Babies with disability: A right to an imagined hopeful future

Communicating hope as a human right alongside medical information

Babies born with disabilities have medical systems wrapped around their lives. This gives medical professions unexpected authority over how babies' future lives are imagined. Babies without disability are routinely accorded hopeful stories of their possible futures. Stories we tell about babies with disabilities, then, are a human rights issue of equal treatment. How the future lives of their babies with disability are characterised to parents can impact upon family and child wellbeing.

What did we do?

I reviewed published accounts of parents' encounters with medical professionals after having a baby diagnosed with a disability. I thought through these experiences from a children's human rights lens to write a chapter for the Routledge International Handbook of Children's Rights and Disability.

- I analysed parents' experiences using United Nations instruments: the Convention on the Rights of Persons with Disabilities (2006) and the Convention on the Rights of the Child (1989).
- My analysis drew from philosophical ideas by Hannah Arendt, Zygmunt Bauman, and Richard Rorty.
- I brought my lived experience as a parent of a child with Down syndrome into my understanding of what parents experience.

What did I find?

- Expertise on future medical risks for babies with disabilities is important. If this information dominates the view of a baby's future, it can deny a baby's entitlement to a hopeful imagined future.
- All babies are a source of hope as new lives that might change the world for the better ('plurality', from Hannah Arendt). This includes babies with disabilities.
- Medical systems can imply babies with disabilities are 'waste lives' (from Bauman). Parents must then do emotion work to dismantle these negative impressions of their children.
- Envisioning babies' futures is an imaginary activity. We ought to imagine ethically (from Richard Rorty) which means assuming that babies with disability have worthwhile futures.

What do these findings mean?

- Medical professionals should communicate the boundaries of their expertise to position medical information as separate to envisaging a child's future.
- Hope is an important quality in imagining babies' futures that can be understood as a human right.
- Parents of babies with disability need communication in hospitals that gives them a broad and hopeful view of their child's possible future.

Where can I find out more?

The chapter is available here:
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"A Letter to New Parents" by Belinda Johnson is part of the 21 Gifts "suitcase for a new adventure". Suitcases are delivered to families in hospitals upon diagnosis of a baby with Trisomy 21 (Down syndrome) and cerebral palsy (CP).

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