



Parenting a Child with Down syndrome: Ethical Issues
Christine Lane, parent of a child with Down syndrome

Discussion questions:

1. Christine's son wasn't diagnosed until he was nearly one year old. How might a diagnosis of Down syndrome influence parents and families' expectations of and responses to a child?
2. What are some of the different ways that a health care system may influence the way Down syndrome is perceived in general?
3. According to Christine, there are relatively few resources available for families of children with Down syndrome. Why do you think this is the case?
4. What sort of ethical concerns are raised by the lack of resources for families of children with Down syndrome and for adults with Down syndrome?
5. In your opinion, what are the biggest ethical concerns around the introduction of non-invasive prenatal testing?
6. In your opinion, how might the availability of non-invasive prenatal testing influence expecting parents' choices?
7. How might prenatal testing contribute to shape our core values, such as values around diversity and inclusion?
8. How do we support individuals in making decisions about prenatal testing while also recognizing concerns about social attitudes regarding Down Syndrome?

Resources:

Canadian Down Syndrome Society: <http://cdss.ca/places/nova-scotia/>

Chris Kaposy. 2013. A Disability Critique of the New Prenatal Test for Down Syndrome. The Kennedy Institute of Ethics Journal, 2013, Volume 23(4): 299-324.

Deanne Smith. 7 Life Lessons From Raising a Child With Down Syndrome. Parents. <https://www.parents.com/health/down-syndrome/raising-a-child-with-down-syndrome/>

Halifax Nova Scotia Down Syndrome Society (DSS). <http://halifaxnsdss.ca/>

International Center for Ethics, Justice, and public life. Ethical Inquiry: June 2015. The Ethics of Prenatal Testing for Down Syndrome: Is Knowing Always Better? <https://www.brandeis.edu/ethics/ethicalinquiry/2015/June.html>

Kelly Grant. 2018. The birth of a revolution in prenatal screening. The Globe and Mail. January 10, 2018. <https://www.theglobeandmail.com/life/parenting/new-prenatal-tests-for-parents-gets-mixed->

[feelings/article37570374/](#)

Lisa Bridle. 2000/2011. Confronting the Distortions: Mothers of Children with Down Syndrome and Prenatal Testing. University of Hertfordshire. Intellectual Disability and Health.

<http://www.intellectualdisability.info/diagnosis/articles/confronting-the-distortions-mothers-of-children-with-down-syndrome-and-prenatal-testing>

Mark Leach. 2013. On Parenting a Child with Down Syndrome. October 13, 2013.

<http://www.downsyndromeprenataltesting.com/on-parenting-a-child-with-down-syndrome/>

Olivia Gordon. 2015. Living with Down's syndrome: 'He's not a list of characteristics. He's my son'. The Guardian, Saturday October 17, 2015. <https://www.theguardian.com/society/2015/oct/17/living-with-downs-syndrome-hes-not-list-characteristics>

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