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“Anything But Sorry”: An Inquiry Into the Cultural Production of Sorrow and the Construction of Childhood, Dreams, and Parenthood

Abstract

“I’m sorry, your baby has Down syndrome” is a phrase that many parents of babies with Down syndrome may have their doctors tell them, as is made clear in the Canadian Down Syndrome Society’s “Anything But Sorry” campaign. This campaign represents meanings about birth, choice, life, and living while sending the powerful message that a life with Down syndrome is a life worth living, celebrating and loving, and not one requiring apology. While such a message is important, and while the message “Don’t say sorry!” is made very clear, a sense of apology, loss, and sorrow remain. The rhetoric of sorrow, however, is not something that needs to – nor should be – feared, ignored, or denied. Rather, sorrow and the ways that it is expressed (including its denial) is a means of characterizing the relationships between parents, children, and disability. Drawing upon two examples within media culture, I demonstrate how these representations in popular culture mediate perceptions and interpretations of sorrow as they appear before, at, and following the birth of a baby with Down syndrome.

Introduction

“I’m sorry, your baby has Down syndrome” is a phrase that many parents of babies with Down syndrome may have their doctors tell them, as is made clear in the Canadian Down Syndrome Society’s “Anything But Sorry” campaign¹. Not only does this phrase illustrate the attitudes and ableism that are within society, and which precede a baby’s birth², but also presents an opportunity to consider *how* Down syndrome is represented in society, specifically, to new parents. This campaign represents meanings about birth, choice, life, and living while sending the powerful message that a life with Down syndrome is a life worth living, celebrating and loving, and not one requiring apology. While such a message is important, and while the message “Don’t say sorry!” is repeated, over and over again, a sense of apology, loss, and sorrow remain. The rhetoric of sorrow, however, is not something that needs to – nor should be – feared, ignored, denied, or even condemned. Rather, sorrow and the ways that it is expressed (including its denial) is a means of characterizing the relationships between parents, children, and disability. In this paper, I focus on how Down syndrome is

represented and mediated through popular culture. I analyze the headlines and quotations from one *CTV News*³ article, as well as those from a chapter in Andrew Solomon’s book—now also a documentary film -- *Far From the Tree*⁴. Each of these instances and representations in popular culture mediate perceptions and interpretations of sorrow as they appear before, at, and following the birth of a baby with Down syndrome.

Theoretical Orientations

My interest in disability and disability studies flows throughout my life and work. I am committed to living with and through disability in ways that position disability as integral to our lives, relationships, and ways of being⁵. Such an orientation towards understanding and living with and through disability has shaped my research interests and my life in significant ways. In particular, I focus on disability and childhood studies⁶. The relations between adults, children, and disability are complex. But we might get closer to these relations by examining the materials that adults produce for children, as well as the materials that adults produce for other adults *about* babies and children with Down syndrome. Therefore, I ask how Down

syndrome is portrayed to parents before, at, and following the birth of a baby with Down syndrome.

Now, the relationship between disability and its representations – for instance, in the media – also matters, and is worthy of careful and critical consideration. Consider the birth of a baby. Deborah Lupton (2013) writes of the “social worlds of the unborn”, and how, through media, through culture, and through representation, so many meanings are generated across time, space, and history⁷. As Lupton notes, “The unborn [...] are complex entities that are composed of medical and scientific practices, technologies and physical spaces, but also of social relations, interpretations and understandings between human actors that are part of a constantly negotiated social order”⁸. Media and its representations are part of this – that is, representations mediate and negotiate so much of the social order that constructs notions of childhood, disability, parenthood, sorrow, and grief. We are all in the midst of representations and responses to the births of babies with Down syndrome. My work seeks to reveal *how* such mediation takes place and following Deborah Lupton (2013), I engage with the negotiated social order. As Maurice Merleau-Ponty says, “The spoken word is a gesture, and its meaning, a world”⁹. What words, what worlds, what meanings, do representations of disability place us within? How do these representations mediate understandings of disability, our worlds, and our relations?

“Anything But Sorry” and the Canadian Down Syndrome Association

The “Anything But Sorry” is a marketing campaign run by the Canadian Down Syndrome Society (CDSS). Beginning in 2017, “The goal of this campaign is to show Canadians that the only wrong way to welcome a baby into the world is by saying sorry, something many families hear after finding out their new baby has Down syndrome”¹⁰. The campaign has a series of videos on YouTube. One video features several young adults, all of whom have Down syndrome, who answer the question “What do you say to parents who just had a child with Down syndrome?”. The actors indicate there are so many options including “Congratulations” and “Holy shit!” – all of which are better than the “S-word”: sorry¹¹. One actor then says that there is really only one word you

shouldn’t say, which is “sorry”. Sorry is the bad word. The “Anything But Sorry” campaign garnered significant and widespread media attention. *CTV News*, for instance, covered this campaign and interviewed several families of children with Down syndrome. Consider the following:

“Anything but sorry: What to say when a baby is born with Down syndrome”¹² reads the news headline from *CTV News*¹³. This online article introduces the Canadian Down Syndrome Society’s “Anything But Sorry” campaign. Part of this campaign features several YouTube videos that address the question: *What do you say to parents who just had a child with Down syndrome?* The campaign shows how “sorry” or “the S-word” is an inappropriate and ableist response to the birth of a baby with Down syndrome. Instead, people should be encouraged congratulate parents whose children are born with Down syndrome, and to welcome the baby with celebration and joy. Additionally, at the end of the article, Ed Casagrande, father of a daughter with Down syndrome, says:

“We need to change the thinking from a feeling of sorrow to a feeling of celebration. People with Down syndrome live meaningful and fulfilling lives full of great accomplishments [...] That’s nothing to feel sorry for”¹⁴

CTV News’s coverage of the “Anything But Sorry” campaign demonstrates that the response of “I’m sorry” is inappropriate following the birth of a baby with Down syndrome—or any disability. While this media coverage and its messages absolutely push against ableist assumptions of disability and Down syndrome, and while this is crucial, this media coverage also illustrates that the possibility of the response “I’m sorry” remains. That is, the sentiment sorrow hovers around us, even as we actively denounce it. How, then, might such a response have been generated? What remains for us as we engage with representations of Down syndrome, with life, with the media and its many meanings, is *how* does sorrow show how Down syndrome has been understood? How has Down syndrome been represented, made meaningful, and circulated? In other words, how has the response “I’m sorry” been made possible in the world, and how might attending to this allow us to more deeply understand how Down syndrome has been

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made to matter in the lives of adults and children?

Constructions of Sorrow and Dreams

In the book *Far from the Tree*, Andrew Solomon explores the relationships between parents and children, and it includes a chapter focused on children with Down syndrome, their parents, and their families¹⁵. Solomon opens this chapter with reference to a popular poem, “Welcome to Holland”, written by Emily Perl Kingsley. Kingsley was a producer on the iconic children’s show *Sesame Street*, and her son, Jason, who was born in 1974, has Down syndrome. Solomon (2012) opens his chapter by stating, “Anyone involved in any way with disability has come across ‘Welcome to Holland’, a modern fable written by Emily Perl Kingsley in 1987. In fact, any such person has come across it repeatedly [...] It is standard issue from doctors to parents of disabled newborns”¹⁶.

The poem is about parental expectations, and how these change following the birth of a disabled baby. Kingsley writes about how, all your life, you might be planning a trip to Italy. You have the flights booked, you have the hotels planned out, you have reservations at all the best restaurants. But then, as you are in the plane and just about to land, you hear the pilot say you’re just about to land in Holland! All of the plans you have made for Italy, then, did not come to fruition. Your plan was changed; your path of travel was changed; your destination was changed. But then, as you begin your visit into Holland, you realize that it is a beautiful place. While yes, it is different than what you were expecting, your trip to Holland was – and is – beautiful.

Kingsley compares arriving at Holland to being like giving birth to a baby with Down syndrome, or a baby with a disability¹⁷. The trip to Italy – from its planning to its arrival – reflects sociocultural expectations of parenthood and childhood. The trip to Italy represents how normative notions of parenthood and childhood are constructed. The surprise arrival into Holland represents the unexpectedness of having a baby with Down syndrome, or the unexpectedness of having a baby with a disability. But, as Kingsley also demonstrates in this poem, happiness, joy, and love remain.

Kingsley’s poem also reflects the Canadian Down Syndrome Society’s “Anything But Sorry” campaign. Like the “Anything But Sorry”

campaign, this poem shows how there is a moment of surprise as the unexpectedness appears and then settles around expectant or new parents of a baby with Down syndrome. However, there is also an immediate sense of there not being anything to be sorry for or about. And while both Kingsley’s poem and the Canadian Down Syndrome Society’s campaign resist utterances of sorrow or loss, a sense of sorrow hovers. It remains. Otherwise, these media depictions of the unexpected, and the potential sorrow that might be generated from the unexpected, would not exist.

Solomon’s chapter continues with a more in-depth account of Emily Kingsley and how she and her husband Charles found out that Jason had Down syndrome. Emily and Charles received notice of Jason’s diagnosis at birth. “The doctor told Charles that such a child belonged in an Institution and discouraged the Kingsleys from seeing the baby”¹⁸. Emily Kingsley recalls how she spent days crying after the doctor told her all the things that Jason would never be able to do – such as distinguish between other adults, never be creative, and never have an imagination¹⁹. Additionally, the recommendation of institutionalization brought immense amounts of horror and sorrow as well. Emily’s account of Jason’s diagnosis demonstrates the sense of sorrow that appeared following Jason’s diagnosis, especially through the words and recommendations of the doctor.

Solomon goes on to state that Jason Kingsley participated in “Early Intervention” programs, which supported Jason’s “normative development”. Jason Kingsley also attained recognition as he was featured on numerous episodes of *Sesame Street*, as well as in numerous inclusion campaigns and activities²⁰. Jason Kingsley also co-wrote *Count Us In: Growing Up with Down Syndrome* together with Mitchell Levitz who also has Down syndrome²¹. However, Jason’s experiences in Early Intervention programs demonstrate two points of note: (1) that “Early Intervention”, as it aims to keep children with disability as close as possible to “normal development” still positions disability and Down syndrome as something that might not be wanted, as something that “ought not be”²²; and (2) Jason’s involvement on *Sesame Street* also reveals a sociocultural desire and/or temptation to show that Jason is “just like” children *without* Down syndrome²³. This notion of “overcoming” Down syndrome or “fixing” Down syndrome

through psychology, medicine, and education, may appear as *alleviating* sorrow²⁴. But even here, amidst representations of “intervention” and even “cure”, media representations of Down syndrome appear acceptable only insofar as they reflect ability, “normal development”, or even sameness. Sameness, or the idea of being “just like” children without Down syndrome, then, alleviates sorrow. But such representations of Down syndrome do not do very much to actually change our expectations of normalcy, of childhood, or of disability more broadly. As such, Down syndrome may still appear as a diagnosis that could generate sorrow – only “fixing” it or “intervening” appear to alleviate sorrow, or at least, soothe the possible sentiments of sorrow.

The sense of sorrow as a result of disrupted or disturbed parental expectations reflects another example in this chapter. Solomon writes of another parent and child – Angelica and Erica. Angelica’s daughter Erica was born with Down syndrome in 1992. Angelica recalls Erica’s birth, where she felt “something was wrong” in her husband’s eyes. She recalls “holding onto the doctor’s arm. Consider the following recollection: “I remember holding the doctor’s arm and saying, ‘Please tell me.’ My husband, I could see it in his eyes”²⁵. Angelica goes on to recall the responses of others who found out about Angelica’s diagnosis. “Not everyone had the grace to respond in kind. A lot of our friends looked at it as a death.”²⁶ Here, we can see a clear connection between Angelica’s story in *Far From the Tree*, and the expressions of sorrow and grief that the Canadian Down Syndrome’s *Anything But Sorry* campaign pushes against. It is also here where the unexpected relationship of birth and sorrow meet, but which is released when we consider (and consume) media and cultural representations of the birth of a baby with Down syndrome. It is also here where Angelica brings forth the issue of the *dream*, or more specifically, the loss of a dream. Angelica recalls, for instance: “When your child is born with a disability, all your high hopes and dreams are shattered”²⁷. Similar to the first article featuring Ed Casagrande, we are shown a response to the birth of a baby with Down syndrome. But then, there is also a representation of mourning expectations, of mourning the lost “high hopes and dreams”, which have been “shattered”. We must, however, also be aware and note that the notion of “dreams”, “dream babies” and “dream children” have also been constructed within our lives

and relationships – including the relationships between parents and children. However, as Angelica comes to realize in *Far From the Tree*, a diagnosis of Down syndrome is nothing to mourn, not be sorry about. Love and care surrounds the relationships between parents and children, just Angelica writes of the love and commitment she has for Erica. Undoubtedly, these representations are impactful and important in the lives of parents and children. Recall the love and happiness that Ed Casagrande’s daughter brings to him and his family. But still, even within campaigns such as the “Anything But Sorry Campaign”, even within analyses such as those within *Far From the Tree*, notes of sorrow hover. Utterances of “I’m sorry” remain. And this, I believe, is crucial to consider. More specifically, denying the expression of sorrow does not necessarily mean a denial of its existence, nor a denial of its continued representation.

In the Midst of Sorrow and Dreams

What are these representations of disability, of Down syndrome, *doing* to you, to me, to us as we live amidst and are mediated by portrayals of disability in our daily lives? As I was considering these representations of disability, I thought about the tensions between sorrow, as well as the response of “I’m sorry” after the birth of a baby with Down syndrome. Although the “Anything But Sorry” campaign shows that the birth of a baby with Down syndrome should bring joy and celebration, what are we to do with representations of loss, of mourning, of sorrow, that are also depicted in the media after having a baby with Down syndrome? Mourning a dream is another way of *being* sorry. These headlines and quotations illustrate how we are caught in between conflicting representations of Down syndrome—ones that say don’t say sorry, ones that seek to change feelings from sorrow to celebration²⁸, but then ones that also depict a sense of sorrow—for which we are culturally coached to say or be sorry! In other words, through these two examples, I think we get closer to the interpretive loop, or cultural expectation, of *being sorry for being sorry*.

Consider another example. Beth Haller, discussing the words of Craig Safan, music composer on the show *Life Goes On*, starring actor Chris Burke with Down syndrome, says:

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“The whole subject of Down’s [Down syndrome] and disability in children is something our generation did not know about. We did not believe it was in our future. Reality may be stretched on this series [*Life Goes On*], but the question is, at the end of a show, do you feel something about a family having a disabled kid? Have you come to some emotional thing inside yourself about Down’s syndrome?”²⁹

Safan’s comments describe an *emotional thing* that adults might *feel* about Down syndrome. Although adults may represent or portray Down syndrome in various ways to children, adults also represent Down syndrome *to each other*. Moreover, there is an entire world that produces (and continues to reproduce) the response of “I’m sorry”. While the “Anything But Sorry” campaign illustrates how we are told to congratulate parents on the birth of a baby with Down syndrome, and told to *not* say sorry, Solomon’s account of the relationship between Angelica and Erica demonstrate a period of sorrow, of the “shattering of dreams”.

This returns us to normative expectations both of parenthood and childhood. Bartholomy (2020), for instance, discusses the simplification of disability and sex narratives, which often result in an

“overcoming” of disability to fit normative, mainstream expectations of audiences³⁰. Additionally, as Tanya Titchkosky writes, “Media representations of disability offers media producers and consumers an opportunity to reflect on the normative assumptions that groups these representations as well as a chance to perceive, know, and do disability differently [...]”³¹. Following Titchkosky, notions of dreams are tethered to normative expectations and assumptions of childhood and parenthood. Dreams of and for children have been constructed, produced, and reproduced in the lives of parents—in the communication of what parenthood ought to be, and of what childhood “ought not be”³². There are also expectations of what we “ought not say”—such as “I’m sorry”, even though there is a whole world of ways that society, that culture, has positioned Down syndrome and disability as a cause of sorrow, mourning, or something that “ought not be”³³. We are therefore caught in the middle of many tensions—we are told not to say sorry, even as representations of sorrow surround expectations of parents and children. This is a confusing and potentially frustrating tension – but it is nevertheless a tension that appears in culture, and it is nonetheless one that mediates the ways that sorrow and its representations *mediate* our lives, expectations, and interactions.

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Notes

1 Canadian Down Syndrome Society. “Anything But Sorry Campaign.” 2017.

<https://cdss.ca/family-support/anything-but-sorry/>

2 Tanya Titchkosky. “Clenched Subjectivity: Disability, Women, and Medical Discourse,” *Disability Studies Quarterly*, 25 no. 3 (2005). n.p. <https://dsq-sds.org/article/view/589>

3 Sheryl Ubelacker. “‘Anything But Sorry’: What to say when a baby is born with Down syndrome”. *CTV News*. November 6, 2017. (accessed July 2020 from <https://www.ctvnews.ca/health/anything-but-sorry-what-to-say-when-a-baby-is-born-with-down-syndrome-1.3665492>)

4 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012).

5 Tanya Titchkosky. *Disability, Self, Society*. (Toronto: University of Toronto Press, 2003); Tanya Titchkosky. *Reading and Writing Disability Differently: The textured life of embodiment*. (Toronto: University of Toronto Press, 2007); Tanya Titchkosky and Rod Michalko. *Rethinking Normalcy: A disability studies reader*. (Toronto: Canadian Scholars Press); Devon Healey. *Dramatizing Blindness: Disability studies as critical creative inquiry*. (Switzerland: Springer Nature).

- 6 Lisa Farley. *Childhood Beyond Pathology: A psychoanalytic study of development and diagnosis*. (Albany: State University of New York Press); Tanya Titchkosky and Rod Michalko. *Rethinking Normalcy: A disability studies reader*. (Toronto: Canadian Scholars Press); Karen Wells. *Childhood Studies: Making young subjects*. Cambridge, UK: Polity Press).
- 7 Deborah Lupton. *The Social Worlds of the Unborn*. (Basingstoke: Palgrave Macmillan, 2013), p.7.
- 8 Deborah Lupton. *The Social Worlds of the Unborn*. (Basingstoke: Palgrave Macmillan, 2013), p.7.
- 9 Merleau-Ponty, Maurice, and Colin Smith. 2002. *Phenomenology of Perception*. London: Routledge. 214.
- 10 Canadian Down Syndrome Society. "Anything But Sorry Campaign." 2017. <https://cdss.ca/family-support/anything-but-sorry/>
- 11 Canadian Down Syndrome Society. "Anything But Sorry: The S-word". 2017. (accessed March 2021 from <https://www.youtube.com/watch?v=AfLfQC2sXOE>)
- 12 I first encountered the "Anything But Sorry" campaign in early 2021. I considered how it disrupts ableist assumptions of birth, life, and people with Down syndrome. I continue to think about this campaign. I am very interested in *how* the response "I'm sorry" has been shaped, how it has come to be, and what it means within and between our relations. What, in other words, precedes the response of "I'm sorry"?
- 13 Sheryl Ubelacker. "Anything But Sorry: What to say when a baby is born with Down syndrome". *CTV News*. November 6, 2017. (accessed March 2021 from <https://www.ctvnews.ca/health/anything-but-sorry-what-to-say-when-a-baby-is-born-with-down-syndrome-1.3665492>)
- 14 Ed Casagrande in Sheryl Ubelacker. "Anything But Sorry: What to say when a baby is born with Down syndrome". *CTV News*. November 6, 2017. (accessed July 2020 from <https://www.ctvnews.ca/health/anything-but-sorry-what-to-say-when-a-baby-is-born-with-down-syndrome-1.3665492>)
- 15 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012, 169-219).
- 16 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012, 169-219, p.169)
- 17 Kingsley, Emily Perl. "Welcome to Holland". Essay Privately Published, 1987.
- 18 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012), 171.
- 19 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012), 172.
- 20 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012), 173.
- 21 Jason Kingsley and Mitchell Levitz. *Count Us In: Growing up with Down syndrome*. (New York: Harcourt Brace).
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- 26 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012), 201.
- 27 Andrew Solomon. *Far from the tree* (New York, Toronto: Scribner, 2012), 202.
- 28 Ed Casagrande in Sheryl Ubelacker. "Anything But Sorry: What to say when a baby is born with Down syndrome". *CTV News*. November 6, 2017. (accessed July 2020 from <https://www.ctvnews.ca/health/anything-but-sorry-what-to-say-when-a-baby-is-born-with-down-syndrome-1.3665492>)
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- 31 Titchkosky, Tanya. "Disability Imaginaries in the News." In *The Routledge Companion to Disability and Media*, 1st ed., 13-22. Routledge, 2020, 13.
- 32 Tanya Titchkosky. *Reading and Writing Disability Differently: The textured life of embodiment*. (Toronto: University of Toronto Press).
- 33 Tanya Titchkosky. *Reading and Writing Disability Differently: The textured life of embodiment*. (Toronto: University of Toronto Press).