

Disability History Association Podcast

Interview with Emer Lucey

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Kelsey Henry: Hello and welcome to another episode of the Disability History Association Podcast. My name is Kelsey Henry.

Caroline Lieffers: And I'm Caroline Lieffers.

Kelsey: And today we will be chatting with Emer Lucey, a PhD candidate in the Department of History at University of Wisconsin, Madison. Emer, thank you so much for taking the time to join us today. We're really so excited to have you here.

Emer Lucey: Thank you so much for inviting me. I'm thrilled to be speaking with you both.

Kelsey: To start, thank you so much for sharing a chapter from your dissertation with us. So before diving into this particular chapter, we would really love to hear a little bit more about your larger project to set the scene for our listeners. Your bio mentions that your dissertation "looks at the history of childhood developmental disability in the United States, analyzing the role of parent memoirs in the construction of autism and Down syndrome in the 20th century." Why did you choose to focus on parents in the story you were trying to tell, and what disability histories actually become available to us when we center the perspectives of parents of children with disabilities?

Emer: Well, thank you for starting off with such a great question. So I focused on parents largely because when I began doing this work, I started with my senior thesis—I've been working on this for a really long time—so my senior thesis in undergrad, I looked at newspaper coverage of autism from 1945 to 1990, and I found a lot about parents. A lot of ways that parents were discussing their children, parent activism and parent organizations, and there's been very good work in disability history about parent organizations. But I found parents in many ways were driving the conversation around childhood disability in particular. I think that's something that is really worth analyzing in the way that that determines our cultural understanding of disability, what our expectations for childhood disability, but disability more broadly, look like for developmental and intellectual disability, certainly, the way that the construction of someone who is developmentally disabled as kind of an eternal child, which we can very much look at, like, Paul Longmore's work on telethons as really beautifully exploring that. But I think the way that parents have been so influential in shaping what childhood disability looks like continues to produce that meaning in American society. And so that was kind of what brought me to look at parents as a place to find how the meaning of disability was being shaped across this period. And I focused it clearly on childhood disability and childhood developmental disability, but I do think that has resonances then with the other kinds of expectations we have for disability rights, disability education, and inclusion in society.

Kelsey: Thank you so much for that. And one small follow-up just on this question of parenthood and what the focus on parents opens up, but also maybe challenges or forecloses in telling histories of disability. I'm sure, I mean, we're all familiar with the "Nothing About Us Without Us" imperative that is a mantra that really came of age with the disability rights movement. And it's an imperative that I think partially relies on an autonomous adult subject with disabilities, and I think that "autonomous adult subject" in many ways has become kind of the paradigmatic proper object of disability studies or disability history, and that is complicated when studying childhood developmental disability. So I was wondering if you could talk us through a little bit more about maybe the necessity of thinking disability relationally, thinking

about families, thinking about parents, when you're writing about children and childhood disability.

Emer: Absolutely. This is something I think about a lot because I don't want my work, which is studying parents of disabled children, to reify in some way the idea that parents should be the primary focus of disability studies, of disability activism, of our concern about disability in the world. I don't want to argue that or inadvertently further that idea, because I think that idea already exists in the world in lots of ways. And I guess that's more what I'm trying to analyze, is why are parents so centered in discussions of childhood disability and what consequences does that have for the way that childhood disability is experienced and understood. So seeing how the way that parents construct the narratives that I study in memoir, in guidebooks, I do oral histories with parents, seeing how these things contribute to a particular meaning of autism and Down syndrome that does continue to be focused as a childhood condition, and the consequences that then has in more recent movements of autistic self-advocates and self-advocates with Down syndrome in countering those existing narratives, I try to see how parents have been encouraged and furthered in shaping particular constructions of childhood disability.

So I do feel like it's kind of a fine line because there is, as I said, I don't want be suggesting that parents are the most important part of disability history, but I do think there is this body of work and this influential part of disability history that parents have shaped that we can't analyze without looking at.

Kelsey: Yeah, that makes perfect sense.

Caroline: To follow up on that a little bit, parent memoirs as we've heard, are a really important part of your project. So what was it that sort of drew you initially to memoirs in particular?

Emer: Where I started with memoirs, again, goes back to that senior thesis where the one thing I found were reviews of memoirs in newspapers. There are a few major autism parent memoirs that got a lot of press in *The New York Times* in particular, and that would be Clara Park's *The Siege* and then Josh Greenfeld had a series of books in the 1970s like *A Child Called Noah*, *A Place for Noah*, and so on. So I read excerpts from these and discussions of them in *The New York Times* and found them interesting. But in particular, I was interested in an idea that I saw repeated in coverage of parent memoirs and coverage of autism generally about the idea that autistic children are unusually beautiful, and that beauty is a constitutive component of the disorder. This is something that I never saw in the history, but it was popping up all over the place, and I became really interested in the way that autism was, what the purpose of insisting on autism as unusually beautiful was.

And so for my master's thesis, I looked at both the scientific literature and then parent memoirs to see the different ways that beauty was addressed, and how beauty was present in the scientific literature up through roughly the time period when a biological etiology became accepted, or at least more accepted rather than a psychogenic etiology. So beauty and a psychogenic etiology went together in the psychological literature, but for parents, beauty continued to be something that they insisted upon. So I thought about, like, in what way does a particular beauty hold power for parents who have a child who's just been diagnosed with autism. And one thing that this resonates with is that beauty is a contrast to Down syndrome. That Down syndrome, if that is the paradigmatic childhood developmental disability, is defined by a characteristic facial dysmorphia. And rather than, while articulating difference between autism and Down syndrome, that physical presentation is a clear point upon which to say my child is not, Down syndrome is unlike other forms of intellectual disability, developmental disability, and their beauty shows how different they are, their beauty reflects the particular characteristics of autism. So there's a lot of discussion in parent memoirs of not just beauty,

but like an other-worldly beauty or an ethereal beauty that this child is like a changeling, who is like a fairy child. So kind of the ways that, there's a lot of that type of poetic language and allusion to identify with the meaning of autism.

Throughout this period, and even today, there's a lot of discussion about the ways that autism is unknowable and like, kind of fundamentally unknowable. So how, I think there was a lot of resonance for parents to connect their child's physical appearance to some sense of them being set apart from the world, that they are not your average child, and there might, and this kind of like, what might be different if the child were not autistic—there's certainly a kind of pathos there, or, in the way that beauty became, beauty resonated. That's the first chapter of my book and hopefully soon an article. But that's how I got started on parent memoirs was, I was like, this is really interesting the way that parents are describing this, and this is very counter, autism as beauty is very counter to the way that parents of children with Down syndrome are creating a narrative of uniqueness and value, which I argue is through joy and being loving. So those two kinds of contrasting natures place autism and Down syndrome into communication.

Kelsey: So we've actually already started to touch on this a little bit, but the next question that I had for you was why focus on autism and Down syndrome within this larger project on childhood developmental disability? And the way that you were just talking about how you found kind of an implicit, maybe sometimes an explicit comparison in the memoirs that you were looking at, in the ways that parents were valuing beauty, like, aesthetic beauty in children with autism, and there was a built-in contrast or comparison to the way that parents of children with Down syndrome were valuing their children. But I was wondering if you could expand on this a little bit more. Why do a comparative history? What compelled you beyond some of these narrative arcs that you were finding in the memoirs that you were working with?

Emer: Absolutely. So that's, the answer I just gave does kind of touch upon, like, how I started with this comparison. And as I've developed it and thought about exactly why compare, I think what I've come around to, or what I've kind of been developing is this idea that Down syndrome operated as a paradigmatic or *the* paradigmatic childhood developmental disability within mid-century America. So, once, in part because of its clear physiological specificity and starting in 1959 its chromosomal legibility, Down syndrome is this immediately identifiable – supposedly – immediately identifiable and distinctive condition. And it operates as something that inspires, like, searches for other genetic anomalies, so looking at Andy Hogan's work, and how that physical, those physical features are something that then genetic, was part of genetic research into, and like led researchers to find other genetic anomalies. So I think the actual aesthetic characteristic created a particular pathway for other developmental disabilities. But over the course of the latter half of the 20th century, autism increased in prominence to become what is today I think the paradigmatic childhood developmental disability, and so it's, these two things have reversed. And I'm interested in the way that that happened and looking at how has the etiological differences in Down syndrome and autism and the kinds of technological opportunities that exist, I don't know if opportunities is the right word, but technological responses to these disorders that exist – or conditions, excuse me, I try not the use disorders – to these conditions that exist has created very different opportunities for parents to claim cultural meaning for each diagnosis.

So the fact that following Down syndrome's identification as trisomy 21 and the growing availability of prenatal diagnosis via amniocentesis and access to abortion, Down syndrome becomes a choice, or at least is constructed, it's understood as a choice, as an optional decision for parents to make. That the availability is there for you to know ahead of birth whether or not your child has this particular aneuploidy, and you can, if you choose you can terminate that pregnancy. And so that idea of this as something that is a choice in life is very different from earlier understandings of Down syndrome as something that just happens and is just a part of the population and is quite different from the unpredictable emergence of autism,

which takes on a very unsettled nature. There is changing diagnostic criteria, there's changing and increasing incidence of autism. There's - over the course of this time period, autism becomes much more common, much more prominent, and significantly more prominent in the cultural understanding, even though at the same time period also rates of Down syndrome within the population have increased. But that is not something - people don't think that. Any time I mentioned this work to somebody who is not familiar with rates of Down syndrome they're like, "oh well most, most pregnancies with Down syndrome are terminated, like, there's very few people with Down syndrome now." And that's not true. But our idea of how many people in the United States have Down syndrome is significantly lower than the reality, I think. And so that relates to the idea of that what is a greater cultural concern, because everyone is like, "autism is everywhere." And certainly when I started doing this work, I think it was an Autism Speaks, which, already, you're like primed for whatever I'm going to say next, but there was an Autism Speaks PSA that ran—so this would be about 2010—and it was, single figure, it started with a boy saying "autism, I think there's someone at my school with that," and then like, he got a little bit older, and it was like "autism... I have a cousin with autism," and it kept like, it kept growing in saying there's somebody with autism closer until it was "autism, my son has autism," and it was like, "autism, it's gonna be everywhere. We're all" -- And it was just this very strange sort of fear-mongering message and I remember it because it was so bizarre. But that is to me what I think about this work and thinking about the idea that people think autism is everywhere. And certainly rates of autism have increased significantly, but at the same time, the particular idea that that is this huge problem and what that means culturally that autism is on the rise, and how does that reflect, you know, the culture today and screen time, and is this - what does it say about America that everyone is autistic, is something that I think is really interesting.

And the way that autism is in its unsettledness, in its etiological unsettledness, in its therapeutic unsettledness, in the spectrum of presentations that autism can hold, autism can take on many different meanings, and does. There was a *New York Times* article, or essay, just a week or two ago by the mother of someone with autism who is saying why are there so many novels featuring autistic characters, why do they all seem so different, like, what does it mean that people love to write a character with autism. And I think that reflects the fact like, people love it because autism is so expansive as a category in our cultural understanding. And that has a productiveness that something like Down syndrome, which is much more settled in our expectation of the diagnosis, does not have.

Kelsey: One thing that was coming up for me, Emer, as you were talking about kind of like the proliferation of narratives like books, TV shows now even about characters with autism—like I'm thinking in particular about the new Netflix, I think it's a Netflix docuseries *Love on the Spectrum*. I haven't watched it yet. Have you seen it?

Emer: I've only seen the, like, trailer, I haven't actually watched the series yet. But I'm familiar.

Kelsey: But I've been thinking, and this goes back to something that you were saying about the ways culturally, throughout history and particularly looking at, like, the second half of the 20th century, we see this equation between developmental disability, even adults with developmental disabilities, associating it with eternal childlikeness. From like a 21st century like cultural observer's perspective it seems like eternal childlikeness is still continually ascribed to Down syndrome, but in some ways autism has been allowed to grow up through this, like, proliferation of pop cultural narratives about adults with autism. This isn't really a question, it's just a comment and I wonder if you have anything to say about that.

Emer: I think, I think that's a good point. And I think it does relate in part to the depictions of autism that we are familiar with, which tend to follow a specific pattern and a specific type of presentation. I don't know if it's actually ever stated, but the character on *The Big Bang*

Theory would be like the first person I think—which now there's also a show about him as a child, I think. Like, that's a, it's a huge CBS show that ran for like 15 years or something, 10 years, and I think that is someone who, it's like that autism is it's, like, quirks, but he is also brilliant and a physicist. And the way that that then shapes our expectation of what autism looks like in adulthood, and that is something that is quite different the expectation of, or, our cultural expectation of Down syndrome. Although I was just kind of thinking as I was thinking about our conversation for today, one thing that I think is interesting about Down syndrome culturally is there are not a lot of depictions of children with Down syndrome. Like, there are - more recently, there have been characters with Down syndrome on TV shows. There was a person on *Glee* who was a supporting character, there's somebody on Mindy Kaling's new show on Netflix, there's a character whose sister has Down syndrome, and so there's teenagers, but we don't often see, like, someone raising a child with Down syndrome. But we see, there's sort of like a jump between prenatal Down syndrome and then Down syndrome in an adult, or almost an adult, while still maintaining certain ideas about kind of like dependency and a need to be protected that I think certainly resonate with that eternal childlikeness, or you know, kind of like -- which dates back to early parent memoirs as well as telethons. But I agree, I think there is this kind of interesting way in which autism is allowed to be across the lifespan in a way that Down syndrome is often connected with that child-like nature.

Kelsey: Thanks for indulging that quick pop cultural pivot.

Emer: Oh, I'll always do a pop culture moment. Don't worry!

Kelsey: I couldn't resist!

Caroline: To pivot back to your dissertation, the chapter that you shared with us is titled "Feelings as Important as Facts: Parents, Guidebooks, and the Construction of Childhood Disability," and it was a really interesting read. Thank you for sharing it with us. This chapter actually focuses less on memoirs and more on guidebooks, particularly from about the 1960s through about the 1990s. So I would love to hear more about this. Were guidebooks for parents of disabled children a kind of new development in this era? And what made them different in your view from the parent memoirs that you've mentioned?

Emer: Yeah, so I do think guidebooks for specific disabilities are new in this period—or I have not found any earlier than this—but guidebooks for parents are not new. And we see guidebooks going back into the early 19th century, maybe earlier. I'm not, I'm not an expert on earlier, but there are parenting guidebooks for a long period. And we can see guidebooks for autism and Down syndrome fitting into some of the tropes of general guidebooks. What separates them, or what at least brought me to guidebooks as something that I find particularly interesting, is the way that parent narratives are utilized within guidebooks. So, there is a lot of overlap between authors of memoir and guidebooks, and, as well as, and this is not to me unexpected, but parents themselves both write guidebooks and are referenced throughout guidebooks. And so this is something that's typical of guidebooks more broadly in mid-century and later 20th century, is that parents are often, like the idea that the expert who wrote the guidebook would reference "I spoke with 20 different families for this book," or would, you know, kind of have like little snippets from parents throughout the book. But I wanted to examine guidebooks to see in what ways are guidebooks resonating with memoir and how are they diverging? How do they, how do these things operate in tandem to shape our expectations of disability and parents' experiences? So there are ways that I think the narratives contained within guidebooks build upon narratives that are already existing or produced by parent memoirs.

Particularly thinking about, so I've already mentioned Clara Park's *The Siege*, which is the first major autism memoir. And this was written in the 1960s so it's relatively early. Autism as a discrete diagnosis was first introduced in 1943. And Clara Park writes about what became the

kind of the general, like, narrative arc of a parent memoir going through seeking diagnosis, her experience, noticing something different with your child, seeking a diagnosis, going to multiple different practitioners, trying to find different treatments, and ultimately creating some kind of resolution. Particularly the sustained metaphor of *The Siege* that she is putting her daughter as the autistic figure, under siege, that there is a child within that you can get to, if you are willing to fight against that, is something that then recurs throughout these guidebooks and becomes a really powerful kind of message to parents about the expectation of what being a parent of a disabled child should look like. And so this is something that I find really interesting and kind of the way that parents are expected to take on a particular identity as the, like, someone who advocates for their child, who fights for their child, who is responsible not only in the general parental sense, but is responsible for your child's recovery, for your child's condition, and whether or not recovery is possible, is something that becomes, that separates autism from Down syndrome in these ways. Because autism memoirs and guidebooks are instilled with a type of hope, typically, that you can get through to your child, that the result will be some form of whether it's, some will say recovery, others will say like, improvement, or might end with like "if you saw my child on the street you wouldn't know that, like, he or she was autistic at first interaction." So that's the resolution in contrast to the resolution that's offered for Down syndrome, which is acceptance of who your child is. These are kind of the two parallel arcs, and one is about the child's recovery and one is about the parents' recovery. And those things are absolutely present throughout guidebooks and parents are kind of conditioned in what way, through these books, you should approach and accommodate your feelings across this period and in what way you are going to become the parent your child needs and kind of create the best opportunity for your child and how that will lead to the best outcome.

So these are things that I see in these guidebooks that, again, I think contribute to what our expectations of disabled parenting look like, or parenting a disabled child looks like, as well as our expectations for what the kind of life of someone with autism or Down syndrome is going to be.

Caroline: That's really interesting. Yeah, I mean, obviously from a sort of disability rights perspective a lot of that emphasis on recovery or cure that you mentioned around autism, for example, is deeply problematic. But also, perhaps unpacking this history goes a long way to helping us understand the cultural moment in which people with autism were living, right, so, yeah. You've already kind of answered this question a little bit, but I want to ask it anyway, more explicitly nonetheless. And I'll preface by saying one of your most compelling claims in this chapter is that guidebooks not only offered information in many cases, as you suggested, to parents from parents -- not just from medical authorities -- and this information could be about navigating your child's legal protections, educational options, medical conditions, treatment opportunities, but these guidebooks also modeled and normalized the feelings the parents might have about their child's diagnosis or suggested potential sort of pathways in which parents' feelings could be sort of shuttled. I'm really interested in asking you just more about this. So you've already mentioned the sort of hope versus acceptance model, right, but what other comparisons and contrasts did you find between how guidebooks depicted experiences of parents with children with autism versus children with Down syndrome?

Emer: So I would say there's a lot of similarities. Honestly, in part, because many of these guidebooks, or at least some of these guidebooks, are written, are produced in the same series so they're from the same publisher, they're following a particular pattern of like, chapter one is diagnosis, chapter two is etiology, chapter 3, you know, like chapter 8 is legal options, and the legal options is always written by the same people. There's a certain kind of modularity actually to some of these books. So the differences, there's differences, but there also is a lot of commonality. And certainly in some type of, some of the emotional responses that parents are expected to have and are validated in are shared across both fields. So, you know, feeling frustrated, feeling upset at diagnosis, and like, parents are encouraged to, like, take the time

to feel those feelings and allow yourself to come to terms with this changing diagnosis and are very much encouraged that knowing more is a way to improve your feelings about this diagnosis. Which of course is a little bit self-serving for someone trying to sell guidebooks, that you should, or publishing more books about disability, that you should always be buying more books to aid in this process. But it's also great for historians because there's lots of books for me to look at. So there are those particular commonalities.

Differences certainly come, and I think differences relate to the understanding of autism and Down syndrome at each time period. So generally, in the books that I'm looking at are post, are in a time when for autism, officially, the "refrigerator mother theory" would not be supported, but unofficially would still be circulating. And the "refrigerator mother theory" is the belief that autism was caused by parents, in particular mothers, through the rejection of their child, the emotional rejection, the idea that the child had been kept as if in a refrigerator in the cold away from the mother's love. And this comes from several prominent people within autism history prominently supported this idea—in particular, Bruno Bettelheim, author of *The Empty Fortress*, who is probably the most prominent child psychologist of mid-century America and was a very popular, like, talk show guest. *Empty Fortress* was a huge, well-read book. So this was a very popular idea that even when it was, had been very much challenged—and, you know, I see in the scientific literature people saying like, "Well, nobody really believes that anymore in 1975 or in 1980," I also am hearing from people like, "Oh, my doctor told me in 1990, that I didn't, that I was at least somewhat to blame." So it's, these ideas linger. But the idea that you are not to blame for your child's autism is something that comes through strongly in guidebooks. And that you should reject any practitioner, any child psychiatrist or physician, pediatrician, anyone who suggests to you that you are the cause, is prominent and that you, part of what you as a parent are responsible for is guarding against those ideas, that you need to seek out treatment that is not psychological in nature, that is not psychoanalytical, that you need to be looking for alternative forms. Because there is, there are going to be people who are just going to try to put you in family psychoanalysis, and parents who were saying like, "this was all I was offered with, and it was horrible, and I now hate the medical establishment as a result." Like, that is something that is discussed in autism guidebooks that is quite different from the narratives in Down-syndrome guidebooks, where, it's not as if there's never any discussion of bad practitioners, because certainly there are, but the register is quite different.

What parents of children with Down syndrome are counseled against is anyone who places limitations on what the possible achievements of the child might be. So being told, like, you should be able to, you should send your child to school, you should be insisting on the best possible education that you can find. And of course that changes over this time period as well based on – and there is a lot of discussion of new legislation, so, IDEA when it comes out, people are really excited about, and the ADA, people are really excited about, people discuss a lot the way that things are getting so much better, and "even now as I'm writing this it'll be better for you when you're reading it," you know? So there is this sense that you should not be, the thing you should caution against is anyone who says your child will never speak, your child will never learn to read, your child should just be put into an institution. There's a strong, as expected, very anti-institutionalization, pro-inclusive education, pro-expansive services. All of that runs through Down syndrome guidebooks in particular. It's present in autism guidebooks as well, but because the ideas about what the best possible treatment for autism are or would be is never really settled, there's less of like, a clear pathway about like "you should be doing early intervention of this particular nature" than there is in -- the Down syndrome books are a bit more prescriptive in some of those ways.

These two things produce a different kind of expectation of interaction with the medical establishment, because on the autism side, parents are directly responding against what they feel like is a kind of hegemonic medical establishment that rejects them as being unfit parents who have caused their children to become autistic, and on the Down syndrome side, parents

are like, the authors and parents are saying there are some bad practitioners, but on the whole, people do want the best for your child, you should be able to find a physician who is going to care for you, and you should be able to find, you know, you should be able to get good care. On the autism side, it's like there are parents saying, "I just don't trust anyone, but other parents." And parents will say that's in, you know, the 1970s, that's not actually a new idea even though it's now something we see often within like anti-vaccination circles, that has this history within autism parenting circles that I think is directly related to parents rejecting the medical establishment's belief in the "refrigerator mother theory." So there are clear divergences in those areas between these books.

Caroline: That's really really fascinating. I think you've again already kind of anticipated this, but I'd love for you to flesh it out more. Do you see these guidebooks or the conversations these guidebooks were starting or reflecting as suggesting that there is like a nascent movement in this period around community formation, parents of kids with disabilities, or identity formation? How do guidebooks fit into that? Is there more to the story? I'd love to hear more.

Emer: Absolutely. So I think community formation and identity formation are absolutely going on, and I think guidebooks are part of it. I hesitate if guidebooks themselves are necessarily the most influential feature. Because one of the things guidebooks typically encourage is involvement in parent organizations, and I think parent organizations are hugely important throughout this period and a bit earlier, and that's something that has been, like, reasonably well explored I think in the historiography. So, like, Catherine Castle's work, Chloe Silverman's work—there is a lot of work on parent organizations and how influential they were in shaping, like, kind of immediately post-war experiences of parenthood of a disabled child and creating advocacy around anti-institutionalization and promoting education and community involvement. So all of that is happening throughout this period, and I would say, so it's hard to know, are guidebooks more important or are guidebooks just kind of, like, a part of what parents are also doing in literal community formation as opposed to kind of the imagined community that is experienced through reading the same books.

So it's hard to say necessarily. But I do think guidebooks support particular types of identity formation and encourage particular types of identity formation in the kind of very involved parent that they are promoting. So parents who read these books are given a lot of stuff that they have to do to be an adequate parent to a child with a disability. It's not an easy or relaxed process—like the type of advocacy that they're expected to do individually for their child, but also in a broader sense within the community is immense. They are supposed to kind of be always the first, the person who is working on behalf of their child at every turn. There's always something more that you should be doing across, throughout these books. And I find interesting how rarely that idea is challenged within this literature. So one thing I bring up in the chapter is one particular person in a book that I think is sort of like, that book is explicitly like, parents talking about parenting—so it's less of a prescriptive guide and more like "here read 15 parent experiences"—but one parent who was like, "I was not going to make my identity being the, like, disability advocate parent, my daughter was not going to find her identity on the basis of being disabled. That was not something I was interested in. I, these meetings are useless. There's never more than two people who know anything at them. I, you know - " So it's entertaining to read. But it's also something that was interesting because you got to the end of the chapter, and the woman who had written it was super involved in her local, you know, ARC chapter or whatever it was, so this is somebody who had been secretary, had been local chapter head, had done all of these things, and still was not encouraging other parents to do it.

So there's something that I find really interesting about the idea that parents, just as much as they are buying in, are also rejecting it, or that some parents are actively rejecting it, and still other parents are never going to be able to participate in this because it essentially demands

that the person who is an adequate parent is a middle-class or upper-middle-class stay-at-home parent. There is not room to have two jobs and be a full-time parent of a child with a disability in the way that that role is constructed within these books is creating a very narrow pathway for who actually is an adequate parent in this construction. This is only speaking to a certain very classed, very much raced as well—these parents are almost all white, not exclusively, but almost all white—and living in East Coast or West Coast usually, and living in large cities or, you know, wealthy suburbs. There's particular patterns of the way that the parents who are discussed in these books fall into, and it does leave out a lot of the other parenting experiences and the experiences of people with disabilities who are not born into that family. And it raises, I think, a lot of questions then about the way that this particular archives is, has a lot of absences.

Kelsey: Actually everything that you just said about the ways that disability parenthood was contingent upon or, like, premised on access to resources, money, time, made me think, like, if you're analyzing the ways that parents actually constructed meaning about childhood developmental disabilities, I'm curious -- if our models for disability parenthood are, like, so predominantly white, middle-class, how do you think that might have racialized definitions of autism and Down syndrome themselves as being white, middle-class problems or conditions?

Emer: So autism in particular was specifically identified as a condition of the white middle-class or upper-middle-class by Leo Kanner, who was the child psychologist who first used autism to, as a discrete diagnosis. So from the start, autism was looked for in families who were white, who had educated parents who were, who fit a particular profile, and that also related then to the expectations of the "refrigerator mother" because the refrigerator mother has educated herself out of maternal feeling, essentially. She has lost her natural womanly nurturing side because she is too cerebral. So there is an ongoing raced and classed expectation for autism that I think then is continually kind of re-inscribed as the parents who seek out an autism diagnosis who have the ability to look for that, to take their child to more than one diagnostician or, you know, seek out a child psychiatrist, are also already going to likely be wealthy, white, educated, and so on. So there's this way that autism, as it falls into that particular category, was sort of over-determined for much of the second half of the 20th century. And it's only after autism diffuses much more broadly into American culture that it becomes a more widely used diagnosis. So I think there, I think your point is right that the expectations for what autism looks like are kind of continually shaped by what we think autism looks like. So if you think autism is -- so it's a self-fulfilling prophecy in that way, even as people are saying, like, autism actually does, we can find autism across all races and classes, it takes a lot of time for that to really change.

Down syndrome is slightly more complex. Because I don't actually know - I think it's a question, I guess, more of our cultural expectation versus like actual prevalence. I think that is related certainly to, like, the depiction of Down syndrome as something that is primarily white. It speaks to just kind of like the general whiteness of American media and the way that things like parent memoirs are almost all written by well-educated white parents. Like who else can get a publishing contract, who thinks "I should write a memoir," but well-educated white people? Like it's rare to, I say this as a well-educated white person, like, the idea that I am worth writing a memoir about is the kind of thing that reflects general, the general white privilege. And so that also infuses, like, whose memoirs are written, how those memoirs are distributed, and published, and how, like which memoirs get picked up for press, and so on. Like all of those things contribute to the idea that these parents are white, and that also relates to—like this, thinking about Alison Carey's work—the way that the proliferation of parent organizations in the 1940s and the 1950s was suburban middle-class white parents who were trying to challenge the idea that disability, intellectual disability, within the family was something to be ashamed of and insist upon that as something that deserved community services, that deserved education and inclusion and remaining within the home and all of these things that then did, I think, become attached to a particular vision of middle class white

family life.

Kelsey: Moving backwards, just a little bit, I have a change over time question for you. I'm so curious, you've walked us through some of the dominant, like, narrative conventions and metaphors and emotions that you found in these parent guidebooks and memoirs, but I'm wondering, like, if we're just looking at this window—like 1960s to 1990s—what changed in these guidebooks about what was expressed narratively and what emotions were normalized?

Emer: I would say, emotionally, there's not necessarily, I don't know that there's a ton of change as far as -- well, let me walk that back. I think what changes over time, there's a greater prominence in parents as, in the significance of parents over time and the significance of parent voices. Earlier guidebooks are more often written by practitioners. When they're written by parents—parents are less likely to identify themselves -- when they're written by parent practitioners, because there are many parent practitioners within both of these, both autism and Down syndrome discourses—parents are likely to identify themselves on the basis of their professional credentials, not on their experiences as a parent. And that's something that really changes over time. So if we look at Lorna Wing as one person who wrote a series of guidebooks, starting with a pamphlet in the 1960s. And Lorna Wing was an autism researcher in the UK, who is very well known. She coined the idea of the spectrum for autism, and she also was the mother to a daughter with autism. And over time, when it starts, she's all business, she never mentions her own experiences, parents are always held at a distance. And gradually she like introduces a little bit of like her experiences working with an Autism parent organization, and by 2000 she's starting off, you know, that edition of her guidebook as a parent writing. And I think that's reflective of the way that over those 40 years or so, parent voices became not only more important, but became *the* important authority within autism.

So this is something that Chloe Silverman writes about, the rise of the "expert amateur" within autism. That particularly, like the idea that the rejection of professionals and the introduction of parent expertise and experience as the sole kind of arbiter of autism is a major change and that is shown within autism guidebooks as well. A similar thing happens within Down syndrome guidebooks, but not to the same extent. Over this time period, parent voices are included to a greater extent, parents are certainly kind of continually looked to as co-experts maybe, or, you know, like, as the significant presence in a child's life and in the experience of Down syndrome, but parents never can, never reach a point where their expertise supersedes professional expertise. And so there's less of, there's not that kind of overtaking that we see in autism discourse.

Kelsey: Earlier on in the interview, you mentioned autistic self-advocates and the ways that adults with autism and adults with Down syndrome also participated in meaning-making around their diagnoses and their experiences that intervened in cultural constructions that came from parents. In some of the sources that you've encountered how have adults with Down syndrome and autism challenged parental constructions of their disabilities? And in this contest for meaning making, how have children and adults with autism and Downs defined themselves in ways that have challenged both the parental definitions of disability that you've discussed with us already and medical definitions of their conditions and experiences?

Emer: This is what I'm really working on right now. The chapter I'm writing currently is about memoirs written by adults with autism and Down syndrome. And so I'm trying to see those points of conflict and what I'm finding so far, there's less conflict through the end of the 20th century, at least in majorly published memoirs, than I had kind of anticipated. And certainly in the 21st century there's a robust discourse of particularly autism self-advocates who challenge parental and medical constructions of autism.

Kelsey: I don't know enough about this. When did the neuro-divergence movement, when would you periodize that? Like 21st century?

Emer: I think it's the late 90s, actually, but I don't know. The person who first coined the term neuro-divergent is Australian, and so I'm not exactly sure when it comes to the US, but I doubt it's that long after. But it's just a little bit after my time period, so I would love for somebody, I'm sure somebody's doing a history of neuro-divergence and I really want to read it. But it's not – I can't claim to have done a ton, in part - I find the 21st century challenging because there is so much there with the rise of the internet in a much more meaningful way that it is a huge other project to start analyzing the way that community and identity and meaning is negotiated with the internet as a meaningful source.

So I find, as far as, adults with Down syndrome are writing their own stories, they're less challenging than, I would say that adults with Down syndrome that I see are giving kind of a complementary narrative, often. So probably the most prominent adult with Down syndrome to write a memoir is Chris Burke, who was an actor, who is an actor. He was in the show *Life Goes On* in the early 90s, which was about a family with a child with Down syndrome as he enters mainstream high school. And this was a show that I don't think it was ever about great ratings, but it was like a kind of cultural moment—people, it got a lot of press and attention. And so he co-wrote a memoir that is sort of half his writing and then half his co-author giving like a more of a contextualized third-person account of his life. And that gives very much a narrative that aligns with the kind of advocacy that parents had been doing as far as advocating for, like, understanding people with Down syndrome as complex humans who can achieve lots of things—there's a lot of emphasis on achievement, which is something that I think will later be challenged in terms of disability rights discourse—but there's a lot of emphasis on achievement and, you know, how much Chris can and did do and everything, and him as an inspirational figure. And so I don't really see that as like necessarily challenging a ton the way that parents write.

What I think is fundamentally distinct about adult memoirs versus the memoirs of parents is that parent memoirs inherently crystallize disability as a childhood experience and a relational experience, in contrast to reading a memoir by someone who is identifying as an adult and is identifying as disabled, forces the reader to examine not only adult experiences, but also to think of themselves in the position of the disabled person as opposed to thinking of themselves as the parent of a disabled person, which is quite a big difference. That being said there were a couple of diaries of people with, adults with Down syndrome that were published in the 1960s, and I would imagine there's more—they're kind of hard to find. So there, there have been similar things that are sort of advocating for greater educational possibilities, greater achievements from people with Down syndrome across this time period that I think more, like, complement what parents are advocating for. The introduction of memoirs by adults with autism come later. So there are, at some points, parent memoirs will have a section that's written by the child. Whether it's like - in one of the Clara Park ones, there's a bit where she includes, I think, her daughter's like, drawings and writings, and there's another one I'm thinking- there's a few that will have some section from the child or teenager's perspective, that give sort of a -- again, it's not like it's countering because it's literally being published along with the parent's memoir, but that do give somewhat of a sense—they counter a bit the idea that autism is something fundamentally unknowable. If the idea is that, like, you can read this and understand it, that becomes a bit less meaningful, I think.

But the first memoir is Temple Grandin's. She first writes a memoir in the late 80s, and then she writes a more widely published memoir with an introduction by Oliver Sacks in the 90s. And she, I think Temple Grandin really does kind of challenge the idea that autism is unknowable and very much introduces the idea that, "No, I just, I know things in a very different way." And so that then becomes adopted as a, much more widely, I think, as a kind of a way to understand autism and Temple Grandin herself kind of becomes - Temple Grandin is an unusual figure because she would be an unusual figure in any group of people, like she is incredibly accomplished, and so she then, I think, does kind of support certain ideas about

what our understanding or our expectations of autism are, or expectations are. So again, it's like, is it really challenging? I don't know. It's certainly challenging in some ways. There's subtle challenges, I think within any book that is written by a disabled person, in contrast to being written by the parent of a disabled person, is going to counter some of the expectations of dependents, of eternal childhood, and so on that we find in parent narratives. But I think the, there is a lot more that comes from self-advocates in the 21st century, so it's more speaking to the epilogue of my book or my dissertation than necessarily, like, what I can examine from the 20th century, I would say.

Kelsey: Yeah, and I wonder how much of a role the internet plays in kind of the formation of self-advocacy networks, in online forums where people with autism and people with Down syndrome are newly articulating themselves in relation to other people, [**Emer:** Yeah] not necessarily within the purview of parents or other people who've defined them.

Emer: Oh, I think it's huge. Also because I think the expectation of audience is profoundly different in forums or networks—you know, associations like the Autism Self-Advocacy Network. The memories that I'm looking at are not a "for us by us" kind of product, they are fundamentally not for a disabled population or disabled audience, and so that really shapes what kinds of stories are told, who is sought out to write them. It's, it's not surprising in that sense that parent memoirs continue to be popular and continue to be published, and part of why I do think this history matters is that we still give an outsized importance to the way that parents write about their experiences in contrast to the way that we listen to adults with developmental disabilities, and understanding like the way that those tropes have emerged and the way that they are shaped very much without the expectation that the audience reading them will be disabled, I think helps make those things understandable.

Kelsey: Yeah, absolutely.

Caroline: It's really interesting. It makes me think back to those *New York Times* reviews of the memoirs that you mentioned, you know, right at the beginning of our interview. And not only are these memoirs not for disabled audiences, but statistically, they're probably also not going to be primarily read by people with disabled children either. So what did the writers and or the *New York Times* like, think the, you know, general reader who has nothing to do with kids with disabilities would learn from these books or get out of these books? Was it like curiosity or powerful lessons on love? Like, what sort of tropes are happening here that are supposed to sort of speak to broader society?

Emer: So definitely powerful lessons on love appear. And that goes back to - probably still the most significant parent memoir ever is Dale Evans Rogers, *Angel Unaware*. And Dale Rogers was the wife of Roy Rogers, The Singing Cowboy, who was a big celebrity in the 1940s and 1950s. She wrote this book that was about their daughter Robin, who was born with Down syndrome and died when she was two. And the book is written as if from Robin's perspective as an angel in heaven speaking to God about her life. And it was a huge best seller, like it was one of the best, one of the second- or third-best, selling book of 1952 across any book. Like it really was massive. And that book is all about what can children with disabilities teach us. They are here as, sent to us as angels to teach us about love and acceptance, and the meaning of life and family and God and so on. Like, that is always kind of an overarching expectation for parent memoirs, I think. Like, the inspirational parent memoir is a big - continues to be a big deal. There was one published within the past six months that I read reviews of that again, was like, "This will really teach you about what parenting is all about." And memoirs take on that role once you expect them not in any way -- to be fundamentally unlike guidebooks. There's nothing about, like, what should, you know, what kind of feeding tube you should use, or should you do ABA versus hearing therapy or something. Like, it's all just emotion and learning from this. And I think that does then place a very different register on who is a disabled person in society that relates again, you know, to telethons, to this idea

of the Tiny Tim figure, the inspirational figure. That as much as, there are, even then, the insistence on achievement that's so common within memoirs, particularly of Down syndrome, but also of autism, becomes a little bit understandable if -- the achievement as opposed to inspiration is a meaningful change. But one that does kind of still place an inspirational valence—like, “look how much this person has overcome, look how much they can do” is a necessity that leaves out a lot of people with disabilities and does have these problematic, a problematic meaning still.

Caroline: That's really fascinating. We've only read one chapter in your larger project, although I think we've alluded to other sections of your dissertation. If you want to talk more about the general arc of your dissertation, what all the chapters are about, I mean, I'm sure people would love to hear about that. Or if you're working on anything else or have future plans that you'd like to share with people, absolutely now is the chance.

Emer: I mean, future plans are finishing it. [Laugh] You know, the dissertation is examining how has Down syndrome declined in cultural prominence at the same time autism has -- and looking at the ways that particularly the introduction of prenatal diagnosis and terminations for Down syndrome have situated Down syndrome as a condition of pregnancy while autism has an expansive unsettledness that allows it to be continually reinvented, used as a cipher across a variety of different meanings as society shifts and changes in its understanding of what autism is. So I look at memoirs, I look at the scientific literature on autism and Down syndrome, I look at guidebooks, I have done oral histories that I'm figuring out exactly how to incorporate, and then I look at memoirs by people with Down syndrome and autism to situate them alongside and kind of within this larger genre of narratives about childhood disability. So that's the project.

Caroline: Sounds great. Look forward to reading the whole thing.

Kelsey: Yeah, I can't wait. Thanks so much for joining us.

Emer: Thank you for having me. This was really enjoyable.

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Caroline: Thanks to everyone out there for listening or reading the transcript. Please join us again next time. Bye bye!