Coleman Fountain, Professor Allan Colver, and Professor Patrick Olivier RES-062-23-2886.

the imagery and objects, we found they provided both an opportunity for the young people to emphasise similar themes we found in the interviews, but also a space within which their agency in managing the narratives and practices around them could be expressed. Key themes that emerged through our team analysis were the medical reshaping of the body and an emphasis on efforts the young people were themselves making to produce their own capable bodies. We turn to this in the following section.

2.1. Reshaping children

During our first interviews with the young people, the participants reflected on how medical interventions were important elements of their childhood. Many discussed, in matter of fact ways, multiple surgeries, regular physiotherapy, injections of muscle relaxant and the wearing of medical devices such as splints and callipers:

P: I had four I think, first one was putting plates in my knees, [pause] and putting cow bone into my foot ... The second one was putting wire into my foot, or taking the wire out, no taking the wire out it was. So I had wire put in my foot, and I had that taken out, and the third one was having my tendons stretched from my hip to my foot I think, so I've got, like, a big scar at the back of my leg, so that was quite sore, but yeah I got that over and done with. And then the fourth one was just taking the plates they put in the first time out.

I: So why was it that they did all these things?

P: It's just to straighten my legs I think? 'Cos when I walk I have a bit of a crouch, so I think that's why they put it in just to sort of make me look a bit more normal, does that make sense? (Sarah, 15; first interview)

Sarah's account is typical of the level of intervention experienced in childhood. Plates, wires and cow bone were added or removed and tendons were stretched to make her legs straighter,

enabling her to walk with crutches. Scars on her legs were material testimony to this reshaping, letting past surgeries speak through the body. While there was acknowledgement of some of the costs of those interventions – time spent away from school, family and friends, periods of intense pain – there was little sense in childhood interviews or interviews with us that such interventions were themselves questioned or felt to be unusual. Instead, they presented these changes to their body as something they had, for the most part, benefited from:

P: I think I do have a good future ... Like what I would be able to do now after I've had me operations and that. And just like I'll definitely be able to be more independent, like if I didn't have the operations. So it's making a lot better ... With me walking and like growing up. (Paul, 16; first interview)

These past interventions reshaped the participants' bodies, and the narratives now told about them continued that process of reshaping, emphasising that the childhood body should be seen as an object of change, something that could/should be remade. Sarah's quote emphasises that embedded in the interventions was the goal of making the body function 'better' and appear as normal as possible. This objective carried on into interventions they were having or were recovering from when they spoke with us. Hannah, for instance, across the methods we deployed, spoke to the surgical reshaping of her body as something that had happened both in the past and the present; something which she did acknowledge had emotionally taken its toll (see Fig. 1):

I've been in and out of hospitals, I've been poked and prodded and I think I just got fed up of being like poked and prodded and operated on and I think I just got sick of being in there getting things done. (Hannah, 18; first interview)

However, in the same interview she explained that she had decided to have further surgery on her hand and leg. The aim was in part to alleviate pain, but also, as she said in her photo-elicitation

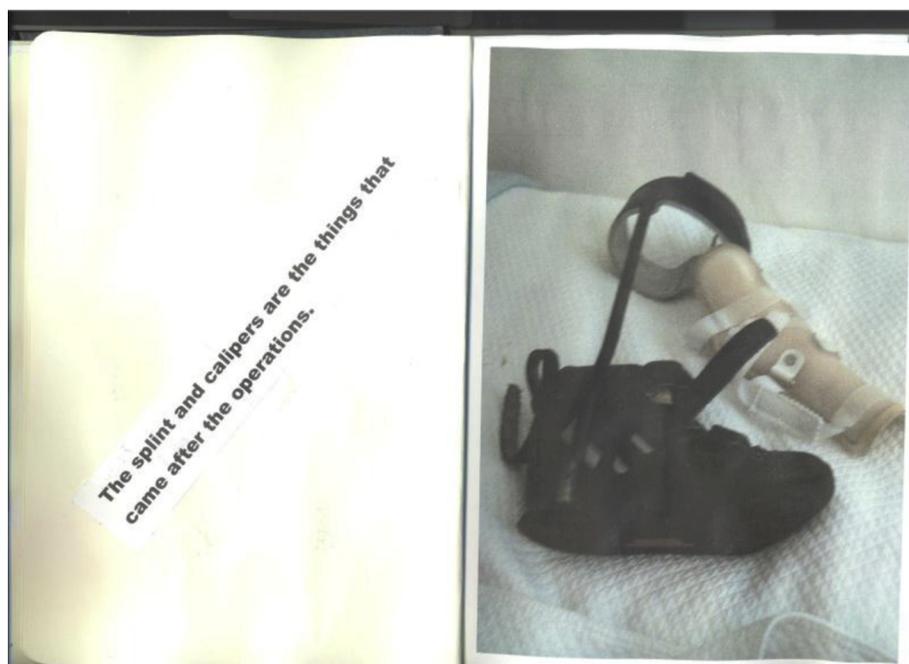


Fig. 1. Hannah, 18; scrapbook.

interview after the surgery, to straighten her legs out; to make them more 'normal', something she reinforced by gesturing towards the body of the interviewer:

... now it's not completely straight, they can't get it like yours, they can't get it, it's too strong but basically now it's like that, like still turned in a bit but more straighter than before. They can't get it like a normal, basically I won't get a normal foot, but it's to me it's more normal than what it was if you know what I mean by that, but it doesn't look like say your foot, but to me it's normal because it's like kind of like other peoples. Does that make sense? (Hannah, 18; photo-elicitation interview)

The emphasis on reshaping the material body in childhood drew the young people into a cycle of approaching the body as something to be worked on, even when they also acknowledged the effects of being 'poked at'. The medical imperative to fix, their familiarity with medical procedures, changes to the body that led to pain, produced a practice focused on an opening of the body to intervention, which stories of promised improvement in function and appearance supported. Even though surgery brought pain and disruption it was experienced as a commonplace activity to be returned to if the body slipped away from normality in its shape and function (see Figs. 2 and 3).

2.2. Unfinished bodies

As Hannah's oral and visual testimony of her latest surgery indicates, in spite of the frequent childhood surgeries, the body was not looked at as wholly repaired. Their stories of the present and the future were not the restitution narratives identified by Frank (1995), in which what has been damaged is fixed, rather the reshaping of the body was narrated within a continuum towards non-impairment, which left impairment present and any claims to improvement transient. Such narratives drew from and encouraged a set of practices associated with bodily improvement. The young people's present and future bodies were understood as 'flawed' and modifiable, and cerebral palsy continued to be identified as an

aspect of the body to be engaged with via medical intervention and even metaphorically removed by amputation:

I: Do you not try to build up your right arm?

P: No ... Just don't like that arm, I just think it is flimsy and gives me away ... I just think that I would want me arm chopped off and replaced with a robotic one (Andrew, 16; first interview)

Disability and its medical management was, in this way, a continuous thread in the young people's narratives and practices that had not lessened in significance as they got older. The majority of the participants, including Andrew, were still receiving regular physiotherapy, often augmented by their own trips to the gym or swimming pool and regular exercises at home:

I: What kind of exercises are you doing, stretching?

P: Yeah just stretching doing this [stretching ankle], going on the bottom stairs just dropping my heel that kind of thing, and just going to the wall and just pushing against the wall and just getting this leg back and then stretching here [pats right hamstring]. (Andrew, 16; first interview)

Working on the body through gym and exercise or diet is not unique to the young people we spoke to of course; the body is, generally speaking, unfinished for everyone. Shilling (2005: 74) refers to the 'cultural' bodywork people do to maintain the body as 'acceptable' in everyday life, and highlights the 'reproductive' work through which bodies are cared for. Generally speaking, the body is a site of practices guided by narratives people tell about it as, for example, old or young, frail or strong, fat or thin, healthy or sick, feminine or masculine, beautiful or ugly. The body is routinely worked on as people establish a body that can be lived with/in. Yet it is likely that whilst continuous with the 'ordinary' bodywork of everyday life, the need to work on the body is of particular significance to disabled young people, something rarely placed in the background by other aspects of life and a project within which medicine has a heightened presence.



Fig. 2. Hannah, 18; scrapbook.



Fig. 3. Hannah, 18; scrapbook.

In particular, there was a sense of fragility in the young people's stories, highlighting the temporal nature of what they did to the body and their relationship to it. Despite the surgeries, and medicine's inherent desire for progress, there was a pull not just towards a desired future free of challenge, but also a realisation that impairment would likely take them back towards a 'failed' body, and that further intervention may be needed. They were, for example, aware of how the ageing process differed for them compared to other young people:

When I was five I used to be able to climb up the windows, but I can't do that now ... my muscles have got tighter and my body has got tighter. I wasn't in as much pain when I was young but now I am in a lot more pain ... I am growing; obviously my muscles aren't long enough because they stop at a certain amount. Basically, I've got the muscles of an eleven year old, instead of a fifteen year old, and I have to get a lot of surgery to make them long enough. (Emma, 15; first interview)

Things that used to work began to deteriorate, in ways that made sustaining the progress narrative difficult. Emma, for instance, a wheelchair user with a history of epilepsy, spoke of how her muscles had got tighter; stretching into less comfortable positions, which had led to increased pain. Surgery was planned to tackle the discomfort she was experiencing as her body developed.

To be clear, this is not to suggest that the body would inevitably fail, or that surgeries were inherently unstable. The body was, in the stories the young people told, located between two poles – a 'normal' non-impaired body always to be worked towards, and the 'flawed' body of cerebral palsy. There were movements between the two, as the young people strived to manage their bodies. There was a recognition that the body was simultaneously one that could be improved and one which could falter. This was evidenced in the way several participants framed cerebral palsy as possibly undermining the lives they were living and the futures they were making (Butler, 2009). For example, at different points Mark spoke about

walking, initially speaking with pride about still being 'on his feet', and demonstrating photographically the work he does to stay that way. During his photo-elicitation interview however, he reflected on the transience of that, indicating how changes to the body might require him to alter his narrative as someone able through work to keep on his feet (see Fig. 4):

I think to get where I am with this disability is a good thing, I'd say it were a great thing. I don't think anyone that's got this far and still on their feet which uh, not being nasty, but not many people are on their feet with this disability. I very rarely see anyone on their feet with this disability ... I'm still on my feet at seventeen and with a bit of weight about me, it's pretty much a good thing. (Mark, 17; first interview)

... from what I've been looking at, when you get older, when you say you're fifty, well not when your middle aged, I think you get, you'll be struggling to walk, because my joints are going, you know stuck in that position then, er so your obviously, I'm never going to be able to walk properly and I'm never going to be able to walk from now until I pass away. So I just feel like if I live my life and what happens happens really. I know I'm not going to be able to walk from now until you know the day but, just if I live my life you know that's what I rather do. (Mark, 17; photo-elicitation interview)

The participants' own everyday comparisons with bodies they read as within the comfort and safety of normality encouraged both their own framing of their bodies as different and lesser and their pursuit of practices that could re-shape their body. This cycle of comparison and attempts towards normality were particularly notable amongst those with siblings who did not have a diagnosis of disability:

P: I would just like to be treated as a person, just like how me brother's treated I would like to be treated in that way.

...



Fig. 4. Mark, 17: scrapbook.

P: Like when I went to college, I was the only one with a disability in the class, so when I started they were like 'Are you alright', or 'Can you go downstairs like that', I didn't like really like that. (Paul, 16; first interview)

Paul acknowledged that in social spaces such as college where he would be with others with comparatively 'normal' bodies he would adapt his movement and use of assistive technology in order to be interpreted by others as belonging. In seeking to be treated as a person through normalcy, as others did, Paul articulated and embodied a version of personhood only accessible via normalcy. When asked during his photo elicitation interview how he would like to be seen, Paul explained that he wanted to be recognised as 'ordinary'; this speaks to both the safety of normality and also the importance of the social context of adolescence and thoughts of adult futures to the relationship disabled young people have to their bodies.

2.3. Aspirational bodies

It is not only the body that is changing through the ageing process; teenage and adult identities and aspirations emerge too, and this temporal dimension also influenced how the young people identified physical challenges to be worked upon. Intervention changed in its meaning and focus. Whereas many young people spoke, as children, about impairment as a limitation on the extent to which they could play at their friends' houses or join in children's games. The older they got the more concerns turned to the ability to live much like other young men and women, including going out with friends, forming intimate and sexual relationships, being able to be self-reliant and living independently, with the 'fixing' of the body intersecting with other forms of gendered and adolescent bodywork. Their use of assistive technology altered as their narratives increasingly stressed these concerns:

P: I use it [a hoist to get into the bath] more now, 'cos I'm getting older and I'm getting bigger. More preferable for me using that piece of equipment rather than my parents lifting me about so it's easier on the both sides.

I: So do you think as you get older that being independent will get more important?

P: I'm a lot more independent now, compared to what I was then. Maybe if I get more independent things will be easier for me and for others. So it's better for me to be more independent. I'm going to be eighteen next year and I will need to be more independent. I'm going to want to go out drinking with mates, meeting girls. Not just these things but other things too, I'm going to want to live on my own someday. So I'm going to want to be more independent now, rather than waiting some years down the line. (Craig, 17; first interview)

Craig's version of who he wanted to be and the body that would enable him to be that person is filtered through gendered norms about what a young man's life should ordinarily include. Mark also spoke of how his hard fought mobility enabled him to stand at the bar drinking alcohol with his mates (although he needed to monitor how much he drank to ensure he didn't fall over). Disability's meaning for the body was influenced by other social modes of being and belonging in the world (a separate paper on the research gives a fuller account of the gendered dynamics maintained within the young people's body practices and narratives (McLaughlin and Coleman-Fountain, submitted for publication)). For example, other gendered differences were apparent in how young women associated their wishes for self-reliance with desires to have a family (although very much a contemporary version of female adulthood that combined education with family):

When I leave uni I want to have a family and get married and not in that order, get married, have a family and if I am going to have my own family it's important that I can do more things for

myself. 'Cos obviously I'll need to help my children out with stuff. (Kate, 15; first interview)

The narratives of leisure, intimacy, education and family were framed by broader understandings of 'normal' transitions to adulthood, marked by progress towards higher education, employment, living on one's own and having a family (Holland et al., 2000). While the direction of such transitional trajectories for all young people can be thought of as varied and increasingly complex in contemporary social realities (MacDonald, 2011; MacDonald et al., 2001; Smith et al., 2005), the 'normal' transitional narrative structure, and the markers of progress towards adulthood it contained, was present in how the participants spoke of their body and appeared to influence the kinds of body intervention they undertook.

The emphasis they gave to gaining control over the body shaped their body practices and stories about such practices. Alongside the formal interventions such as surgery and physiotherapy, which others advocated, they were designing their own everyday interventions that turned walking, climbing stairs, or making a cup of tea into a therapeutic activity:

... occasionally pouring something from one container into another is difficult but if I really do concentrate I can do it like I can make cups of tea and stuff so I can pour the kettle into the cup (Kate, 15; first interview).

Their own interventions were crafted from and drawn into their adolescent narratives which stressed that what they were working towards was an 'ordinary' body that could do 'ordinary' adolescent things. This was not a heroic version of independence and self-reliance (for example the Paralympian 'super-human'); this was about the ordinary independence enacted in making a cup of tea. The body was often worked with so that the young people could manage to do things that other people do:

P: I sort of try and steady myself, so I don't too much and I don't do too little, because my problem is that I'm quite stubborn, so I don't tend to do to little anyway. I tend to just sort of do it all in one go ... I just sort of go for it really.

I: And what so you're insistent that you're going to do stuff?

P: Everything. Everything a normal person probably could do. But I have to sort of steady myself because obviously if I do too much then, say like my feet will hurt, or my ankles or whatever ... I don't know like, the distance a person could walk, I tend to sort of think 'Oh no I'm fine', my mams like 'Do you want to sit down', and I'll be like 'no' [laughs]. (Sarah, 15; interview 1)

The bodies others had sought to create during their childhood, against norms of body function and appearance, was now a body they sought to create against norms that mattered to them, including keeping up with peers and living as 'capable' young men and women.

Through the participants' varied responses to ageing we can see the unfinished body symbolically and materially changing. Medical imperatives to fix and re-fix, join with social desires to do everyday ordinary things in ordinary ways, to provide a different rationale for the importance of always working on the body. Getting older, and being older, placed new expectations on the body, and on 'doing', which the young people sought to embody as they negotiated the transition into adulthood. These practices ran alongside the surgical transformations they were undertaking to normalize the body. Surgical and everyday interventions reflected the position of

disabled bodies on a continuum between the flawed and fixed, as the young people negotiated the changing experience of the ageing, growing, aspiring body.

3. Conclusion

The disabled bodies of the young people in our study were read through the entwined stories of medicine, surgery, and physiotherapy; of body enhancement and failure; of the ordinary, normal and functional; as well as narratives around ageing, adulthood, independence, and their sometimes unease at social difference. The remaking of the body was carried out in light of distinctions made against others, and perceived inconsistencies in their ability to *do* and *be* like others, as such narratives provided images through which disabled bodies are judged as wanting. These comparisons positioned the disabled body as something to be looked at, and provided images against which it could be made sense of, setting down routes to let the young people and those around them see how the body could be reshaped. As a result, the young people's bodies were objects of ongoing interventions through which they were materially changed. There are several conceptual and political implications, about the evolving relationship between institutional and societal understandings of disability, ageing bodies, and body practices and narratives, to draw from the ideas and representations the disabled young people shared with us.

First, disability brings a different temporal relationship to the body. A diagnosis at or around birth triggers a cycle of intervention aimed at ensuring a positive future is still imaginable and achievable for the child. However, regardless of the level of intervention and its immediate successes, imagined futures remain fragile. The contingency of any repair relates not just to the distance still found between the normality it doesn't quite achieve, but also on the awareness that the repair itself can only be temporary in the context of an ageing body. This means that ageing is experienced differently, while socially valued futures secured around imaginaries of independence, family, friendship, and achievement are still believed to be possible if worked at by changing the body; the heightened speed at which physical ageing appears to take place, requires a degree of self-monitoring and regulation if such imaginaries are to be made real.

Second, the narratives and practices of this group of disabled young people indicate there is much to be concerned about in the continued policing qualities of normality and ordinariness in society; a dynamic of policing that is deeply unequal and unjust in the varied focus its gaze directs towards some and not others. It is not just the heroic super-human who disabled young people are judged against, as problematic is the 'normal' young person they are asked to aspire to be. Critical disability studies and child and youth studies are right to argue that regulatory dynamics and requirements to adapt and achieve are increasing in an environment that valorises self-reliance and neoliberal biocitizenship. What this paper contributes to the debates on neoliberal citizenship and normalcy is that these imaginaries have power not just as discursive devices. They also should be understood as having effects on the things people do to their bodies to enable them to be recognised within such imaginaries. From turning everyday activities into opportunities for working on body strength and agility, to undergoing painful surgery and physiotherapy, discursive validation of normality is embedded literally on to the body itself. An additional effect is the production of hierarchies between those who are seen as doing everything they can to minimise their disability and those who are judged for not doing enough. While medicine and its powerful institutions, status and actors, play an important role in the production and maintenance of this hierarchy, it is not only imposed from above, but also from within everyday practices of

comparison, belonging and developing the body people themselves undertake.

Finally, the paper produces a particular account of how we might still recognise the agency and possibilities embedded in the work disabled young people do on their bodies. The role of disabled young people in pursuing their body projects means that it would be problematic to only see such projects as done to them. There are forms of embodied, relational agency at work here as they draw medical practices into the versions of self-hood they are developing. Their own negotiations of social space and desires for the future play their part in influencing their approach to their different bodies. At times this appears to involve a disavowal or distancing from those aspects of their bodies that are different, but at others it involves a positive working with such differences, within which they take pride and wish to make visible to others. Their quest for normality is not an unquestioning one, it contains some challenge to others to see a 'normal' life as possible while differently embodied. This challenge contains alternative imaginaries through which society could view 'analogous bodies'. While disabled young people are required to do more to fit, they also make visible the fantasies included in medical imperatives of fix and cure and encourage society to recognise the 'misfit' (Garland-Thomson, 2011) as well as the normal.

References

- Aries, P., 1962. *Centuries of Childhood*. Jonathan Cape, London.
- Asberg, C., Lum, J., 2009. PharmAD-ventures: a feminist analysis of the pharmacological imaginary of Alzheimer's disease. *Body Soc.* 15, 95–117.
- Bagnoli, A., 2011. Making sense of mixed method narratives: young people's identities, life-plans and orientations. In: Heath, S., Walker, C. (Eds.), *Innovations in Youth Research*. Palgrave Macmillan, Basingstoke, pp. 77–100.
- Barnes, C., Mercer, G., 2010. *Exploring Disability*. Polity Press, Cambridge.
- Birke, L., 1999. *Feminism and the Biological Body*. Edinburgh University Press, Edinburgh.
- Braidotti, R., 2002. *Metamorphoses: Towards a Materialist Theory of Becoming*. Polity, Cambridge.
- Butler, J., 2009. Performativity, precarity and sexual politics. *AIBR Rev. Antropol. Iberoam.* 4 (3), 321.
- Canguilhem, G., 1989. *The Normal and the Pathological*. Zone Books, Brooklyn, NY.
- Coleman-Fountain, E., McLaughlin, J., 2013. The interactions of disability and impairment. *Soc. Theory Health.* 11, 133–150.
- Conrad, P., 1992. Medicalization and social control. *Annu. Rev. Sociol.* 18, 209–232.
- Conrad, P., Schneider, J.W., 1980. *Deviance and Medicalization: From Badness to Sickness*. C.V. Mosby, St Louis, Miss.
- Corker, M., Davis, J.M., 2002. Portrait of Callum: the disabling of a childhood?. In: Edwards, R. (Ed.), *Children, Home and School: Regulation, Autonomy or Connection?* Routledge Falmer, London, pp. 75–981.
- Darbyshire, P., MacDougall, C., Schiller, W., 2005. Multiple methods in qualitative research with children: more insight or just more? *Qual. Res.* 5 (4), 417–436.
- Davis, L.J., 1995. *Enforcing Normalcy: Disability, Deafness and the Body*. Verso, London.
- Draper, J., 2002. 'It was a really good show': the ultrasound scan, fathers and the power of visual knowledge. *Sociol. Health Illn.* 24, 771–795.
- Foucault, M., 1975. *The Birth of the Clinic*. Vintage Books, New York.
- Foucault, M., 1977. *Discipline and Punish: the Birth of the Prison*. Vintage Books, New York.
- Foucault, M., 1990 [1976]. *The History of Sexuality*. In: *The Will to Knowledge*, vol. 1. Penguin Books, London.
- Frank, A.W., 1995. *The Wounded Storyteller: Body, Illness, and Ethics*. University of Chicago Press, London.
- Garland-Thomson, R., 2007. Shape structures story: fresh and feisty stories about disability. *Narrative* 15, 113–123.
- Garland-Thomson, R., 2011. Misfits: a feminist materialist disability concept. *Hypatia* A.J. Fem. Philos. 26, 591–609.
- Goodley, D., 2011. *Disability Studies*. Sage, London.
- Goodley, D., Runswick Cole, K., 2013. The body as disability and possibility: theorizing the 'leaking, lacking and excessive' bodies of disabled children. *Scand. J. Disabil. Res.* 15, 1–19.
- Holland, J., Thomson, R., Henderson, S., McGrellis, S., Sharpe, S., 2000. Catching on, wising up and learning from your mistakes: young people's accounts of moral development. *Int. J. Child. Rights* 8 (3), 271–294.
- Holdsworth, C., Morgan, D., 2005. *Transitions in Context: Leaving Home, Independence and Adulthood*. Open University Press, Maidenhead.
- Holt, L., Lea, J., Bowlby, S., 2012. Special units for young people on the autistic spectrum in mainstream schools: sites of normalisation, abnormalisation, inclusion, and exclusion. *Environ. Plan. A* 44, 2191–2206.
- Honig, M.-S., 2009. How is the child constituted in childhood studies. In: Qvortrup, J., Corsaro, W.A., Honig, M.-S. (Eds.), *The Palgrave Handbook of Childhood Studies*. Palgrave, Basingstoke, pp. 62–77.
- Hubbard, R., 1989. Personal courage is not enough: some hazards of childbearing in the 1980s. In: Arditti, R., Klein, R., Minden, S. (Eds.), *Test-tube Women. What Future for Motherhood?* Pandora Press, London, pp. 331–355.
- Illich, I., 1977. *Disabling Professions*. Marion Boyars Publishers, London.
- James, A., James, A.L., 2004. *Constructing Childhood: Theory, Policy and Social Practice*. Palgrave, Basingstoke.
- James, A., Jenks, C., Prout, A., 1998. *Theorizing Childhood*. Polity, Cambridge.
- Kelle, H., 2010. Age-appropriate development' as a measure and a norm: an ethnographic study of the practical anthropology of routine paediatric checkups. *Childhood* 17, 9–25.
- Kelly, B., 2005. Chocolate... makes you autism: impairment, disability and childhood identities. *Disabil. Soc.* 20 (3), 261–275.
- Kullman, K., 2012. Experiments with moving children and digital cameras. *Child. Geogr.* 10 (1), 1–16.
- Lester, J.N., Paulus, T.M., 2012. Performative acts of autism. *Discourse Soc.* 23, 259–273.
- Lupton, D., 2013. Infant embodiment and interembodiment: a review of sociocultural perspectives. *Child. A Glob. J. Child. Res.* 20, 37–50.
- MacDonald, R., 2011. Youth transitions, unemployment and underemployment. *J. Sociol.* 47 (4), 427–444.
- MacDonald, R., Mason, P., Shildrick, T., Webster, C., Johnston, L., Ridley, L., 2001. Snakes & ladders: in defence of studies of youth transition. *Sociol. Res. Online* 5, U86–U103.
- McDowell, L., 2000. Learning to serve? Employment aspirations and attitudes of young working-class men in an era of labour market restructuring. *Gen. Place Cult.* 7, 389–416.
- McLaughlin, J., Coleman-Fountain, E., 2014. Displaying disabled youth: visual narrative, photography, and disabled young bodies. *Sociol. Res. Online* (submitted for publication).
- McLaughlin, J., Goodley, D., Clavering, E., Fisher, P., 2008. *Families Raising Disabled Children: Enabling Care and Social Justice*. Palgrave Macmillan, Basingstoke.
- Morrow, V., 2001. Using qualitative methods to elicit young people's perspectives on their environments: some ideas for community health initiatives. *Health Educ. Res.* 16 (3), 255–268.
- Nishizaka, A., 2011. The embodied organization of a real-time fetus: the visible and invisible in prenatal ultrasound examinations. *Soc. Stud. Sci.* 41, 309–336.
- O'Kane, C., 2008. The development of participatory techniques: facilitating children's views about decisions which affect them. In: Christensen, P., James, A. (Eds.), *Research with Children: Perspectives and Practices*, second ed. Routledge, Abingdon, pp. 125–155.
- Phillips, M.J., 1990. Damaged goods: oral narratives of the experience of disability in American culture. *Soc. Sci. Med.* 30 (8), 849–857.
- Prout, A., 2000. Children's participation: control and self-realisation in British late modernity. *Child. Soc.* 14, 304–315.
- Rich, M., Chalfen, R., 1999. Showing and telling asthma: children teaching physicians with visual narrative. *Vis. Sociol.* 14 (1), 51–71.
- Roberts, J., 2012. 'Wakey wakey baby': narrating four-dimensional (4D) bonding scans. *Sociol. Health Illn.* 34, 299–314.
- Roberts, S., 2011. Beyond 'NEET' and 'tidy' pathways: considering the 'missing middle' of youth transition studies. *J. Youth Stud.* 14, 21–39.
- Rose, N., 2000. The biology of culpability: pathological identity and crime control in a biological culture. *Theor. Criminol.* 4, 5–34.
- Rose, N., 2006. *The Politics of Life Itself: Biomedicine, Power, and Subjectivity in the Twenty-first Century*. Princeton University Press, Princeton, N.J.
- Shildrick, M., 1999. The body which is not one: dealing with differences. *Body Soc.* 5, 77–92.
- Shildrick, M., 2002. *Embodying the Monster: Encounters with the Vulnerable Self*. Sage, London.
- Shildrick, M., 2005a. The disabled body, genealogy and undecidability. *Cult. Stud.* 19, 755–770.
- Shildrick, M., 2005b. Transgressing the law with Foucault and Derrida: some reflections on anomalous embodiment. *Crit. Q.* 47, 30–46.
- Shilling, C., 2005. *The Body in Culture, Technology and Society*. Sage, London.
- Silva, C.F., Howe, D., 2012. The (in)validity of supercrip representation of Paralympian athletes. *J. Sport Soc. Issues* 36 (2), 174–194.
- Smith, N., Lister, R., Middleton, S., Cox, L., 2005. Young people as real citizens: towards an inclusionary understanding of citizenship. *J. Youth Stud.* 8, 425–443.
- Stiker, H.-J., 2000. *A History of Disability*. The University of Michigan Press, Ann Arbor.
- Turmel, A., 2008. *A Historical Sociology of Childhood*. Cambridge University Press, Cambridge.