



Policy
Ethics
And
Life
Sciences

Re-Shaping Young Disabled Bodies: Stories of medical and self-intervention

Edmund Coleman-Fountain

Janice McLaughlin

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.

Childhood Interventions

Medical procedures a regular occurrence:

- Plates added and removed; wires added and removed.
- Bones broken, muscles feathered, and tendons stretched
- Regular physiotherapy at home and school; wearing splints; receiving injections of Botox or Baclofen.

“I had four I think, first one was putting plates in my knees, [pause] and putting cow bone into my foot... The second 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 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, current Interview)

Childhood Interventions

Interventions done to them instead of something they pursued

- Those interventions reshaped the body.
- They frame intervention as embedded in everyday life, but also in the way of everyday life.
- The interventions opened the body up to medical management and the insertion of devices or materials that were reshaping its boundaries.

“I’ve had a fair few operations in my life, so that can sometimes cause me pain. For example, I’ve had both my hips reconstructed, and had metal plates put inside, ‘cos they were dislocated... my hips, both of them were completely dislocated, so they obviously had to do something quickly to avoid things like arthritis and that. So they completely took them apart and reconstructed them.” (Craig, current Interview)

Childhood Interventions

Interventions confirmed their sense of difference:

- As children the stories they told included the sense that such things did not happen to other children.
- In childhood interviews the way they talked about the body framed it as something flawed and to be worked on.
- As children, their stories about their own bodies were about how to ‘fix’ them to respond to social unease with their different bodies.

“The way I walk... people who stop and stare at me, I would quite like to change that.” (Sara, ‘SPARCLE’ interview)

Current Interventions

Their bodies still objects of medical intervention:

- Surgeries and physiotherapy continue.
- Their growing, changing bodies are an important reason they give for why new surgeries or treatments become necessary.

“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 am growing, obviously my muscles aren’t long enough because they stop at a certain amount...I have to get a lot of surgery to make them long enough.” (Emma, Current interview)

- Despite this, there was an overarching a narrative of getting better. More strength, mobility and function, and less pain.

Current Interventions

- Childhood memories were often set in a story of progress, the sense that there was a body they were working towards.

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. (James, current interview)

- An ongoing project worked on through formal interventions like surgery and physio and everyday interventions that turn walking, climbing stairs, or making a cup of tea into a therapeutic activity.
- That ideal is not a 'super human' one in their stories, instead it is the everyday effort of producing an 'ordinary' functional body.

“Things like pouring... from one container into another is difficult but if I really do concentrate I can do it like, I can make cups of tea... I can pour the kettle into the cup” (Kate, current interview)

The Unfinished Body

The body was to be fixed and adapted:

- Interventions focus on mobility and body strength
- They are regular, intricate, repetitive; part of the everyday
- In what they say and do, the body is divided into areas they work on and bits that give them away.

Interviewer: Do you not try to build up your right?

Participant: 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, current Interview)

The Unfinished Body

That body is a growing, aging one:

- The body is apt to change over time.
- Change is something to be prepared for.
- Managing the body continues.

“I know this is gonna get worse, well when I say older I’m on about in my fifties, sixties... I know how cerebral palsy is, I’ve seen people... when I get older I will probably be in a wheelchair just because I know how my muscles will be, but to be honest I’m not really that bothered... I just take things when they come and deal with them. That’s all I can do, isn’t it?” (Hannah, photo-elicitation interview)

Entanglements

Practices and storied purpose endured from childhood.

- Moving their bodies towards normality.
- The body something ‘unfinished’ and to be fixed

Body an object of ‘entangled’ stories/practices that give it meaning:

- Surgery, medicine, physiotherapy;
- Technologies, equipment, body enhancement.
- Norms of adulthood and independence;
- The ‘normal’ body;
- Cerebral palsy as ever-present, making the body ‘flawed’;
- Disability as something to be worked on.

Concluding remarks

- Narratives of progress and symbols of recovery – like no longer using a wheel chair – erase the work involved in making such bodies and hide the fragility of that ‘success’.
- The ‘normal’ bodies that surround them are a continual source of contrast to their own and the work they do.
- The ways in which their ‘flawed’ bodies trouble their social position as emerging adults is an important background to the extensive body work they undertake.
- They articulate a pride in what they have reshaped their bodies to be, but also a sense that their body can undermine the self they are making through that body.
- As their bodies age they can ‘give them away’.