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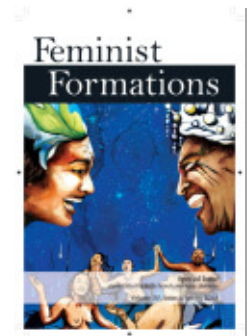
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Subtle Neglect and Yuckiness: Queerness, Disability, and Contagion in Mother Narratives

Margaret F. Gibson

Discussions of queerness are steeped in fear about what, and who, queerness will reproduce. Such alarm intensifies when queerness is brought into proximity with children. Meanwhile, the mere possibility of disability inspires calls for segregation, cure, or even elimination. This article asks, what can we learn from the narratives of queer parents of disabled children about queerness, disability, desirable reproduction, and the logic of contagion? A reading of selected passages from interviews with queer mothers of disabled children offers an illustration of discourses of contagion and risk associated with queerness and disability. In one interview, we see how the dominant cultural understanding of disability as threatening leads to the assumption that a non-disabled child's proximity to a disabled sibling represents parental neglect. In another, a mother describes the "yuckiness" of repeated requests to discuss a relationship's end with providers due to associating queer relationships with familial destabilization and damage. Parent narratives at the interstices of queerness and disability tell stories of uncertainty, indirect supposition, restraint, anticipation, shock, and humor. As they use a wide range of shifting strategies to negotiate and contest normative social understandings of who, and what, should be reproduced, parent narratives offer moments of repurposing within constraints.

Keywords: children / contagion / disability / mothers / narratives / parents / queerness

Queer gestures toward a category of identification as well as a set of practices that challenge normative ideas about gender, sexuality, and kinship. As such, dominant cultural understandings of queerness are steeped in normative fears

about what, and who, queerness will reproduce. Such alarm intensifies with the proximity of queerness to children. As Eve Kosofsky Sedgwick writes, “[A]dvice on how to help your kids turn out gay, not to mention your students, your parishioners, your therapy clients, or your military subordinates, is less ubiquitous than you might think” (1991, 23).

Over two decades later, Sedgwick’s observations remain salient. Debates and discussions on the risks posed by queer individuals and relations routinely invoke the sacral Child in a consistent refrain: “But think of the children!” (see Berlant 1997; Clarke 2001; Edelman 2004; Rosky 2016). In such framings, queerness can be as much about failure to reproduce normative relations of kinship, race, and culture as about the identities of the individuals concerned (Ahmed 2006; Butler 2004). Given this robust discourse, it is unsurprising that when people who identify as lesbian, gay, bisexual, transgender, and queer (LGBTQ) parent, the developmental trajectories of not only individual children but the health and welfare of entire social orders are called into question (Gibson 2014a, 2014b).

What happens if we bring together these fears for the children with notions of contagion? The contagion is framed as that which threatens both individual and social well-being (Chen 2012). Discourses of contagion call up affect-saturated histories where certain people, traits, ideas, or substances have been understood as producing undesirable—perhaps even irreversible or life-threatening—effects for those with whom they come into contact. Scholars and activists have long documented the ways in which queerness in North America has historically functioned as a shorthand for contagion, of ill-health and ill-feeling, as a signifier for bodies, relations, and desires in need of avoidance, containment, and/or elimination (Kinsman 1987; Warner 1993). Certainly, public discourses and cultural practices surrounding HIV and AIDS provide clear and continuing examples of these insistent associations (Patton 2002; Treichler 1999). However, evidence of epidemic fears, of wanton demands for banishment and quarantine, extend beyond the officially medicalized and viral.

The presumed contagion of queerness is entrenched in histories that situate the professional and popular scrutiny of sexuality as key to maintaining other notions of purity, particularly in terms of race and empire (Ordovery 2003; Rohy 2009; Stoler 1995). As Siobhan Somerville (2000) has argued, the delineation of sexual deviance has always been primarily concerned with the demarcation and protection of racial hierarchies. Jacqui Alexander’s work on the “palimpsest” of queer containment traces how the designation of certain bodies and practices as perverse extends through time and space as justification of colonial and imperial violence (Alexander 2006). Contagion can be a slippery logic to grasp where queerness is concerned, as it sometimes doubles back to recruit certain (white, middle-class, able-bodied) queer individuals and communities as support for the homonormative and homonationalist advancement of Western nation-states (Duggan 2003; Puar 2007). The tenuous and much-heralded inclusion of certain

kinds of queerness bolsters normative neoliberal and militarized projects that function to produce and sustain oppressive social hierarchies of race, class, and disability.

Disability, too, can be found at the core of contagion discourses. Tracing when and where disability appears across time, space, and kinship is a key strategy in arguments for how disability can be prevented, eradicated, or “cured” (Clare 2017). As many disability studies scholars have argued, the concept of disability has long been used as a prime justification for the containment, incarceration, and segregation of a wide variety of raced, classed, gendered, and disabled people for the sake of the society, nation, and capital (Ben-Moshe, Chapman, and Carey 2014; Chen 2014; Puar 2009). While all biomedical labels are oriented toward the designation of disease and risk, certain diagnostic terms dredge up particularly trenchant symbolics of epidemic, contagion, and urgency. For example, critical autism scholars have highlighted the ways in which autism’s designation as an epidemic anticipates the need for increased surveillance of the bodies and minds of children, and invites palpable fears about autistic children and their futures (Bumiller 2009; McGuire 2016). As a result, the discourses of the autism epidemic invariably produce increased demands on and recriminations toward the parents and, especially, mothers of autistic children (Douglas 2013).

Queerness and disability entwine in complex ways around and through notions of threat and risk, bodily damage and speculative futures (Clare 2017; Kafer 2013; McRuer 2006). Sexuality and reproduction operate as linchpins in eugenic ideologies and practices, from the sterilization of the feeble-minded and sexually perverse to the genetic monitoring of fetal tissue (Ordovery 2003; Snyder and Mitchell 2006). Mitchell and Snyder describe the concept of “ablenationalism” as that which promotes the elevation and inclusion of select “able-disabled” individuals as a means to advance the interests of the state in neoliberal contexts (2015, 55–57).

Simultaneously, the pressures of “intensive mothering” have spread through the neoliberal landscape such that mothers (and, to a degree, anyone in the “mothering” role) are asked to devote more of their labor and attention to securing their individual children’s success in highly classed, raced, and nationalist terms (Fox 2006; O’Reilly 2016). The combination of intensive mothering with developmentalist fears has resulted in the belief that mothers should be engaged in constant surveillance of their children’s development. This maternal attention is not only to ensure that they *know* if their children are not meeting milestones, but also to do whatever they can to promote an idealized development under the guidance of professional knowledge and authority. In other words, women who reproduce must reproduce well, ensuring that the offspring they produce are in line with those forms of human life deemed socially desirable, in accordance with (but surpassing the reach of) paid professionals (Blum 2015; Landsman 2009). To add to these complex webs of association between

disability, contagion, queerness, and reproduction, medical surveillance falls heavily on mothers who bear disabled children, and mothers' own genetic and behavioral riskiness and moral responsibility come under open-ended scrutiny (Salmon 2011; Titchkosky 2007; Landsman 2009). In some sense, the mother herself is often framed as a potential contagion, where bad (read: nonnormative or socially undesirable) mothering practices, choices, or behaviors are implicitly understood to be transmittable, as having the potential to infect offspring. Meanwhile, children themselves continue to be surveilled, contained, and subjected to violence as a risk to desirable social futures: disabled children, children of color, indigenous children, poor children, queer and trans children.

In the context of disability and queerness, then, mothers are again held to account for what they do, and do not do, to reproduce unwanted ways of being. Indeed, the association of both queerness and disability with fears of what could (or has) spread, what is (or will be) reproduced, come to support a mandate of quarantine: keep the queer and the disabled away from our presumably non-queer, nondisabled children—or, even more troublingly, eradicate queerness/disability from the children where it may appear. However, when queerness, and possibly the origin of disability, may also reside in the mother, how does quarantine proceed? Who is to stay away from whom? Who causes what? What causes whom? Interrogating the logic of contagion and the related practice of quarantine, indeed, asks us all to consider what it is that we want more—and less—of in our social worlds and our futures (Fritsch 2015; Kafer 2013). What types of children, and what parents, do we want to reproduce? Which futures are allowed to be desirable, and what do we do with the children and parents who exist in the here and now?

This article asks, what can we learn from the narratives of queer mothers of disabled children about queerness, disability, desirable reproduction, and the logic of contagion? I address this question through a focused analysis of passages from two interviews completed as a part of a larger ethnographic study on how LGBTQ parents experienced their interactions with disability-related services (education, healthcare, day care, social work, respite, etc.) (see Gibson 2016, 2017).¹ While interviewees in the larger study had a wider range of gender identities and familial arrangements, the two interviews excerpted here were with three cisgender mothers (one couple and one single parent) who were lesbian or bisexual, all of whom were white. The larger set of parent interviewees included one trans parent, three parents of color, and three cisgender fathers. None of the parents interviewed were living in poverty. Given the consistent associations of contagion with poverty, racialization, and colonization, further investigations of how contagion operates in racialized, indigenous, trans, and low-income parents' narratives are certainly needed.

Passages from these particular interviews were selected that most clearly addressed questions of surveillance and contagion. These were not, however, specific questions that I asked in the interview, nor does this analysis encompass

these two transcripts in their entirety. Other parents in the study may well have offered very different ideas.

The two passages selected engage with the complex discourses that situate queer/crip contagion. In doing this work, I rely not only on critical theory but also on narrative methods of discourse analysis (Bridgens 2009; Fisher and Goodley 2007; Goodley and Tregaskis 2006; Gee 2005; Riessman 2008). I examined how these parents responded to, resisted, incorporated, and modified dominant discourses in which disability is seen as only and always a problem in danger of spreading, and mothers as responsible for working to reduce disability's impact and/or taking the blame for its appearance.

The two interviews selected here are not presumed to generalize as representatives or types of parent experience or queer mother experience, and indeed do not even present the entirety of either transcript. In contrast to some narrative work on health (e.g., Frank 1995), I do not propose a set of common storylines into which parent narratives can be sorted. Instead, I bring together excerpts from the narratives shared with me as a way to explore how these particular parents explain and make sense of their experiences of rubbing against *expert* or otherwise dominant stories of queerness, disability, and contagion. I cite them in detail to encourage further reflection and questioning on the part of researchers and others, and to unsettle the notion of a standard narrative or counternarrative.

I also draw upon other disability studies work that examines how moments of everyday language produce and foreclose possible valuations of bodies, minds, and ways of being (e.g., Clare 2017; Kafer 2013; Titchkosky 2007). As such, I analyze extended exchanges rather than cutting and grouping sentences or words purely by content. In responding to the call to consider queer/crip contagion, I also attend to where these narratives may be repurposing normative beliefs, practices, and language. Queer and crip can be used as verbs as well as nouns, and in their nonnormative actions can themselves be difficult to contain or segregate. I hope that contagion can, in this sense, offer new connections across experiences through what Mitchell and Snyder call “politics of atypicality,” challenging and offering alternatives to the practices of quarantine and cure, and the imperatives of neoliberal inclusion (2015, 117–18).

Proximity and “Subtle Neglect”

Contagion discourses rely on ideas of contact, of contiguous space and time as a point of causality where people or other vectors of possible transmission converge (Chen 2012; Halberstam 2011). Proximity becomes key in terms of risk, the likelihood that what one is, has, or will be will then affect others. In familial closeness, spatiotemporal and relational elements intermingle, such that women, in particular, are tasked with regulating the appropriate amount of time, space, and affective connection among family members (Ahmed 2010).

Dominant discourses of disability and parenting rely upon and produce normative notions of proximity to delimit desired relations and paths: people are seen to be close or distant to others, for example, or progressing toward or away from desirable outcomes and timelines (see McGuire 2013). Following Sara Ahmed's queer phenomenological orientation of "bringing what is 'behind' to the front" (2006, 4), interviews with parents offer opportunities to question the spaces and backgrounds in which professional encounters occur. While the scenes described in the parent interviews varied widely, many interviewees discussed encounters between themselves as parents and different types of professionals, particularly gesturing toward the challenges of negotiating time and space as they moved across professional expectations and environments.

In one excerpt from an interview with co-parents Jan and Annette, their memory of an encounter with a clinician serves to highlight larger discursive beliefs about the spaces where disabled children and their family members should, and should not, be. Throughout, notions of proximity and contagion bring the mothers' attention to the times and spaces in which difference may be seen and (re)produced, and to the ways that difference can be seen to spread within and across kinship relations, and how family members are differentially cast as vulnerable/valuable, responsible, dangerous/expendable.

Annette and Jan tell the story of an encounter when their son, Simon, was at his second or third visit at a private occupational therapist's office to help him with his handwriting and other fine motor skills. Annette starts the telling by asking Jan, "Remember that time when we were at the occupational therapist's office?"² She then describes the scene, accounting for each parent with each of their children, one (Jan) in the therapy room with the designated patient, Simon, and the other parent (Annette) caring for the younger child, James, in the waiting area. Already, we see that what happens in and around disability service systems cannot be restricted to the formal encounter between patient and clinician in the designated clinical time and space, to what might be written up in an assessment or clinical note. This encounter takes place in a liminal zone, a waiting room where the one parent and sibling are not only waiting, but also playing. We see both parents also engaged in the work of waiting and being with their children, although only one parent might appear in the clinical record of progress notes, if at all. We can assume these parents had already organized their individual and family activities to prepare and bring both children and both parents to the appointment, but until then, they had assumed that only one child, the child "in there," the realm of official therapeutic scrutiny, was going to be under the professional's gaze.

In other words, Annette is *not* waiting to hear what the therapist has to say about her younger child.

Annette: So, and we, we brought James in there, so he's playing with me in the waiting room and I think you [Jan] were in there. And [the occupational

therapist] comes out, and she's like, oh you know, and she sees little James, and she says to us, basically, you have got to get that kid—James—into some programs. Preschool, daycare, anything. Because right now, his role model is an autistic older brother. And, like, he's going to, like he's not autistic, you can see that he's not autistic. And

Jan: He's going to pick it up.

A: He's gotta, like, get away from this kid. Pretty much. Was what I got. No, what else? And, yeah! That we subtly neglected James.

J: "It's called subtle neglect."

A: Was what she said. I was just like [gasping for air noise].

I: In the waiting room!?

Annette alerts us that the occupational therapist (OT) offered unexpected and apparently unsolicited advice on how to parent their youngest child, James. Annette's tone makes the therapist sound as if she is speaking off the cuff, in a casual but calm tone. Annette relays a story of a therapist who meant no ill harm, a story that is held in contrast with the devastating impact of her words.

The content and tone of Annette and Jan's exchange with the OT draw directly from dominant, medical, and educational notions of desirable reproduction. According to the occupational therapist, the presence of their eldest child, who has received an autism diagnosis, might produce autistic traits and behaviors in his younger sibling and hence transmit a way of being that the OT presents as undesirable. Such a transmission is accomplished through the older boy's proximity and his status as a role model to his younger sibling. The therapist exhorts the parents to take on the additional labor of seeking out and funding programs, such as preschool or daycare, so as to expose younger sibling James to normative (non-autistic) relations. This normative exposure is framed as a kind of inoculation against (the reproduction of) autism. Annette describes the OT as stating that "anything" would do, a move that underscores the presumed natural threat of autism and the related need for urgent parental response. These parents were being told that they had to do something to separate their children, right away.

There is a close proximity between the two young children, something that Annette describes as troubling for the therapist. As she explains what the therapist was saying, Annette tries out several phrases indicating that therapist saw a categorical difference between the two kids prefaced by an unfinished prediction of James' future: "And, like, he's going to, like he's not autistic, you can see that he's not autistic. And . . ." The two children are placed in separate categories, one "autistic," one "not autistic," calling on either "you" the parents or a universalized "you" to acknowledge the obvious visibility of this difference. These two children are not the same. Nevertheless, in Annette's telling, this divide between brothers is framed by a looming uncertainty about James' future: "he's going to . . ." Temporality is a component of the concerning proximity in

terms of the time they spend together, but also in the feared alteration of the what is yet to come. Contagion relies on a before and an after.

Jan then picks up her partner's unfinished prediction: "He's going to pick it up." Continuing the syntactic structure of Annette's final series of phrases, "he" is still James, the child that (everyone can "see") is "not autistic." But "autistic" has changed from adjective to an implied noun. We had "an autistic older brother" and a "not autistic" younger brother. Now we have an "it" that is unnamed but immediately interpretable to all as the thing that makes non-autistic more, or entirely, autistic. "It" is unclear in its exact identity, as either "autism" or "autistic behaviors" or "autistic traits," but unlike the framing of those who are or are not "autistic," now we have a possibility that James will "pick [something] up," and it will be to his detriment. "Pick it up" can be read as instructive ("he will pick the alphabet up when he goes to school"), social ("the things he picks up from his friends!"), or as contagious ("I worry he picked something up at school"). This ambiguity in the expression links it with both with the suggestion that James needs a different (read: normative or non-autistic) educational and social experience—preschool or daycare—and also with the medicalized setting of the waiting room and diagnostic categorization of James as "not autistic."

When Annette recounts that the therapist communicated, "He's gotta, like, get away from this kid," we once again move away from "it" of autism/autistic traits or behaviors and back to the children. James continues as the assumed subject. Up until this point, Simon (or perhaps just Simon's autism or "it") has been present as a threat, but not as an active agent. He has been linguistically left in the other room, and indeed we never learn how close he was to this encounter, nor whether he witnessed the exchange. Annette here brings him in again, still as the threatening object, but now as "this kid" rather than "an autistic brother" or the implied source of "it." "This kid," Simon, reflects the designation of James as "that kid," flipping around the associations of proximity so that Simon is represented as closer (this one) to the clinician's perspective, and James as the more distant (that one), but, it seems, not distant enough. In voicing her understanding of the OT's statement, Annette highlights the imminent threat of contagion the OT sees in Simon's physical proximity to James. She uses a different social register in this statement from before, shifting from "you have got to get that kid" and "you can see that he's not autistic" to a more informal and adamant "He's gotta, like, get away from this kid." In this changed phrasing, and then in her subsequent phrases, Annette backs away from the certainty of her retelling. "Pretty much. Was what I got." She was there, as was Jan, but she flags that her words should not be interpreted as exact, or as objectively removed from her own memory and understanding. She offers me, the audience, the possibility that she may have "gotten" something wrong, and that this summary was how the therapist's words were received but may not have followed the OT's wording or intent.

Annette then adds to her summary of the encounter. “No, what else? And yeah!” Here her phrasing shifts back to the more professional/formal register: “That we subtly neglected James.” Jan then supplements and supports this addition by apparently quoting the OT: “It’s called subtle neglect.” Annette endorses this quotation by finishing up “Was what she said.” In the change between Annette’s summarizing statement and Jan’s quotation, the syntax becomes depersonalized and more diagnostic/clinical. “That we subtly neglected James” puts Annette, Jan, and James in a particular type of relationship. “It’s called subtle neglect” asserts a categorical statement from expert authorities beyond the room, about the types of relationships seen among certain abstracted parents and certain abstracted children. The OT is, in this phrasing, informing Annette and Jan that their behavior can be diagnosed in a professionally known, expected, and pathologized way, and that she, as a professional, has the authority and status to do so.

The concept of inappropriate proximity also clings to this unofficial diagnosis. “Neglect” identifies a lack of parental attention and presence, here toward James, in direct contrast to the presence of feared attention and proximity of Simon as an “autistic brother.” In keeping James in the presence of Simon, and simultaneously in their own presence rather than at preschool or daycare, the OT claims that Annette and Jan are not truly present at all. “Neglect” is a category of child maltreatment that is broadly recognized as a form of extremely inadequate—even abusive—parenting that might even result in the removal of a child from parents’ custody; its application in child welfare is largely associated with indigenous and racialized mothers, and mothers living in poverty (Swift 1995). “Subtle neglect” modifies the accusation, suggesting that Annette and Jan did not likely intend this lapse in good mothering, perhaps in recognition of their whiteness and middle-class privilege. “Subtle neglect” also suggests they, as nonprofessionals, would likely not recognize their own inadequacy. “Subtle neglect” in this case constructs a parental absence in *not* moving away from the rest of the family for at least part of the day. We have a “neglect” from too much attention, proximity, and togetherness.

Thus, we have moved from a statement about what Jan and Annette need to do differently in order to keep their younger child from “picking it up” to an accusation of their significant inadequacy as mothers. And the threat from this “subtle neglect,” once again, is that their younger child might be too close to their older, and might become more like him. In positioning this feared proximity and similarity as a demonstration of parental “neglect,” the OT condemns particular traits, children, and parental behaviours as so undesirable as to be threatening or even harmful.

The emotional impact of this statement is clear in the interview. Annette recounts “I was just like” and then makes a loud and prolonged gasping noise. This gasping indicates not only emotion but a physical response to the OT’s words, where she was temporarily unable to speak or do anything but try to

breathe through the shock. I then asked, probably due to my own understanding of space, “In the waiting room?” This is an odd verbal clarification, in retrospect, but I remember feeling that this was an unprovoked and unanticipated attack by the professional in what is usually a more public space, and in front of their children, and that this could only add to the shock and the inability to speak back that Annette’s gasp communicated. I was picturing myself as a parent, and also as a professional in this situation, and neither part of me would want such an exchange in a waiting room. Jan seems to endorse this focus on the space and timing of the exchange with a hearty “Yeah.”

After coughing following her gasp, Annette comes back to words and offers a clarification: “Nice lady,” to which Jan agreed, “Yeah.” In listening to the recording, it is clear that these were not sarcastic dismissals of the professional, but suggestions that “in spite of” this exchange she was still someone they valued and worked with. The two parents then try to find other ways of reading the exchange, possibly attributing the OT’s statement to a different cultural framework than their own, although Jan contradicts the cultural attribution Annette initially hazards.

A: I don’t know if it was just a [European country] thing, bit of an accent there, but she was blunt, right. And, “best for everybody,” right?

J: [Other ethnicity], that’s what she was.

A: Ah, okay. But then I felt like we had to debrief that for like an hour!

J: Yeah.⁴

This shorter exchange can be read as a way Annette and Jan are explaining the interaction with the service provider, trying to move away, once again, from the idea that the OT could or should have known how hurtful that statement would be to them. Indeed, Annette suggests the OT thought the suggested parenting arrangement would be in “everybody’s” best interests, rather than harmful to any of them. The casual othering inherent in the parents’ turn to the OT’s accent and ethnic background operates as a way of making sense of the harmful exchange in the waiting room. The parents mark the therapist as foreign, even as they attribute positive personality traits to her (“nice lady”). They move the narrative from one of negative personal intent to the possible role of “foreign” training and culture, before reasserting that the impact on them was very personal and, indeed, costly. “But then I felt like we had to debrief that for like an hour!”

As Annette and Jan invoke affective upheaval with this use of the word “debrief,” their use of language is in direct contradiction with dominant “taken-for-granted” expectations of parents of children with disabilities. In such depictions, parents are “upset” or “shocked” solely because of their child’s diagnosis and disability itself, often requiring reassurance from a professional (Landsman 2009). Here, the parents’ upset and shock is not attributed to the child’s diagnosis or disability but emerges from the suggestions and accusations of a professional

and the differential valuation of their two children, their parenting, and their family as a whole. The narrative content of dominant discourse is repurposed to critique the very system from which it emerges.

In this passage, we also see Annette emphasizing the time and energy that is required, not only in getting the family to places and talking to people and making decisions, but also in dealing with the feelings that remain after these encounters. The conversation in the waiting room was brief, as we hear it recounted, but it required extra time and “debriefing” from already busy parents before they could move on with their other activities. We see the time and energy and emotion that contending with one dominant storyline/interpretation of their family and parenting costs them. Moving away or back from or through this story takes joint effort, in addition to and lasting long after the actual encounter.

Queerness in terms of the mothers’ identities and queer family structure is neither explicitly referenced in this account, nor in the statements the OT makes. However, as Annette and Jan move through in the language of affective upheaval, they create what can be considered a queer-crip space for alternative valuations that then can spread into their familial relations and meanings. First Annette invokes the devastating impact of the professional’s comment but then follows with a marked shift that offers a return to the particularity of her children and away from diagnostic categories and professional opinions.

A: It just killed me. And then I finally came to—Simon’s a great older brother! A great older brother. And, you know, James chews his clothes and chews shit like Simon does, and I don’t know if it’s because James is anxious or because he’s copying him. I think it’s because he’s copying him. And that’s kind of unfortunate, because it’s gross. But he’s a great older brother.

J: Yeah.⁵

When Annette explains that at first the experience “just killed me,” she states the deadly impact of certain moments where children—and in this case, their parents—don’t measure up within dominant and expert-driven value systems. Annette describes how this assessment of her family was unliveable for her, as a parent, until she could snap out of it or move away from it: “And then I finally came to.” The official discourse of professional authority, autistic segregation, and neglectful mothers left no livable space for Annette’s child and for her family. As others have written, such devaluation of autistic people has had deadly consequences in too many instances (McGuire 2016).

With the repetition of “Simon’s a great older brother. A great older brother,” Annette reasserts her own knowledge of her family and their relations beyond the professional assessment, and reasserts Simon’s personhood and value. Simon has a name for the first time in the account, and he is the subject of the repeated phrase. Annette does not reify the division between her children, and even states that James may, indeed, have learned to act like his brother, but that this

is not a reason to keep the children apart or take away the “great older brother” status. Simon is a person with meaningful contributions and relations, rather than a diagnosis that may spread. She “comes back,” in language that suggests awakening from unconsciousness or arriving in a new place, to the knowledge that something of value could be “learned” from an autistic brother. This possibility that the mothers could hold alternate futures, and that their particular queer-crip family could thrive without professional approval, simultaneously supports a queer-crip refashioning of space, time, and relationship that rejects normative predictions and priorities (Kafer 2013; Mitchell and Snyder 2015).

To be sure that I understand her perspective on this event and on her children more generally, Annette clarifies: “You know what I mean?” She does know, as does Jan, that I also have two children, one of them with an autism diagnosis. This knowledge may have facilitated the entire narrative, the expectation that I would know what she means, and be able to identify with the strong emotions the story recounted and evoked for these parents. Annette then clarifies her own stance:

A: You know what I mean? So I don’t care if it’s about autism or anyway, I did say. But. Uhhhh. That was really

J: That was hard. Yeah.

A: That was a really hard moment. And she didn’t mean it that way.

J: But we sort of took it, like, hard. Yeah.

A: That was like, ohhhhhh.

J: Yeah, subtle neglect.⁶

As Annette trails off in explaining her verbal response to the OT in that moment, I learn that this immediate and verbal response is not the important part of the story for her and for Jan. They are back with the emotional upset, the impact of the OT’s words in that moment and as they retell it, regardless of the OT’s intent or their own beliefs about their children. They move away from blaming the individual professional, once again clarifying that “she didn’t mean it that way,” but the impact is the same, and almost beyond words. As a conclusion to the longer narrative, Jan reintroduces the OT’s term “subtle neglect” as central to how, and why, they “took it, like, hard.” Even if, as Annette says, “I don’t care if it’s about autism or anyway,” the impact of others who *do* care is very real.

In a coda to this narrative, however, Annette and Jan move back to a critique of their own accusation, and a normalization of their parental inadequacies and their children’s differential treatment. This time they cite an encounter with a different professional.

A: And I’m telling my therapist and she’s like, [*whisper*] every second child is subtly neglected. [*J and I laugh.*] That’s what she does. She normalizes everything for me. Every kid is like that! It’s all fine.

J: And wait until you get the third one. The third one is not subtly neglected.

[All laugh.] Explicit neglect!

A: [coughing/laughing] Outwardly!⁷

This passage moves quickly from almost inarticulate pain to riotous and communal laughter. In changing the meaning of “neglect” into something that can be laughed about, the OT’s accusation is transformed into a joke among the three of us, leaving us all laughing at the impossibility of meeting dominant standards of what mothers should and should not do. Children are no longer presented as “autistic” and “not autistic” but as children in the context of a family that, inevitably, has limited resources and differential treatment. The pathology of the accusation, and the pain of the response, are both diffused. Contagious laughter that has been honed by our shared queer-crip mothering slant then spreads between us, and incites communal critique that extends beyond this family and this moment.

“Yuckiness,” Unwanted Conversations, and Blame

While queer-crip contagion can certainly appear as the feared transfer of disability from one child to another, with resultant recommendations for inoculation and quarantine, contagion can also interpret queer acts and relations as a “cause” or reinforcement of impairment and distress. Not all audiences will make the same affective connections or come to the same conclusions about what they mean: “To be affected by another does not mean that an affect simply passes or “leaps” from one body to another. The affect becomes an object *only given the contingency of how we are affected*. We might be affected differently by what gets passed around” (Ahmed 2010, 39; original emphasis). Thus, responses to a series of professional questions about family members and relationships may be heard as a relentless construction of “what and who caused problems for others.” Even as narrators may have their own explanations, audiences often expect certain series of events to flow through their narratives. Any individual telling could be going upstream.

In this section, I consider an excerpt from one recently separated parent, Lenore. Lenore talks about the dissolution of her lesbian/queer marriage as both something that is directly connected to parenting a child and something that is tricky and risky to discuss, particularly because service providers often ask that she do so. In this passage, the topic is presented as difficult to explain, risky to address, and costly to tell. She makes sure that I understand enough about her own history of being asked such questions in order to contextualize her not wanting to tell, or only wanting to tell if it will be understood in a particular way. The emotional impact of telling when only certain questions are asked, or only certain answers are understood, comes across in how the parent shapes her narrative of not wanting to tell at all.

Strains to and ruptures in relationships are common themes in discourses of what disability and queerness can cause. A core element of discussions about “burden” in parenting a disabled child is the belief that a child’s disability strains parents’ couple relationships (Clare 2017; McGuire 2016; Titchkosky 2007). Within mainstream Western culture, unhappy marriages and failed relationships are often touted as further evidence of the ‘problem’ of disability and its inevitable, negative impact on caregivers, an impact that is seen as unconnected to any systemic or sociocultural factors. Indeed, a number of parents I spoke with addressed ways in which their couple relationships—including same-gender and different-gender relationships—have been negatively affected in the process of parenting and interacting with disability service systems.

An archetype of the “unhappy queer” also exerts particular pressure on queer-identified individuals and families to be happy or to be cautious how their unhappiness is broadcast (Ahmed 2010). In the context of more evidently “queer” relationships, such strain or separation can be used to reinforce larger discourses about the undesirability of LGBTQ relationships, and offer fodder for arguments against queer parenting (Riggle, Rostosky, and Horne 2010; Riggs 2007). Work by Halberstam (2011), Chen (2014), and Mitchell and Snyder (2015) also urges us to reconsider instances of queer-crip failure as productive in their refusal of neoliberal logics and resulting critiques. In this light, the halting and circling narrative structure of the account that follows can be seen as a refusal to “give a straight answer” in order to reclaim the terms of how experiences are understood to relate to each other. It is in this sense of productive failure that “yuckiness” emerges as an affective indictment of normativity.

This exchange occurred after I had asked Lenore who was in her family and clarified what legal custody arrangements they had. First, I cite the curiosity of “service providers” as the reason behind my own questions. Lenore then picks up on my mention that “people want to know” and goes on to recount her struggle in talking about the dissolution of this relationship with a range of providers/questioners.

I: I’m just sort of thinking of all those interactions with service providers and some of the texts that we talked about; sometimes people want to know what the legal status of all those legal arrangements are.

Lenore: Yeah. Probably one of my least favorite things to discuss. Because I think that one of the—I don’t know if you want me to answer anything about the service provider piece, but when—for example, uh, at the school, or Sophie has a psychiatrist/psychologist team, and she has a speech therapist, and she has a, our pediatrician, and she has occupational therapy at school, and she has all different sorts of the respite workers, respite services, things like that.⁸

Here we see Lenore starting to make an explicit connection between “one of my least favorite things to discuss” and “because,” but the explanation is suspended. She apparently shifts back to clarifying the scope of my own interest, and then,

reassured (nonverbally) that I do want her to “answer anything about the service provider piece,” she begins to list examples of providers with whom she and her daughter, Sophie, interact. As she outlines the frequency and number of her interactions with service providers, the relevance of this list to why she does not like to discuss her separation is still tentative, but I learn how often she is asked to answer questions and explain things.

Lenore then explains further, about “one of the really big challenges is,” and as the audience I might anticipate more of the reason why this is a difficult topic, but the causal connection is still hesitant and unclear.

One of the really big challenges is, we—at least my soon-to-be ex-partner—attribute the breakdown of our marriage to the stress of disability parenting. Like, that is what she says. She says that is the reason she had to leave. She could not cope living with a child with such serious disabilities. And having no time, ever, to herself. That’s what it felt like.⁹

Lenore recounts her partner’s experience in terms of common burden narratives, using terms such as “the stress of disability parenting,” “the reason,” “could not cope living with a child with such serious disabilities,” and “no time.” She frames this as someone else’s experience, apparently, but ends with “That’s what it felt like.” As listeners, we still do not know what Lenore, herself, “felt,” although we can postulate what feelings being asked to recount this “breakdown” over and over to different professionals might then bring up for Lenore.

Lenore then brings a more systemic analysis together with her ex’s explanation of the reasons for separation. In this new formulation, she recounts that while there are so many service providers asking questions, there are, in other ways, not enough services. This becomes the new problem, beyond “stress” or “serious disabilities.”

And we could not get—she [the co-parent] has chronic health issues and we could not get enough respite services or support or anything like that to be able to help fast enough, I think, to be able to meet her need. And so she was really frustrated with that because she said that she didn’t want our relationship to break down but it did, just for plain old, what we ended up doing for the last about two years of our relationship was just tag teaming.¹⁰

Here Lenore explains more about how the “disability parenting” is not the only presence of disability or illness in their lives. When one of the mothers also has “chronic health issues,” the absence of services ostensibly for the child becomes a more acute problem. This highlights the possible assumption in service provision that only one person can have a support need within a family. Here Lenore flags that she is offering her own interpretation, “I think,” about meeting “her need,” and not necessarily repeating what her partner had offered as explanation.

She then returns to the language of the partner “because she said that she didn’t want our relationship to break down” and we hear “but it did, just for

plain old” as a mundane explanation, and she turns to the everyday experience of living with their child.

Introduced and framed by “Because our child has very serious problems,” Lenore starts what seems to be an expected narrative of stress, highlighting the work that they were not able to do.

Because our child has really serious problems and in order to even be able to go to the grocery store or be able to go the bathroom in private, the other person had to be on. So we never saw each other. And when we did we were exhausted.¹¹

This passage more clearly circles toward explaining the “reasons for why the marriage dissolved” and “service provider piece,” and focuses on presumed universal and everyday experiences such as going to the grocery store or the bathroom with a lens of constantly having to “be on.”

Lenore then offers another piece of the explanation by telling another causal story, explaining why they moved to a particular city. In this explanation, she also provides an example of “really serious problems” and “not enough support.”

So we had some promise of . . . why we moved to Toronto is my in-laws live north of Toronto. And they had promised they would help. They took Sophie a couple of times and they were like, whoa, we can’t do this.¹²

This smaller story describes a significant attempt, a family move, in order to get support as a family, this time outside of formal service systems. But, once again, it also describes another failure in support where the care providers, here Sophie’s grandparents, found they could not continue to offer the promised help. Lenore has listed many people, from her former partner to different professionals to family members, none of whom have been able to meet the “needs” of their daughter, or of Lenore herself.

At this point, Lenore starts to rework the narrative of ostensible relationship “failure” into an accounting of systemic failures to support the mothers and their child, even as providers continue to ask questions about the mothers’ and child’s possible inadequacies. Only once I, the listener, have enough of the background does she answer my original question and come back to why she does not like to talk about the marital breakdown.

And so we couldn’t get the right kind of help fast enough, I should say, to make the difference. And then, so, I’m in the process, since last summer, of dealing with service providers who always ask, “Are there changes in your family structure?” And I have to say, “My spouse and I have separated.”¹³

In going from the tone and narrative particularity of “why she had to leave” and “whoa, we can’t do this,” to “changes in your family structure,” and “separated,” Lenore shifts from an informal/everyday to a professional/clinical/legal

register that makes “changes in your family structure” a category that needs to be asked about and noted. “And I have to say” suggests this is a reluctant disclosure of a separation, a requirement for those much-needed but elusive and insufficient services. I am reminded as the interviewer that I have just started our conversation by asking questions, yet again, about her family and how it has changed.

Lenore then returns to “challenge,” a term she had introduced as part of her explanation of why this is difficult to talk about before explaining her ex-partner’s rationale for leaving the relationship. Here, however, the “really big challenging piece” is in meeting the formal and abstracted notions of “changes in family structure” and the questions it imposes. She starts to question the questions. Why is this topic, this change, something professionals are so eager to discuss? And what interpretations do they bring to her answer?

You know, that’s also a really big challenging piece. Because to go right to I think we’re handling it as well we can, doing the very best that we can, given the whole situation, that it was like uh, it’s not as if anybody’s offering me any extra services or supports or anything like that.¹⁴

Lenore then asserts her own queer-crip challenge by pointing out the productivity of this “queer failure” of parental separation (Halberstam 2011; Mitchell and Snyder 2015).

Now I’m doing this on my own, for the most part. With [co-parent] taking Sophie every other weekend, which is surprisingly good respite for me. Which is interesting. Something we didn’t have before.¹⁵

Only through the dissolution of the couple’s relationship could they find additional “respite” as individual parents. Separation does not have to only equal loss but also a refashioning of how time and space are divided outside of professional or systemic supports.

The conclusion to the queer-crip story that she tells is affective and ongoing, as she responds to providers’ fears of the contagious ill-feeling that separation and “changes” may cause her daughter. As in the narrative of Annette and Jan, encounters with service providers have an ongoing emotional impact on Lenore’s everyday experience. Here she starts to summarize but struggles to find the exact word to describe how these interactions continue to make her feel.

But there ends up being um, almost like a, I’m kind of embarrassed, not that I’m embarrassed but an interaction that happens like, ‘Oh, poor Sophie, her family has split up, we’ll watch for, if she has bad behaviors or challenging behaviors or things like that, it could be because of the divorce you know.’¹⁶

Lenore here describes a quickly developing process of attribution in which her daughter’s well-being and behaviors are seen as always already *in response* to the parents’ separation. Blame hovers, ever ready, in these interactions with

service providers, where a contagious series of effects are anticipated to flow from queer relational reconfiguring. The possibility of embarrassment, of being caught doing something socially censured, is also floated but rejected as not quite encompassing Lenore's feelings. Perhaps she knows that she is being asked to be embarrassed but that this has its own assumptions of parental wrongdoing, as seen in "Oh, poor Sophie." This interpretation of "change in family structure" introduces additional surveillance, as the professionals "watch for" particular behaviors with a causal explanation on reserve. Thus, while Sophie's behaviors may not have been deemed significant enough to respond to with additional services, and may have formed her ex-partner's rationale for leaving the marriage, they may now be seen as needing attention because the cause can be attributed to her parents and "changed" family structure.

Lenore is not telling a "happy family" story with a queer, separated, crip twist, but instead addressing change as a part of "the whole situation" of families and relationships. "Are there any changes in your family structure?" is revealed as a standardized question that holds people and parents to a standard of impossible constancy, a heteronormative "happy ending" background for idealized child development. Belief in this normative story urges all involved to scan the horizon for inevitable failures and their contagious effects.

The inescapability of a heteronormative interpretation that queerness causes problems, particularly in proximity to children, becomes most explicit in Lenore's concluding statement.

And some of this stuff is all normal and natural and any child who goes through divorce would get that. But there seems to be some level of just yuckiness of it, when discussing queer divorce with people who are not queer. I just don't want to have that conversation. I just don't want to have it. Yeah.¹⁷

Lenore starts with an allowance that some of the "difficulty" she faces in her encounters could be part of separation and divorce more generally, and not necessarily only about disability and queerness. Perhaps this is the interpretation or objection she anticipates from me, or from other readers/listeners, including the providers themselves. But Lenore returns to the specifics and messiness—the "yuckiness"—of her own experience.

"Yuckiness" echoes but repurposes the disgusted withdrawal that accompanies fears of contagion and their ableist and racist histories. By prefacing her following statement with "but," she asserts that the "normal and natural" explanation is not sufficient to account for her subjective experiences in answering providers' questions and anticipating/responding to their reactions, and she realigns the dominant notions of matter-out-of-place, people in need of surveillance, that are so central to hygiene and pollution discourse (Valverde 2008). "Yuckiness" is shifted from its usual association with queer, crip, racialized bodies and relationships to the demands and responses of neoliberal providers, as they seek to pin pathology on certain Others.

Lenore's use of "yuckiness" offers an affective objection that centers queer-crip perspectives to scrutinize normative service providers and discourses. She highlights the importance of facing "not queer" questioners as key to the "yuckiness," such that in talking to "not queer" people about her "queer divorce," there is a different potential uptake than in talking about "not-queer" divorce or in talking with "queer people." She does not give stories of providers attributing Sophie's problems to the parents' queerness, or holding the parents directly responsible for causing their daughter pain through their queerness and divorce. And yet her interpretation—her feelings of "yuckiness," her observation of what "seems to be"—is central to her explanation. In talking with me, a researcher she knows to be a queer parent of a disabled child, she hazards that I will understand this as a reliable and meaningful explanation. She takes the chance that I will understand that queerness does not automatically harm children, and that queer divorce does not have to support anti-queer beliefs, and that she is not necessarily a bad mother if her child has "problems."

Disability is central to these repeated experiences of "yuckiness." Lenore's reluctant accounting and the unavoidable interpretations of service providers are required and justified through the landscape of professional monitoring of disability. In "queer" families without disability identities and labels, "non-queer" questioners might be more readily avoided and dismissed. However, Lenore's account of the neoliberal landscape wherein "good" parents of disabled children are required/expected to obtain "interventions" even as there is a scarcity of available and affordable services. This framework of required screenings by multiple professionals brings with it a measured calculus of risk where "yuckiness" must be broached and handled by individuals seeking supports. "Yuckiness" can then be seen to spread into her family's life against Lenore's will, despite her narrative and interpretive efforts and desires. In contrast to Annette's and Jan's account, there is no humor spreading at the end, but an affective taint that defies clear categorization, one that left me feeling both shared outsider anger and discomfort at my own complicity in the work of questioning and interpreting.

In her story of ongoing professional scrutiny and unmet needs both contributing to and continuing following her divorce, Lenore's presentation of "yuckiness" offers a perspective on the contagious elements of dominant anti-queer and antidisability explanations. "Yuckiness" moves us away from outright verbal slander or overt denial of service as the dominant modes of hierarchy under neoliberal service provision. Instead, the tone and environment in which questions are asked and answers received emerge as the focus, and danger lurks. Notions of causality and desirable reproduction circulate in the assumed, the unasked, and the perpetually questioned aspects of Lenore's everyday experience, as well as in how she feels when called upon to answer. In asserting that she "does not want" to talk about this, she makes me understand that she may have to talk, and that she knows she cannot fully restrict the interpretation

that others bring to her words. By flagging the power relations and concomitant interpretive frameworks into which her accounts are questioned and received, she asks that we, her audience, question what we ask and how we hear the response. What will we do next with this story?

Conclusion: Impure Resistance

In this analysis, I build upon the work of Fisher and Goodley (2007) to the extent that I use two examples of mothers' narratives to show the inadequacies of individualistic, linear, disability-as-tragedy scripts, or future-oriented "challenge" narratives that prioritize expert-led efforts toward "normalcy." However, I have also been influenced by critiques from Ruth Bridgens (2009) that we need to take into account the ways that parents have real limits on their narrative and material resources. Parents should not be typecast as uniquely "creative" and "empowered." My encounters with parents and their narratives in this project reinforce that there is no singular storyline of parenting and disability. Nor is there a stable duality of "dominant narrative" and "counternarrative." It is dangerously reductive to see parents as only and always presenting empowered narrative creativity when there are so many social and institutional forces that impose constraints on how parents can talk, think, and behave, even as they tell stories about their families to a researcher. Further, as Halberstam notes, "it is odd that we want to connect gay sex, wherever we may find it, to political radicalism" (2011, 151). The investments of queerness, disability, and parenting do not always coalesce. In these interviews, more than one set or series of emotions, and more than one narrative structure, might be considered dominant. The stringent requirements of constructing meaning within complex histories and relations may make a neatly coherent narrative unattainable—even undesirable. Such failures to be contained and consistent may themselves be the starting points for queer/crip analysis, and spread unexpectedly.

I find the work of Judith Butler (1993, 2005) particularly helpful in steering between seeing parents' narratives as "only" counternarratives or "only" reproductions of dominant stories. Butler uses a contagion-appropriate phrasing as she highlights that there is no possibility of a pure resistance to any discursive stance, and talks of the "resources inevitably impure" that we all rely upon in the construction of subjectivity and identity (Butler 1993, 241). Since we all act and create meanings within a discursive sociohistorical context, we cannot escape the meanings that are available in our place, time, and embodiment, but we also reproduce and repurpose these very meanings in our own daily lives. Thus, queer mothers in this study cannot avoid broader discursive meanings and associations of terms such as diagnosis, mother, denial, or future. The narrative format and content have both been shaped by what has come before, and parents themselves contend with the connections and causalities that they know are expected and the terms that are, to some extent, predetermined.

But any telling also has its moment, encounter, audience, purpose, and cannot be relied upon to faithfully reproduce the expected terms in exactly and only the expected ways. The realm of performative slippage, recombination, and repurposing are where this analysis hopes to focus our attention, to the transmission of meanings that move through and beyond contagion to question the clear bounds of quarantine. These “resources inevitably impure” are all that parents have to draw upon, and yet they do so in varied, creative, and innovative ways. As scholars who traverse disciplinary barriers and theoretical notions of purity, our own attention to contagion and quarantine may lead to further interrogations, particularly of the colonial roots of those disciplinary bounds (Chen 2014). What are we being asked to desire in our own work, and what are we accused of subtly neglecting from our very proximity? What are we being asked to reproduce, eliminate, or cordon off in our scholarly practices, and where do critiques lurk in yuckiness? How are we asked to conceptualize queerness and disability as neatly contained within certain clearly demarcated bodies and their desires? Just as importantly, how do we develop a theory that accounts for its own debts, its reliance upon the accretions of moments and relations, on the work done by people who grapple with the risks they are asked to embody?

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Notes

1. The original study included fifteen parents who (1) identified as lesbian, gay, bisexual, trans, or queer, (2) identified as parents to at least one child with a designated disability (whether or not the parents concurred with any or all diagnoses or assessments), and (3) received disability-related services for their child in the Toronto area. An additional six key informants were also interviewed; these were selected by their established activist, research, and community development work with either LGBTQ parents or parents of disabled children. Their interviews were not used as primary data but rather as guides for the questions and analysis in parent interviews.

2. Interview with co-parents, February 9, 2014.
3. Interview with co-parents, February 9, 2014.
4. Interview with co-parents, February 9, 2014.
5. Interview with co-parents, February 9, 2014.
6. Interview with co-parents, February 9, 2014.
7. Interview with co-parents, February 9, 2014.
8. Interview with parent, January 15, 2014.

9. Interview with parent, January 15, 2014.
10. Interview with parent, January 15, 2014.
11. Interview with parent, January 15, 2014.
12. Interview with parent, January 15, 2014.
13. Interview with parent, January 15, 2014.
14. Interview with parent, January 15, 2014.
15. Interview with parent, January 15, 2014.
16. Interview with parent, January 15, 2014.
17. Interview with parent, January 15, 2014.

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