



Pathologisation of disabled childhood as an impediment to independent living

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Socially produced dependency

- ❖ Disabled adults and children experience similar forms of exclusion on the basis of perceptions of their dependencies as something natural and inevitable due to the presence of impairment or in the case of children, their age (Clark, 2018);
- ❖ Risk of infantilization disabled people face is perpetuated through policies and practice which promote paternalism (Callus et al., 2019);
- ❖ the position of disabled children within the disability movement and society as a whole remains unchallenged;
- ❖ Protective paradigm of children's rights and best interests principle.

Social-relational understanding of disability

- ❖ Disability is a 'product of the social relationships between those with and those without impairments in society' (Thomas, 2004, p.28).
- ❖ Oppressive relationships wherein disabled people are marginalized into the position of inferiority and powerlessness.
- ❖ **Effects of disabling environment \neq the impairment effects** (type of restriction that has to do with the nature of the impairment) (Thomas, 1999).

Disabled children and independent living

If disabled people are able to experience independent living from a young age then they are afforded similar opportunities to develop their own life course and personal networks as their non-disabled peers. (European Network on Independent Living, 2014, p.19)



International human rights law and disabled children's participation in decision-making

States Parties shall assure to the child **who is capable of forming his or her own views** the right to express those views freely in **all matters** affecting the child, the views of the child **being given due weight** in accordance with the **age and maturity** of the child.

(Article 12 (1), UN Convention on the Rights of the Child, 1989).



**United
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States Parties shall ensure that **children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.**

(Article 7 (3), UN Convention on the Rights of Persons with Disabilities, 2006)

International human rights law and disabled children's participation in decision-making

General Comment no. 5 (CRPD) recognised the importance of disabled children's participation stating the following:

'Respecting the evolving capacities of children with disabilities and supporting them in having a say in choices that have an impact on them is critical' (Committee on the Rights of Persons with Disabilities, 2017, para. 75).

The Committee further emphasizes the need to **respect children's evolving capacities** in its General Comment no. 1 on legal capacity by setting up the obligation of states to **'ensure that the will and preferences of children with disabilities are respected on an equal basis with other children'** (Committee on the Rights of Persons with Disabilities, 2014, para. 36).

Research sample and data collection method

Sample criteria:

- Disabled children and young people aged 10 to 22;
- From England and Serbia;
- Have undergone elective orthopaedic treatments in their childhoods;
- Parents of disabled children and young people

Sample: 16 interviews with disabled children and young people (England and Serbia combined); 15 interviews with parents (England and Serbia combined).

Method:

In-depth semi-structured online interview

Medicalisation vs. pathologisation of disabled childhoods

- Disabled children are exposed to a host of remedial treatments, therapies or surgeries (Bricher and Darbyshire, 2005; Mclaughlin and Coleman-Fountain, 2014);
- Disabled children are more likely than non-disabled children to experience long hospital stays, long and painful recoveries and rehabilitation;
- Medicalisation different from pathologisation (Sholl, 2017)



Testimonies – understanding of independence

Mother: The doctor absolutely does not like to see children in wheelchairs. She [doctor] always emphasizes it. If a child can, if a child tries hard, she would prefer to prolong it as much as possible, the involvement of the wheelchair, because then a child is static and then there's no progress.... She's always insisted saying that Jelena [daughter's pseudonym] did not need a wheelchair, yet. She doesn't like to see children in a wheelchair, hence she'd been trying on her [daughter] everything that's possible...



Testimonies – disability as a negative difference

Mother: And then when we had him, I think one of the things with him was, you know, we've never sort of mentioned the disabled word with him. We just said, you know, you're just different. And I think that's one of the problems that, you know, with labelling, that people do like to label people. And you know, we're all individuals and you can't, you can't make a sweeping comment. So I think I sort of pulled all that into play with him. And I wanted him to feel normal. I wanted him to feel like his friends. I wanted him to know that, you know, he was the same as everybody else.

Researcher: And when you mentioned labels, do you think disabled as a word brings up some negative connotations and negative perception of identity?

Mother: Yeah, 100% I think it does. Yeah, I was reading an article and it was saying that they shouldn't call people disabled, or they should call them diff/abled, because they are differently abled. Because disabled implies that you're less somehow. And well, in my opinion, it implies that you're less somehow and that's not true. You're just different.

Testimonies of children and young disabled people

He didn't seem really familiar with the problem I have or maybe he did but he didn't offer a good solution as doctor B [pseudonymized]...something like that. He said he wants to replace my ankle on the right foot or to do surgery on my right arm because he thought that my right arm is also poorly because my right leg was worse than my left one...as my right leg was more affected by cerebral palsy so he assumed that's the case with my right arm as well but it wasn't like that. And then he wanted to perform surgery anyway.

In most of the cases, he [a doctor] ignored me, like he basically had conversations with my mother and father only, and he completely ignored me, so... I was just there like some sort of object for trying out...I don't know...his new ideas.

Making sense of the data

- ❖ Understanding of independence – is self-sufficiency a signifier of independence?
- ❖ Perception of disability as a negative difference
- ❖ Pathologisation of impairments - children's impairments do not have to be labelled as 'abnormal' or as a diminished state of being or suboptimal functioning that deviates from the typical norm but may still warrant medical attention in order to alleviate impairment effects and improve children's quality of life. Avoiding pathologisation does not imply a rejection of medical treatments but it involves conscious decision not to attach a negative value to impairment as a bodily difference as Sholl further argues that 'that some conditions can be depathologized while still being medicalized' (Sholl, 2017, p.269)
- ❖ Dis/empowering children in encounters with healthcare professionals → a disregard for child participation



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