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The body as disability and possibility: theorizing the ‘leaking, lacking and excessive’ bodies of disabled children

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The disabled body has come to occupy more than an ‘absent presence’ in critical disability studies. Disability theory has addressed an original somatophobia through debates between social modellers, realists, phenomenologists, psychoanalysts and postconventionalists. We briefly trace these debates and then the present article considers two readings of non-normative impaired bodies. Through a focus on the embodiment stories of disabled children we consider those times when their bodies demonstrate some forms of ‘leakage, excess, lack or displacement’. Our first reading, ‘disability’, adopts a social psychoanalytic lens to alert us to the cultural constitution of the disabled body as lack. Our second reading, ‘possibility’, adopts a postconventionalist stance and considers the disabled body as productively demanding imaginative theoretical and practical responses. We aim to explore the ways in which the impaired body can be embraced as a unique embodied entity through which to revise how bodies should and could be lived in. Our hope is that understanding these dual parallel processes allows us to keep together disability and possibility as key elements of the difference of disability.

Keywords: leaky bodies; disabled children; critical disability studies

Critical disability studies of the body

There has been a plethora of research studies that have accessed and theorized the lives and experiences of disabled children (Cocks 2005, 2008; Connors and Stalker 2003, 2007; Jahoda et al. 2010; Rabiee, Sloper, and Beresford 2005; Scott 2000; Stalker et al. 2011). From this work we are all too aware of the disabling physical, cultural and socioeconomic barriers faced by children and their families in the social contexts of education, healthcare, leisure and the wider community. Questions still abound, however, about how disabled children experience their bodies and how, crucially, others experience and respond to their bodies. During the collection of accounts of disabled children and their families – through the study we will describe later – a number of stories of embodiment were told that highlighted some children’s bodies tendency for ‘leakage, excess, lack or displacement’ (Shildrick 1999, 80). The stories that form the focus of the present article touch upon some of the private, intimate, challenging and surprisingly confirmatory aspects of (impaired) bodies. We were struck by the different ways in which children and their families spoke about

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their bodily functions. Their feelings included embarrassment, reticence and shame. Simultaneously, discussions of some of the more intimate elements of non-normative bodies were expressed in terms of relief, pride and indignation at the reactions of (non-disabled) others. The bodies of disabled children, while sharing much with other children, are marked in distinctive ways. We know that disabled or non-normative families experience more surveillance than others (McLaughlin et al. 2008) and private matters are, therefore, often made very public to significant others such as professionals. Children with impairments may challenge norms and goals associated with expected child development and psychological standards of what counts as a maturing body. Moreover, some impairments might be seen as more leaky than others (Shildrick 2009), while discussions of the same impairment throw up very different meaning-making processes, as evidenced by Ogden's (2007) discussion of irritable bowel syndrome (IBS) and Vidali's (2010) re-appropriation of the term 'spastic colon' as an alternative to IBS. Feelings of shame or relief will be deeply affected by these markings. Through listening to the stories of children we have found ourselves searching for disability theory that could not only make sense of their narratives but develop our own sensitivities to their reflections on – and their personal experiences of – their bodies. We were influenced by Lather's (1986, 262–7) assertion that:

... not only must theory illuminate the lived experience of progressive social groups, it must be illuminated by their struggles. The goal of theoretically guided empirical work is to create theory that possesses 'evocative power'... by resonating with people's lived concerns, fears and aspirations, emancipatory theory serves an energising, catalytic role.

The research question we address in the present article, therefore, is: How can we provide readings of intimate accounts of the bodies of disabled children that evoke wider considerations of the politics of disability? Our aim is to take seriously these accounts and consider the ways in which they highlight disability not only in terms of cultural lack but also in terms of personal resilience and embodied potential. Our task is not simply to pitch an understanding of their bodies in the context of disabling society but, crucially, to consider the ways in which their non-normative bodies provide opportunities for emancipation. Such considerations require responsive disability theories that simultaneously analyze the conditions of exclusion and illuminate emancipatory potential. Such an aim fits well with critical disability studies.

In recent years, the disabled body has come to occupy more than what Shakespeare and Watson (2001) called an 'absent presence' in critical disability studies. An initial somatophobia has been tackled through growing debates between a number of theoretical orientations. While we acknowledge a huge body of literature associated with sociology of health and illness and sociology of the body (Frank 1994; Shilling 2005; Turner 2008), we follow Thomas's (2007) advice to (re)connect theories of the body with critical disability studies literature. Before exploring theoretical resources we want to acknowledge that discussing the fluid or leaking bodies of disabled children raises serious ethical and moral issues. We have been here before when we wrote about the real, relational, systemic and cultural violence experienced by disabled children (Goodley and Runswick-Cole 2011). Publicizing potentially traumatizing stories risks victimizing children and contributing even further to a pathological account of their lives. In the present article we continue to

recognize the tensions in (re)telling difficult stories. Regardless of the fact that our research passed university research ethics committee procedures, we still worry that these accounts might feed into a voyeuristic interest in the tragic stories of disability. We are, also, anxious that in writing a research article we are in danger of domesticating or objectifying very real stories of oppression. However, our attempts to take seriously the embodied experiences of disabled children reveals deeply held cultural discourses around disability that require not only our attention, but also our response. Hence, the present article is written in response to some of the stories of non-normative bodies shared with us by disabled children and young people and their families. While we remain anchored to their personal experiences, we attempt in to show how their accounts resonate with social theories around the body.

In British disability studies, materialist theories of disablement acknowledged the reality of impairment but shifted the attention away from the body (impairment) to society (disablement), particularly the structural and historical conditions of disabled people's marginalization (Oliver 1990; Barnes 1998; Gleeson 1999). The ensuing framework of analysis – the social model of disability – emphasized analyses of the socioeconomic causes of oppression in sharp contrast to the impairment-obsessed focus of dominant disability discourses associated with medicalization, psychologization and rehabilitation. The body and impairment appeared to remain on the outskirts of disability theory and this prompted some scholars and activists to reinsert bodily concerns back into the social model discourse (French 1993; Crow 1996; Shakespeare 2000). They argued, respectively, that the harsh realities of tiredness, the limiting consequences for social interaction and debilitating experiences associated with some impairments have often become obscured by the structuralist focus of the social model.

One of the more popular theoretical developments around the body has been made by realist disability theorists (Shakespeare and Watson 2001; Shakespeare 2006; Siebers 2006). They argued that separating the body and culture – impairment and disability – ignores the realities of the body. There are real bodies that exist materially untouched by culture as extra or pre-discursive phenomena. Impairment is a key reality of the disability experience. For some it is a predicament, for others unimportant but, for all, impairment is a manifestation of biological limitation (Shakespeare 2006, 40). This realist conception of impairment has contributed to the drafting of universal definitions of disability such as 'International Classification of Functioning, Disability and Health' (ICFDH-2) or 'the ICF model', where disability is an umbrella term for impairment, activity limitations, and participation restriction, and forms part of a broader classification scheme covering three domains: body functioning and structures; activities and participation; and environmental factors. Moreover, a realist approach fits well with a Nordic relational model of disability, which approaches the study of disability with three main assumptions: (1) disability is a person – environment mis/match; (2) disability is situational or contextual and (3) disability is relative (Tøssebro 2002, 2004). For Campbell (2009, 95) a relational model understands disability as a phenomenon emerging out of interactivity between real impairments and disabling modes of socio-economic organization. Realists have encouraged discussion about the biological realities of 'non-normative bodies' (Shildrick 2009) in ways often in opposition to social modellers. Nevertheless, by locating the body in the biological register, then the non-normative body is in danger of being theorized and understood through orientations that are commonly aligned with such a register; such as medicalization and rehabilitation (Koch 2008).

A more sustained social theoretical analysis of the body has been provided by phenomenologists, whose ideas have been well represented in analyses of the dilemmas and possibilities of embodiment (Paterson and Hughes 1999; Hughes and Paterson 1997, 2000; Hughes 2000, 2002a, b, 2004; Michalko 2002; Titchkosky 2003, 2008; Overboe 2007). Phenomenologists attend to the capacities of the body to be a source of self and society. As Goodley (2011a, 86) has argued, a ‘carnal sociology’ has emerged, drawing on the work of such people as Merleau-Ponty (1962), theorizing the body as the place where self and society interact (Shilling 2005; Langdridge 2007). Embodiment refers to how the body operates in the world at the intersections of the corporeal and institutional (Sherry 2006). Comportment, for example, reflects conventions. Ability is a response to environment demands. Illness is a narrative written onto and lived with through recourse to a whole host of powerful narratives such as medicine and self-help. Bodies are sites for subjectivity and consciousness, our active vehicles for being in the world. Practical engagements with our surroundings inform the intentionality of the body. Senses provide thickness of meaning that then constitute the world around us. We open our selves and bodies onto – and by doing so – create environments (Merleau-Ponty 1962). The experience of disability and impairment is conceptualized through reference to the social self and its production of the life-world (Hodge 2006), where the cultural constructions of disability and impairment are played out within and through the body. These accounts, then, allow us to consider the ways in which impaired bodies are constituted through and with the relationships between the body and the environment.

Social psychoanalytic interventions into disability studies have had less impact on debates than other camps but their significance is starting to be felt (see Goodley, forthcoming, for an overview). This perspective uncovers societal, political and cultural knowledge/practices that impact upon the development of the un/conscious and the psyche. Marks (1999a, 1999b, 2002) has provided the most sustained analysis, suggesting that critical disability studies and social psychoanalysis are distinct though overlapping perspectives. First, each demand changes to psychic and environmental structures rather than just attitudes. Second, disability studies and social psychoanalysis reject medicalization in favour of more relational encounters. Third, each reject unitary, rational, fixed and stable conceptions of the individual and consider categories such as in/sane, un/healthy and dis/abled as cultural continua that raise questions about human worth. Fourth, both psychoanalysis and disability studies have attended to the ways in which the self is made in relationships with others. This feeds directly into disability studies work that has long acknowledged how the disabled self has been consistently devalued by non-disabled others (Hunt 1966). Interestingly, in terms of the focus of the present article, psychoanalytic theory has traditionally had a lot to say about the intimate, private and leaky nature of bodies (Shildrick 1999). One of the key tasks of psychoanalysis is to map how bodies and bits of bodies are positioned in relation to one another (Parker n.d.).

Postconventionalist theories, a term coined by Shildrick (2009), aim to reframe the disabled bodies along the lines of capacity, potential, interconnection and possibility (Bayliss 2006; Gibson 2006; Goodley 2007; Goodley and Roet 2008; Hickey-Moody 2009; Overboe 2007; Roets 2008; Shildrick 2004, 2007, 2009). These theorists embrace poststructuralist and posthumanist orientations including the work of writers such as Haraway (1991) and Deleuze and Guattari (1987). A postconventionalist position is captured well by Haraway (1991), who describes social theory as providing subtle understandings of emerging pleasures, experiences

and power with serious potential for changing the rules of game. What people are experiencing, she argues, is not transparently clear, and we lack subtle connections for collectively building effective theories of experience. This is particularly the case when bodies challenge normative standards of embodiment: as in the case of the children described in the present article. For Shildrick (1999), many theoretical conceptions of the body have in mind the normative, seemingly biologically given, standard morphology, integrated and fully functioning body as an implicit standard. The consequence for non-normative bodies is clear; they are marked as the antithesis of the standard: 'Against an ideal of bodily perfection that relies on the singular, the unified and the replicable, monstrosity, in the form of either excess, lack or displacement, offers a gross insult' (Shildrick 1999, 80).

Postconventionalists borrow, then, from phenomenological, poststructuralist and, to some extent, psychoanalytic theories to dispute the 'given-ness' or 'already there' of any body. The body is, for Braidotti (2003, 44), neither a biological nor sociological category, but an interface, a threshold, a field of intersecting material and symbolic forces; a surface where multiple codes (sex, class, age, race, etc.) are inscribed. The normative body is understood as being fashioned and materialized through cultural, political and social conditions ranging from surgery to self-help. The non-normative or monstrous body – a body that appears as an object of fear and curiosity – is considered, therefore, as an opportunity to think through values, ethics and politics that congregate around particular bodies. In this sense any intimate bodily function is also a function of a body within given standards of embodiment while also, potentially, a moment of disruption and reflection on what counts as a valued body. Through these reflections non-normative bodies are recast as unique embodied entities through which we can consider how bodies should and could be lived (Overboe 2007). A postconventionalist views non-normative bodies not as invalid or lacking, but in terms of affirmation, possibility and becoming (Braidotti 2003).

In the present article we build on debates between social modellists, phenomenologists and realists to develop further the two positions of the social psychoanalytic and the postconventionalists to engage with the embodiment stories of disabled children. Our first reading, 'disability', adopts a social psychoanalytic lens to in order to alert us to the cultural constitution of the disabled body as lack. Our second, 'possability' – a neologism coined by McKenzie (2009) to describe the ways in which impaired bodies demands imaginative responses – is explored through a postconventionalist stance. We conclude with reference to Haraway (1991), who argued that we need a way out of the maze of dualisms in which we have explained our bodies to ourselves. Our hope is that understanding these dual parallel processes allows us keep together disability and possability as key elements of the 'difference of disability' (Michalko 2002). At this point, we acknowledge that our chosen terminology – which includes 'impaired', 'non-normative' and 'disabled' – risks maintaining a dualistic view of bodies. Nevertheless, we use these terms to acknowledge their widespread usage in the lives of disabled children and aim to move through the present article to a position that acknowledges a nomenclature of bodies-as-disability-and-possability.

The present study: objectives and methodology

The present paper draws on a number of accounts of disabled children and their parents collected as part of a project funded by the Economic and Social Research

Council (RES – 062-23-1138; <http://post-blair.posterous.com/>), ‘Does every child matter? Post-Blair: interconnections of disabled childhoods’. Our over-arching aim was to ask what life is like for disabled children/young people and their families in the aftermath of the changes for children’s policy and practice since 1997 set in motion by the New Labour government in Britain. To meet this aim, we identified six key objectives:

- (1) To identify the extent to which Every Child Matters (the guiding philosophy of the then British government around children’s services) and related policies are reflected as a policy discourse and a reality in the provision of enabling environments for children and families within the contexts of health, care, education and leisure
- (2) To explore critically how disabled children are being supported to meet the aims of the policy constellation around Every Child Matters to be ‘healthy’, ‘stay safe’, ‘enjoy and achieve’, ‘make a positive contribution’ and ‘achieve economic well-being’
- (3) To merge critically the agendas of children, parents and professionals and related social theories associated with sociologies of childhood and families, disability studies and critical pedagogy
- (4) To investigate how the ‘parent’, ‘professional’ and ‘disabled child’ are constructed across contexts, over time, nested in a host of policies and practices and how these relate to notions of ‘good’ parenting, ‘good’ professional practice and ‘well-adjusted’ children
- (5) To identify and interconnect enabling forms of health, care, education and leisure from the perspectives of disabled children and their parents/carers alongside a consideration of professional perspectives
- (6) To examine critically interactions between children, parents and professionals in terms of the ways in which disabled children and their families are empowered to take an active and enabling role in the spheres of health, care, education and leisure

With these objectives in mind the research was carried out over a period of 32 months from September 2008 to May 2011. The study took place in England and there were six phases to the research.

Pilot study

A variety of innovative methods deployed by the study required careful piloting. The form of interviews employed for the different groups identified later were piloted by Group A, which included two parents of disabled children aged 4–11 years, two parents of children aged 12–16 years and two professionals and four children aged 4–16 years.

Narrative inquiry – retrospective stories of disabled childhoods

We built upon the narrative tradition, methodologically and analytically, in order to capture the experiences of parents of disabled young children. In Group B, six parents of disabled children aged 14+ years were interviewed three times to reflect on their experiences with their disabled children.

Children's accounts: interviews with two groups of children, aged 4–11 and 12–16 years

Group C – our disabled child informants – included five children aged 4–11 years and six aged 12–16 years and were interviewed three times. In our work with children, we adopted the following principles: to treat children as experts and agents in their own lives; to use multi-methods in recognition of the different ‘voices’ or languages of children and to seek to establish a climate of listening. We were aware of the need to adapt the research tools to suit each child or young person (Goodley and Runswick-Cole, forthcoming). While our original research proposal aimed to explore ‘ethnographically the lives of disabled childhoods’ and ‘draw on the accounts of disabled children through participatory interviews’, our attention quickly shifted to what we could learn from the existing participatory ethnographies of our co-researchers. Listening to disabled children we found that a key ‘method’ of giving voice preferred by them was found in their use of technology – and specifically photography.

Focus-group interviews with professionals – exploring care and intervention

As the research progressed, six focus groups were held with different professional groups Group D. We talked to voluntary sector workers, teachers, early-years professionals, and teaching assistants. Scenarios were used to generate discussion, partly informed by the issues that emerged in the ongoing interviews and ethnography.

Longitudinal narrative case studies of parents of disabled children

Group E comprised seven parents whose disabled children whose ages ranged from 4 to 16 years. Narrative interviews mapped families’ engagements with aspects of care, education and leisure at key points. The parents were interviewed four times over an 18-month period.

Growing up – an ethnography of children's social worlds

We spent a total of 50 ethnographic days over the 18 months of the study. This allowed us to access contexts such as nurseries, schools, children's parties, supermarket visits, and theatre events. Through a process of observation – ranging from non-participatory to participatory – we explored the intersections of education, care and leisure.

Overall, our Group F participants included disabled children aged 4–16, their parents/carers and professionals who work with disabled children, including teachers, third sector workers, health workers and social workers. Children had a range of impairment labels including autism, cerebral palsy, developmental disability, Down's syndrome, achondroplasia, profound and multiple learning disability and epilepsy. Katherine acted as research fellow to the project and was involved on a day-to-day basis with the design and implementation of the empirical work (as well as the analysis). Katherine accessed families via parent support groups and other community contacts. Our sampling also had an element of snowballing to it as potential families were informed by word of mouth, emails and via websites about

our research. The ethnography involved Katherine attending children's birthday parties, bowling, shopping with families. She was also invited to impairment-specific leisure activities, including an autism-specific social club, parent groups, and user consultation meetings set up by local authorities, services and professionals to access the views of families. A few of the families involved in the interviews were also involved in the ethnography, but the latter was extended to include different children and their families.

The data for the present article draw on the accounts of five families – from Groups B, C and E. These families were chosen because of the embodiment stories that they shared. Interviews varied in style; all were open-ended and covered a range of issues including participants' experiences of health, social care, education and leisure. Parent and carer interviews tended to be more in line with the normative approach to semi-structured interviews. Interviews with children ranged from semi-structured interviews to more participant-led activities such as playing computer games, watching TV, discussing photography and exploring personal items that were of significance to the children. In other cases children did not want to be interviewed. In these occasions they were provided with digital cameras, if they so wanted them, and asked if they would be prepared to document aspects of their lives important to them. The children and parents came to divulge personal stories and confess intimate feelings as a consequence of the familiar relationships they had built up with Katherine over, in many cases, nearly two years of involvement with the research project. The longitudinal nature of their research involvement permitted parents and children to open up about their lives as they built a relationship of trust with Katherine. Katherine's own positionality as a mother of a disabled child, and her willingness to share this with the families, undoubtedly shaped the research in positive ways. It was less helpful in some meetings with the children when, we felt, that they did not want to speak to someone who reminded them of their own mums. The use of digital cameras and other child-led methods were adopted instead (Goodley and Runswick-Cole, forthcoming). In the course of the analysis of interview transcripts and other information collected we visited and re-visited the data to search for themes. We have developed a synthetic analytical framework through the deployment of a diverse array of theoretical perspectives in the analysis of the data. We took challenges from critical disability studies to utilize a mixture of theoretical approaches that, often, intersected with gender, queer and critical race studies (see Goodley and Runswick-Cole [2010] for an extended overview of our approach to analysis). For the present article, the stories of children's bodies that we share drew us towards disability studies theories around the body, in particular the social psychoanalytic and postconventionalist theories we introduced earlier and develop later. In the course of the analysis we visited and re-visited the data to search for themes (Snow et al. 2004), with two emphases in mind: (1) to search for accounts of children's bodies; and (2) to seek rich data that speak of the lives of disabled children and their families. Consequently, the stories of five families emerged as rich contexts for exploring the non-normative body. We feel it important to 'out' ourselves in relation to analysis. As a mother of a disabled son (Katherine) and a parent who has worked alongside a self-advocacy group (Dan), these experiences have, we feel, alerted us the silences around non-normative bodies. We never approach analysis in a dispassionate way nor seek objectivity in our interpretations. Instead, as qualitative disability studies researchers, we seek to tease out themes and findings and connect these with theories that illuminate the significance of those

themes. Furthermore we were driven by a specific aim, which is worth reiterating; how can we provide readings of intimate accounts of the bodies of disabled children that evoke wider considerations of the politics of disability? Hence, the analyses presented in the present article connect theory/data around two readings. Our first reading, 'disability', adopts a social psychoanalytic lens to in order to alert us to the cultural constitution of the disabled body as lack. Our second, 'possibility', adopts a postconventionalist to capture the affirmative possibilities of the disabled body.

Bodies as disability: a social psychoanalytic approach

Through re/reading the accounts from our families we have found ourselves drawn to psychoanalysis. We appropriate psychoanalytic theory because it gives us some tools for a cultural reading of the making of normative bodies and the (mistaken) promises of autonomous lives. In the present article we turn, albeit briefly, to the psychoanalytic theories of Jacques Lacan. This approach has previously been used by disability studies writers (Frank 1994; Davis 1995; Michalko 2002; Wilton 2003; Shildrick 2004; Goodley 2011a, 2011b). For our purposes, Lacan's phases of maturation – real, imaginary and symbolic – give us a framework for understanding disabling reactions to the embodiment of disabled children. The real phase describes the early carer – child dyad in which the child is a mass of turbulent movements, of sprawling limbs, a desiring entity; gazing and being gazed at, touching and being touched. The body is experienced as fragmented: an embodied reality that we keep with us throughout our lives: an unconscious body which is mourned (as that narcissistic, nurtured period of life which we never get back) and refuted (as a disorganized body that fails to match the expectations of bodily control demanded by the cultures in which we live). The imaginary phase depicts the growing sense of a self as distinct from others. This is the self viewed in a mirror: a fixed, whole and unitary image. The body captured in the reflection contrasts markedly with the reality of the fragmented body. However, as part of the process of making a self, an ego, a conscious sense of who we are (as distinct from others): we fall for the image in the mirror, repress the fragmented reality of bodies, and so commence our lifetime journey of trying to fit with the idealized image of bodily mastery and control depicted in this original image. Unconsciously, the reality of the fragmented body remains – contrasting with the idealization of the masterful body – and this leads to a sense of insecurity and a feeling of lack. The symbolic phase describes the child's entrance into language and, therefore, culture. Where the imaginary permitted a distinction of one's self from an 'other', the symbolic phase allows the child to speak of this separation – of 'I', 'you' and 'them' – in an order outside of the child. However, following Goodley (2011b), just as the imaginary phase gave the child ontological insecurity (in terms of the failure to match up to the original image/fantasy of the autonomous self and the split away from the real phase's desire of and by the original m/other), these insecurities are multiplied exponentially in the symbolic; because of the sheer size and expanse of language. We risk being alienated by the endless possibilities of speaking of ourselves and, therefore, find our place in the symbolic lacking. We find ourselves lacking in language.

The body described by Lacanian psychoanalysis is a normative body. Hence, the insecurities and feelings of alienation depicted through the three phases relate to non-disabled bodies. These bodies reflect 'the master discourse of the white, masculine, hegemonic, property-owning subject, who posits his consciousness as

synonymous with a universal knowing subject and markets a series of ‘others’ as his ontological props’ (Braidotti 2006, 51). When impaired or non-normative bodies enter the fray, this results in ‘disability’; a number of reactions that replay the real, imaginary and symbolic phases that can be found in the collective normative cultural unconscious.

A fragmented ‘real’ body

When Kurt was born, well the midwife, she’d never seen anything like it. She couldn’t tell me anything, she had never seen a baby born like this ever. So my first thought was . . . It looked like someone had got a pair of scissors and cut the baby in half so there was no genitalia to say what sex it was, at first they told us it was a girl, but I wasn’t overly sure I thought well, I stopped my husband from phoning and telling everyone what sex it was until we’d seen the specialist. They wrapped his bladder up, which was exposed on the body, they told me later, so that had to put cling film over it to protect it. I lost my temper because everyone wanted to look at him, it was like being a guinea pig so people from all over the hospital came to look at him. In the end me mum lost her temper and shouted ‘would you all get out of this room, it’s not a freak show!’ You know people have to learn but at the end of the day they just turned up in droves gangs of them just looking and that really annoyed me, so I had that to cope with. (Kate, mother of Kurt)

Kurt’s body is, quite literally, a fragmented body. As Michalko (2002) and Shildrick (2004) note, non-normative bodies have the potential to remind everyone of their own fragmented bodies that they have been forced to reject though still, simultaneously, mourn their passing. The midwife’s response to Kurt’s embodiment (shock) and the subsequent gaze of medics (fascination) capture the culturally ambivalent ways in which non-normative bodies are emotionally felt and understood. Non-normative bodies engender psycho-emotional reactions in others (Reeve 2002); and we know that some of the earliest responses, diagnoses, comments of professionals about children’s impairments remain with parents for years to come (McLaughlin et al. 2008). Perhaps what we know less about is the deeply ingrained and contrasting psycho-emotional responses of non-disabled professionals to non-normative bodies, which reflect not simply professional knowledge but unconscious reactions to fragmented bodies that are all too familiar to non-disabled people (Shildrick 2009). Kurt’s story of embodiment says as much, or more, about other’s own embodied emotional experiences and their feelings of lack. There is a risk that these reactions are internalized by Kurt and his family, threatening to create epistemic invalidation (Marks 1999a) or, put simply, internalized oppression (Reeve 2002).

A leaky ‘imaginary’ body

Mark, aged six years, has the label of autism. He lives at home with his parents and his older sister who is seven years old. Mark attends a special unit at a mainstream school.

Sorry to bring this up but last summer it was horrendous and that’s all because he wouldn’t have a poo at school and I didn’t click it all the time but it really was hard, it was all up the walls, it’s taken the whole year to get him back to normal again and its only just, this summer starting a little bit again and we’ve sort of had to pull him in line with the routine of it all again. I hate it, it’s just like, poo up the carpet, the wall on the

fingers on toes, it's just horrible for anybody to have to deal with that and your having to carry him upstairs and constantly asking 'have you had a poo, do you need a poo? Do you need a poo poo or so you need a wee wee? You know, because I don't want him to do it in his pants! And I can tell when he's come downstairs and not flushed the toilet and washed his hands and I say let me smell those fingers and he runs back upstairs, flushes the toilet and washes them, and he knows, but at school he's perfect with it and at home. (Angela)

Disability studies have had very little to say about bodies that literally leak like those of Angela's son. Reeve (2010) describes this absent analysis as a form of ableism in disability studies theory, where the self-contained, bounded and normatively shitting subject is implicitly assumed to exist, and more troubling less contained subjects remain abject; hidden, ignored, reduced to the non-human. Angela's painful story of her son's leaking body should be understood in terms of their cultural location. For Davis (1995, 134), bodies that appear to be unwhole, altered or uncontrollable are a direct reminder of the repressed fragmented body and also a kind of hallucination of the imaginary's mirror phase gone wrong; a body that seemingly lacks the normative standards of being toilet-trained contrasts markedly with the original fixed and autonomous image of the mirror. Simultaneously, a non-normative body threatens to engender ontological insecurities in the non-disabled viewer because that viewer is simultaneously caught up in an endless process of displaying their own autonomy. Non-disabled people are disturbed by disability because it reminds them of their own fragility (Michalko 2002, 95). The social pain of disability, for Michalko, is not to be found in disabled people but in the non-disabled people majority. Angela's story is a narrative encounter with normative culture and a host of expected and demanded embodied ways of being-in-the-world as they relate, in this case, to pooing. This draws us into a very specific embodied arena associated with 'odour poetics', the rhetoric of bodily control, the politics of shit (Vidali 2010).

An inappropriate 'symbolic' body

Mandy is 16 years old and has the label of moderate learning difficulties. She lives at home with her mum and dad. She attends a mainstream secondary school.

There was just... they started saying silly things like, Mandy is being inappropriate with the boys, inappropriately touching that was it and I was like 'oh, oh!' What do you mean inappropriately touching and they said she is touching their arms and touching their legs. I said well you have to understand that when Mandy's language skills were much poorer than they are now, rather than make this awful 'uh, uh, uh' sound that she had, the speech and language taught her to touch your arm when she was a lot smaller, touch your leg. So when you are sat down and she wants to talk to them she will touch their arms. When they said she was inappropriately touching we thought she was touching breasts or touching genitalia they made everything so sordid sounding. But in my mind, she has an interest in boys, she has an all teenager interest in boys so she is showing that she's looking probably for a relationship some time in the future and I hope for her she can. Children used to hug her and the teachers used to hug her and the secretary used to hug her and then we'd read her report and it would go 'Mandy has a tendency of hugging people'. Because they are hugging and communicating that way she thinks it is only natural. (Charlotte)

Our sense of our sexual embodiment is understood through the discourses associated with the sexual body. Charlotte finds the words used to describe her daughter's

expression of embodiment – which might be sensual or a form of communication rather than sexual – as sordid and shameful. These words are lacking. Mandy, too, appears to be doubly alienated as she lacks the words to enter the (admittedly alienating) symbolic through which to voice her body. In lacking the words to describe or justify an ‘appropriate’ sexual encounter she is, potentially, denied sexuality. When Mandy is recognized in the symbolic this is in terms of pathology. Her hugging is reported on as a problem in the normative register. The lacking non-normative body is, therefore, monstrously, perhaps psychotically, caught up in these psychoanalytic processes of the ‘oedipalizing cage of negation’ (Braidotti 2006, 61) a place of utter lack.

Bodies-as-disability provides a clear narrative of the ways in which the ideals of the normative ableist imaginary and symbolic threaten to marginalize non-normative embodiment. While this provides a helpful form of cultural critique one is left wondering if there is a way out for disabled children and their families. A postconventionalist reading gives some hope.

Bodies as possibility: a postconventionalist approach

Braidotti (2006) suggests that psychoanalytic theories posit a logic of irreparable loss, unpayable debt, guilt and perpetual mourning. The Lacanian normative lacking body is one caught up in the logic of lack (Braidotti 2006); it is a body tied to a phallogocentric mode of thought that rests on a semi-religious attachment to the conception of desire and lack (Braidotti 2003, 56). The Lacanian body is a body already there, a ‘body-as-being’, one with a history that has shaped it. A postconventionalist perspective, as imagined by writers such as Braidotti, Haraway and Shildrick, proposes a ‘body-as-becoming’; made through connections in the present and forward-looking to the future. Bodies share multiple alliances, symbiotic connections and fusions. Bodies become through their relationships with others (Braidotti 2006). Here, then, there is a turn of tack, away from non-normative bodies that are cultural lacking to non-normative bodies that are imbued with new possibilities. It is, for Braidotti (2006), about affirming the force of the affirmative and positing an ethics based on the transformation of negative into positive passions. The postconventionalist body is one in which the old subject formation (so typified by psychoanalysis) is replaced with the notion of the subject as a cluster of complex and intensive forces, environmentally bounded, potentially nomadic rather than settled (Braidotti 2006). This is the body that seeks to break free from oedipalized and normalized modes of governance and organization which constitute the body-as-lacking. And the good news here for critical disability studies is this: that bodies most likely to be primed for such breakages are those often associated with the monstrous, other, abject and pathological (Shildrick 1999).

This is a dream not of a common language, but of a powerful infidel heteroglossia. It is an imagination of a feminist speaking in tongues to strike fear into the circuits of the supersaves of the new right. It means both building and destroying machines, identities, categories, relationships. (Haraway 1991, 181–1)

Braidotti (2006) defines this process of building and destroying as ‘nomadic subjectivity’ through which people challenge the distinction between ‘the same and

his Other'; dislodging dominant subject positions and developing new ways of becoming in the world. This, she argues, is a kind of radical materialism for the poststructuralist age (Braidotti 2006, 61). For Braidotti, women and other 'others' who are the carriers of the hopes of the minorities – to which we can add disabled children – are ideally placed to resist the oppressions of the Same (Braidotti 2006, 57). This, she argues, is an approach to intensity and passion, which is free of the lack and confession (characterized in psychoanalytic descriptions) of desire through, and not away from, the flesh. The postconventional body is 'a multi-layered subject that is embodied, but dynamic, corporeal and in-process. It has to be built up over and over again and its expression is therefore concomitant with the constitution of the social field' (Braidotti 2006, 57). Rather than desiring what we lack (such as the autonomous mirror image of autonomy or a recognized place in the symbolic), desire as a yearning for interconnections with others lies at the heart of this vision of subjectivity and embodiment. Desire occurs in the encounters between differently embodied and embedded subjects who are joined in the sameness of the forces that propel them (Braidotti 2006, 57). Such a reading of embodiment allows us to say some very different things about disabled children's bodies and their becomings in the world.

An authoritative body

Greg is 10 years old. At the time of the interview, he lived with his mother, father and older sister. His parents have recently separated. Greg attends a mainstream school, and a conductive education centre at (some) weekends. He loves sport, loves talking and has just won a letter-writing competition in which he wrote about 'why my mum is my hero':

I was at McDonalds with cousins and all that. And I was just eating my meal and a little kid he was just staring at me nonstop. He was actually eating his meal looking at me. And I was 'WHAT THE HELL ARE YOU LOOKING AT?!!!!' He was eating and looking and me and I was like mm, and then when I came home I was like 'mom, give me a hood' How could I teach people not to stare? I mean my friends don't stare because they had a friend who actually is...disabled. I sometimes stare back. There should be a law that that kids must not stare or you go to prison for 4 years. And if you do that again you are sent for life, and if they do both they'll be executed. Imagine the judge 'You are going down for staring'. We could CCTV cameras for staring. £10 fine just for staring. Hey, that would be fine.

Greg's embodied politics appear to capture him 'elaborating a site, that is to say, a space and time' (Braidotti 2006, 46) through which to challenge the processes associated with the pathological stare. Greg's narrative arouses an affirmative passion and desire for the destabilization of a number of identities (Braidotti 2006, 52) including, in this case, those that stare and those who are stared at. We know from Garland-Thomson (2006) that staring is saturated with meaning. Greg turns the stare back on to those bodies that threaten his ontological security.

A direct action body

For Kurt, being born with no bladder meant that this had been a daily experience for him and 'no big deal' though he'd not told any of his close friends. One day he

plucked up the courage to tell a couple of pals about his use of a catheter. By the end of the day, his new name around the school was ‘wee-wee boy’. This had made him very angry. He got his revenge against the main bully of the school, who has using this new name, by emptying his urine bag into the boy’s schoolbag, out of sight of the teacher in the maths lesson.

The notion of the cyborg presented by Haraway (1991) has often been taken up in literal ways connecting human – machine, human – animal and human – technology. In one sense we could read Kurt as using the urine bag as a form of cyborg activism. He certainly has found new uses for his prosthesis. While it might be seemingly straight forward for thinking through, for example, notions of interdependence between disabled people and technology it is often more difficult to think of interdependence when the body appears to exhibit its biological authority. However, following Goodley (2011a), if we read Haraway (1991) more closely perhaps even these realists have missed the really subversive nature of Haraway’s argument: that the boundaries and relationships between human subjects can be revised – built up in new ways while old ways are destroyed – in order to think or dream more productively about those human subjects. Kurt’s body work would be seen as a form of what Braidotti (2006, 53) terms nomadic subjectivity: where one refutes the settled, fixed labels placed upon one’s self and becomes nomadic – learning to ‘reinvent yourself and desiring the self as a process of transformation’. However, this nomadic subjectivity first requires claiming a fixed location: something other than ‘wee wee boy’. This requires challenging the ‘same’ of the same – other binary: de-territorializing the dominant (ableist) symbolic (Braidotti 2003, 540). Clearly, Kurt and Greg before him are engaged in the important task of dislodging dominant subject positions, which Braidotti (2003, 55) lists as ‘masculinity, heterosexuality, whiteness, gerontocracy, Euro-centricism in the imperialist mode’ and to which we could add ‘ablebodiedness’ (McRuer 2006). Kurt takes control of his leaky body in similar ways to that described by Vidali (2010), directing its leakage in ways that lay foundations for possible future interactions with the boys in his school. Other tasks mark instead the ‘conditions for the affirmation of new subject-positions and thus lay the foundations for possible futures’ (Braidotti 2003, 55). And to this task we now turn, in reference to a story about sex and disability.

A sexual body

Estelle is a mother of disabled child who works with an organization for disabled children.

Oh, it’s awful isn’t it!? But it was like Jo she’s got a severely autistic son. He’s 15 now when he was 14 we had a lot of this down here [rubbing the genitals] and making noises and things like this basically and she did panic about it but one of the other women has got an autistic son but he is 21 now and he’s in residential. . . and she said oh it is all normal that, you just to have to go with it. I mean I got a phone call funnily enough. It really threw me on the helpline it was the parent of an autistic girl. This mother, Jane, had to buy her daughter a vibrator to get her sexual pleasures and it didn’t even cross my mind, you don’t think do you. I mean we were having this conversation about vibrators over the phone and I was thinking what a conversation to be having over the phone. Did I know anyone else, is there any special autistic sexual aids you can get? Not that I know of! I thought a sexual aid is a sexual aid I didn’t think there was one for autistic people.

They're all the same, go to an Ann Summers¹ party and things like that. She was asking me all these questions about aids for autistic people! (Estelle)

Braidotti (2006) argues that all organisms are collective and inter-dependent but they also boast a parasitic element to them; they need other organisms. This is an organism that stands against the unitary mode of 'embodied man', who is assumed to be masculine, white urbanized, speaking a standard language, heterosexually inscribed in a reproductive unit and a full citizen of a recognized polity (Braidotti 2006). The postconventionalist body is always in a process of becoming, in the act of constructing and actualizing possible futures: 'in a web of rhizomatic connections. It is a vision of the subject as endowed with multiple sexualities' (Braidotti 2003, 47). The narrative presented earlier captures the ways in which the outing of sexuality of one body (Jane's daughter) from a self-contained privatized bounded unitary-like subject moves to a position that reaches out for connection with other bodies (whether or not those bodies necessarily want to connect). This captures the body's inherent fluidity, lack of completion and interconnection with other bodies (Shildrick 2009, 25). The body-without-organs offers a 'way out' (Goodley 2007, 153) through moving the location of desire outside of the fixed boundaries of the body-as-organism, heralding connections with others. For Shildrick (2009, 102), such a body turns towards the positivity of intercorporeality rather than an anxiety about its dangerous significations: 'The body without organs, the body in a process of corporeal becoming, that mobilises desire as a fluid indeterminacy that has no fixed aim or object, and which could always be otherwise' (Shildrick 2009, 132).

Intercorporeality affirms a notion of polysexuality, where sexuality becomes dispersed not binary, multiple not dualistic, in constant flux not fixed (Braidotti 2006, 50). Jane's daughter's sexuality only becomes recognized through a complex flow of exchanges, information and support networks. Left alone, the sexual body might not be recognized at all. Hence, Jane's narrative illuminates the aims of an affirmative nomadic subjectivity that not only attempts to undo the structures of phallogocentric power – which repress and deny young disabled women's sexualities – but also to 'express and empower constructive alternatives' (Braidotti 2006, 55). The story begins with uncomfortable discussions about sexuality and disability and ends shopping in Ann Summers.

Conclusions

Whether we like it or not, the historical condition of postmodernity has accelerated the displacement of the key categories of definition of subjectivity... All that was solid keeps melting into the ether of the cathodic, digitalised and disembodied Eye/I of the new world order. (Braidotti 2003, 55)

While the data reported in the present article draw on a small number of accounts we are, nonetheless, drawn to the possible applications of our findings to many disabled children and their families. Our stories of embodiment capture, in some small way, the complex cultural ways in which bodies are shaped by and shape the socio-cultural conditions in which they emerge. Disability studies have encouraged many debates around the body. What we hope we have achieved in the present article is to

demonstrate that old body – culture dualisms fail to capture the complex realities of living with non-normative bodies. Furthermore, while sensitized to the ways in which non-normative bodies are marginalized in real, imaginary and symbolic ways, we are keen to emphasize and celebrate those times when non-normative bodies resist and affirm. Haraway (1991) has argued that we need a way out of the maze of dualisms in which we have explained our bodies to ourselves. Our hope is that viewing the dual processes together allows us keep together disability and possibility as key elements of the difference of disability (Michalko 2002). While remaining mindful of the ways in which disabled children's bodies are culturally placed in a position of lack, the accounts we have collected have reminded us of the existence of differently embodied and embedded subjects which scream out for connection. Our differently embodied and embedded children and their families have given us a chance to think again about what it might mean to become emancipated together.

Note

1. Ann Summers is a specialist shop based in the UK which supplies sexual aids: www.annsummers.com.

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