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Making Independent Bodies? Disabled Youth, Adult Citizenship and Care

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Narrative

- **Stories are social and personal:**
    - We are immersed in stories, which shape our own:
    - The world is always already storied (Lawler, 2008)
    - Stories are something we ‘do’ with others.
- **Narrative Engagement:**
    - ‘… describes the process of confrontation with multiple storylines that young people encounter as they begin to make their identities through social practice.’ (Hammack, 2011: 241-242)

Stories and Practices

- **Relationship between practices and stories:**
  - Disabled young body reshaped by stories and practices.
- **Narrative of an ‘unfinished body’:**
  - Disabled young people reflected on past interventions and the way in which their bodies were ‘fixed’ as children.
  - Disabled child’s body seen as ‘different’, ‘wrong’.
  - Current reshaping of the body influenced by adolescent norms of embodiment, which shape their stories and the bodies they seek.

The Current Study

- **Organization:**
  - Economic and Social Research Council funded
  - Research team: Janice McLaughlin, Allan Colver, Patrick Olivier and Edmund Coleman-Fountain.
- **Focus:**
  - Embodied transitions towards adulthood and the stories disabled young people tell, produce and enact
- **Sample:**
  - 17 young people with cerebral palsy
  - 13 from 'SPARCLE'; 4 from local school.
  - Aged 14-20; 10 male, 7 female.
  - 11 interviewed for 'SPARCLE' five years earlier.
- **Methods:**
  - 1st interview
  - Photographic practice
  - 2nd 'photo-elicitation' interview
  - Creative practice
  - Comparative analysis of 'SPARCLE' interviews

Embodied Citizenship

- Independence is increasingly seen as possible and required of disabled people in contemporary society
- Current welfare policy, informed by a focus on cutting welfare spending in an era of budget deficits, in areas such as the Employment and Support Allowance and the Personal Independence Payment, stresses the importance of disabled people aspiring to and achieving self-reliance.
- The 2012 Paralympic games has also provided new symbols of apparent disabled self-reliance and recurring narratives of disability as something that can (should) be overcome in order to succeed as an individual.
- Within welfare policy and some of the rhetoric around the Paralympics a conflation is made between normative concepts of independence (as self-sufficiency) and the ideal citizen, seen as able-bodied or aspiring to greater ability. This suggests a model of *embodied citizenship* that is dependent on what people do with their bodies, and what their bodies let them do

Embodied Citizenship

- Consequently bodily capacity and self-management have implications for who is valued as an adult citizen.
- The demonization of the ‘welfare scrounger’
- The celebration of those who transcend their disability
- We are interested in exploring how disabled young people’s approaches to their bodies and the actions they take to ready themselves for the future are influenced by the current imaginaries of embodied independence and citizenship emerging from government policy and events like the Paralympics.

Body Intervention

- Our current project is already highlighting ways in which disabled young people can engage with their bodies and the broader contexts influencing that engagement.
- Intervention begins in childhood
    - “Erm 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.” (Sara, 15; Current Interview)
- And carries on into adolescence:
    - “…my legs are now really straight… and I have proper kneecaps. But they used to be really turned in and they used to knock each other… my legs were, like, so bent and honestly looked horrendous, and now they kind of look like perfect legs really. ‘Cos they also made my knee cap, ‘cos my knee cap was up here, and they repositioned it down there, so it was, like, my knee caps were all dodgy as well, but now I’ve got proper erm shape knees, and, like, lovely shaped legs.” (Kate, 15; Current Interview)

Body intervention

- Surgery sits alongside other interventions including physiotherapy, splints, mobility supports and sporting activities such as swimming and the gym.
- These ongoing interventions were often (but not exclusively) tied to a narrative of progress.
  - "walking with the cadets has helped my balance get better though. When I was younger I used to fall over all the time, but the walking has strengthened my legs and I don't really fall over now. I have to remind myself though to exercise my arm. If I forget to exercise it then it kind of 'creeps up'" (James, 18; current interview)
- However, while about progress the stories the young people told about the multiple interventions taking place across their life so far were not restitution narratives as identified by Frank (1995), in which what has been damaged is fixed. Rather there was a reshaping of the body along a continuum towards non-impairment in a way that left impairment intact.

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The body unfinished

- The body was materially changing. Bones and muscles had grown and lengthened, giving a different experience of impairment, at times producing more pain as muscles got tighter, demanding further physiotherapy:
    - “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; current interview)
- The surgically reshaped body was not finished or ‘fixed’, but was one bound to ‘open up’ – to use Shilling’s (2012: 101) phrase – to the world around it in new ways. Different ‘flaws’ began to appear for some as their bodies changed.
- This is not to suggest that the body would inevitably fail, or that surgeries were inherently unstable, but that the body was, in the stories the young people told, located in between two poles, of an ideal non-impaired body to be worked towards, and the ‘flawed’ body of cerebral palsy. There were movements between the two, as the young people strived to manage that which was ‘wrong’.

Intervention and Independence

- What the young people framed as ‘wrong’ about their bodies was defined both by physiological properties, and how it appeared to be in ‘the way’ of the transitions they were making towards adulthood.
- Flaws were a product of both changes in the body and also emerging changing relationships they had with the world and their aspirations about the future.
- We want to further explore the changing relationship to an ‘unfinished’ and changing body in the context of transitions to adulthood and consider the significance of notions of adult independence and citizenship within how that transition is both narrativised and practiced.
- Work on transitions present the impaired body as a static object that moves through various spaces unchanged (it is instead the contexts in which impaired bodies are found that change over time).
- Disabled young people’s impairments are altered by both the process of ageing and also the interrelationship between past interventions and current changes in the body. Past and present interventions have social goals embedded in them, understanding the nature and source of those goals helps understand how the body itself can be made different by the wish to be something else.

Intervention and Independence

- Whereas many young people spoke, as children, about impairment as a limitation on the extent to which they could participate in play, like going to their friends' houses or joining in children's games, the older they got the more concerns turned to questions of independence, as well as their difference in the eyes of others.
  - "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." (Craig, 17; current interview)
- Such everyday practices as socialising and dating and living on one's own are important markers of moving towards adulthood. A common social marker evident in our participants was that of being self-reliant:
  - "I will need to do stuff myself, I want to live by myself at some point. I think it is important I find ways of doing things I can manage with." (Jenny, 16; current interview)
- Self-reliance was also articulated in the context of normalised (and gendered) notions of having a 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; current interview)

Intervention and Independence

- Reducing the need for others to do things for them or with them was seen as an important marker of moving towards adulthood and also an important reason to work on the body's strength and mobility:
  - "I think I's absolutely massive to do things for yourself, it gives you that sense of, well carrying a bag in my eyes, is quite a good thing, it might fall off your lap three or four times but you get there in the end and yeah just things like that give you a little, little buzz. It might not be much, but carrying a bag or getting a pint back you know, carrying a drink back with having to use your hands to push like, its quite good and to do things yourself is a lot better than getting other people to do it..." (Mark, 17; current interview)
- Surgeries and the work done on the body was closely tied to such aspirations:
  - "Like to be honest when I was in year nine I didn't really think what am I going to do in the future.... 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...I'll definitely be able to be more independent... with me walking and like growing up.... Instead of being more childish, being more adultish. (Paul, 16; current interview)
- The comments from the young people here are captured as they plan for and think about moving towards adulthood, the makers they identified as equating to an independent adulthood - living on their own, going to work, have a family - were in the future. We would like to explore their relationship to and the body work they do to achieve what they aspire to as being adulthood, over time.
- This seems to us particularly important to do now, because the present moment of economic challenge means such markers may be becoming difficult to obtain or retain for all young people.

Embodied Transitions

- Drawing from work that examines the significance of embodiment to transitions into adulthood. For example, Hall *et al.* (1999) see youth citizenship as identity work, in which the young fashion themselves in view of a society's normative ideals, while Holland *et al.* (2000: 274) argue that, in becoming competent social agents, young people regulate their bodies by embodying normative practices of adulthood.
- Such work has not explicitly focused on the difference disability may make.

Embodiment and disability

- Drawing from embodiment literatures in order to interrogate the ‘normative’ embodiments that underpin taken-for-granted constructions of adult citizenship.
- Our approach stresses the significance of the social meanings ascribed to impaired bodies – what they do and how they look – to creating experiences of being disabled.
- Working (broadly) in critical disability studies, we explore how the contexts in which seemingly ‘impaired’ bodies are located shape the meanings and uses made of those bodies. Our intent is to stress the importance of embodiment to citizenship, addressing what disabled young people, as emerging citizens, do to their bodies (and what their bodies enable them to do), and the stories they frame their activities in as vital elements of how they find a social position as independent adults.

Care and Independence

- Through the promotion of work, enforced by the conditionality of welfare, the present coalition government encourages a specific model of independence constructed as the basis for achieving full citizenship as a capable member of society.
- The Department for Work and Pensions defines independence as an ‘individual’s ability to carry out a range of key activities necessary to everyday life’ (DWP, 2012). Defining independence as such, the government endorses a version of the ideal disabled citizen as someone who relies on themselves before others or the state.
- Disability activists argue that the form of independence they campaign for is significantly different to one centred on self-reliance. Instead they talk of a ‘sense of autonomy and self-determination… achieved by having choice and control over any assistance needed to go about daily life’ (Morris, 2011: 5). In this articulation, independence includes and is enabled by care practices that encompass interdependency as a crucial component to the social fabric of society and to citizenship.
- Such practices exist in the web of relations people are part of, from family and friendships to institutional support such as education and health and social care.

Care and Independence

- The version of independence we are hearing in the current study is not the heroic self-sufficient individualism of a neo-liberal version of the Paralympics ‘Super Humans’, this was an ordinary independence aware of fragility and interdependence:
  - “I was making a cup of tea this morning, if you’re not gonna make a cup of tea you’re probably not gonna be able to drink while you’re in your own house… I’d be thinking about that for a while now, I don’t think I’d be able to live without my mum there, so I don’t think moving out will be on my agenda any time soon, but yeah it is something to be thought of and obviously you need to be able to do things for yourself, cook, make drinks, just look after yourself in general.” (Mark, 17; current interview)
- It was also one aware of – and not shamed by – the need for support if some form of independence was to be achieved:
  - “My grandma knows me more than you know my friends and stuff like that and she knows what I can do and what I can’t, and erm you know my friends obviously know what I can do and what I can’t, but especially with the home environment and then you’ve got social, when I’m at football…. You know its more social and they don’t tend to ask you a lot more so you can be more independent with your friends, but when you’re at home ‘cos they know maybe your struggling with something, they will constantly ask if you want to help, when your not at home they won’t ask you ‘cos they probably think ‘she can probably do it herself.” (Rachel, 20; current interview)
- Rachel wants to be in both worlds: the social world of friends and her intimate world of family, both of whom nurture a supported form of independence

Care and Independence

- As with striving for independence we want to place care in a broader socio-economic context.
- Acknowledging the multiple sources of care also raises awareness of possible failures to care within social groups and agencies, notably in contexts of economic uncertainty, policy change and social upheaval.
- Introducing interdependency and care into citizenship debates has been an important move by disability scholars and feminist theorists in arguing that being in receipt of care ought not be a barrier to being granted full citizenship. However, little of this work has looked at the link between citizenship and interdependency in the context of disabled youth making the transition into adulthood.
- It is vital to consider how care relationships are part of how disabled youth move towards adult independence and how care relationships can be unsettled by such moves. It is particularly important, in a context of uncertainty in which self-reliance is championed, to continue to consider the role of care in sustaining emerging citizens.

Overall focus

Our analytical focus is on

(a) the work disabled young people do to prepare their bodies for adult citizenship

(b) the familial and institutional relations of care that inform that work and the forms of independence they seek.

Aims

- To examine how disabled young people understand independence and to explore what value they give to it in contexts of economic uncertainty and challenge.
- To explore how impaired bodies shape the experiences of disabled young people moving towards adulthood.
- To investigate what versions of citizenship are available to and sought by those whose body capacities are different from the norm.
- To explore the care relationships that influence disabled people's paths to adulthood.
- To consider what other social factors, such as gender or class, are significant in disabled young people's approaches to and paths towards independence.