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Beyond Mystery Babies:
Undiagnosis in a Diagnostic Age

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Beyond Mystery Babies:
Undiagnosis in a Diagnostic Age

by

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Dedication

For Alexander.

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Beyond Mystery Babies: Undiagnosis in a Diagnostic Age

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Supervisor: Kathleen Stewart

This dissertation analyzes shifting understandings and lived experiences of undiagnosed disabilities, probing contemporary notions of bodily and intellectual difference. Thanks to new biomedical technologies and diagnostic frameworks, diagnoses are now possible for many people who would have received an ambiguous label of "multiple disabilities" in the past. This gives new forms of hope for diagnostic knowledge, while calling into question the social and practical significance of extremely rare diagnoses about which little is known.

This study asks what it means to be – and often to remain – undiagnosed in the contemporary U.S., and how this shapes broader beliefs, meanings, and practices surrounding disability. In a time of rising disability prevalence, complete with increased public awareness, shifting modes of clinical versus genetic identification of differences, and new forms of representation, what does it mean to remain undiagnosed? What might reside in these shadows? This analysis pays particular attention to family experiences, belonging, and the affective dimensions of disability in the everyday, and draws on anthropology, disability studies, and science and technology studies. Ultimately, this dissertation argues for a conceptual shift in approaching undiagnosis, calling for renewed attention to the complex social worlds of these individuals and their families as an emergent disability community.

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Chapter 1

What's in a Name? Undiagnosis in a Diagnostic Age

Case Notes

I got to know Mary during several disability leadership trainings. Her son, Jonathan, was nine years old when we met. He is blind, does not speak or sign, has intellectual disabilities, and walks with the help of a cane; he's considered to be on the deafblind spectrum, although he still has some hearing. Jonathan loves horseback riding and rides regularly at a therapeutic center in the city where he lives. When the boy meets someone, he slowly traces their hands with his fingers, paying careful attention to any identifying features, such as scars or jewelry.

Jonathan was born at 26 weeks gestation, a full three months premature. He is his parents' only child. Mary confided one day that she was scared to try for more, in part because her caregiving responsibilities had her spread so thin already. A so-called "million-dollar baby," Jonathan spent 14 months in the neonatal intensive care unit (NICU), and his mother was diagnosed a decade later with post-traumatic stress disorder (PTSD) from the ordeal. Jonathan's survival is largely the result of stunning advances in newborn care over recent decades, yet he embodies a curiously modern paradox: his disabilities are inextricably linked to medical progress itself. In the past, children like Jonathan did not live. The same technologies that enabled his survival have also helped ensure his bodily and intellectual difference. Or so we think.

Medical specialists suspect Jonathan might have an underlying and unidentified genetic disorder. It is possible that there is more to his story than just prematurity, that he was never slated for the assumed non-disabled (or "typical") future that his parents imagined. Lacking a diagnosis, his doctors simply refer to his condition as "the Jonathan Syndrome." His family has undergone extensive genetic testing in the hope that, one day, they will receive a diagnosis. For now, however, they wait.

FRAMING UNDIAGNOSIS

This dissertation consists of a collection of essays designed to be read either individually or as a cohesive study of undiagnosis. The first essay brings readers into the fray of undiagnosis, but the analysis pans out to questions of narrative, kinship, care, fringe, and enclosure in the chapters that follow. Together, these form part of a broader project on diagnostic ambiguity within disability worlds in the contemporary U.S.

This chapter uses ethnographic research to re-frame undiagnosis as an identity marker and lived experience that must be taken seriously in and of itself, even in an era that privileges genetic technologies and their associated frames of knowledge. It argues for a conceptual shift in approaching undiagnosis, privileging the complex social worlds of individuals – like the ones encountered throughout this study – whose diverse forms of intellectual, physical, sensory, and/or psychological difference defy categorization. This approach is grounded in the ambiguity of the present rather than in aspirations of future diagnostic identity. What happens if we re-configure undiagnosis as a state – a way-of-being – in its own right? Finally, this essay explores a curious thread underlying

this broader project: in a time of unprecedented disability diagnoses, complete with increased public awareness, shifting modes of clinical versus genetic identification of differences, and new forms of representation, what does it mean when millions of people remain undiagnosed? What might reside in these shadows, and what might be learned by bringing ambiguity and flux to the center of analysis?

The National Institutes of Health (NIH) estimates that 30-40% of children known to have disabilities in the United States do not have a diagnosis. There is no label for their recognized differences, which might include sensory impairments, behavioral issues, complex medical needs, physical disabilities, or distinctive facial features, to name a few possibilities. Forty percent is a staggering figure, yet there is a surprising lack of research on this population and, in many ways, it is regarded more as a collection of dispersed and individualized bodies rather than a potentially powerful, cohesive community. Appearing to be made up of mismatched pieces to different diagnostic puzzles, they do not make sense medically, politically, or socially. They are the children and adults who, until quite recently, were met by specialists with a shrug and a placeholder designation of “multiple disabilities.” To gain insights into family experiences with undiagnosis, this dissertation analyzes data gathered from a 16-month ethnographic study of families in the undiagnosed and rare disability community in Texas. This project also involved extensive digital research conducted via social media to connect with parents in the geographically dispersed undiagnosed disability community around the U.S.

For families, clinicians, and other disability specialists, a diagnosis is assumed to be paramount for several reasons. To begin, it is an instrumental tool

for securing medical resources and access to therapies. It is also supposed to reveal key pieces of medical information, such as life expectancy or the risk of co-occurring medical conditions. Diagnoses can point families toward possible therapeutic techniques, communication strategies, behavioral strategies, or educational approaches that have worked for others with the same condition. While securing a diagnosis can be a critical part of accessing such potential answers, the process is often much more complicated in cases of rare genetic syndromes or otherwise undiagnosed (or currently undiagnosable) disabilities. In such situations, a diagnosis might take years. It might never come.

From an affective standpoint, a diagnosis can usher parents into pre-existing disability communities. Whether via social media or in-person, such groups provide critical emotional support to families who might otherwise feel adrift and isolated, although this is typically not the case for parents of children with extremely rare diagnoses, for whom the communities simply do not exist. There are other possible emotional and psychological benefits to a diagnosis. It can reassure parents that they did not “cause” their children’s disabilities. Speculation regarding cause or blame was a fixture of my conversations with parents, particularly mothers. One woman had wondered if a fall late in pregnancy caused her child’s seizures and intellectual disabilities. Another was concerned initially that an illness early in her third trimester had contributed somehow to her daughter’s unexplained birthmarks, large head, low muscle tone, and developmental delay. A father who worked in the Texas oil fields worried that his exposure to chemicals had caused his son’s Rubenstein-Taybi syndrome, which occurs in approximately one in 125,000-300,000 births. These examples recall S. Lochlann Jain’s writings on cancer patients and survivors. As Jain

writes: “Trying ‘to know what the past holds,’ what alternatives and what necessities it contained, can become a near obsession…” (2013, 44). A diagnosis can offer an important antidote to such questioned pasts and temper parents’ imagined alternative futures for their offspring.

Parents spoke at length in interviews about their “diagnostic odysseys,” referring to the weeks, months, or often years spent searching for a diagnosis for a rare disease, disorder, or genetic syndrome. The period is typically marked by a series of visits to specialists, extensive testing, and results that are misleading, inconclusive, or simply turn up no answers. Within the constraints of the resources available, parents often seek help from all angles possible. Families visit specialists in their hometowns, states, and across the country. They join listservs and Facebook groups, attend conferences, read articles at *PubMed.gov* religiously, and network with other families in similar situations. Like Jonathan’s parents at the beginning of this essay, they hope to eventually secure a diagnosis – most likely one for a rare and sometimes little-known disorder. Children who are undiagnosed are not looking for the commonly recognized labels. Cerebral palsy, autism, and Down syndrome simply will not cut it. Their families have to dig deeper.

The rare and undiagnosed disability communities are inextricably linked, and the groups share considerable slippage. A disorder is considered rare if it affects fewer than 200,000 people in the U.S. It takes an average of seven years for someone with a rare disorder to receive a correct diagnosis. In the interim, they are undiagnosed, misdiagnosed, or a combination of the two. Virtually all of the families I met whose children had rare disorders had experienced a period in which their child was undiagnosed. For a few, this lasted only a several weeks or

months. For many, it took years. It was not uncommon to hear of individuals who did not receive a diagnosis well into their teens.

BEYOND MYSTERY BABIES

I borrow the term “mystery babies” from a mother I met. I was at a retreat for families of children with Charge syndrome, a rare genetic disorder found in approximately one in 10,000 live births. I struck up a conversation with the woman, who lived in a small Texas town. She and I had both stepped outside during a break between morning presentations, and I sipped coffee from a Styrofoam cup while she slowly smoked a cigarette. Since all of the attendees were either families or disability experts, there was an assumed common ground that facilitated spontaneous and easy exchanges. We were all insiders, in one way or another, and rapport was taken as a given.

I asked if she was a parent and explained that I was a researcher and also a disability sibling, and it went from there. Her daughter had not received a Charge diagnosis until adolescence – an increasingly rare occurrence with this syndrome, thanks to growing awareness of it among physicians. As she told me of her family’s struggle to obtain concrete answers regarding her daughter’s multiple sensory and intellectual disabilities, she recounted years of blurriness. “She’s a mystery baby,” the doctors and nurses would say, throwing up their hands. “She has her own syndrome.” Mystery baby. Her words stuck with me. The term implied individualization, it hinged on anomaly. It left me confused, anxious from its open-endedness.

Mystery babies are marked by a lack of diagnostic belonging, and families are acutely aware of their corresponding shortage of key affective and logistical

resources. They are largely on their own, at least until a particular category expands to include them, or a new genetic test reveals an underlying mutation that unifies these seemingly illogical bodies. Hearing impairments, unusual combinations of facial features, extra fingers, gastrointestinal or respiratory trouble, premature births, irregular heartbeats, cleft lips, missed developmental milestones. The pieces exceed current knowledge and are more than the sum of their parts.

How do these mystery babies connect to broader understandings of disability? There is a tendency to speak of disability in concrete terms, as if the labels are fixed, static, and universal, yet anthropology shows clearly the dynamic, socially situated nature of disability diagnoses and lived experiences. There have been pronounced shifts in what childhood disability means today, as exemplified by dramatic increases in diagnoses of neurological and developmental disabilities. The bodies and faces of disability have changed, yet undiagnosis remains a largely overlooked facet of this general phenomenon.

For the parents I met, diagnosis was equated with hope, curative potential, and new futures. It was associated with clarity, rendering difference concrete through biomedical knowledge claims. Angelman syndrome, Charge, Mowat-Wilson, Rubenstein-Taybi, Prader-Willi, Trisomy 13. Each of these designations referred to a diverse range of disability portraits, faces, and possible long-term outcomes, and yet a diagnosis remained a thing. It was sticky, making sense out of bodily, intellectual, and mental difference, and rendering new interpretations of the person in question for clinicians, therapists, family and peers. Significantly, it was also imbued with optimism for previously unimagined possibilities.

A diagnosis groups patients under umbrellas and, perhaps especially in our digital age, those umbrellas can give way to communities brought together by assumed commonalities in experiences, challenges, and needs. Anthropologist Paul Rabinow refers to such groupings as “biosocialities,” communities formed as a result of today’s biomedical technologies and modes of emerging classification (1996). A diagnosis can give families hope for futures once thought unattainable, or a window into life expectancy, risks, and needs. For children, it can secure necessary educational and therapeutic services that would otherwise be out of reach, since a diagnosis is still thought to be the cornerstone of meaningful and appropriate interventions – particularly when subsidized.

One must only take a cursory look around to realize that, in the contemporary U.S., disability is everywhere. It weaves together questions of kinship, bodies, care, biomedical progress narratives, normative ways of being, and the good life. As Rapp and Ginsburg have made clear (2010, 2013), it is central to the human experience and, as such, demands anthropological attention. The topic of disability is a fixture in today’s media. People encounter an onslaught of speculation regarding the so-called autism epidemic; witness the resurgence of clustered measles outbreaks, a direct result of the anti-vaccination movement; or wonder about the possible arrival of the Zika virus, which can cause an array of birth defects. In these public venues, media consumers meet debates about neurodevelopmental disorders like ADHD, their prevalence, and how, whether, and when to medicate children accordingly. Perhaps they shake their heads at the constant flow of “inspiration porn” on social media – those disability tales with a heartfelt ending, complete with clickbait headlines like “This young boy with cerebral palsy got a dog, you’ll never guess what happened

next!" While its forms vary, there is no question that disability populates our media worlds, public concerns, and social imaginaries.

Despite the unprecedented openness to disability discourse and imagery in the contemporary U.S., the promises of cure, prevention, and inspiration hold a privileged place. To regard undiagnosis as a recognized disability status in its own rite, rather than as a means to a diagnostic end, fundamentally unsettles disability's cultural scripts. Furthermore, it marks a rupture with the dominance of biomedical knowledge by asserting that a lack of a diagnosis cannot be equated with a failure of medical progress. Undiagnosis, in turn, goes against normative understandings of disability in both social and medical frames.

Let's return to the mystery babies, their varied and seemingly incongruous impairments defying diagnostic common sense. What happens to the textures of everyday life and lived realities as these children start to make sense in new ways, such as through genetic testing and newly identified and named conditions? Again and again, parents in interviews recounted their struggles to obtain a clear diagnosis, "clear" being a questionable term for what was often, at best, a haphazard label.

Without access to local families in similar situations, these parents of undiagnosed children tended to connect via social media, using Facebook, blogs, and disability websites to share and gain insights regarding undiagnosis. I spoke with several who actually helped diagnose their own children this way. As one mother described, her diagnostic journey was very do-it-yourself, or "DIY and circuitous." She retraced the steps, beginning with the moment she found a blog from another parent whose child had similar features. When she finally received

confirmation from a physician in another state, he simply gave her a report with general information about the syndrome that was that. As she recalled:

> At the time the visit was actually really disappointing. The answer to every question was “We don’t know” and that was really hard, but it taught me a lot since I talk to families. It was the responsible thing to say, because he really didn’t know.

The stories kept coming. Parents and professionals spoke of NICU nurses who told new mothers that their children would not survive, although they did. The doctor who suggested not giving a newborn the tracheostomy he needed to breathe. Extended family members and physicians alike assuming the next step after a mystery baby’s birth was to start the paperwork, charting a course for abandonment of the new child into an ambiguous, unspecified future without her biological parents.

As I listened, I recalled my first encounters during a previous project with abandoned deafblind children in Guatemala – not fully deaf or fully blind, mind you, but fully on the deafblind spectrum. They lived in a local nursing home and took a private bus to school in the mornings. It was their only outing. I was horrified, so sure that such a thing would not happen closer to home. Back in the U.S., I heard a rumor that the state foster system was “giving deals” to parents willing to take in children with disabilities, but I could not find any details. Women told me of their husbands leaving. One man held out until their daughter was eight, but then divorced his wife after she refused to give up the girl, who was deafblind due to a rare genetic syndrome. Throughout my project, I heard stories upon stories, the sedimentation of affect – anxiety, love, blame, searching, doubt – that accumulated in these spaces and worlds.

Multiple parents I interviewed distinguished their experiences from those of parents who children had more widely known disabilities, specifically Down syndrome or autism. Some attended mothers' groups or local parent support groups, but their children – and, by extension, their families' narratives – were the outlying cases. One mother, Dani, spoke fondly of her participation in a local group for so-called "special needs" parents. Her daughter was diagnosed as an infant with an extremely rare genetic mutation and was two years old at the time. Dani was excited to connect with other parents and also to give her daughter opportunities for playdates, which the girl loved. As Dani described:

> Most of the children [in the group] are on the spectrum or have Down syndrome, but they're really nice to talk to and they do playdates all the time…We went to a girls' night out two weeks ago. It's nice just because, even though the diagnosis is not the same and they don't understand the genetics, because autism is so - let's say it's common - so you find a lot of info of what to do and what not to do. Even though they don't understand my situation and she's the only one who has a feeding tube in that group, they're still really understanding and they always try to invite her to go to stuff, too. Even if she's not walking or talking.

This example is significant, in that it illustrates the central role of bodies in the undiagnosed and rare disability communities, something that has been pushed to the side in much of disability studies in favor of a focus on politics and rights, social stigma, and more structural aspects of disability experiences.

Another mother, who runs a national network for families of undiagnosed children and adults, echoed similar sentiments in regard to the lack of sibling supports for her non-disabled children. The only sibling group close to her family was run by an autism organization. As she explained:

> The opportunity [for sibling support and community building] is there, but the chances are that most of the siblings are going to have sibling issues

> relating to autism. If they're talking about the sibling issues they might not be the same or similar…Some families with rare or undiagnosed conditions will have a sibling with a feeding tube or a trach, whereas with autism you're not likely to see that.

In these cases, bodies emerged center stage as split, fragmented, and visibly quite different. Their tracheostomies, feeding tubes, seizures, crashes, special diets, chronic pain, and repeated surgeries. Here, it was increasingly difficult to focus on the social or historical facets of disability experience and not also the physical. Bodies were central to the analysis.

Dani, the mother of the two-year-old girl mentioned earlier, laughed as she recalled an early conversation with a pediatric cardiologist. Trying to reassure the new mother after the initial diagnosis, the doctor smiled at her and said: "Don't worry, some of these kids live until they're 10!" Upon hearing these words, Dani immediately burst into tears. "I don't know if he was trying to say something to comfort me, because he really didn't think it looked good." But what constitutes a good prognosis in the face of such limited knowledge?

The theme of survival is central to discussions of undiagnosis. As S. Lochlann Jain argues, diagnosis and prognosis are the specialists' "double helix" (2013, 29). Without a label, we cannot know the future – or so it appears. However, often times a diagnosis of a rare disorder proves to be no more illuminating. For many of these diagnoses, this is only the first generation and very little, if anything, is known about what might happen if or when the children become adults.

One father, whose daughter has an extremely rare trisomy mutation, explained: "There's no way to prognosticate…While some [children with his daughter's diagnosis] have lived longer…it's kind of a crapshoot." Yet he

remained optimistic. He was told initially that his daughter would die in utero or, best case scenario, within days of her birth. When he and I met, his daughter was four. He knew of one child in existing medical literature who lived to the age of eight. Another mother, Grace, spoke of raising an undiagnosed teenage daughter in a digital age. The girl was diagnosed via gene sequencing while in high school, as described in-depth on her blog and also in multiple national media stories. Grace spoke of having to tell her daughter that she would not have a typical life expectancy after they received the testing results; she had to inform her, she explained to me, because the information was to be included in an article on the family's experience and her daughter would read it. Here, diagnosis, technology, and family collided in unsettling ways.

I was continuously surprised by how many parents acknowledged that their children would not have survived in previous eras, for one reason or another. Although I initially assumed that this was an unspoken or perhaps implicit truth, I now see it as a starting point. Their sons and daughters embody new possibilities of personhood and life, literally, and we all know it. Biomedical technology and the powers of neonatal intensive care units now sustain life for the previously unlivable. These types of bodies and forms of being are the tangible products of a particular social and historical moment, and constitute a living project in its first generation.

One conversation stuck out. As I chatted with a young mother over lunch, I could not get over how young she looked, an instantly recognizable archetype of a high school cheerleader – petite and blonde, with a softly feminine pixie nose and a wide grin. She called out and waved to friend after friend as they passed

by. When I first saw her, I assumed she was either a teenage mom or a sibling of a child with disabilities whose parents were attending the event.

I encouraged her to riff on her NICU experience, wondering where it would lead. “You know,” she told me,” once you get past the shock of it all, most of the time you’re just bored in there.” It was so matter-of-fact, so obvious. When her daughter was born, she recalls how the doctors took her from the room with no explanation. She heard nothing for 45 minutes, until the obstetrician returned. “Your baby is deformed,” he said.

Deformed.

The family was in the NICU for four months. My companion was almost nonchalant about the experience, laughing ruefully as she recalled the hijinks that went down. “You have no idea,” she said, as she began to recreate the textures of that world. A father arrested by his baby’s crib; the nameless little girl, abandoned at birth by her mother, whom they all prayed for, gathering around her crib while their own children slept. She asked if I have heard of gastroschisis, a condition in which a baby is born with their intestines protruding from a hole in the abdomen. I had, although I did not know where. Television, perhaps? “Do you know how the doctors fix it?” she asked me. “They hang the intestines from a bag in the air, attaching it to the crib,” she continues, “And gravity pushes them down.” I pause. “The first time, I was like WHAT???” she recalled. “But that happened maybe four times when we were in the NICU. By the end, I’d look over at the crying parents and just say, ‘Oh, come on now. They’ll go back in there, it’s just gravity! Everything’s gonna be fine, I’ve seen it three times already.’” I remarked that she should write a book about her four months there. “You have no idea,” she replied.

Parents were aware of their role at the vanguard of undiagnosis as a distinctive disability experience. In many of these cases, the anxiety about the unknown connected directly to the fact that there were few adults, if any, with their child's disability. There was no way to predict the future. And yet, I came across parents of adults with rare conditions who had little interest in connecting with the new diagnostic generation. It simply was not on their radar. Perhaps it was too painful and they were too tired after years of struggling with school systems, physicians, therapists, and now the embattled world of adult services. Perhaps they simply did not identify, these families whose children came of age in a pre-digital era that was, in terms of disability information and access, a world away from where we are now. These families were potential leaders in understanding certain diagnoses over the life course, but they were anything but excited about their position on the front lines.

I think, too, of a mother I met. I will call her Julie. "He's a good project." This is what the specialists said about her child, Owen, who was just a baby. He had the typical list of seemingly haphazard symptoms: low muscle tone, developmental delay, poor eye contact, little to no speech. I heard these same terms rattled off casually by parents. Her son was diagnosed at the age of three weeks, although she told me could have known sooner had the hospital run a genetic panel after his birth. Three weeks, though. It was one of the fastest diagnostic stories I encountered. No goose chases or misadventures, no "Owen Syndrome" designations. Owen had a diagnosis. Or, rather, genetic testing identified the gene mutation behind what could not be explained previously. Owen had a highly specific and rare gene mutation.

I was struck by the potential differences of knowing so early. “I feel lucky for the diagnosis,” Julie told me. “Not to have this diagnosis, but to have *a* diagnosis.” I nodded. She said that the worst possible thing for a parent is not knowing, a sentiment I heard again and again. *But what does the diagnosis mean*, I pushed. “I don’t think it means anything,” she replied. She continued:

> Nothing…If you can’t tell me what my child’s going to look like in one, two, four, 10, 12, 15, 20 years, than you’re not of any use to me. But I think it gives people some peace that it’s nothing they did and it’s nothing they can undo. That internal peace for people is really the best thing that this has done.

Such stories highlight the potential pitfalls of diagnoses in the rare and undiagnosed disability community, and demand a closer look. There can be clear logistical, medical, and affective benefits to a diagnosis, to be sure. However, the stories above suggest strongly that new and often quite obscure labels – many without a name, referencing only the identified gene mutation – actually undermine broader possibilities for mobilization and meaning within the undiagnosed community, perhaps isolating families in new and insidious ways.

RE-CONCEPTUALIZING UNDIAGNOSIS

In most of my conversations, the diagnosis was the end goal. It was a journey with many hiccups and wrong turns on all sides, sometimes lasting well into adolescence. But why was it so paramount – particularly when the special education services were already in place and medical complexity was minimal? Diagnostic knowledge was equated with power. This was taken as fact.

To be undiagnosed, I was told, is to be neither “typical” nor diagnostically marked. There is no easy explanation or canned answer to the inevitable questions, and no elevator speech. One is diagnostically stateless, nameless, protected by fewer resources, rules, or practices. Each visit to a specialist becomes a request to be ushered in from a stateless status to a more concrete transitional stage with the promise of a clear label, group, and biomedical claim. Within this formulation, the dominant focus on diagnosis as the end-goal works against the formation of cohesive coalitions within the undiagnosed community and does little to meet the affective needs of this group.

As anthropologist Tanya Luhrmann writes: “One of the oldest ideas in human thought is that when you name something mysterious and out of control, you gain mastery over it” (2000, 45). This logic erases the lived experiences and meaning of undiagnosis; it is a perspective rooted firmly in notions of progress, in which securing a diagnosis is a necessary step for obtaining recognition, services, and, indeed, being a compliant patient and subject. Moreover, it is detrimental to the undiagnosed community – again, up to 40% of children with known disabilities – and obscures the fundamentally fluid, dynamic nature of disability as an experience that is social, historical, and embodied.

This project breaks with the dominant framing of diagnosis as the gateway to answers and clarity, problematizing how such labels simultaneously empower and constrain the people they describe. Someone who lacks a diagnosis is assumed to be in a liminal state, trapped between the stages of initial identification of difference and the end-goal of identifying and classifying the cause. This construct obscures the complexity of diagnosis today. Perhaps unwittingly, it ensures that the undiagnosed population remains firmly situated in

the margins – a community in waiting, framed as inherently incomplete and not fully belonging, marked as fundamentally different even within the disability community.

Disability studies scholar Lennard Davis (2013) has written that disability continues to fall outside of dominant diversity paradigms, those shiny new ways of ordering and affirming difference. He argues that this boils down to one key problem: medicalization. Disability remains perceived as a medical category (outside of certain academic circles) and the concept of diversity does not apply to the disabled, ill, or dying. There is no room for such bodies. Diversity works as a concept, he says, because people are all different and equal as long as they are "not that kind of different" (2013, 14). Here, the old distinctions of normal versus pathological continue to reign. As a de-historicized bodily condition perceived of as needing a cure, disability cannot be welcomed by a diversity paradigm. The embodiment of a clinical curiosity, members of the rare and undiagnosed community are, indeed, that kind of different.

How does our contemporary diagnostic fervor unfold in cases of undiagnosis? There is not yet meaningful space for the undiagnosed within the broader disability community or beyond. While undiagnosed, they inadvertently challenge dominant understandings of biomedical power and scope. They confuse. Upon receiving a rare diagnosis, they are pulled out of the diversity and potential community of undiagnosis. They are individualized, named, and over-determined. After all, what could be more medical than receiving a genetic diagnosis that no one else has?

In contrast, there is a real, untapped, and potentially transformative potential in reconceptualizing undiagnosis as more than just a liminal state

between unknowns and biomedical truth. Such a reframing might give way to a new and newly meaningful disability politics of undiagnosis for the millions of families in the U.S. with undiagnosed children. Within disability anthropology, it is critical to interrogate the baseline assumptions of diagnostic power, asking instead how a diagnosis (and, indeed, undiagnosis itself) both emancipates and constrains. What is at stake for the many families who knew of only a handful of cases of their child's diagnosis around the world? Or the families who have yet to find other known cases, with their child designated as an anomaly on a global scale? And what potential might exist for scholars, along with families and allies on the ground, to help reframe undiagnosis as a powerful platform for a distinctive embodied and affective disability experience?

CLOSING THOUGHTS AND FUTURE PATHS

This essay and the chapters that follow call for a fundamental shift in focus to the complexity of undiagnosis as a lived experience – cultural, social, and embodied. Diagnostic categories now proliferate, simultaneously naming and codifying difference in new ways and engendering previously absent disability worlds. Yet, for this growing population of children, their parents' questions often far outpace the current knowledge, both in the case of the rare and undiagnosed populations and also in terms of some of the more prevalent, widely-recognized disability diagnoses. There is much to be gained from rethinking undiagnosis in terms of its political and affective possibilities, moving away from the assumed focus on biomedical ambiguity.

One popular refrain in disability studies is that everyone will eventually become disabled, if only through the process of aging. Such claims are

shortsighted and fail to grasp the lived experience of disability as simultaneously embodied, social, and diagnostic. The diagnosis matters – not because it reveals a deeper truth, but in its power to organize and render intelligible the otherwise unwieldy. But what might this mean in a time when diagnoses are on the rise and more easily distributed than ever? When disability is being framed increasingly as the new diversity? And yet, at the same time, people who are undiagnosed – unnamed, yet still without question disabled – continue to reside in the shadows, often without the affective, medical, or logistical supports that can accompany recognition. What is at stake when parent after parent of an undiagnosed or rare child laments that their son or daughter does not "just" have autism or Down syndrome?

The undiagnosed community constitutes an important counterpublic, to borrow Michael Warner's (2005) concept, within today's disability worlds. Undiagnosis challenges dominant assumptions about disability and embodied experience. Despite the large numbers of undiagnosed children and adults, they nonetheless hold a subordinate status within current disability publics, as articulated clearly by parents. Demanding a space for undiagnosis is not simply a consolation prize or gesture toward inclusion. Rather, reframing undiagnosis as a counterpublic challenges the mythical holism of contemporary disability multiculturalism. It marks a more radical resistance to the acceptance of name-as-meaning. Undiagnosis does not simply denote an unruly or amorphous patient population, nor is it simply a liminal stage between identification of difference and securing a name. It is time to think seriously not only about what a diagnosis can do, but what undiagnosis does and undoes on the individual and collective level. What happens when people rest within this space?

As the study of social and cultural life, anthropology can play a central role in illuminating contemporary notions of human difference. Renderings of difference are constantly in flux, and disability is no exception. The question of membership looms large. Who is considered disabled and through what forms of recognition? What are the limits of this category? What does it mean to live on the margins or even in the non-category? Rethinking undiagnosis in a diagnostic age marks an opening, a pause to dwell in this zone of potentiality.

POSTSCRIPT

In disentangling the practical and affective possibilities of diagnosis, the themes of precarity, hope, and imagination emerge full force. The aspirational category of the "typical" child is increasingly precarious. Today in the U.S., previously unexceptional aspects of childhood draw scrutiny. Shyness, introversion, daydreaming, spinning in circles, playing with trains, not eating one's vegetables, fears of loud sounds, a tendency to interrupt, a failure to always follow instructions, avoidance of crowded or loud spaces, needing help to stay organized, a lack of interest in sports, mood swings. These are all taken, in various combinations, as possible symptoms of a disorder. Buzzwords like "toxins" abound and alternative vaccine schedules for young children, while scientifically unproven to impact development, are generally accepted as within the realm of normal practice. What does it mean ethnographically, practically, and politically when more children than ever both have a diagnosis and are undiagnosed? What are the implications for those whose forms of difference eschew existing labels? What might the future of undiagnosis hold?

Chapter 2

Framing Disability Anthropology

This dissertation examines questions of undiagnosis, whether as an ongoing state or a past memory following the diagnosis of a rare syndrome or disorder. It dwells in its ambiguity and, when undiagnosis is transient, pauses in its aftermath. These essays can be read individually or as part of a cohesive ethnography. They draw from cultural and medical anthropology, disability studies, and science and technology studies, as well as memoirs and popular press coverage, situating disability as an ethnographic object that animates contemporary life. The essays use scenes and case studies of kinship, digital worlds, fringe practices, medical encounters, narrative, and enclosure to ask where disability lurks and what it holds. A seemingly taboo and marginalized lived experience, disability is nonetheless omnipresent. It is a fixture of our lives, even when unacknowledged, skirted, or shunned. This is the underlying thread uniting the essays in this dissertation.

Disability is not only about the normal versus the aberrant, nor is it simply a question of social constructions versus scientific facts. Rather, it unfolds within broader webs of bodily experience, scientific and medical knowledge, culturally and historically situated notions of health, personhood, the good life, political and economic realities, kinship structures, and modes of care. As Rayna Rapp and Faye Ginsburg argue, it is a highly relational designator (2013). The line between disabled and non-disabled (or “typical’) is a moving target. This is illustrated, for instance, by shifting understandings of autism spectrum disorders and

corresponding increases in diagnoses witnessed in the U.S. in the last two decades.

While they are not the focus of this project, autism spectrum disorders play a central role in the current childhood disability climate in the U.S. Indeed, I would argue that it is impossible to examine disability worlds today without considering the seismic shifts surrounding autism. Current data on disability prevalence in the U.S. shows clearly that the faces and bodies of difference have shifted from previous generations. Recent decades brought dramatic rises in childhood disability diagnoses in the U.S., most notably in the areas of neurodevelopmental disorders and mental health (Houtrow et. al, 2014). At the same time, the prevalence of physical disabilities in children decreased significantly. Overall, disability prevalence in children rose nearly 16% in the first decade of the twenty-first century, driven largely by the nearly fourfold rise in diagnoses of autism from 1997-2008 (Boyle et. al 2014, 1037). Notably, boys and/or children from families below the national poverty level were more likely to receive a diagnosis of a developmental or neurodevelopmental disability (CDC 2015).

Philosopher Ian Hacking (2009a, 2009b, 2009c, 2010) has written extensively on the proliferation of autism in the contemporary U.S. Following Susan Sontag's *Illness as Metaphor* (2001), he argues that autism is the defining condition of our time, and he attributes the apparent spike in diagnoses to the broadening of the spectrum and increased public awareness; for Hacking, there is no autism epidemic. Essentially, we now think more about autism spectrum disorders and thus we encounter them more. The spectrum has become a tool for categorization and designation of certain forms of difference. This ties into

Hacking's larger project of theorizing how and why certain conditions emerge and spread during specific sociohistorical moments (Hacking 1995, 2000).

In anthropology, the fluidity of the disabled/typical divide has been demonstrated perhaps most persuasively by Nora Groce's (1985) study of deafness in 18th and 19th century Martha's Vineyard, Massachusetts. Groce used archival research and interviews to show that deafness, which was unusually common on Martha's Vineyard due to genetic isolation of its settlers, was not regarded locally as a disability or even a significant difference. The island's deaf population flourished from the early-1700s until the mid-1800s, giving rise to a distinctive local form of sign language. Deafness was both common and commonplace, and hereditary deafness was a recessive trait that could be traced to a group of families that settled there in the second half of the seventeenth century (Groce 1985, 23). In some towns, the rate of deafness was as high as one in 25; the island average was one in 155, compared to over one in 5,000 for the general U.S. population (Groce 1985, 3). In turn, the Vineyard community was fully bilingual in sign language and spoken English, and conversational sign abilities were assumed (1985, 56).

Groce's study tracks the extent to which deaf islanders were fully integrated in everyday life, politics, and economics. This began to change as the island community became less isolated, beginning for its deaf population after the establishment of the American School for the Deaf in Hartford, Connecticut, in 1817. This introduced a residential education model for deaf children in the U.S. As the younger generations of deaf islanders moved away for school, the local deaf population dwindled. Furthermore, the island became a travel destination for mainlanders during the early 1900s. Visitors brought their own

views about deafness as something to be stigmatized, along with assumptions of spoken (verbal) English as the lingua franca of daily life (Groce 1985, 94). Similarly, hearing islanders began to marry outside of the community, thus reducing the likelihood of having a deaf child. The last deaf native speaker of Martha's Vineyard Sign Language died in the 1950s (Groce 1985, 2).

A View from the Field: Anthropology and Disability Studies

The history of deafness in Martha's Vineyard shows clearly that distinctions of disabled versus typical are deeply contextual. Groce's study demonstrates the role of social structures, institutions, and ableism (or anti-disability beliefs or practices) in rendering difference as disability. In this vein, some deaf activists today argue that they are part of a linguistic minority and not a disability group, much as autism self-advocates (i.e., individuals with autism advocating for their own rights and needs) often espouse a neurodiversity framework, in which autism constitutes a form of human variation and not disability.

Such perspectives connect closely with the social model of disability, which holds that it is society that disables people, not the body or mind (Oliver 1996). This framework was central to the interdisciplinary field of disability studies, which emerged from the disability rights movement of the 1970s and 1980s in Europe and the U.S., bridging scholarship from the humanities and social sciences with on-the-ground disability activism. One fundamental aim of disability studies was to position disability as a socially constructed category, rather than a biomedical reality, and scholars focused on the social and cultural forces that rendered certain bodies or conditions "abnormal" in specific

sociohistorical contexts. While a medical model of disability held that an individual's physical or intellectual limitations were intrinsic to their condition, disability studies scholars emphasized the role of socially imposed challenges in the lives of individuals with disabilities (Barnes 1998; Barton 1998; Williams 2001). Rather than emphasizing treatment, cure, or rehabilitation, these scholars stressed the need for a society that was more welcoming to people with disabilities, emphasizing accommodations, equal rights, and possibilities of social change.

Many early disability studies scholars expanded psychologist Erving Goffman's theory of stigma, developed in the 1960s, which continues to animate the discipline. Goffman (1963) argued that individuals with disabilities were one of several groups with "spoiled," or non-normal, identities; asserting that they were stigmatized by mainstream society, he addressed the role of social forces in shaping disability. He also discussed the partial stigmatization of families of individuals with disabilities, arguing that they possessed knowledge of – or were "wise" to – the stigmatization of their loved ones.

Although the early disability studies texts were central to establishing disability as an academic field and situating it, broadly speaking, within a greater focus on identity politics and rights-based claims, rather than a rehabilitative or medical framework, there are theoretical limitations to this body of work. Disability continues to focus largely on the social construction and political experience of disability, with the intention of challenging the marginalization of this population (Barnes 1998; Barton 1998; Davis 1991, 1995, 2006; Oliver 1996; Williams 2001). While the political and social bent of these texts is useful for probing disability as a constructed, rather than "natural" or medical, concept, it

often leads to significant shortcomings. Embodied and affective experiences of and with disability are commonly overlooked, and the complexity of disability in daily life – a topic ripe for ethnographic attention – tends to be glossed over with large brushstrokes.

While an emphasis on the social and structural dimensions of disability has been critical to building awareness within academic circles and also as a rights-based platform, it runs the risk of falling into its own ambivalence regarding which bodies and experiences count. There remains notably little space for the more unwieldy, unsavory, or simply confusing disability worlds, or for dwelling in the details of the everyday. Where is the space for people who are nonverbal, who lack symbolic communication altogether, or are violent? Who do not have a formal diagnosis? Whose impairments and syndromes and secondary health conditions have grown so enmeshed that they are no longer simply the sum of their parts? How might scholarship include people who are so different at the level of the body and mind to fall outside of a constructivist account or diagnostic subculture?

Even the recent shift toward a cultural or biocultural model of disability, which focuses on the relationship between the body and society, falls short in cases where impairment and difference are extreme (Adams, Reiss, and Serlin 2015, 9). For instance, many of the undiagnosed children at the heart of this dissertation have extremely complex medical needs in addition to significant sensory impairments and/or intellectual disabilities. They are profoundly different from their typical peers and are marked as such – visually, socially, and, medically. There is little question that they are fundamentally atypical at the level of the body, yet they arguably make less sense socially, due to their lack of

diagnostic intelligibility or, perhaps, the rareness and vagueness of a highly unusual genetic disorder. Only a few decades ago, these individual would have been grouped together under the umbrella of “multiple handicapped,” a term that implied ambiguity but not necessarily singularity. This has shifted, due to biomedical technologies and an emphasis on specificity, particularly through genetics. Ethnography offers a way into these narratives and experiences, opening disability worlds that remain largely cut out from a more socially focused analysis.

Anthropological approaches to disability tend to complicate the earlier disability studies models, which stressed the socially imposed, rather than physiological, challenges facing people with disabilities. In contrast, anthropologists focus such topics as personhood (Biehl 2005, 2007; Gammeltoft 2014), biopolitics (Campbell 2005; Foucault 2010[2004]; Kohrman 2005; Tremaine 2008), bodies and embodiment (Csordas 1990; Desjarlais 1997; Lock 1993, 2001; Scheper-Hughes and Lock 1987), citizenship (Das and Addlakha 2001; Phillips 2010), and political economy (Bourgois 2009; Scheper-Hughes 1993), thus probing the dynamic nature of disability and other medical categories. Anthropology is uniquely positioned to reveal the role of dynamic socioeconomic, cultural, and historical forces on shaping the significance, form, and lived experience of impairment and illness (Bagatell and Solomon 2010; Cohen 2000; Groce 1985; Ingstad and Whyte 1995, 2007; Kohrman 2005; Rapp 2000; Rapp and Ginsburg 2010; Scheper-Hughes 1993; Whyte 2005; Wool 2015). Additionally, studies demonstrate that even seemingly clear diagnostic categories vary greatly, and are compounded by factors such as access to education, information, and therapeutic services (Rapp 2000; Rapp and Ginsburg

2010). Concepts of disabled versus typical are not absolute, nor do they always translate across contexts (Groce 1985; Hacking 1998).

The essays in this dissertation build on and aim to contribute to anthropological writings on disability, personhood, community, and kinship, and center on the question of how to make sense of people who defy diagnostic common sense. How are new forms of personhood produced through practices that both recognize and objectify differences (Cohen 2000; Kohrman 2005; Lock 1995; Rapp 2000)? These chapters also engage with ethnographic and other studies of the power of strategic interventions to dramatically alter lived experiences of disability, including sign language (Baynton 1996; Groce 1985), communication techniques (Savarese 2007), psychopharmaceuticals (Martin 2007), transportation (Kohrman 2005) and cochlear implants (Blume 2010). Along these lines, one theme throughout this dissertation is the impact of digital worlds and new forms of connectivity and communication on disability today.

The chapters here examine data from my fieldwork in Austin, Texas and at disability events at multiple sites statewide, as well as additional data gathered via digital ethnography. I draw, too, on my preliminary research in Guatemala. In my initial imaginings, the project was far less expansive and paid no attention to the digital. I had not anticipated the extent to which these disability worlds relied on social media and digital communication, nor had I planned for the recurring themes and questions that arose during my early investigations in Guatemala. I was in for some surprises.

In terms of issues of topic and region, I was struck by the overlap between many of my early observations in Guatemala and what I encountered as I became increasingly involved in the disability community in Texas. The list was

telling: grassroots initiatives led by families amidst state failures to meet their children's needs; abandonment and isolation; and a tenacity among activists to raise awareness and improve services within systems of government-based supports that were patently inadequate. Methodologically speaking, as I moved forward with my project it became increasingly apparent that traditional, on-the-ground ethnographic methods were inadequate to study undiagnosed and rare disability communities, given the level of geographic dispersal and digital connections. What might it mean to compose an ethnography of disability populations that had no known diagnosis or perhaps shared one with only a handful of people around the world?

Texas was an ideal site for this project in many ways, thanks to its grassroots disability organizations, including ones for rare disorders, as well as vast disparities in disability services, medical care, and inclusion. The state consistently ranks at the bottom nationally in terms of disability services and inclusion. According to the 2016 version of annual disability rankings by United Cerebral Palsy, Texas was fiftieth in the nation ahead of only Mississippi.

The data is telling. Compared to their peers in other states, Texans with disabilities are more likely to live in large-scale residential institutions. While institutionalization was once the norm, this shifted significantly with the 1999 U.S. Supreme Court *Olmstead v. L.C.* ruling, which held that individuals with disabilities had the fundamental right to live in their communities and not be segregated. Such institutions have been phased out in many states and, per the most recent data, 15 states no longer have any public institutions at all (United Cerebral Palsy 2016a, 8). Texas currently has the greatest total number of adults with disabilities living in large state institutions; its institutionalized population

accounts for one-seventh of the national total (National Council on Disability 2012, 10). Indeed, there is an acute shortage of programs to facilitate community inclusion. Over 100,000 Texans are on waiting lists for basic home or community-based services (United Cerebral Palsy, 2016b). In contrast, there are 18 states that have either no waiting list or very small ones, meaning that individuals are able to access necessary services without a multi-year delay (United Cerebral Palsy 2016a, 10).

Beyond the problem of waiting lists, the conditions in Texas' public institutions (or state-supported living centers, known as SSLCs) have been widely condemned by disability rights advocates. The state entered a Settlement Agreement with the Department of Justice in 2009, following a 2008 federal investigation into conditions at the centers. The settlement was intended to ensure ongoing monitoring of conditions in the SSLCs and compliance in key areas, including health and dental care, therapeutic services, protection from abuse and neglect, and communication. In their four-year report, the monitoring panel reached the following conclusion: "...it appears unlikely that the State will meet substantial compliance with the majority of provisions anytime soon. Action is required, be it at the initiation of the State or DOJ" (2014, 2). There have been multiple confirmed allegations of abuse and neglect of residents at the SSLCs, including deaths. In 2016, testing revealed that three of the SSLC's had tap water with lead levels comparable to those found in Flint, Michigan (Martin 2013).

The Texas educational system also shows significant failures regarding the needs of students with disabilities. This became a national story in 2016 and 2017 when a *Houston Chronicle* revealed that the state had systematically excluded tens of thousands of students from special education for over a decade.

In 2004, the Texas Education Agency quietly enacted a policy stating that no more than 8.5% of students could receive special education services. This was an arbitrary cap that served only to save money by skirting federal special education protections. In the years following its implementation, the percentage of special education students in the state dropped precipitously; within a matter of years, Texas had the lowest rate of students in the country, far behind the national average of 13% (Rosenthal 2016). It is the only state that has implemented a limit for special education. Once this story went public, U.S. Department of Education launched an official investigation in the state. The state eliminated the enrollment limit in March 2017, six months after the original article broke.

Based on its approach to special education and community services, Texas lives up to its national reputation as one of the worst states for children and adults with disabilities and, it follows, for their families and caregivers. Despite the on-the-ground social and institutional constraints facing Texans with disabilities and their families, many people I met were extremely active in local disability initiatives and were, moreover, deeply embedded in broader disability networks. Having been involved in disability work personally, professionally, or as a researcher for most of my life, this did not stand out initially. Only looking back did I realize how taken-for-granted it was in this community that families drew significantly on knowledge and insights of fellow parents, siblings, or a variety of professionals from around the state, country, or beyond to meet needs that were local and often quite mundane. Schooling, communication devices, behavioral techniques; tips to make a routine doctor's appointment or dental exam, or to redirect problematic behaviors. Each step typically involved guidance, input, and

information seeking from multiple outlets. These often expansive networks of knowledge production and sharing seemed to fundamentally distinguish disability families from their peers.

SITUATING DISABILITY ANTHROPOLOGICALLY

As Rayna Rapp and Faye Ginsburg have argued, disability is a fundamental aspect of the human experience and thus warrants anthropological attention (2010, 2013). It is curious, then, that a discipline so focused on marginalized groups, structures of power, and identity and lived experience has largely avoided attention to disability. This has begun to change, with a surge of recent ethnographic work on disability, including mental illness among veterans (Finley 2011; MacLeish 2015, 2016; Wool 2015), neurodiversity (Grinker 2008; Solomon 2010; Thomas and Boellstorff 2017), disability in the global South (Friedner 2016; Gammeltoft 2014) or in postsocialist contexts (Hartblay 2017; Phillips 2010), and among families in the U.S. (Mattingly 2014; Rapp and Ginsburg 2001). Expanding understandings of disability anthropology to include not only physical, intellectual, developmental, and sensory disabilities, but also mental illness and chronic health conditions, expands the field even further (Lurhmann 2016; Nakamura 2013). Indeed, upon a closer look one might argue that disability has gained a significant foothold in the discipline.

This dissertation draws from both cultural and medical anthropology, as well as disability studies, the history of medicine, and science and technology studies, to examine disability as a complex, sticky ethnographic object. Fundamental to this perspective is the notion that disability is central to collective

understandings, hopes, and anxieties about kinship and care, independence and personhood, the normal versus the pathological. Disability is both omnipresent and marginal, humming beneath debates about health practices, birth, education, abortion, and maternal and child health. It shapes travel plans in the age of Zika, provokes media speculation of disability or mental illness to explain idiosyncratic leaders, and is an often unacknowledged facet of police violence against civilians. A moving target that saturates everyday life for everyday people, disability nonetheless fails to capture the same anthropological attention as such markers as race, gender, or sexuality (Rapp and Ginsburg 2010).

Yet ethnographic approaches and attunements to disability have much to offer. By training its lens on everyday disability worlds (MacLeish 2016; Wool 2015), ethnography offers the potential to push beyond or reinvent existing dominant narratives of disability, adding new dimensions to scholarly and applied understandings of what disability means and does in contemporary life. Similarly, anthropologists continue to illuminate the blurriness of diagnosis and community, both in the context of prenatal diagnosis (Gammeltoft 2014; Rapp 2000) and during childhood or beyond (Biehl 2005; Jackson 2012; Mattingly 2014). The case of disability raises key questions regarding the relationship of the individual to society, which lies at the heart of the anthropological project.

While there is noted recent attention to particularly public disability communities, particularly autism, the more unruly cases are often untouched. To appreciate and understand disability as a fundamental aspect of the human experience, it is imperative that anthropology carve a space for the unruly and aberrant. The essays in this collection, which focuses on experiences with undiagnosed and extremely rare disabilities, are an attempt to begin this

conversation. Ethnography enables a shift away from narratives of perfection or ideals, moving instead to the various overlooked, silenced, or unspoken realities of lived experience. It makes room for complexity. This approach also generates important ruptures in widely shared assumptions about various facets of disability worlds, such as the taken for granted "goodness" of kinship and family, for instance, and facilitates a space to address questions of violence (to self or other), sexuality, or failures of care.

METHODOLOGICAL CONSIDERATIONS: DIGITAL EXPERIMENTS

My fieldwork combined anthropology's hallmark of participant observation with digital research in online spaces. This was not the original plan. I turned to social media largely by accident, stumbling upon it unintentionally as an obvious solution. Following the suggestions of parents and professionals I met at disability events or through contacts, I began cautiously – sifting through disability blogs, following disability studies scholars on Twitter, and Facebook friend-ing the people I interviewed. I adopted a layered approach to gathering digital data to add depth and nuance to my situated ethnographic work. I created a Twitter profile focusing largely on disability and academia, which I used to connect with multiple families, disability activists, and organizations in the rare and undiagnosed community.

I was shocked by the level of access that this allowed; not only was I able to connect with and then request interviews (via phone, video, or in-person whenever possible) with key people and groups across the country, but we could stay in touch subsequently through the same virtual platforms they used with their peers and colleagues. I also launched *Disability Fieldnotes*, my

anthropology of disability blog, which provided a bridge between my detailed, private fieldnotes and my scholarly writings or presentations. The blog was a space to play around with my thoughts publicly, a writing experiment predicated on reader feedback and building connections. It mirrored the use of blogs among parents in the rare and undiagnosed community – pictures, responses to news stories, ruminations.

There was no getting around the centrality of the digital for the undiagnosed community. It was the defining aspect of the stories I kept hearing. Mothers staying up late poring over Google searches, reading listserv emails, combing through online message boards. Just searching, asking invisible and anonymous peers for help, looking for anything beyond the all-too-brief information they received from specialists. Trying to weed out the charlatans from the allies; unable in some cases to find more than a handful of other families in the country whose children had similar descriptions. Picking, choosing, and piecing together data as best they could. And sometimes the results were stunning.

One mother, whom I will call Katherine, put it best when describing her search for a diagnosis for her daughter: “It was very circuitous,” she told me. “Every point of the journey was very DIY and fringe.” Her youngest child had a rare genetic syndrome, M-CM, or Macrocephaly-capillary malformation, a “multiple malformation” syndrome, resulting in overgrowth in the body and head, as well as pronounced differences in the skin, vascular system, brain and limbs. Common features include macrocephaly, body asymmetry, extra or fused digits, general delays, and doughy skin. The syndrome did not appear in medical literature until 1997. There have been less than 300 reported cases worldwide as

of 2017. When I spoke with Katherine, she knew of 150 confirmed cases. Katherine founded and work for a nonprofit dedicated to raising awareness about the syndrome and connecting with families. It also operates a registry to track the total number of cases. I had heard of M-CM only once previously: from a Salvadoran mother I met at a disability event in Houston. Chatting between presentations, she suggested that I check out the organization's web page and look them up on Facebook. I was curious.

Katherine founded the M-CM network following the birth of her daughter, who was eventually diagnosed with the syndrome. A web developer and producer by trade, she runs the organization's website and is its Board president, all from her home in New York state. She found me through Disability Fieldnotes, my fieldwork blog, and reached out to share her story. When we spoke, her daughter was five. The organization was four years old.

Katherine recalled the first weeks after her daughter's birth. The girl had birthmarks covering her skin, extremely low muscle tone, and one side of her body was larger than the other. The doctors did not know what to think. Initially, they wondered if perhaps she had a new and undiscovered form of congenital Lyme disease. Lyme, she told me, was on everyone's mind in the region at that time. As she recalled: "They tested her and they tested me, and they were going back and forth with the infectious disease people. It was just so irrational." Next, the girl was misdiagnosed with a different syndrome by a prestigious, nationally known children's hospital – an event that stayed with the family as they continued on their diagnostic quest. Other doctors were hesitant to question this diagnosis, given the hospital's sterling reputation.

As Katherine recalled, she spent countless hours searching online for information about her daughter's mismatched collection of symptoms. She posted her first query in a Yahoo group about hemihypertrophy – overgrowth on only one side of the body – and the listserv manager directed her to some families whose children had similar profiles. One of the families kept a public blog.

"I read every inch of that website, including the comments. The picture of this child as a newborn looked to me almost exactly like my daughter as a newborn. But this person didn't have the same diagnosis," Katherine told me. Another visitor to the site had left a comment saying that her daughter also resembled the child in the photograph, and posted the link to her own blog. Katherine immediately went to the site. As she told me: "I really credit her with the diagnosis."

Armed with her new information and possible diagnosis, she began visiting a series of doctors to determine its accuracy. Through a Facebook group for parents, she identified a geneticist with expertise in M-CM who lived in Michigan. They traveled there and he confirmed the diagnosis. From a Yahoo group to a specialist's office halfway across the country, Katherine's journey was shaped by her participation in digital worlds – not simply as a source of entertainment, leisure, or communication, but as a critical instrument in her diagnostic toolkit. Indeed, it was central to her role as a parent and caregiver. Here, as in other stories I heard, Google, listservs, Facebook pages, and blogs were key. Beyond searches for knowledge or information, or even building networks, they constituted a distinctive form of digital care that was critical for families in the rare and undiagnosed disability community.

Like Katherine, many parents I encountered spoke at length about their "diagnostic odysseys," referring to the weeks, months, or often years spent searching for a diagnosis for a rare disease, disorder, or genetic syndrome. The period is typically marked by a series of visits to specialists, extensive testing, and results that are misleading, inconclusive, or simply turn up no answers. Within the constraints of the resources available, parents often seek help from all angles possible. Without access to local families in similar situations, social media provided these families with opportunities to connect with others in similar situations who knew firsthand that diagnosis could be an ongoing struggle. Digital media also served as a conduit for information and a site of knowledge production that was simply unavailable for previous generations of parents and children.

Of course, privilege, education, and social capital were not absent from these stories. Katherine and her husband lived an atypical life for many: they were professionals who decided to abandon urban living in a major East Coast city to raise their children in the countryside. Their careers were such that they were able to continue working as freelancers, affording a degree of geographic flexibility and economic stability that is simply unavailable to most people – and certainly to most parents of children with disabilities. This system works better for some than for others. And yet, the Salvadoran mother in Houston was connected to Katherine's organization. Even within an unequal social and economic playing field, these digital spaces still usher in new possibilities for networks and sharing that might be precluded by geography. Without access to local families in similar situations, social media provided families with opportunities to connect with others in similar situations who knew firsthand that diagnosis could be an

ongoing struggle. Digital media also served as a conduit for information and a site of knowledge production itself that was simply unavailable for previous generations of parents and children.

But there were no guarantees. Hearing parents' otherwise positive stories of using the internet to gain insights into their children's undiagnosed or rare disabilities, I could not help but wonder about the potential for misinformation. In a competing sea of publically accessible knowledge claims, studies, and autobiographical blog posts, how was a non-expert (in the clinical sense) equipped to sift out the good from the bad, the accurate from the misleading? From vaccine skepticism to alternative treatments for autism spectrum disorders and beyond, there is no doubt about the potential for digital access to turn otherwise questionable claims and baseless theories into sources of speculation, anxiety, or hope.

DISABILITY ETHNOGRAPHY AS A PUBLIC PROJECT

I use Katherine's story to illustrate how disability families increasingly incorporate digital worlds into their care practices. From sharing their personal stories in blogs or via social media, queries to listservs or Facebook groups, or the comments section of an article or personal essay, public disability writing, stories, and inquiries take shape in visible and increasingly accessible fields. There have been several relatively high profile examples of this in recent years, such as Matt Might, a computer science professor turned undiagnosed syndrome expert, whose blog post about his child's diagnostic journey, "Hunting Down My Son's Killer," went viral and led to a feature piece on the family's story in the *New Yorker* (Mnookin 2014).

When I spoke with Dr. Might, he described his family's "diagnostic yo-yo": "Every time we got a diagnosis it was like, 'Let's Google this, let's figure this out.' And usually, with rare exceptions, we could then say 'Okay, let's rule this out.'" He spoke of his wife's active engagement in online communities and research from the beginning: "Cristina was very networked very early on. Every time we had a diagnosis she would sort of poke into a community and we made some lasting friendships. We are still very connected to families in the rare and undiagnosed community across the map." In Dr. Might's view, the essential tools for finding more children with his son's extremely rare syndrome were Wikipedia, his personal blog, and Google. As he explained: "Once you've got a community, Facebook and Twitter are good. But they're not very good at finding the second case…Facebook itself is not set up to help us find that second patient." The family's story grew extremely visible following the 2014 *New Yorker* feature. "It feels like every parent with a rare disease reached out to me," Matt told me. "I want to do what I can."

Through his initial blog post, Matt entered a new sphere of digital disability writing. He opened his family's story to consumption by a potentially vast public, and the results were staggering. While this is a higher-profile example, it falls in line with an overall shift in how families of children with undiagnosed or extremely rare disorders are generating new disability texts – texts rich in autobiographical data, but which flip memoir as an instrumental tool to obtain scientific information, find answers, and build networks. Ethnographic studies of disability can make an important contribution to digital disability writing. What happens when the products of ethnographic fieldwork – the genre of disability ethnography – are available for public consumption as part of the research process itself? When

fieldnotes stand in as a publicly accessible snapshot of an ongoing project, inviting comments and viewers, reaching potential audiences, framing the work as an archive in progress? What might public displays of ethnographic vulnerability do for our work and for our readers?

Making our work public – such as through blogs or publishing in open access venues – opens our writings to the people we study. I encountered this recently after a talk I delivered at a disability symposium for families and professionals. A mother I have known casually for several years – let's call her J – came up to me and immediately mentioned a piece I had written for *Somatosphere,* an open-access, but certainly academically-focused, site geared toward medical anthropologists. "Invisible cages, invisible cages," she said, referring to my piece, which explored scenes of institutionalization and isolation. "I think about these cages all the time," she told me. "I read everything." J lived south of town in an apartment with her adult daughter, who has a rare genetic syndrome, as well as her husband and two adult sons. She had her kids young and did not have college degree, although she began working at a disability agency in Austin last year and was fiercely proud that her supervisor had seen something special in her, as she put it, and was willing to look beyond her lack of formal education. But, thanks to social media and digital accessibility, she was reading ethnographic texts online.

In this context, ethnography becomes publicly accountable and accessible. It becomes political by virtue of these features, which facilitate the networks, knowledge sharing, and long-distance diagnostic community formation now enabled by digital technologies. It can be folded into families' already exhaustive Google searches and genre-jumping, forming another information

source in their arsenal of knowledge. It can become a tool of care, reinterpretation, and shifting community understandings. Ethnographic work that is accessible – both in terms of venue and tone –adds to the body of digital writings and musings that can destabilize assumptions about disability and diagnosis. It shakes up the notion of the singular case, pulling the classic anthropological trick of bringing outliers in from the margins, relating them to a broader whole.

Much like “DIY and fringe” processes described by Katherine, the M-CM mother, or the unexpectedly public trajectory of Matt’s initial blog post, disability ethnographies can offer snapshots into shared dimensions of daily lives while highlighting the specificity of a scene or moment. They can jump. They tell stories that might not yet be there, not publicly. And they have the potential to usher in new insights – by virtue of the peculiarities of our genre, of our insistence on at least pretending to suspend judgment – that are searchable, available, and shareable. The writing itself can become part of the care structure, a mode of public storytelling. Ultimately, this is a decidedly public project with implications stretching far beyond our institutional settings and, sometimes, even into the intimate spaces of care - digital or otherwise.

This study of the rare and undiagnosed disability community raises critical questions regarding how to examine these digital disability worlds ethnographically and incorporate them into a more holistic analysis of lived experiences with disability. Furthermore, it probes how disability research might alter the relationship between the ethnographer and research participants, open new modes of dissemination, and engage with multiple publics. I would argue that, as John Jackson writes: “The digital rewires anthropological possibility,

creating new frames and stills of, from, or for our most romantic of disciplinary dreamscales" (2012, 495). Much as the digital has altered disability worlds, so, too, has it changed how ethnography can apprehend, analyze, and describe them.

Anthropologist Tom Boellstorff argues that digital anthropology is first and foremost a technique, not simply a domain of investigation (2013). As with traditional ethnography, it hinges on participant observation. My Twitter, Facebook, blog, and listserv engagements were, indeed, classic examples of participant observation. I entered existing social worlds, participated in the norms and practices of everyday life, and, in so doing, built (digitally mediated) relationships with an otherwise inaccessible group of research subjects. Each domain constituted a separate fieldsite, generating a project that was fundamentally multi-sited in digital and physical spaces.

This is the other side of digital methods: exposure. My writings and musings were disseminated to audiences who would not otherwise have had access. They were not hidden beyond journal paywalls, but could appear with the ease of a Google search on an iPhone. What I had not anticipated was the extent to which I became a part of this. As Bonnie Nardi has written: "Unlike many topics we study, virtuality concerns not only our research, but also our practice. We are just as entangled in the virtual as our informants" (2015, 25). Just as traditional ethnographers become part of the everyday life at their fieldsites, participant observation in digital fields involves entanglements that can easily travel beyond the researcher's control. My task of examining families' engagements in digital disability worlds quickly blurred with my own involvement,

making me both researching subject and object of analysis in this disability domain.

What's more, fieldwork for this dissertation demonstrated the enormous shift in terms of scale of potential audiences and interlocutors. My Twitter account, which I use primarily as a digital archive for disability news and for sharing my writings, has the potential to reach 65,000 people through channels of online dissemination. In a given month, at least 1,500 users will view my profile and get a window into my work. My blog has been visited over 11,000 times. I am not a unique case. Anthropologists are only beginning to reckon with the theoretical, methodological, and practical implications of today's digital domains. There is much to learn, but there is also much to gain through ethnographic engagements with these digital these new worlds. This project is a cautious – if unintentionally public – step in that direction.

SOME NOTES MOVING FORWARD

The essays that follow can be read individually or as a complete text. They center on questions of undiagnosis, whether past or present, spanning questions of storytelling, kinship, affect, isolation, and rumor. Each essay (or chapter) is interspersed with an Interlude, or a shorter piece of ethnographic writing connecting the threads of each chapter. This approach draws on recent works by anthropologists who embed distinctive or experimental writing in their broader projects, pushing the genre in new directions and perhaps even testing the boundaries of what counts as ethnography (Gandolfo 2009; Pandian 2012; Raffles 2010; Stewart 2007 and 2009; Tsing 2005).

It is important to note several key points that are not fully addressed in this dissertation, due to constraints of time and research logistics when dealing with a small and dispersed sample size. Although it is not the focus of this project, it is important for readers to bear in mind that disability rights in the U.S. unfold within broader inequalities. For instance, more affluent parents are far more likely to have the social capital, knowledge, connections, and extra time necessary to challenge a school district that refuses to comply with federal special education laws. Similarly, many of the grassroots disability organizations with whom I engaged over the course of my fieldwork were founded by relatively educated, socially connected, and/or affluent families; this was also the case with my primary fieldsite during my preliminary research in Guatemala. Like class, race is a markedly under-examined area of current scholarship and research on disability. There are widely documented racial and ethnic disparities in regard to diagnosis, educational access, and health for Americans with disabilities, and future academic and applied work on such topics is critical for building a more robust understanding of disability worlds and experiences. Differences in rural, urban, and suburban experiences with disability are another key are for future study.

The essays that follow are animated by a belief that disability is central not only to the human experience, but to our cultural and social worlds. It lies at the center of current debates on vaccines, surrogacy, prenatal testing, and abortion. It blurs the lines between eugenics and progress, assimilation and erasure. It complicates individualistic notions of independence versus care, interdependence versus autonomy. Disability is both marginalized and

omnipresent. It is sticky, animating everyday encounters, future hopes, and collective fears and anxieties. To this stickiness we now turn.

Interlude:

Estuardo

I met E. in August, closed in his metal bed with railings and bars all around. He jumped and jumped with his hands planted firmly on the vertical bars, shaking them like an old cartoon King Kong, all black and white lines overlaying old film. He whined mournfully, “Abierta! Ah-beeee-yar-tahhh” and I said, “He said abierta!” to everyone who passed. “No, no,” they assured me. “He doesn’t talk. You just thought you heard it.” I heard him say door, abierta, his name. On repeat. La puerta, la puerta. Abierta. Abierta. Estuardo! Estuardo! He doesn’t talk, they told me. I wondered what the benefit was, what they gained from the denial.

The sound of metal shaking punctuated the air. E. was six years old. The powers that be at the facility kept in his cage-bed because he was overly mobile, or so I was told. I tripped over the thought, clumsily trying to make sense of the metal. Overly mobile? Overactive or just energetic? The nurses couldn’t deal with him, they said, running about and bothering everyone. The other young residents were tied down to their wheelchairs and were mostly unable to steer themselves around. The notable exception was a young boy who operated his electric chair by tilting his head from side to side, thanks to a special mechanism. The chair was designed for children with no mobility below the neck; ironically, the little boy could move his arms and torso just fine. Still, he sped around the sidewalk in his chair, head moving in quick pops of control, concrete flying behind his gleeful laughter as he spun in circles around the patio, dorm rooms, and hallways. I

caught sight of him as soon as I arrived, as we ran around together – him in his chair, me sliding cautiously in my loose sandals – and he led me to E.'s room.

Abierta, abierta. If we let E. out he might run into the kitchen, people explained, and hurt himself. Cut, boil, shred, fall, slip, bleed, bruise. I recall my own kitchen hijinks years ago and the wait for a ride to the town clinic that followed. It was a Sunday night and I was opening a can of soup, standing between the microwave and the sink in the shared Victorian house I lived in for a few months. Perhaps I was fighting a cold while trudging through six months of winter. The soup can's aluminum top stuck right at the point where the red and white label collided with the layers of rimmed silver closure. The dollar-store can opener that never quite sliced through anything like it did my finger. Redness exploded, a cool jelly darting onto the wall next to the toaster oven, just to the left of the yellowed stovetop. Blood everywhere, but really not that much – how much can really come from an index finger, after all? My roommates started screaming; I asked them to hand me the phone and I walked outside after sponging up my mess. I sat on the white swing hanging from our porch, inhaling the starchiness of a Midwestern winter night as I waited for the car to arrive. It ended up only a few stitches. *He could hurt himself in the kitchen*.

* * *

At this point, I pause and wonder where to continue. I place myself in these absurdities – the violations inherent to locking one inside – through my own experiences. I take the scraps long forgotten that, for whatever chain of associations or synapse recognition or scent, are triggered by the imagery of enclosure.

* * *

He could hurt himself. Abierta, abierta! And then a cry, more of a wailing sound, really, that captures everything I can assume I would feel if locked in. How can I know, really? And I start to get lost in the metaphors, the layers of comparisons. I think of the teenagers I used to teach, who had their own stories of huffing glue, running away, selling themselves, and then, as if by magic, of the opposite side of the coin – boyfriends, sex maybe just a little too soon or with just a few too many, sisters and laughter, dancing, pop music, endless makeup tips, commentary on body parts, stretch marks, shaving, hairstyles. They, too, had their battles with being locked inside – of themselves, their chemical blurs, departures, foster families, detention facilities, jail. I was supposed to have the kids lift their tongues to show me that they had swallowed their pills each time I administered them, but I tended to forget. I wasn't going to be the one to push pills down their throats, so I just turned my head and smiled.

* * *

That summer, I saw cages. I now see them everywhere, whether in present or falling back into my collages of memory. But the haze of misprescription looms large in this story. Prescribed spaces, domains, or patterns; formulas to follow and roles to be played. The cages continue to pop up, small dots of increasingly bright color across my memory maps. I seek them out, still unsure what I want to find.

* * *

E. and I sit in the grassy center of the courtyard gathering leaves. They are not yet dry and hold onto their deep forest green with a vengeance, guarded by a waxy coating that will soon wear away. They bend slightly as I grab them with my right hand, putting them into a clumsy pile I hold with the other hand and

then (once I have enough) placing them into a cluster on the grass itself. I have to be careful that they don't blow away, since a storm is coming and I feel the occasional droplet starting to fall.

He runs intermittently around the grass, darting up onto the concrete sidewalks, behind columns, peeking into doorways. His walk is jerky, slanted, and relies on bent knees to carry him cautiously with clanging stomp-stomp-stomps across the open space. People crowd on the exposed staircase in front of us, standing there inexplicably, having finished up their own appointments at the medical clinic located elsewhere in the building. I love it. They wrap up their exams – maybe give a little blood here or a sample there – and then meander down the corridor to the sunny staircase where they can watch the kids with disabilities sit there in their chairs, getting mealy-meal shoved unforgivingly into their mouths. The flow of onlookers is steady, just coming and going as the doctors and nurses finish with them and push them out the way they came.

As E. stalks back toward me, I see him pick up speed. Soon, he works his way up to a staccato run and – bam! – throws himself against me with all his weight. Fifty pounds? Forty? I have no idea. The arms fly around my waist, he buries his head into my stomach, and I can feel the saliva seeping through the black-and-white stripes of my knit shirt. He bites me –not without hesitation – and I pull back, tell him no, and we sit down. He laughs the hysterical laugh of someone who gets little practice with pleasure. There's a lightness to it, as if the laugh itself will blow away in the breeze like a balloon, just up-up-up, faster and faster until there's nothing to do but watch.

He is unsure of what to do, seems unaccustomed to being "out." He stands there, just spinning in stillness, eyes combing the courtyard, coasting over

me. I sit in the grass and the morning wetness catches on my skirt, the outline of each green blade carving itself into the backs of my thighs. We pause without a sound and I know it's time: I grab the leaves and throw them. They rain over the boy's head and laughter takes over. E. falls to the ground, giggling with abandon, and tosses the leaves over himself in the air again and again so they will never stop falling. I am laughing, too, unable to fight off the simplicity of the moment. We continue with this game, grabbing leaves, collecting them in haphazard piles, dancing with them, running them over our hands, throwing them up to catch the stormy winds, letting them roll down onto us. He will not bite me again, I know. He sits in my lap as we continue the game, guiding my hands to catch new leaves, coming back to the temporary safety that I pretend to offer. One of the nurses tells me that we need to come inside, since it is starting to rain. There is a drop or two, but no umbrella necessary. Certainly not worth putting the boy back into his bed-cage. I surprise myself by cursing at her audibly as she turns away, not quite under my breath. Perhaps the people on the stairs hear me, I see it on their expressions. I doubt they know English, but I'm quite sure they know the words I just said. Their eyes try to admonish me. My blood boils and I calm myself only because I know the boy can feel it.

We ignore the nurse and the people on the stairs. I push them out of the moment and they exit our reality, just as before. We bathe in the leaves for the rest of the hour.

Chapter 3

Disability Anthropology and the Question of Storytelling

When it comes to disability, what does anthropology bring to the table? What can it contribute to other disciplines and genres of disability writing? This essay centers on these questions of form and possibility, asking what an ethnographic attunement to disability adds to existing disability literature, whether scholarly or otherwise. Rather than focusing on the theoretical or methodological facets of disability anthropology, it asks what it means and does to write disability ethnographically. To do so, it builds on recent experiments with ethnographic writing by a variety of anthropologists (Biehl 2005; Pandian 2012, 2016; Raffles 2010; Stewart 2007). Ultimately, it argues that anthropology's most significant contribution to disability writing is its ability to suspend critique, put politics on hold, and disentangle – through words and scenes – the less explored territory of difference in the everyday.

As a discipline, anthropology cannot be separated from its literary component (Pandian 2016, 426). The writing is always present, combining literary and theoretical elements with the often equally open-ended rigor of fieldwork. Anthropologists thus have access to a level of potential literary experimentation that blurs the lines between ethnography and other genres. In the last decade, there has been a surge in ethnographic writings that push the boundaries of tone, voice, and structure, as illustrated by such texts as Kathleen Stewart's *Ordinary Affects* (2007), Hugh Raffles *Insectopedia* (2010), and João Biehl's *Vita* (2005), among others. This places disability anthropology in potentially fruitful relationship with other forms of disability writing, whether

academic, applied, journalistic, or literary. While sociologist Avery Gordon wrote that the "professionalized social sciences" are more constrained by publishing or stylistic norms than are literary fields, this is arguably not the case in anthropology (1997, 25). The question, then, is what disability ethnographies might contribute as a distinctive subgenre of disability writing?

COMPOSING DISABILITY ANTHROPOLOGY

As a fundamental aspect of the human experience, disability is central to questions of social organization, belief, and culture. It is shifting and dynamic, changing in concert with shifting perceptions, technologies, and anxieties. It is composed partly of bodies and minds, but also of complex assemblages of social and cultural forces that stick to such embodied forms of differences – whether real, imaginary, or some combination of the two – in ways that are sometimes predictable, sometimes surprising, and rarely as clear as one might assume.

Anthropological studies of disability are often assumed to fall under the umbrella of medical anthropology, but this need not be the case (Nakamura 2015). Anthropology is perhaps uniquely attuned within the social sciences and humanities to exploring disability as a distinctive social world, one that involves but is never reducible to bodies and minds. Disability is an ethnographic object that merges embodied experience with collective anxieties, beliefs, norms, and histories; with policy, care, notions of personhood, power, and citizenship; about what it means to speak, about intimacy, about communication; with underlying questions about lives worth living. Disability becomes a collection of forces,

ideas, practices, and aspirations. It is undeniably sticky, skirted around and yet omnipresent.

While disability studies has traditionally examined the more political aspects of disability experience, I would argue that anthropology offers something different. For this project, I approach disability through what Bruno Latour calls *compositionism*. As he explains: "…compositionism takes up the task of searching for universality but without believing that this universality is already there, waiting to be unveiled and discovered" (2010, 474). Latour positions compositionism as an "alternative to critique" (2010, 474). He writes:

> With critique, you may debunk, reveal, unveil, but only as long as you establish, through this process of creative destruction, a privileged access to the world of reality behind the veils of appearances. Critique, in other words, has all the limits of utopia: it relies on the certainty of the world beyond this world. By contrast, for compositionism, there is no world of beyond. It is all about immanence (2010, 475).

This perspective is, I argue, central to disability anthropology. It is through such engaged writing – indeed, through composing disability ethnographically – that anthropologists can bring new understandings of what this facet of human experience means and does, how it is felt, and what we have yet to say about it. It is here that we can contribute to the insights of other disciplinary approaches to disability, from the social history of diagnostic categories to current demographic data, policy documents, or disability studies' writings on the role of social exclusion, marginalization, and structural forces underlying ableism. Yet this reveals little about how a particular world feels. The textures of a space, the surprises, ambivalence, or contradictions of what is said versus felt, lived, witnessed.

Composing disability in this sense privileges the minutiae of a scene, the details of a body, the affective zones of a space over any broader narrative. This framework enables ethnographers to explore what might be lost otherwise, due to assumptions, exclusions, or the inability to hone in on the everyday. It carves out openings to discuss the stories that are not supposed to be told, the ones that work against and are constrained by emancipatory discourses of rights and equality. It allows us to get dirty. What emerges when we take writing seriously as embedded fully in the process of disability ethnography, from data collection to the ultimate monograph? How might this lend itself to a new genre, both within anthropology and more generally within the literature on disability?

THE QUESTION OF GENRE

As Anand Pandian writes, anthropology is both an "empirical and literary encounter" (2012, 566). Through the ethnographic process, different temporalities of data gathering, analysis, and writing converge repeatedly. Like some of Pandian's work (2012), my ethnographic writings on disability double as experiments in time, tacking between fieldwork, writing, and reflection.

In a blog post from 2015, I wrote of my own ambivalence as a disability anthropologist:

> After spending over a year doing continuous research, I found myself frozen in a state of paranoid introspection. Why was I doing this at all?
>
> The feelings began in January, all set for the New Year. Perpetual overthinking, not to be confused with depression. I wasn't depressed, not at all. Not even anxious, really. Just stuck in a state of perpetually overanalyzing everything in terms of disability, health, and personhood. I could not get out of it, could not turn it into something productive, could not really move forward.

> Why was I suddenly convinced that everyone I knew and loved was undiagnosed or dying? Where had this fear come from? I'd never operated this way, yet I suddenly felt frozen. An itchy scalp triggered bizarre fears of meningitis; I almost convinced myself I was having a heart attack one night, or perhaps a pulmonary embolism. Everywhere, everyone began to be coded as somewhere on the autism spectrum.
>
> I watched disability horror stories unfold in the news. A young, African American man with autism in the city where I live was shot and killed by a neighbor after knocking on his door early one morning, presumably confused and scared because he had run away from his group home. He lived across the street from his killer, who, irony of ironies, had side gigs training people in home handgun safety. The media and police cast it in terms of a disability inevitability. I was stunned by the explicitness of the denial of personhood, of the lack of value of a life. Here, disability, race, and gender were a deadly combination – because of what the public made them out to be. Because they were a reasonable cause of death, complete with a requisite "Our thoughts go out to the family."
>
> I saw the growing opposition in Texas to closing institutions for adults with disabilities. This, despite ample national examples of viable alternatives. Despite a 15-year-old U.S. Supreme Court ruling and the state's agreement with the federal government. People argued that institutions were the only safe option. Indeed, when the young man I mentioned above was shot, several news outlets used it as an example of why adults with disabilities were "better off" in institutions. *It's for their own good*.

My writings for this project dwell in the entanglements and interconnections between seemingly disparate stories, moments, and media, blending blog posts with field notebooks, personal essays with fiction. Much of the data appears extraneous to the question of undiagnosis in particular, yet it is very much part of that same world. Themes of anxiety, violence, safety, diagnosis, media, community, identity, appearances, abandonment, and rights emerged repeatedly, demanding attention while pulling the focus away from a clear question of diagnostic meaning. The result rests in the pauses, in the

openings of seemingly different stories told too many times that, at some point, begin to converge.

On Reading

Questions of readership and form in anthropology are in a time of flux, as new approaches to writing about or with ethnography take shape through current digital technologies. Due to its design, my project explored the relationship between written form, audience, and the digital at all stages, from gathering data to disseminating my findings. As such, it offers a useful case study of genre across two domains: first, the question of fieldnotes in a digital age as potentially public, accessible, and shaped through online encounters; and, second, the way in which the subsequent texts generated through ethnographic labor become part of a newly accessible body of online disability writings.

In "Ethnography Is/Ethnography Ain't," anthropologist John L. Jackson revisits Clifford and Marcus' seminal edited volume, *Writing Culture*, to ask what it means to write culture in a digital world (2012). Thanks to digital technologies, ethnographers are now more accessible to their research subjects than ever. From academic websites to blogs, open-access journals, Twitter, YouTube, other online venues, our works and our online selves are available and observable. The notion of the anthropologist dropping in for fieldwork and then leaving has fundamentally shifted and, as Jackson writes, "The researcher is ever-more researchable" (2012, 494).

He describes this new relationship of the research subject as "emergent backstage access" (2012, 493). Not only are ethnographers and other scholars

openly searchable, but we can also use these same digital technologies to disseminate our materials quickly, as well as to obtain new forms of public (or non-academic) feedback. Of course, this also leaves our work more open to critique than in the past. We are accountable to our subjects in new ways and, in turn, the ethnographic process is both more vulnerable and more open than perhaps ever before. All of those anthropology graduate seminar debates on accountability to one's subjects take on a new salience in this digital real-world.

What happens when the products of ethnographic fieldwork – the genre of disability ethnography – are available for public consumptions as part of the research process itself? When fieldnotes stand in as a publicly accessible snapshot of an ongoing project, inviting comments and viewers, reaching potential audiences, framing the work as an archive in progress? Deliberately showing the fragments, missteps, and frustrations of ethnographic research? Playing with words and tone, emotion and discipline, the question of how personal to go, of the uneasy relationship between research and researched at all stages (at least in my mind)? What might public displays of ethnographic vulnerability do for our work?

Throughout fieldwork for this project, writing was a central and intentionally quite public process. I gathered data digitally by maintaining an almost daily written presence on social media, whether through Twitter, my blog, or occasionally as a contributing writer on disability topics for various websites. I reached out to new audiences and potential interlocutors through this continuous archive of my project; it was in constant disseminations, available and accessible to anyone who came across the work. The writing was, in many ways, central to the digital methodology itself. Just as I could not engage ethnographically with

my on-the-ground interlocutors without dialog and observations, that dialog took the form of writing – at least initially – in my digital ethnographic work. From the 140 characters of a Tweet to more traditional essays, my words formed an archive of my thinking and shifting public engagements throughout the project.

The section below is taken from "Truthtelling," an essay posted on my fieldwork blog on October 19, 2015. It is a real-time snapshot of the moment when I began to think seriously about the relationship of disability anthropology, digital scholarship, and ethical writing beyond the parameters of simple research requirements.

> At some point this year, my dissertation shifted from a (largely unwritten) traditional ethnography to an intentional experiment on writing/thinking/doing disability as a scholar. This was a change borne out of necessity, namely an ongoing writers' block stemming from my constant worry about the question of truth. Truthtelling, to be exact. How to form my data into a cohesive project that is 1) mildly elucidating; 2) useful for scholars, families, and professionals in the disability field; and 3) does both 1 and 2 while also doing no harm to my interviewees. This was the hard part.
>
> As both a relative of someone with a disability and an anthropologist, I know firsthand that these stories can be dangerous. A family's tales of stoned left unturned, unexamined research studies, the bad luck of geography and time, neglecting to get a second opinion or perhaps listen to the first. Of affective, medical, and therapeutic worlds that have not caught up to the daily needs and lives of these children.
>
> Context is huge, and hugely personal, when dealing with a child with undiagnosed disabilities. I recall a woman I wrote about in my Master's thesis, whose son's abilities were seriously compromised by a lack of services during early childhood. I wrote about her experience in my thesis – uneasily, knowing that perhaps I shouldn't – telling myself that the story was meaningful. Others could learn from this illustration that disability was dynamic, and that social shaping could be paramount. Did the mother read it? I have no clue. But I mailed a copy to the disability organization where she worked at the time and I've thought about it for over a decade. In my current work, this was not an experience I wanted to repeat.

I know, too, that in my own family's disability history there are stories I simply will not tell. All families have these. Details and ruminations that would traumatize through seemingly sterile memories or the insertion of present knowledge onto past predicaments. And so I remain silent, focusing instead on the generative power of this personal knowledge. The question was how to reconcile my ethics of disability anthropology with disciplinary and literary expectations.

The notion of truth is, of course, fraught. Matters of perspective, detail, and the everyday are more subjective than we care to admit, whether as anthropologists or otherwise. For storytellers of the scholarly variety, this raises significant challenges – all the more pressing in research like mine, in which these narratives are embodied physically, emotionally, and intellectually by the children of the parents I interviewed.

Recently, I wrote my first short story in years. It was more of an experiment than anything else, but the words flowed in a way they hadn't in months. The protagonist was a teenage girl with an undiagnosed sibling, and the story was based loosely on narratives from multiple interviews I conducted for my dissertation. It's fair to say it was strongly influenced by my own experiences, yet not at all a piece of nonfiction.

I wrote 20 pages in two days. Workable, usable pages. Twenty pages not of a particular truth, but of a story I felt needed to be told and read. I felt no need to pause to flip through fieldnotes – no need to verify a quote or double check the age of the speaker. I was free to invent the incidentals as I went along. No IRB looking over my shoulder, no anxiety about my research subjects challenging or being harmed by my words. As a scholar, this experiment with fiction was one of the most liberating and productive experiences I have had.

Fiction in anthropology is a taboo. Ditto for journalism. Worries of blurring genre lines, about compromising the strength discipline that is increasingly challenge by the public as a fanciful holdover from past eras. Sure, we hang our hats on counting Zora Neale Hurston among our disciplinary forebears, but for the most part anthropology thrives by embracing subjectivity while asserting scholarly rigor. It is an argument I largely swallow, but that many in our peer-reviewed society do not. And I cannot help but ask, why bother? If my aim is to reach people with my data – which consists, let's face it, of collections of stories – what is the best medium? Voice? Genre? I wonder if the really real that ethnography seeks to capture exists in the composite sketch or the singular case. I am currently exploring this through my writings, which have become an exercise in distillation and compilation, rather than a comparative analysis

> of individual stories. The ethnographic case something as maybe something more, but maybe not. I think, too, of what I regard as one of the primary contributions of anthropology: the reminder to remain wary of truth claims and steadfast narratives, whether from academics or others.
>
> The takeaway? I can say definitively is that I am both intellectually and ethically uneasy about writing a typical ethnography. Rather than be stymied by tedious debates about replicability of findings or the risks of reflexivity, I would prefer to make things up as I go along. I mean this literally, using fiction, reflexive blog posts, jottings, and other experimental or informal writings as an accommodation to help move through the ambiguities and danger zones in my work.

The essay gestures toward my own ambivalence about writing disability. The stakes are topical, stylistic, and ethical, relating to assumptions about where disability resides in anthropological analysis and how it engages with issues of power. Notably, I was quite concerned about doing harm. There is much talk in anthropology and IRBs about protecting informants, such as from retribution or punishment. But what about the weight of their words after the fact, even when rendered anonymous? It's an important question and, despite its paternalistic undertones, deserves attention. I was speaking with parents about their children, their experiences as caregivers amidst struggle. Abortion decisions, prenatal diagnosis, marital stress, doubts, self-blame, speculation, mourning for an imagined future. These were central to many (if not most) of their narratives that would be difficult to broach in disability studies, where the pressure to have a pro-disability, anti-ableism framework is acute. What might ethnography do differently?

As Tobias Hecht wrote in regard to ethnographic fiction: "Ethnography can take one into rituals and mundane daily events, into gossip and funerals, into the worlds of work and leisure. It can go almost anywhere except, of course, into the

mind of another person" (2006, 9). From a personal standpoint, I was deeply uncomfortable putting some of my interlocutors' recounted experiences down as fact. It was not that I questioned their accounts or even out of an interest in alternative perspectives, but simply out of a nagging worry that, as a parent, they might later regret their divulgences. And, in truth, some of their stories did seem outlandish, such as when parents invoked vaccines as a possible cause or trigger of their children's conditions. Speculation was the norm, sometimes verging on conspiracy theories, and was no doubt exacerbated in an age of Google, where seemingly plausible misinformation is available within seconds.

I wondered if fiction might provide an out or, at least, some breathing room. I approached it cautiously as a means to place different stories in dialog with one another, to toy with their overlaps. Dealing with not-quite-real informants, the ethics of storytelling opened up enormously and, within that new space, I was able to think in new ways about the real. I followed Hecht's call to embrace partial truths and recollections with an ethnographic attunement. In Hecht's case, this meant formally fictionalizing the stories of his key informant, once he realized they were largely the products of embellishment, borrowing, and imagination. For me, however, fiction was simply a writing experiment. It offered a chance to ask myself how I imagined these stories might end or what they could contribute. Ethnographically, however, I was drawn to the openings in the more unruly narratives of real life. Why venture into fiction when the ethnographic writing itself can tell so many unacknowledged stories of actual lived experience?

DISABILITY'S AFFECTS

I used my fieldwork blog to think through my encounters with disability worlds. I cast a wide net, asking unruly questions, probing uncomfortable bodily and affective spaces of everyday life. The registers of experience for which language often fails. This was a compositionist project, to follow Latour, but also involved close attention to affectively charged case studies. Anthropologist Zoë Wool describes this ethnographic attention to "zone[s] of life…full of visceral intensity and uncertainty," writing of the intimacy of lived experience and every encounters in her fieldwork on injured soldiers at the former Walter Reed Medical Center (2015, 3). She argues that ethnographies of the intimate and ordinary capture a different sort of attention to experience than what is conveyed by composite stories or statistical data, highlighting instead the jarring yet mundane occurrences of daily life (19-20). One soldier pauses an interview to urinate with the door open as Wool directs her gaze elsewhere, another panics when he thinks he has forgotten his medication during an otherwise unremarkable trip to a buffet, an error that could cost him his leg. As part of an ethnographic study what she refers to as life in a "marginal ordinary" space of postwar injury, such scenes help piece together the textures of the everyday as embodied, dull, affectively charged, discordant, and, at times, uncomfortable (or thought to be) (23).

This intentional attunement merges what Clifford Geertz (1973) famously called "thick description," with more recent work on affect theory (Gregg and Seigworth 2009; Massumi 2002; Stewart 2007, 2009). In such works, affect is framed as an analytical tool that bridges the embodied, social, and political scales across which lived experiences and cultural realities unfold. It emerges at the frontier between individual bodies and broader norms, practices, and belief

systems, producing new ways to visualize and theorize life. This framing highlights social worlds and lived experiences as ongoing processes, highlighting partiality, flux, and contingency, and is particularly well suited to approach scenes and moments of disability in daily life. This was especially true for stories that were difficult to tell.

My blog entry below, “The Diner,” was posted in March 2016 after a particularly jarring, yet not necessarily unusual, event while visiting relatives. It was read by over 150 people that month alone, according to my website statistics, and was shared multiple times by readers on social media.

> “Aunt K. used to be happy when she was young. Now, she’s angry.”
>
> My head snaps to the side, surprised by my three-year-old son’s statement during his after-school snack. Had he gotten this from me? Undoubtedly. Aunt K., my younger sister and his only aunt, has Charge syndrome and is largely isolated from the world around her. She has no community activities, and interacts almost solely with my parents, the staff at her house, and her roommate. She and I connect less and less with each visit. The erosion of personhood is a curious thing to witness.
>
> She used to be happy when she was young. Now, she’s angry. It’s an oversimplification that glosses over many years in the middle, but it’s not incorrect. I would not say she’s angry, though. I would say done. Now, she’s done.
>
> My son was never scared of his aunt until the incident at the diner. It was sometime last year and he and I visited; in the fall, I believe. He, my father, Aunt K., and I trooped to one of the few restaurants where she now went. We stopped taking K. out for many activities years ago, when I was in eighth or ninth grade. Her tantrums and self-abuse were too much. It never ended well. She would shout and bite one of her hands fiercely, while flailing with the other arm and hitting herself on the side repeatedly. People stared. They weren’t wrong. This was the kind of thing one stared at, it just was.
>
> So, for better or for worse, we stopped taking her out. She’d go to the grocery store or post office with my dad, but for the most part an “outing”

involved bringing something home from the drive-thru. It was an eminently anti-social affair. One notable exception? The diner.

The four of us walked into the diner and selected a large, circular booth. I immediately paused as we sat, thinking we should leave it for a much bigger party. I didn't think much of my hesitation at the time. We ate our meals, not exactly happily but seated without incident. My father helped K. get ketchup for her hamburger. We all pretended not to notice that she separated bun from meat, hunched over, having long abandoned or lost the basic table habits she had as a child. I talked and played with my son. The expansive booth spread out before us, creating much more space than necessary for a party of four.

She snapped at the end of the meal. I have some ideas of why, but I really don't know. My interpretations are filtered through my speculation at how I would experience K's life – it's guesswork to say the least and is anything but scientific. I'd seen her slipping into this state for years, increasingly isolated, less of a person, less able to be. Social isolation is a devil, perhaps more so for someone who can barely communicate formally.

She started shouting and hitting herself. It escalated almost immediately. My father tried to coax her out of the booth, but she was deep in the circular layout and had no intention of leaving. She had gotten lost in the space. Just like the old days, she bit her hand – those same callouses and scars, the permanent purple of the skin. She shouted. She hit herself, jumping up and down in the booth. My son was three. And he had never seen anything like this. He was terrified.

"Mama!" He clung to me.

He and I moved to an adjacent booth and watched the scene play out. There was nothing I could do. My father tried our family's brand of broken, halting sign language to tell K. to leave, but she was in it. In it. The restaurant was silent and staring. Waitstaff. Patrons. Everyone. And, again, they were right. This wasn't a cute disability-as-difference quirky moment. It was a 150 lb. adult woman having a full-on physical meltdown that dominated the entire space.

Realizing that we couldn't do anything, I called one of K's staff. She didn't hesitate: "I'll be there in 10 minutes." I told my father. "She can't get here any faster?!" he exclaimed. But it wasn't her job to be on-call. We were in charge. And we simply couldn't handle it.

The staff member came and got K. out almost immediately. I believe she took K. back to her house, but the details are fuzzy. My father was visibly shaken. My son was terrified. I knew we had turned a corner and there would be no more outings with Aunt K. unless we had a third adult. A strong one. If the expectation was that I could help, it was out of the question. I had a child of my own now. I couldn't drop my own life and rush in for K. It was impossible, both physically and emotionally.

In thinking through the horror of the encounter, I am profoundly grateful for one thing: nobody called the police. Because they could have and, if I'm honest, I am not convinced they would have been wrong. K.'s actions that day were beyond disruptive. They were scary to anyone who had to watch. She was out of control. We were powerless. No longer a cute child of four or five, she did not get a pass for that. Yes, she was only physically harming herself. No, she would never intentionally harm anyone else. But, given the violence of her movements and screams, nobody had any way to know that. And I cannot blame them.

In the aftermath, I talked to my son at length about Aunt K. He was terrified. A shy child who cringes at the sound of a yell and chokes up if another child cries, it was too much. I explained that Aunt K. cannot talk and she gets frustrated. That she would never hurt him. That her feelings are directed at the world and at herself, at being locked inside for no good reason and unable to articulate even basic things beyond "want French fries" or "go car."

I talked at length about all the things they had in common. I loved them both, I reminded him. She loved candy and had a secret stash all over my parents' house. Didn't he like candy, too? Aunt K. always wanted to rest in their family room with old "Sesame Street" DVDs playing. Didn't he want the extra screen time? I tried to frame Aunt K. as an in for these secret indulgences – sweets, TV – that he knew were restricted otherwise. I focused on what they had in common, not the vast differences that anyone could see.

But my son is three. These were heavy, heady things. How much could he understand? He continued to cower whenever he saw Aunt K. He refused to go to the table for family meals, my parents sitting silently and awkwardly with K., the three of them eating, as he and I waited – hungry – hiding on the stairs or in the family room. He would cry if he got too close. She was officially, without a doubt, the most violent person he had encountered. It was sad, but there was no sugarcoating what he had witnessed and I saw no sense in denying or talking around it.

Once he and I got home, he kept bringing it up. “Aunt K. was very angry.” “Aunt K. yelled.” I would sigh and try to explain things again, shifting my language in an attempt to help his young mind digest the concepts, careful not to say too much.

And then a strange thing happened. One day, I overheard him playing with two figurines from a toy playground set. One was supposed to be him, the other was Aunt. K. “Come on, Aunt K. Let’s go!” he exclaimed, holding the dolls and running across the room to his beloved train table. “Aunt K., let's play with trains!” He was pretending that the doll was Aunt K. and using it to interact with her in a way that was not possible in real life. Through the dolls, they could talk and play. He could begin to understand her, to build a relationship with his only aunt. He did this for months. I’m not sure when he stopped.

My parents were nervous when we visited at Christmas. Did Aunt K. need to stay at her house the whole time? Did we need to begin celebrating Christmas without her? Was she “ruining” it for my son?

No.

While he couldn’t exactly play with his aunt, he was no longer scared. He didn’t run or hide when he saw her. Instead, he’d grab my hand and smile. “That’s Aunt K.” he would whisper, as if we were sharing a secret. She loved candy, he loved candy. She loved TV, he loved TV, and that was enough.

The other day, he announced “I need to see Aunt K!” This was before the comment about how she was once happy, but now she was angry. She had clearly been on his mind. But he no longer worked through it with his doll, instead broaching the subject – in his way – with me. Months later, he would occasionally ask if Aunt K. could talk. “No,” I replied. “Does she have to learn how to talk? Babies have to learn how to talk,” he would say. No, I told him. She just can’t talk. She is not able. “Does Aunt K. talk like this: ‘mmmmmm, mmmmm’?” he would then ask, a cross between a grunt and a hum. I paused. “Yes. Yes she does.”

I offer this story as a standalone. There is no bigger, deeper message. Or maybe there is. I will say that a curious thing happened here. The doll. The restaurant. The subsequent interpretations by a very quiet three-year-old. She had clearly been on his mind. And I’ll leave it at that.

Note: The day I wrote this, my son saw the Aunt K. doll and announced "That's Aunt K!" When asked what he thought about her, he replied "Aunt

> K. is cute." Later that evening, we FaceTimed with my parents and he immediately asked where Aunt K. was. He was disappointed to hear she was not there. A few mornings ago, he had announced "I need to see Aunt K." I have no answers for any of this nor can I offer much of an interpretation. But there's something here to be learned about how he processed this and how he has come to interpret her difference (or not). I just wish I could harness it.

This essay is intentionally unfinished and open-ended. There is no tidy message and the rawness of the situation – the sense of urgency and helplessness – sharply contradicts a focus on the external and social aspects of "disabling" an individual, resting instead on the bodily acts and affective saturation of the scene in the diner. The ethnographic attunement turns to space, gesture, bodies, and affect.

Some of the comments I received noted the essay's treatment of ambivalence regarding disability. It struck me that this was, in the context of disability studies, noteworthy. I was not supposed to tell stories like this. Stories like the viral blog post, "My Son Has the Kind of Autism No One Talks About," in which a mother writes of her son's aggression and violence, confiding to a limitless public audience that "For the longest time, I would flinch when he ran up to me…" (2015). Stories like these were too loaded, too far beyond the simplistic realms of mainstream media images of disability, aspirational rights discourses, sterile biomedical claims. They opened the door to an affectively loaded world of stories often overlooked or obscured, perhaps inconvenient or unsavory. As Kathleen Stewart explains:

> There's a politics to being/feeling connected (or not), to impacts that are shared (or not), to energies spent worrying or scheming (or not), to affective contagion, and to all the forms of attunement and attachment…There's a politics to difference in itself – the difference of

> danger, the difference of habit and dull routine, the difference of everything that matters (2007, 16).

Such approaches to ethnography and other forms of writing have the potential to profoundly impact how we think through, understand, theorize, and describe disability, whether as anthropologists or otherwise. As Ian Hacking argues, texts play a key role on broader conceptions of difference; they both capture and create cultural scripts for engaging with these categories and lived experiences. In regard to autism spectrum disorders and their treatment in emerging literature, he writes: “The autobiographies, novels, and blogs are entrenching a language in a domain where there was no language at all fifty years ago, and not much twenty-five years ago” (2009b, 506). He goes on to say: “We are participating in a living experiment in concept formation of a sort that does not come more than once in a dozen lifetimes” (2009b, 506).

Following Hacking’s analysis, how might we use ethnography to shift how we learn, speak, write, or read about disability? This genre, which spans anthropology and disability studies, has the potential to expand our understandings through new language, theoretical frameworks of difference, and forms of attention. For instance, Wool (2015) and Stewart (2007) both dwell in the ordinary, highlighting the visceral, affectively loaded worlds of otherwise unremarkable scenes. Their writings demonstrate anthropology’s perhaps unique ability to uncover social worlds and experiences that hide in plain sight, pushing the reader to pause in the assumed or unaskable.

UNDIAGNOSIS AS A WRITING EXPERIMENT

Writing on health care in Papua New Guinea, anthropologist Alice Street reminds us that biomedicine is assumed to be a diagnostic enterprise and asks a simple, yet unnerving, question: what happens when it is not? Individuals with disabilities that are evident, yet undiagnosed, defy assumptions of biomedical control, social organization of bodily or intellectual difference, and easy explanations. They fall beyond diagnostic common sense, upsetting the balance of what is assumed to be known and knowable. The notion of undiagnosis, in fact, hinges on assumptions of biomedical power. Undiagnosis only becomes aberrant when it is assumed the physicians, geneticists, and other specialists "know better." The notion of nameless forms of difference and the associated lack of prognosis or knowledge claims unsettles.

Undiagnosis carries marked temporal elements, most notably in the form of an imagined future that is less obscure. This recalls S. Lochlann Jain's writings on cancer and living in prognosis: "Data and narrative each have their place, though neither ever really assuages the stupefaction of living in prognosis" (2013, 29). While potentially inaccurate, a prognosis rests on a particular future. In contrast, undiagnosis remains unanchored, suspended in narrative and data that fail their storytelling task. It is imagined as a state of possible, but not promised, becoming, animated by the underlying notion that the really real lived experiences of the body will somehow be rendered even more real through the logic of future diagnosis. But how might ethnographers convey and also disrupt this narrative, harnessing anthropology's ability to deliberately craft a space for uncertainty and flux, resting in the unknown or emergent?

But the realities of ethnography as a project are not always so practical, which brings us back to the question of fiction. What if we realize we cannot trust our interlocutors, as described by Tobias Hecht in *After Life*? Or, as in my case, if we simply are not comfortable telling stories as we received them? When the writing stops. When the subject matter rattles. When we just can't do it. The story that follows emerged from such a block. Not quite a composite, but the creative sedimentation of the layers of interviews, talks, overheard conversations, hushed remarks, and searching questions after presentations. A snapshot not quite ethnographic, not quite something else. A dwelling in the in-betweens and ambiguities of disability ethnography as a genre in flux, an approach in process. A story.

Interlude:

Locating Disability

SYMPTOMS OF POSSIBLE DISORDERS IN A CHILD:

Appears to be shy

Likes to play by oneself

Prefers puzzles or televisions to stories

Daydreams

Sings off-tune

Spins in circles

Likes playing with trains or cars

Picky eater

Dislikes loud sounds

Temper tantrums

Interrupts

Does not always respond when name called

Does not always follow instructions

Needs to have instructions repeated

Trouble staying organized

Blurts out answers in class

Guesses when asked to solve a problem

On the go

Butts in on others' conversations or games

If infant, has trouble falling or staying asleep

Mood changes

Difficulty expressing oneself if nervous or anxious

Dislikes brushing teeth

Bad at sports

Peculiar preoccupations

Dislikes tags on clothing

Prefers one-on-one play to groups

Male

STRATEGIES TO REDUCE THE RISK OF VARIOUS CHILDHOOD DISORDERS:

Breastfeed

Don’t smoke in the house

Don’t have an underweight baby

Don’t have a preterm birth

Don’t have a baby who has to stay in the NICU

Don’t have a baby who needs oxygen

Read to your child

Talk to your child

Don’t abuse your child physically or emotionally

Don’t vaccinate

Buy organic mattresses

Don’t eat fish while pregnant

Eat lots of fish while pregnant

Sleep with your infant

Make sure our infant sleeps alone

Give your child ample time to develop at her own pace

Utilize early intervention services (ages 0-3)

Ensure ears are clear, get tubes if necessary

Do not expose to anesthesia, a potential cause of learning delays

Listen to your pediatrician

Ignore your pediatrician if advised that everything is fine

Chapter 4

A Death in the Family:

Disability Activism, Mourning, and Diagnostic Kinship[1]

INTRODUCING DIAGNOSTIC KINSHIP

"We are all family." I heard the refrain constantly during my research on deafblindness advocacy in Guatemala. The concept of deafblindness has changed significantly in recent decades, widening its scope to incorporate a population of unprecedented diversity. My project centered on families – primarily mothers – as well as on disability professionals in Guatemala's nascent deafblind movement. In this chapter, I revisit their stories to probe everyday experiences with deafblindness as an amorphous unifier, grouping together individuals whose bodily forms appear to have nothing in common aside from this label. Through this case study, I examine how a deafblindness diagnosis converges with everyday affective and logistical needs to generate new formulations of family within this community.

This essay extends Rapp and Ginsburg's work on "kinship imaginaries" (2011), which reframes what kinship is, means, and does for families of children with disabilities. It also builds on scholarship on disability family activism (Silverman 2012), as well as on care and parenting (Bérubé 1996; Jack 2014; Kittay 1999; Landsman 2009; Simplican 2015), highlighting the complex intersections of diagnosis, kinship, and political and social change. Through an

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ethnographic analysis of the death of a deafblind child, whom I will call Baby F, this essay introduces the concept of diagnostic kinship to refer to the distinctive disability communities that families form around their children's shared diagnoses.

Diagnostic kinship is particularly significant in the context of rare (or low-incidence) disability categories, such as deafblindness. For such populations, the geographically dispersed nature of individuals and their families poses a major obstacle to forming networks. The inability to obtain membership in a public community of support hinges on an individual's diagnosis. Without a diagnosis for their child, parents I spoke with frequently reported feelings of isolation from any broader disability community. In these cases, the root of their children's disabilities were too obscure or unknown, thus pushing offspring and parents alike from more common diagnoses and recognizable advocacy and support movements (e.g., within the autism community) and cutting them off from recognized categories of empathy and understanding. These children and families were marginalized by virtue of demographics – their numbers being too small, too scattered.

This essay positions diagnostic kinship as a critical alternative to the continued erasure of people with disabilities – and, by extension, their families – who are deemed currently to fall outside of clear diagnostic categories and their corresponding disability populations. I use erasure to refer to disability's vanishing act outside of the parameters of accepted labels – beyond Down syndrome, for instance, or blindness. In turn, it includes both the theoretical and deeply embodied elements of rare, undiagnosed, or otherwise ambiguous disability worlds. By examining the umbrella category of deafblindness – itself a

misleadingly clear marker obscuring the diversity of bodies and experiences unfolding under that label – this piece highlights the messy and partial reality of diagnostic categories and the communities they engender. If disability studies is to be inclusive, it must account for the diversity of diagnostic forms, including those that defy clear categorization. This framing pushes back against the nagging presence of a medical model, which frames undiagnosed and rare syndromes as individualized anomalies. Ethnographic studies of these disability worlds, however, reveal that they cannot be reduced to singular cases or isolated experiences.

This essay also extends anthropologist João Biehl's ethnography of social abandonment, *Vita* (2005), which analyzed the life history and writings of a diagnostically ambiguous woman inside of a Brazilian institution. Catarina, the subject of Biehl's ethnography, was found ultimately to have a rare hereditary condition, and her diagnosis is the culmination of a fascinating text that pushes readers to ask whether her illness is in fact real. In contrast to a search for answers and certainty, this essay asks a related question: what might it mean – ethnographically and practically – to consider those cases in which diagnosis remains ambiguous or partial? How might meaningful communities emerge around disability experiences that are assumed to be highly individualized and isolating?

Diagnostic kinship is also a useful window into the intimacy of bodily and affective experience surrounding disability in the family. Merging affective experiences and political action, it challenges the assumed placelessness of atypical or otherwise unexpected disability forms, carving out new possibilities for cohesive communities around diagnostic precarity itself. The corporeality of

disability and care in daily life offers an important reminder of the acts, behaviors, and adaptations that become embedded in families' experiences. Here, the strange becomes familiar at the level of the body. Feeding tubes, bottles of medications, makeshift communication systems, the flat notes of almost-moans for the not quite verbal, hand flapping, slanted postures; the act of bathing or feeding a child long past those first few years of life; the communicative openings of touch, rather than words. These are the bits and pieces of a disability aesthetic that are obscured when the body falls out of view. While perhaps not easily wrangled into a particular explanation, these fragments must be reckoned with nonetheless. For the purposes of the broader project at hand, perhaps the provocation of diagnostic ambiguity – of its sounds, textures, and bodily collisions – is its insistence on resting in the spaces of messy articulation.

WIDENING PARAMETERS: THE SHIFT TO THE DEAFBLIND SPECTRUM

The concept of deafblindness changed dramatically in final decades of the twentieth century. The popular image of profound (or total) deafblindness, such as Helen Keller, is no longer the rule. Although the term sounds deceptively straightforward, deafblindness now denotes individuals on a spectrum of both visual and auditory impairments, who often have additional disabilities. It hinges on the presence of dual sensory impairments, yet many people on the spectrum have additional intellectual and/or physical disabilities. Simply put, deafblindness is not what one might assume, describing instead a wide range of bodies, minds, and lived experiences.

The shifts in the causes, definitions, and manifestations of deafblindness have changed significantly over the course of the last century, connecting closely

to innovations in public health. Rubella was the primary cause of deafblindness in the United States and Western Europe through the 1970s, prior to the development and widespread use of vaccines. If a woman became infected during pregnancy, her child could be born with Congenital Rubella Syndrome (CRS), leading to vision and/or hearing loss, as well as medical complications. Deafblindness began to change dramatically with the development of an effective rubella vaccine in the late-1960s and the subsequent introduction and distribution of the vaccine for measles, mumps, and rubella (MMR) beginning in 1971.

At the end of the last century, disability experts observed a curious shift in the deafblind population: as rubella faded from the scene, children diagnosed with deafblindness increasingly displayed multiple disabilities and/or health conditions in addition to their visual and auditory impairments. The population showed an unprecedented degree of diagnostic diversity and complexity. This stemmed in part from medical innovations in the 1980s and 1990s, which enabled premature and/or medically complex babies and those who contracted severe infections early in life to survive; these children embodied previously unattainable medical outcomes. Heightened awareness and knowledge of sensory impairments were also critical to the expansion of the deafblind population, since medical and educational experts were more attuned to forms of sensorial difference than in previous periods.

While the elimination of rubella reduced the deafblind population, as traditionally construed, it simultaneously opened a window for new types of bodies to be considered under this diagnostic framework. As in the past, these emerging faces of deafblindness had both auditory and visual impairments. Unlike before, however, the increasing presence of multiple disabilities,

behavioral issues, or additional medical conditions lent a new complexity to the widening category of deafblindness. In Guatemala, as elsewhere, children with the diagnosis today often display a range of impairments and residual hearing and vision. Many would have been categorized in the past as “multiple handicapped.”

The shift in diagnostic framing raises key theoretical questions about the interplay of biomedical categories, social recognition, and cultural and political context, as well as the impact on families. To disentangle the intersections of diagnostic ambiguity and kinship in daily life, this essay offers an ethnographic snapshot of the death of a young student at a special education facility where I volunteered. The events described took place at one of the three branches, or schools, operated by the *Guatemalan Deafblindness Initiative* (GDI), a grassroots disability rights and education organization whose members referred to themselves often as “una familia,” or one family. By offering a glimpse into these collective responses to the death of a young child from this program, Baby F, I show how this community of parents actively reimagined kinship in the everyday as an affective network of support built around their children’s shared positions on the deafblind spectrum. Through this umbrella diagnosis, they altered existing cultural scripts about what families are and do in an effort to construct new and previously inaccessible disability worlds. In turn, this case study shows that the diagnosis of deafblindness itself can engender new kinship formations.

The ability to create and maintain this diagnostic kin community was simultaneously enabled and constrained by the marginalized place of people with disabilities, and exacerbated by the lack of social recognition and intelligibility of the deafblind spectrum. The typical GDI family with children at my main field site

in Quetzaltenango shared two key features: one, the family lived within an hour or so of the city, and, two, the family included a child (or niece, nephew, or grandchild) who fell somewhere on the deafblind spectrum. Within this diagnostic umbrella, the children had a diverse array of additional labels, including cerebral palsy, spina bifida, rare genetic syndromes, undiagnosis, and a wide variety of communication, behavioral, therapeutic, and medical needs. Impairments sustained from birth injuries were markedly more present than during my later research in the U.S.

In a global context, this diversity of bodies recalled Tom Boellstorff's concept of "dubbing culture" (2003), which examined how identity categories travelled and translated outside of their points of origin. What happens when an identity category, such as the umbrella diagnosis of deafblindness, is applied in different cultural settings? What pauses, tensions, or even clashes emerged in the space between the on-the-ground realities and the label, as applied in this new setting? As Boellstorff writes: "To 'dub' a discourse is neither to parrot it verbatim nor to compose an entirely new script. It is to hold together cultural logics without resolving them into a unitary whole" (2003, 226). Like the visible gap in a dubbed movie between words one hears and the actual movements of the actors' mouths, I was struck by the fluidness surrounding deafblindness locally. I spoke with one GDI administrator who openly admitted her lack of concern to a strict diagnosis based on dual sensory (i.e., visual and auditory) impairments, arguing that the children all had multiple disabilities and lacked other educational opportunities. I initially found myself asking if the children I was meeting were "really" deafblind? I soon realized that this was beside the point. The significant issue was the power of the diagnosis to garner both therapeutic

and educational resources, but perhaps equally important, its ability to usher parents into an otherwise inaccessible community. These families were united by their shared experiences with deafblindness – however different the experiences may have been, and however blurry the parameters of the spectrum.

THE STORY OF ALEX

This deafblindness movement in Guatemala can be traced to the efforts of a single family beginning in the mid-1990s. The mother, Helen, took a volunteer role at a shelter for orphans and abandoned children in the capital city. When Helen arrived for her first visit, all of the other children were participating in a group activity except for one little boy, Alex, who was in his room. She inquired with a staff member and was told that he was completely deaf and had some vision. He was the only child with known disabilities at the shelter.

Alex had been abandoned in a market in the southwestern region of the country. Someone – perhaps a family member – wrapped him in a blanket, placed him inside of a cardboard box, and left him in the women's restroom. As the story went, a local woman found him and took him home, but changed her mind once she realized the extent of his disabilities. He was taken to the police station, processed by a local court, and subsequently sent to the shelter in the capital.

Helen and Alex grew closer through her visits. Although she had never worked with people with disabilities, she was fascinated by the boy. He was thought to be approximately four years old at the time, although his actual birthdate is unknown. Helen decided to fund and arrange surgery to remove the cataracts in his eyes to restore some of his vision. She and her family brought

Alex to stay in their home for one week prior to and following his surgery so that they could care for him, petitioning the shelter to let them assume his caregiving needs on a temporary basis. At the time of my fieldwork, he had been living with the family for over a decade and they had formally adopted him.

Helen threw herself into finding educational opportunities for Alex, determined to keep him from languishing in another shelter facility. She was told he could not attend the local school for the blind, because he was deaf; he was turned away from the school for the deaf due to his blindness. Helen contacted other service providers, but had few leads. Programs for children with multiple disabilities simply did not exist in Guatemala and, to complicate things further, the government did not recognize deafblindness as a specific category of disability.

After exhausting local options, Helen contacted several deafblindness experts based in the U.S. They put her in touch with a group of Argentinean parents who, when faced with similar obstacles, founded their own educational center. Helen grew increasingly involved in this dynamic transnational community of families and professionals, and she and her husband arranged to attend a Latin America-wide conference for parents of deafblind children. Armed with the personal insights from other parent advocates around the region, and with critical international support, the family launched GDI in 1997 and expanded the organization steadily.

During my research in Guatemala, the organization operated three educational centers: one just outside of the capital and two in cities in the western highlands region. It ran a *Programa a Distancia* (Distance Program), in which a special education teacher conducted home visits to children with

disabilities in rural areas, and sent support staff to several shelter facilities to provide services to abandoned children in institutions. In addition to these direct service projects, it sought to raise awareness in communities, schools, universities, and therapeutic settings to increase knowledge about deafblindness and people with disabilities. Ultimately, GDI aimed to become the primary educational training center and resource provider on deafblindness and multiple disabilities in Central America.

In Guatemala, as elsewhere, such family-led efforts typically emerge out of necessity. At the time of my research, there was virtually no government support for special education in Guatemala, and disability programs were extremely limited. Since its inception, GDI has worked within broader global structures of deafblind advocacy. The deafblind movement in Guatemala represents a localized example of this global shift to the deafblind spectrum. It also illustrates the diversity of today's deafblind population, as well as the contestations surrounding the politics of diagnosis. Indeed, one of the most striking aspects about this movement was the demand for public – and legal – recognition of a population whose diagnostic label belies the diversity of bodies it described. Through this living experiment in shifting biomedical categories, deafblind children and their families demanded entry into a society that did not yet recognize them.

The lack of attention to disability in Guatemala combined with the relative unintelligibility of the deafblind spectrum, generating needs that were both pragmatic and affective. On the one hand, these children needed educational and therapeutic services; they could not just sit in their homes, cut off from communication and socialization. On the other hand, their families were often in

desperate need of support. Many had been cut off from their own relatives due to lingering beliefs that disability was either contagious or resulted from parents' wrongdoings; it was a disease or a punishment, and was best left alone.

Within this context, the recurring theme of community loomed large for students and their families. It was a necessity. *GDI es una familia. Somos una familia*. I heard these phrases repeatedly. Part of me dismissed it as jargon. However, as illustrated below by the story of Baby F, this group was actively re-writing the meaning of family itself around its shared diagnostic identity and locally-situated needs.

A Death in the Family: diagnostic kinship in action

"Somos todos una familia," said parents and staff alike. It was one of the first things I heard from Sara, the director of the GDI branch in Quetzaltenango. On my second morning there, I arrived at the educational center to attend a human rights training seminar, which was organized by the Parents' Committee, a leadership and fundraising group consisting of parents from the school. There were just under 30 parents in attendance, with only a few men; about one-fourth of the women wore traditional dress (*traje*). At the end of the session, Sara came to the front of the room and said she had to make an announcement. Baby F, a boy in the classroom for the youngest students, was in extremely serious condition at a local hospital. He had fallen into a coma over the night and his organs were failing. Although the parents consented to disconnect the respirator early that morning, a doctor arrived later and insisted on putting him back on it; even so, it was only a matter of time. As all of this unfolded, the hospital was

being fumigated and no one – including F's parents – could enter the facility. Their son was dying, no guests allowed.

The parents in the audience, who had listened quietly during the morning's seminar, sprang into action. The mothers took the lead. Within minutes of the announcement, they assembled a telephone tree to share any updates about the boy's condition; they also arranged for a group to visit the family's home that morning as a sign of support. Then, the women started to discuss the child's imminent death. One volunteered that, from her own experience, the hardest times came after the child's death. The mothers agreed that they needed to strategize to provide ongoing support for the weeks to come. Another woman who lost a child previously said that the sadness would not truly hit while one waited for death to come – while in the moment, busy, distracted - but afterward. That would be when the family would need the most support.

Many in the room had tears in their eyes as they discussed Baby F, and the sound of tissue packages crinkling and sniffles punctuated the air. It took me days to write up the notes from the event, not knowing the child or family, unsure of my boundaries as a volunteer and researcher in this institutional space. All I could think was: "Those people lost their baby." My initial reaction to the news about Baby F was that death was a private affair to be handled by family and close friends, and that I was an outsider who needed to be polite and get out. I was startled when parents and teachers asked me to stay and be a part of the day's events – to help with the children, prepare the center for the afternoon visitors, and greet Baby F's family. Uncomfortable with the unanticipated intimacy, I agreed.

As the impromptu planning session winded down, participants were invited to have some coffee and baked snacks. I chatted with Samuel, the father of a 13-year-old boy with multiple disabilities who loved to play checkers and communicated through limited sign language, gestures, and grunts. Samuel told me that his son's intellectual disabilities grew over the years as a result of his lack of appropriate education services; without language and formal learning, he lost skills.

Samuel and I talked for the next 20 minutes. He was a well-dressed, professional man in his fifties, clad in a cable-knit sweater over a plaid button-down shirt. He worked as a civil engineer, and spoke of projects locally and around the country. His wife had passed away the previous year. He began to ask questions about caring for people with disabilities in the U.S., and was surprised to hear that many adults lived in group homes or small, fully-staffed houses in their communities, rather than with parents or other relatives. I mentioned that my sister had such an arrangement – an unassuming two-bedroom house, complete with a fully stocked kitchen, roommate, cat, and around-the-clock aides. She lived a five-minute drive from my parents' home, where we both grew up. Samuel was visibly taken aback. "Is it also true that adult children place their parents in asylums when they get old?" he asked. I paused.

The mothers from the morning meeting were clustered in one of the offices, getting updates via cell phones from Baby F's family and relaying messages accordingly. Samuel needed to return to work, so we parted ways. I headed inside toward the center's four classrooms to see if I could be of use. I came across Carla, a teacher and physical therapist, who had only one student that day and invited me into her class. News came through while we were talking,

and one of the teacher assistants asked me if I could watch a group of students. Mothers typically held a major role helping in the classes, but today they were out of commission. Baby F had died in the hospital and the women needed to begin preparations. His family would visit the school later that day; with them would be the child's body, if they were able to retrieve him from the fumigated hospital. The mothers needed to acquire decorations, food, and supplies for the event. They had only a few hours to prepare.

The children went home at midday, as usual, and one of the fathers volunteered to drop me off at a nearby shopping complex to grab some lunch and relax before returning to the center. The discord with the morning scene was surreal. Mercedes SUVs rolling in alongside pickup trucks filled with shoppers. Two pet stores complete with baby schnauzers, a husky, and clownfish; a food court with Burger King and Domino´s Pizza; and a Hiper Paiz, or WalMart, which sported signs listing the content of each aisle in both Spanish and Quiche. I walked around for two hours, just taking it all in, killing time, and wondering why on earth I was at a mall, watching a Maya woman with packages balanced on her head chat on a cell phone in front of Taco Bell. Salsa music trickled out from speakers in the women's bathroom.

When I returned to GDI from the shopping mall, my taxi driver promptly announced "Someone died here." Startled, I asked how he knew. He pointed to the bow-shaped decoration made of white plastic paper, similar to a garbage bag, which had been placed on the building's front gates. It was about one foot high and three feet wide, prominently announcing the death to all who passed by.

People began filing in at 4:00 p.m. White and green plastic picnic chairs were arranged in a semi-circle in the lobby outside of Baby F's former classroom,

where I chatted with parents and family members. The staff kept to themselves for the most part, clustering in the classroom to arrange decorations, prepare snacks for later, and console one another. The teachers and aides wore more or less matching outfits: tight jeans and fitted white tops. I began to feel out of place in my knee-length black dress.

A white, cloth-covered table and white backdrop sat at the front corner of the room opposite the entryway, where the men of the family would later place the tiny, white cloth-covered coffin. Staff arranged bouquets of flowers – all white or yellow, lots of gladiolas, daisies, spider mums – on the floor surround the table, where they also propped white candles wrapped in metallic ribbon. Every 20 minutes, someone announced that F's family would arrive shortly. This became a ritual over the two hours, which I spent chatting with the mothers about my sister, marriage, future children, and, lastly, my research. The mood was quiet, yet not necessarily somber. Pensive, pending, matter of fact. Finally, Baby F´s sister walked in crying. She began to make her way around the room hugging each person, one by one, as they whispered to her. Things were beginning.

The little boy's sister sobbed. Within minutes of arriving, she asked permission to hold one of the children from Baby F's class. She pressed her face close to the girl's – nose touching nose, breathing silently. She then turned and walked outside with the child in her arms, returning a few minutes later to deliver her back to her proper parents. A mother and I caught each other staring, smiled, and left it at that. Baby F's parents walked in about five minutes later. The change in the room was immediate, as people began to cry audibly, hug one another, and mutter condolences to the family. Several male relatives carried in the tiny coffin and placed it on the table in the front corner of the

room. Approximately 10 people accompanied them, crowding into the small space. Attendees gathered in a jagged line at the center of the room to offer their condolences to the parents, one by one, again hugging, crying, and saying a few words. When it was my turn, I realized that I had no idea what to say. I hugged the parents and sister silently, both for fear of saying the wrong thing and also because I knew I, too, would start to cry.

After the condolences, Baby F's aunt rose to address the crowd. She thanked the community for its show of love and support, and then led them in two prayers. She spoke, everyone repeated what she said, and at the same time a teenage boy from the family chanted his own prayer on the off-beats, almost as a harmony. The effect was startlingly fluid and musical. Next, Baby F´s father stepped to the center of the room to speak. His voice shook as he thanked God for sending the family Baby F, for teaching them what it meant to be, to have, and to love a child with disabilities. He said that anyone who thought that he and his family would give up their deafblindness advocacy after Baby F's death was mistaken, that they were going to continue supporting GDI´s efforts for children with disabilities. He would break for a few days to honor his son's death, but would recommence his activism the following week. The father, who celebrated his birthday at the school several weeks prior, was adamant that he and his wife would remain committed to the organization, which he referred to as his family. He used the term several times. Finally, he said that he knew that Baby F was now in a better place with a new body – one without pain, without convulsions, without sickness, without suffering.

Next, Sara, the school director, spoke on behalf of the organization. Her voice was very soft, almost difficult to make out in the crowded space. She

reiterated the strength of the community, and that everyone would continue to support Baby F's family as they had since the beginning. She thanked the parents for bringing the child into their lives, saying that he would remain alive in everyone´s mind and memory. "We will continue to see him," she said, "because he is here with us.

Reflecting on the events, it is impossible to overemphasize the stress on diagnostic kinship as a key source of support and unity. The attendees framed their community in two complementary terms: first, under the diagnostic umbrella of deafblindness, which united their children's seemingly divergent bodily forms and impairments; and second, through their shared involvement in this locally distinctive school community. The connection among those in attendance was palpable, visible through eye contact, soft words, body language, nodding silences, and mere presence. It came off as strikingly genuine. The parents (and, to a different extent, teachers) took Baby F´s death as a cause around which to mobilize. It was such a show of strength and power, a community coming together in action. For these children and their accidental activist parents, rewritten families were much more than a kin group or source of affective support. They were a lifeline, even after one's final breaths.

At the close of the speeches, Baby F's family departed – some men having shed tears, a few silently and determinedly dry-eyed. They headed to Huehuetenango, where the father's family lived. After they left, staff and families milled about drinking sweetened coffee from Styrofoam cups and eating cheese sandwiches that some of the mothers and teachers had prepared earlier. The staff informed me that classes were canceled for the following day. Many of the families had decided to travel to attend the burial.

Coffee cups empty and sandwiches eaten, people began to trickle out for the night. We all gave everyone the requisite hug and kiss, muttered something utterly neutral (“Take care!” or “See you next week!”), and headed out the front door. Having been there only during the daytime, I was startled by how difficult it was for me to navigate the terrain in the dark: turn left, walk across the dirt path, be careful not to fall into the meter-deep gutter lining the side of the road on one corner, dodge cars at the roundabout, and wait for the bus, an old decommissioned U.S. school bus, in front of the metal fence at the makeshift bus stop. “Los Trigales, Los Trigales!” the driver’s assistant called out. I hopped on and made my way down the aisle, sitting next to a tall, thin man in business clothes.

Sure enough, there were multiple familiar faces scattered around the seats, all minding their own business and staring out darkened windows as the bus hummed through the city. I recognized a husband and wife a few seats up who were sitting with their sleeping daughter, who was blind. She was the child Baby F’s sister had turned to during the wake. When I met the girl the following week, she ran her hands softly over my face, reading my features, recording a tactile portrait to store for the future, just as she had with Baby F’s sister. It was a silent act, almost unerringly intimate. The pads of her thirteen-month old fingers traced my nose, eyelashes, mouth, jaw. They followed the lines to remember the face, not as I might struggle to recall features of someone I have just met, but as part of a non-visual recognition and memory that put me to shame. I was amazed by the seemingly instinctual nature of the act, the use of touch as communication and recognition. I had felt this before, but something about the little girl stayed with me, perhaps the uncanny nature of our encounter on the public bus,

careening through streets that suddenly seemed unrecognizable in the darkness as we headed home after a death.

"BUT I DON'T HAVE TO EAT WITH THE CHILD, DO I?"

For these parents and children, diagnostic kinship provided critical support and countered the pervasive alienation of families like theirs. It also offered an idealized alternative to what were described as widespread failures of extended families and local communities to assist with basic care needs. GDI's directors and teachers spoke consistently of the isolation of their students' families, due largely to the strength of stigma against disability. As Laura, the director of the smallest and newest GDI branch, explained: "Extended families have neither contact with nor interest in the child with the disability. There is a great deal of discrimination." Reasons ranged from shame (*vergüenza*) to the widespread notion that disability is a curse (*maldición*) brought on by the sins of parents. There was also fear that it was contagious, something threatening to contaminate others. Some people I spoke with attributed this to religion, without specifying what branch or denomination, while others claimed the roots of shunning stemmed from indigenous beliefs.

Part of the anthropological project is to render the strange familiar and the familiar strange. Much of what I encountered during my preliminary research on Guatemala surprised me initially. Stories of abandonment and neglect, of being cut off from extended families, peer groups, or religious communities. I thought back to this during my later research in Texas, when I encountered multiple parents who spoke with anguish about being asked to leave their churches because of their children's disabilities. Ostensibly, this was because the churches

lacked the infrastructure to accommodate the children, an effect of their exemption from the Americans with Disabilities Act. However, families remained haunted by the sudden disappearance of community and social support. As one mother explained: “We felt excommunicated.” I began to wonder if the modes of erasure and abandonment at my fieldsite in Guatemala were so different from what I might find closer to home. What might this reveal about the public intimacy of disability aesthetics? What did it mean when bodies deviated in particularly – and particularly visible – ways, and how did this undo expectations of bodily, sensory, and intellectual integrity?

During my discussions with Sara, the director at my primary fieldsite, she spoke at length of the need to reach out to extended families through awareness-building programs. She said that there was a significant problem in this region in that children with disabilities were often hidden in their parents’ homes. Alternatively, she explained, families would attempt to cover up their child’s difference: “Parents will lie about it. If you say, ‘But, yes there are children with disabilities here. Look, that child over there is unable to walk,’ the response will be, ‘But it’s because he doesn’t want to.’” Sara stated that it was the norm in this region of Guatemala to abandon parents of a child with disabilities, as well as the child. This was rooted in fear that disability was a sickness that could be passed to others within a family if contact was allowed, and resulted in taboos against eating or sharing food with people with disabilities. According to her, this was an extremely strong cultural current and was part of what made disability work in this region of the country so distinctive. It is worth noting, however, that my subsequent research in the U.S. revealed many of these same themes. They were simply a bit deeper under the surface of everyday conversations.

Such insights are the direct product of comparative ethnographic work and are thus highly relevant to disability studies. My initial focus on complex diagnostic forms in Guatemala pulled my attention toward forms of care, kinship, and isolation that I thought, at times, I had not and would not encounter closer to home. Only by juxtaposing these ethnographic scenes with my subsequent research in the U.S. did it become clear that many of these same phenomena – including diagnostic kinship – traveled and translated in seemingly diverse spaces. Through this comparative perspective, the familiar began to appear stranger than I had realized.

To counter misconceptions about disability, GDI launched a program to reach out to relatives and build awareness and community support. The school hosted special days when it invited specific relatives of the students to participate in classroom activities, games, and lessons. Sara reported significant resistance from extended families at first, quoting one grandparent who said, “I’ll come, but I don’t have to eat with the children, do I?” Gradually, the initiative took off, with more family members attending each time. Sara said that families were often amazed when they came to the center and saw the students' work. "I never knew a child with disabilities could do that!" Bit by bit, the program was changing perceptions.

I was struck by the perceived danger attached to sharing a meal with a child with disabilities. This phenomenon highlighted the mundane, everyday processes of isolation (Povinelli 2011). As Elizabeth Povinelli writes, abandonment unfolds as a slow burn, rather than a spectacle. There is no isolated event or moment of rupture, but rather a meal denied, medication not given, set of eyes averted, window shades drawn, birthday ignored, invitations

not extended. In turn, the cases of disability in general and diagnostic ambiguity in particular offer new possibilities to explore the classical anthropology question of the relationship between the individual and society through the lens of exclusion. Here, abandonment took hold through the sedimentation of everyday acts, such as a refusal to eat with another person.

To gain insights into how these processes operated on the ground through everyday practices and underlying beliefs, I found it was often more fruitful to ask not what an individual believed about a sensitive or controversial issue, but to reframe the question in terms of what they thought others in the community might hold true. This methodological sleight of hand took the weight off the informant-as-truth-bearer, opening a space for the nagging doubts that one knows should be dismissed as superstitious but are not so easily abandoned in practice. I recalled a conversation with a friend in Quetzaltenango who happened to have worked previously at a local shelter for abandoned children with disabilities. She spoke of a former co-worker who left the job after getting married and subsequently gave birth to a child with disabilities, although I was not told what type. The woman's husband blamed her for the disabilities, claiming it was her fault because she had worked at the shelter. At this point in the story, my friend and I both shook our heads, but there was a pause. "That's not possible, is it?" she asked. No, I reassured her. And yet, on some level – if speaking honestly – I knew we both had our doubts, despite knowing better.

Notions of maternal marking or responsibility are hardly unique to Guatemala. As historian Leslie Reagan (2010) explains, for example, the belief that a pregnant woman who encountered a child or adult with visible disabilities on the street might somehow pass them onto her otherwise typically developing

fetus was once common in the U.S. In a similar twist of logic, parenting a child with disabilities is often spoken of in almost pre-ordained spiritual terms. “God only sends special children to special families” was a refrain I encountered frequently during my later fieldwork in the U.S. In both the U.S. and Guatemala, I heard repeated claims that sought to make sense of the appearance of disability in the family. Particular parents had particular children for a reason. They were up to the challenge, the logic held, and they would fight for their children. The children were referred to as miracles and angels, the mothers as warriors and saints.

On the opposite side, I encountered several parents who had previous experiences with disability in their families and were shocked that it could happen again. One woman, a presenter at a disability advocacy conference for families in Texas, spoke of her experiences having both a sister and daughter with Down syndrome. There were audible gasps of surprise from the audience. How could that be? Such responses hinted at the underlying affective, illogical terrain of making sense of disability when it emerges. Yes, disability is a part of the human experience, but questions remain regarding how, why, and when it appears in individual families, and how it is interpreted. To dismiss such nagging doubts or fears as superstitious or unscientific fails to capture their ethnographic – and lived – significance. It also privileges the assumed reign of biomedicine in the U.S., despite widely known examples of contemporary medical folklore, such as the lingering fears connecting childhood vaccines to autism (Biss 2014, Kaufman 2010, Mnookin 2012). One central task for anthropologists and other disability scholars should be to take superstition and collective conjecture seriously as both localized and more far-reaching phenomena. By probing the similarities and

fissures of what happens when a particular category or mode of understanding travels, scholars can build broader comparative knowledge of disability experiences and encounters in a cross-cultural perspective.

During my extended fieldwork in the U.S., I spoke with a mother of a young boy with a very rare genetic mutation who shared similar thoughts. She described how, when her son was born, her extended family struggled with the notion that they had already encountered disability. They had met their quota, in a sense, and thus believed on some level – albeit based on emotion, rather than reason – that it could not possibly happen again. As she explained:

> My cousin is profoundly, profoundly disabled, both mentally and physically. He had a birth accident. My aunt has taken care of him forever, but the one thing her mother told her was "Don't ever stop working." And she didn't, but she also made herself and her life miserable. It was always "I got stuck with this lot in life and everybody else gets the normal family and the normal childhood." And I just saw that happening and I wasn't going to be angry at myself and at everybody else…It's really, really sad. And she'll admit it's a really sad life. It wasn't for lack of money. It was just personal…Her husband left her when her son was three and it was possibly the worst case scenario, and I know when we found the diagnosis everyone in my family was like "How could this possibly happen to us? This has already happened."…It felt like a real, "what did our family do to deserve this?" I don't know. I think you just take what you get.

The passage above rests on the underlying assumption that disability is undesirable and will, in turn, negatively impact families and kin relationships, a topic that has been explored by scholars in a variety of cultural contexts (Gammeltoft 2014; Rapp 2000). It positions the family with disabilities in contrast to a mythical and ideal other, failing to account for the fact that family structures, experiences, and narratives are complex, dynamic, and multi-dimensional assemblages. Disability cannot happen twice, or so goes the thinking. But why?

Digging a bit deeper, it becomes clear that a superstitious and emotionally infused logic lies just below the surface, just out of sight; a still pervasive interpretive frame that embraces a curious combination of ableism, medical folklore, and homogenizing views of what disability is and how it operates.

FIELDTRIP

Near the end of the summer of Baby F's death, I traveled by boat, truck, and bus from my guesthouse in a tourist town lining Lake Atitlan to meet a GDI teacher from the capital at a nearby village. She was making her weekly visit to local families of children with multiple disabilities, offering tips and strategies to encourage basic daily living skills and also just to check in and see how everyone was doing. The children we met had a variety of combined disabilities – intellectual, sensory, and physical – and spanned an age range of almost 20 years. As I stepped off the bus, children at the house across the road ran out to greet me. I was immediately surprised to see that at least two of them had visible disabilities, indicated by both atypical facial features and communication styles. Although disability experts did not know why, this area had a particularly high incidence of multiple disabilities. It was instantly apparent.

After visiting several families we made our way to the final home of the day, which consists of several structures clustered around a dusty yard. The teacher was startled to find one of the buildings closed up tightly with a small padlock, the kind one might use on a suitcase. She had not seen this before, not here. She peeked through a small hole in the wooden panels nailed together to form the home's door and walls, and she immediately pushed back sharply, summoning a small girl of maybe six or seven years who played nearby. The girl

said that the woman of the house – the mother – had gone with her daughter to a nearby lake to wash the family's clothes with other local women. Was there a spare key, my companion asked? The girl ran to fetch it, eager to please this professional from the city and eyeing me curiously. She opened the padlock and we stepped softly into the room.

There were three twin bed frames in the dark room. There were no lights on, although the elaborate stereo complete with a three CD player suggested that the structure had electricity. Jagged, narrow sheets of light filtered in from holes in the metal roof. A young man lay on one of the beds. My companion said he was in his early twenties, although I would have put his age at much younger. His mouth twisted into a surprised grin and he squealed with pleasure at our arrival. He was alone, lying in the dark on a wooden plank of a bed frame with no mattress. Unlike the others in the room, his bed was wrapped tightly in a patchwork of carefully taped together black trash bags. The stench of urine was lighter than I would have anticipated – he had no access to a bathroom, closed up like this. The black plastic was hot to the touch, warmed by his body.

The young man could not talk and had never received therapeutic services, aside from these new weekly visits. Indeed, I was told that such services barely existed in Guatemala at the time of my research, and certainly not in rural areas like this. The tendons in his legs were hardened from years of not moving. We massaged them and encouraged him to bend his knees as best he could, just for a little exercise. We laughed and joked and, although he could not speak or sign, the young man communicated through shrieks of joy, sly smiles, and peaceful sighs.

His mother returned after a half hour or so, along with her daughter. The girl, a teenager, also had visible intellectual disabilities. The mother told me that her husband was in the States in search of agricultural work. He'd been there for years. The teacher interjected, deferential yet firm, and asked why the woman had left her son closed up in the dark heat, alone. She had not witnessed this before and was struggling visibly to make sense of the scene.

The stereo, replied the mother. *If we don't lock it up, someone will take the stereo.*

The example pushes back against idealized models of family and caregiving, offering a critical reminder that care is fraught. It invites the reader to pause in the image of this young man, left alone in a dark, warm room, the smell of urine wafting through the air. My initial impulse following this encounter was to place the scene in opposition to my observations of GDI's families, but to do so would tread dangerously on the terrain of inspirational versus tragic forms. On the ground, family and care are not so simple. Inserting an ethnographic lens into disability studies, as I have in this piece, reveals clearly that idealized and imagined forms of caregiving and kinship do not necessarily match reality. We must look beyond a normative frame, asking instead what forces, conflicts, tensions, and both pragmatic and affective needs complicate how these concepts take shape in daily life. This is a fruitful area for critical disability studies, and much can be learned about underlying assumptions regarding care and care roles by staring into the murky territories of love, neglect, and even violence. Simplican (2015) cautions that recipients of care work must not be framed as wholly vulnerable and lacking agency, arguing that scholars must account for caregiving in the intimate spaces of conflict and risk. Nancy Scheper-Hughes

(1993) and Anna Tsing (1990) show clearly that maternal love cannot be taken for granted, with care expectations and abilities shaped by individuals, structural constraints, and local worlds. Ethnographic consideration of such failures to care – as in the case of the young man behind the padlocked door – highlight the dynamic, potentially fraught realities of caregiving and kinship as unfolding, embodied, and often mundane.

AFTERMATH

I continued to return to these ethnographic scenes long after moving my research closer to home. Six years after Baby F., four years after shifting my research to the U.S. to study diagnostic ambiguity and disability marginalization closer to home, I logged into my computer one day and learned that a child I had met conducting fieldwork in Texas had passed away. He, too, was on the deafblind spectrum and had multiple disabilities as a result of a rare genetic disorder. Had he been born only a few decades earlier, he would have gone undiagnosed because his syndrome had not yet been discovered. His parents were very active in a statewide group for parents of kids with this diagnosis. I remembered them telling me they were thinking of adopting a child with disabilities; so many children were abandoned and left in "the system," they explained. They understood what it meant – or could mean, perhaps – to parent a child with complex impairments and medical needs, and they wanted to share their skills and knowledge.

I began to think of how disability and death weave together. Two seemingly separate categories, particularly in the disability studies literature that focuses more on the social and rights-based aspects of disability experience –

stigma, ableism, and practices that push disability to the margins. Yet disability is increasingly less marginal as more and more children receive diagnoses, enjoying new forms of public recognition and visibility.

Despite the scholarly tendency to separate disability as a cultural and political reality distinct from the bodies through which it unfolds, parents I spoke with consistently stressed corporeality. Bodily experience, rupture, and memory loomed large. Mothers I met in Guatemala began their disability narratives with scenes from pregnancy and birth. They spoke of children caught in the birth canal, worries about exposure to chemicals from fathers working in agriculture; access to medical care and good nutrition came up frequently. I heard that women who received an epidural did not "love" their children the same way, as they had not experienced the full pain of childbirth – a claim not unlike the so-called natural childbirth movement in the U.S., which frames birth without medical intervention as more natural and thus desirable. To borrow the classic anthropological trope of purity and danger (Douglas 1966), the common thread was an anxiety about outside intrusion. There was a persistent belief in an imagined non-disabled future thrown off course, perhaps by the sin of a parent, an illness, vaccine, birth accident, or other exposure. A moment that altered what was otherwise supposed to unfold without incident.

I recalled a young mother I met in Quetzaltenango. Thin, pretty, and well-dressed, she mentioned that her mother lived in the U.S. We chatted while watching her toddler twin girls play on gymnastic mats, working on physical therapy exercises. The story of the twins always got to me. One "normal" and expected, the other not. One daughter ran in circles, jumping and crawling on foam shapes in primary colors. Her sister lay on her belly, smiling calmly, clad in

all pink. The mother spoke of complications during the birth. She was not offered a C-section (“Even in a private hospital?” I asked, having been told such things only happened in the public facility) and there were complications. The little girl was stuck in the birth canal and suffered oxygen deprivation. Both girls went to the neonatal intensive care unit (NICU), where the firstborn thrived. Her sister’s condition did not improve and she didn’t begin to gain weight until they were put in the same bed together.

Several years later, I met a father at a family deafblindness symposium in Texas. He was an activist from Spain who traveled the world sharing his family’s story with disability parents, educators, and advocates. His daughter, like so many I heard about, was born so premature that she would not have survived in previous eras. She spent months in the hospital, and the treatments that kept her tiny body alive resulted in extreme damage to her sight and hearing. She is considered deafblind. Her father recalled how she suffered a series of hospital-related infections and had to be kept for a time in isolation, protected from other invading germs. The fetal form, misplaced on the outside world, out of sync, and locked away. Curiously, the child’s twin sister flourished. To date, she has no markers of the early arrival that the girls shared. But bodies like theirs are too young and too new for hard data. The outcomes are not yet known, as they have only existed for a quick breath of recent biomedical history.

During a presentation on parent activism, the father riffed on his own questions about how his daughter experiences the world. “She would poke her eyes,” the man explained to the meeting attendees. He raised his hand to demonstrate, extending a bent index finger and moving it quickly, jaggedly, toward his eye. The microphone captured the room’s silence. “Again and again,

she pressed her fingers into the sockets. Can you imagine?" he asked, then continued. "But to her, it didn't hurt." He paused. "No, I imagine she saw stars. Sparkles, maybe, little lights." A woman in the audience raised her hands and reached for the microphone, crying. "Thank you for that beautiful story," she said. "It brought me much peace." Her daughter's left eye had been surgically closed to prevent her from indulging in the same activity.

These "strange" or atypical behaviors fell within the parameters of the "normal" and familiar within this disability world. This is not to say they were sanctioned, but much like practices of self-abuse (e.g., a child banging his head on the floor or biting himself), they were part of regular life. Those were the extreme cases, of course, and often it was simply a matter of harmless tics and quirks. While at GDI, for instance, I attended multiple meetings of parents during which children grunted indecipherable noises or had other verbal outbursts, yet nobody registered this as out of the ordinary. These mannerisms went largely unmentioned within this disability space, similar to anthropologist Zoë Wool's (2015) ethnographic observations of returned and injured soldiers in the U.S. Wool noted the shifting nature of what counted as "normal" or expected expressions of the body was markedly different for soldiers at her fieldsite, a residential facility at the Walter Reed Medical Center, as opposed to in public spaces. Just as a new prosthesis, wheelchair, or crutches might be "unmarked and unremarkable" on the grounds of Walter Reed, the embodied habits of children at GDI held a fundamentally different role on the school grounds (Wool 2015, 134). It was not simply that they were accepted or without stigma. Rather, they became ordinary aspects of everyday life, with such expressions and actions lying within the realm of situated expectations of what bodies are and do.

The Spanish presenter's daughter was deafblind, the result of extended experimental treatments in the neonatal intensive care unit following her birth, 21 years ago and four months too soon. Although his daughter's eyes could not take in sensory data about the world when they were open, the story shifted once they were shut. A good firm push with the fingers – perhaps tentative at first, but then deeper – and what? Stars and sparkles? The girl retained sufficient retinal activity to stimulate this probing spectacle, at least that's what the father had been told. Thus his daughter's eye pushing, which appeared at best to be an antisocial habit and at worst self-abusive, was a form of leisure. It was a perhaps a thing of beauty, bodily explosion of the senses, a critical indulgence for someone in need of sensory engagement. And, among the father's audience that day, it was a behavior that was only so shocking.

After his presentation ended, I waited until other audience members had a chance to speak with him and then approached him as he exited the room. I introduced myself and we began speaking in Spanish about my research and his international advocacy efforts. Within moments, he mentioned GDI and their work in Central America, and asked if I knew the founding family. I was caught off guard by our connection through global deafblindness work. "How incredible that you're from Spain, I'm here, and we all know each other!" I exclaimed giddily.

"Of course we know each other," he replied, casually as we parted ways for lunch. "We are all family."

Interlude:

Pens

There are dozens of black pens, all dented and pushed almost flat from use. They turn up in forgotten spaces, accidental remnants of a brief phase of facilitated communication, or FC, in the family's home. Inky flair Paper Mates, used only with glossy, thick white individual sheets of paper, legal-sized. FC remains controversial in the disability community, perhaps especially for parents vis-à-vis professionals. The promise of FC is nothing short of fantastic: it offers those without language a chance to communicate. There is only one problem: it is not supported by scientific evidence.

Through FC, the production and articulation of language becomes a two-person affair. Parent, child, writing instrument. In the case of the pens, the child would hold one loosely, her father molding his fingers over hers, and they would together. The promise, the promise, but also the nagging questions. How did she learn to spell? Why could she only communicate using this method and not by typing on her own or using more elaborate combinations of signed speech or even pictograms? There was no way to verify accuracy with FC or even to determine the authorship. Whose hand wrote what? Parent or child? When it came on the scene several decades ago, some prominent intellectuals who happened to have children with disabilities spoke out in favor of FC; experts balked. Associations for psychiatrists, psychologists, speech therapists, pediatricians – they all opposed it. Some equated it with a Ouija board. The facilitator – parent, teacher, whomever – was unconsciously taking the lead, scripting the story.

Perhaps.

As the black pens smashed down on the page – letter after letter, inch after awkward inch of oversized words spelled with curious accuracy – the girl's stories shifted, darting around new corners. There were few words, to be sure, but they painted a possible inner world. "Bad things" that happened, the classroom aide who called her an "idiot," reflections on her preferred pets, explaining why she didn't want to write that day. Fact, fiction, or somewhere in that blurry haze of the everyday, ink seeped onto the white pages – always the same thick paper, heavy stock and handled with great care.

Chapter 5

Disability Fringe[2]

FRAMING THE FRINGE

Disability anthropology centers in part on classic medical anthropology questions of how to interpret bodies and minds that are considered atypical, analyze the corresponding embodied realities, and explain these individuals and groups within broader social and cultural worlds. Questions of where people fit and why they are as they are loom large. Ethnographic studies highlight the cultural and historical variations in such perspectives, cautioning that what is considered a disability in one space or moment is not necessarily universal or timeless.

Throughout disability ethnographies and news stories, one finds accounts of real and persistent questions about why and when disability happens, and what to "do" about it. Tine Gammeltoft (2014) and Rayna Rapp (1999) painted rich ethnographic portraits of parent responses to prenatal testing results – questions of "how bad" a preliminary diagnosis or increased risk of disability might be, the uncertainty of what it could mean for a child and her family, the nagging doubt that the physicians and genetic counselors might be wrong, the general slipperiness of risk. Families, bioethicists, clinicians, and disability activists debate the so-called Ashley Treatment, a growth attenuation procedure designed to restrict physical and sexual development (Battles and Manderson

[2] A portion of this chapter was published previously: Lewis, Elizabeth. "The Anti-Vaccine Movement, Bad Science, and Fake News." *Nursing Clio.* March 16, 2017. https://nursingclio.org/2017/03/16/the-anti-vaccine-movement-bad-science-and-the-rise-of-fake-news/

2008; Gunther and Diekema 2006; Kafer 2013; *Lancet* Editorial Board 2007). Named for the first patient to undergo this procedure, doctors removed Ashley's breast buds and uterus, and received estrogen therapy to prevent growth. The controversial procedure freezes patients in a childlike state and size, with the idea of facilitating lifelong caregiving for individuals with significant needs. In response to similar bioethical questions, the National Down Syndrome Society has issued a position statement on corrective facial surgery for people with Down syndrome, reminding readers that cosmetically masking the physical features of Down syndrome does nothing to alter the underlying disability.

These examples underscore the messy mosaic of knowledge, practice, and belief surrounding disability today. Despite the promises of genetic testing, prenatal diagnosis, neonatal care, innovative therapeutic interventions, and new forms of sharing and accessing information digitally, disability remains fraught as a category of organizing and delineating difference. What bodies are regarded as atypical and how? To what ends and per what trends? Is such difference to be prevented or should it be considered a form of diversity? These are questions of meaning making and legibility that seek both to explain and organize forms of embodied (or diagnosed) experience that are perhaps visible in new ways. But massive gaps remain in collective understandings of what disability is, does, and means, both at the level of the individual and the social. In these spaces, science, myth, and speculation come together in an effort to make sense of an otherwise blurry reality.

Anthropologists have long been interested in the relationship between myth and society, asking what the stories we tell ourselves might reveal about broader anxieties, concerns, or undercurrents. Framing disability as a sticky

ethnographic object, this essay asks what forces, stories, and rumors stick to it in the form of conspiracy theories and fringe beliefs. It uses two examples – the anti-vaccine movement and the role of facilitated communication techniques in the Anna Stubblefield trial – to probe the contemporary worlds of disability fringe. Both examples gained extensive media coverage in recent years, bringing together questions of disability, autonomy, the public good, competence, and compliance. Each case study traffics in different ways in the fringe zones of alternative treatments or techniques, questionable science, and conspiracies of outsiders doing harm, secreting knowledge, or infringing on individual rights. Ultimately, this analysis illustrates that what might appear to fall on the fringes of contemporary disability worlds can, upon a closer look, produce critical insights into the anxieties, questions, and aspirations of disability itself in its collective imaginings.

VACCINE DOUBTS, AUTISM ANXIETY, AND BAD SCIENCE

"Everything I give my son, I try first. You learn that as an autism mom."

It is a sunny morning in early fall and we have just sat down to breakfast at her suggested restaurant, a macrobiotic vegan spot that has been in the neighborhood for over two decades. Beans, quinoa, and roasted vegetables, and it is not even 10:00 a.m. I try to follow as she catches me up on medical marijuana for kids with certain disabilities and health issues. She rattles off the varying ratios of chemical properties allowed by different states' medical marijuana bills, mingled with the names of specific formulations. Charlotte's Web, ACDC, 34 to 1, 24 to 1, oils, extracts, black market, diluting, reconstituting, mixing. She mentions a CNN special that I need to watch. I know little about the

subject, except that it is increasingly embraced at both the medical and policy levels, and I am aware that at least some of my own biases are likely, well, biased. 28 states have passed comprehensive medical marijuana laws, and an addition 17 allowed limited medical use of products with low-TCH, high non-psychoactive cannabidiol (CBD) (National Conference of State Legislatures 2017).

I am curious about what this Texas medical marijuana activist and autism mom can tell me about a disability world I do not know and where our conversation will lead. I ask how she initially secured the medical marijuana that she began using with her son, age 9. “You find a drug dealer and you ask him,” she told me. “And he’ll ask somebody who knows somebody, and then you can get oils and extracts.”

She is in her early forties but looks at least a decade younger. No wrinkles, thin and muscular, clingy long striped sundress. She tells me she lives in the suburbs, drives a minivan, and has not smoked pot since college. She begins to reflect on the various meetings and events she attended to get her initial drug connections. “These guys would come up to me…I’d go to Republicans Against Marijuana Prohibition meetings,” she says, “and afterward they’d be like ‘Hey, if you need something…” At the time of our interview, she had an arrangement to receive CBD extract in the mail. I ask if she ever worried about getting caught by law enforcement. “If it were a plant – the bud or something – then I might be more worried. But it’s a syringe full of extract. They’re not looking for that.”

She describes her son as “classic autism,” but says his diagnosis is “high-functioning.” The medical marijuana helps, she says. With it, she sees

improvements in her son's eye contact and communication skills, and greater interest in activities around him. He even dances better, more rhythmically. She later mentions – almost casually – a decrease in violent behaviors and aggression, but does not elaborate. She observed "gains" three days after starting him on the extract at the beginning of the year. I realize she is new to this scene, but is already a leader in the local movement of parents advocating for medical marijuana.

"I'm a card-carrying Republican, a hard-core Republican," she tells me, pausing to gauge my response. "I know, that blows everyone's mind." My shock must be evident. Apparently, I am eating a vegan dinner for breakfast with a suburban mom who is also a sometimes drug dealer, but happens to be on the far-Right politically in an extremely conservative state that also has some of the worst disability services in the country. I try to digest this information. She mentions that she and her husband used to host Bible study at their home in the suburbs, and she met one of her marijuana activist colleagues through their church.

I know that medical marijuana has gained mainstream traction and that multiple states have either passed bills legalizing this treatment or are in the process of debating them. In the year after my meeting with this mother, the Compassionate Care Act was passed in Texas, in part due to the advocacy efforts of parents like her. It was widely lauded by the disability community. Months later, I attend a local disability fundraiser where families who worked with this mother receive an award for their efforts. The families shared stories about the impact of these policy changes on their children. By all accounts, it was a victory. Yet still, sitting here with my quinoa and beans, I cannot shake the

nagging feeling that we are treading on fringe territory. Her own activities with medical marijuana remain illicit, since her child does not have the necessary diagnosis of epilepsy under the Act. She interjects occasional comments about whistleblowers, research cover-ups, government secrets, and turning to underground channels to get information and, of course, her son's medication. Curious, I steer the conversation away from the intricacies of U.S. drug policy and medical marijuana activism and back toward her son. Our talk soon shifts to the most widely recognized disability fringe community: vaccine skeptics.

She tells me that she knew something was different with her son, in part because she was able to chart typical development in his twin sister. "By 14 or 16 months, I knew he was off. I had delayed vaccines and he'd only had three. One of them was the DTAP [diphtheria, tetanus, and pertussis vaccine], though, and the MMR [measles, mumps, and rubella vaccine] and DTAP are 'the ones' that everyone freaks out about," she explained. She tells me that her son had a minor surgery requiring anesthesia when he was 12 months old and was different from that point forward. "I'm sure that's what triggered my kid's autism. Which tells me that if an environmental chemical or factor can trigger that, then why couldn't vaccines?"

She describes her son moving backwards developmentally after his surgery and, in particular, becoming aggressive and hitting at approximately 14 to 16 months. "I thought it couldn't be autism, because I had not vaccinated him. I did not give him the full vaccine schedule." I asked how she proceeded once receiving the diagnosis, when he was three. "Treatments!" she replied. She quickly rattled off a list:

> What kind of treatments have we done. We did speech therapy, occupational therapy, ABA. We did RDI, which is Relationship Development Intervention. We did all these kind of behavioral things that the doctors tell you to do. And then we did a gluten free, casein free diet, which he's still on for the most part. A number of interventions. Bioset. Homeopathy. Homeotoxicology. Vitamins. Minerals. Chelation. Anything.

Of all the treatments they tried, however, the CBD extract was the only one that produced visibly significant results and, indeed, it neatly straddled the line between a treatment that is both increasingly sanctioned while still raising eyebrows – at least, in a state that did not yet have legalized medical marijuana. The list itself is telling, revealing a logic of picking and choosing from a variety of mainstream and alternative approaches. Speech and occupational therapy; Applied-Behavioral Analysis (ABA), the most widely-practiced autism therapy; chelation, in which a patient takes medication that supposedly removes harmful minerals, "cleansing" the body; and diets that cut out dairy and selected grains to restrict gluten and casein, a popular but scientifically unsupported alternative treatment (Wang 2015).

In the last decade fringe treatments for autism have proliferated so much that the U.S. Food and Drug Administration released a Consumer Health Information Bulletin in 2014: "Beware of False or Misleading Claims For Treating Autism." The document cautions parents to be wary of "miracle cures" or approaches that claim to treat multiple conditions, and reminds them that "[p]ersonal testimonials are no substitute for direct scientific evidence" (FDA 2014, 2). Yet the personal experiences of other families remain a critical source of knowledge for parents of children with disabilities. The result is a curious double-bind: disability advocacy groups have long encouraged parents to act as experts, following the logic that they know their children better than anyone, and

should equip themselves with the knowledge – clinical, educational, and legal – to advocate for their children in a system that might otherwise not meet their needs. Indeed, it is often critical for securing necessary services. The trick is that parents must not take things too far. But what are the boundaries and, if crossed, the consequences?

In her study of autism and gender, Jordynn Jack (2014) traces the emergence of the "mother warrior" figure in the anti-vaccination movement, embodied by the public actions of actress Jenny McCarthy. Emboldened by moving stories of tragedy and hope, unprecedented access to digital information, and emergent and far-reaching social networking platforms, these mothers (and, presumably, also some fathers) believe that autism is mainly a product of environmental triggers and toxins, which might include vaccines, gluten, mercury, and processed foods. The women are united by a shared politics of suspicion, coupled with the insistence that they have the authority as mothers to interpret scientific evidence. This is also a relatively privileged population, raising questions about who can claim the authority to deny individual responsibility for public health. Within this group, surveillance of one's child combines moral and medical judgments with a distinctly libertarian ethos, and is a fundamental responsibility of parents. In Jack's analysis, these women perform motherhood through their vigilance and, in so doing, put forth knowledge claims regarding both the cause and treatment of certain disabilities that seem to emerge after birth: vaccines.

For some families I met, these parent narratives – particularly firsthand accounts – were taken as fact. Vaccines were invoked to explain a variety of diagnoses, not just autism. One mother told me that her two sons were born with

intellectual disabilities because she had always lived on the coast. “I ate so much fish,” she said. “And vaccines have mercury. When my kids got the vaccines, the mercury had a negative interaction with the mercury in my body from all of the fish.” In her view, the vaccines had interacted with another environmental factor – namely mercury – resulting in her children’s disabilities. At one disability training, I was surprised when a noted local disability rights activist addressed the room, announcing in her introduction that she was the caregiver for a relative with autism who was “vaccine-damaged.” Her tone was adamant, almost defiant. No one questioned her, yet I continued to wonder every time I received an email about local advocacy efforts from her account. This woman was in a clear leadership position in this community. What did other parents make of her claims?

In my previous conversation with the medical marijuana activist, she was firm that vaccines were only one of multiple environmental triggers for autism. As she said:

> There’s all kinds of things that it could be. I don’t think there’s any one thing. I know a lot of kids are triggered on vaccines. You can’t just hear the exact story over and over and over again and say ‘Oh, bullshit.’ I’m sorry, there’s thousands of them. My kid’s not one of them, but there’s thousands of them. Tens of thousands of moms telling the exact same story…My story is exactly like all of the vaccine stories, only it happened with anesthesia. It was the exact same thing.

This historical emergence and cultural impact of the anti-vaccine movement in the U.S. has been explored closely by a variety of writers, including Steve Silberman (2015), Seth Mnookin (2012), and Eula Biss (2015). The infamously retracted 1998 article in *The Lancet* by Andrew Wakefield launched

this bizarre movement among a small, but vocal, subset of parents in the U.S., a telling reminder that sometimes emotion and hunches matter as much as, if not more than, facts. Among believers, the autism-vaccine link feels true. Vaccine doubts filled the gap between existing medical narratives and collective needs to explain new diagnostic trends. Writing about parents of children on the autism spectrum, anthropologist Sharon Kaufman explains: “Something unnatural, not ‘normal’ has happened that science is not explaining” (2010,12). Here, biomedicine sometimes takes second place to feeling.

Today’s vaccine doubts took hold through collective anxieties about rising autism rates, social media and digital technologies, and an emergent nostalgia for a past American era. There is a curious overlap between the “Making America Great Again” slogan, which galvanized Conservative voters in 2016 beyond any predictions, and what Biss calls “preindustrial nostalgia” (2014, 115). This concept captures the idea that certain products or practices that are considered traditional or “natural” are safe, authentic, and good. Such nostalgia covers a range of contemporary phenomena, from the Paleo diet to the locavore movement, yoga, unmedicated childbirth, and anti-vaccine beliefs. Each of these examples hinges on the notion that the world was somehow better when it was less complicated and, one might say, less “modern.” For vaccines, this is a nostalgia for an imagined past untainted by inoculations and their risks, real or otherwise, yet curiously unmarked by disease.

The anti-vaccine movement’s most curious success is its longevity. The movement stems from a study that has long been disregarded, and the anti-vax community represents an extremely small segment of the population. Yet we recognize the story. We hear the news several times a year about new

outbreaks, about the controversies over personal belief exemptions, the risk of growing pockets of un- or undervaccinated children in places like Austin, Washington state, or in communities in California. The anti-vaccine rhetoric emerges in political debates, newspaper stories, and visits to the pediatrician. It skews white, relatively affluent, and educated (Ross 2015). They are members of particular social worlds, and their networks play a key role in their decisions regarding vaccines (Brunson 2013). As a study of disability fringe, it shows clearly that distinguishing fact from fiction is a deeply social process. And this is not quite as simple as it might appear.

As essayist Eula Biss argues (2014), inoculation is a gamble. We know that vaccines can provoke serious reactions in a tiny portion of the population. We know, too, that the introduction of standard vaccines dramatically improved child mortality rates over the course of the last century. The question, of course, is whether this gamble is worth it. Despite the successes of modern public health, the fact remains that we cannot inoculate ourselves from doubt, particularly in a climate of widespread and persistent medical folklore of the dangers of vaccines. The vaccine is not simply an event – an isolated shot or jab – but rather a continuous process protecting the health of the patient and also the social body. In Biss' framing, vaccinations become an ethnographic object, around which multiple fears, associations, anxieties, and beliefs converge. Our deepest fears are, for Biss, informed by complex webs of history, power, stigma, economics, myths, and shared nightmares (2014, 37). They are fundamentally intimate and unavoidable, yet they shift according to the particularities of the moment. And, for Biss, they include disability.

To doubt vaccines involves not fact or science, but a curious politics of affect and information curation. Anti-vaccine proponents rely on a cluster of anecdotes and claims gleaned from multiple sources, merged by the questions, motivations, and beliefs of the knowledge seeker. The pieces of information come together through multiple sources, online and otherwise, they become part of a narrative; they draw strength from the backward-looking fantasy of a better life in a less complicated era, of Biss' preindustrial nostalgia. Vaccine fears are perhaps the most widely publicized example of a broader social anxiety surrounding toxins – indeed, the notion that modernity itself is toxic – and the anti-vax movement is animated by such fears of bodily pollution. Practices and products seen as traditional, natural, and seemingly untainted by big industry are, it follows, deemed good. They are safe and authentic – reflecting the way things should be – triggering nostalgia for an imagined past untainted by vaccines and their toxic needles, yet curiously unmarked by outbreaks of preventable disease. In this perspective, parents are correct to be suspicious of vaccines. They are foreign bodies, toxins, tools of the government. The 2000s have been marked by an inexplicable rise in autism diagnoses among children, the thinking goes, and something must be to blame. Vaccines have proven to be a persistent and sticky target. Here, it is useful to turn to anthropological insights on conspiracy theories. As Kathleen Stewart and Susan B. Harding explain:

> Investigative reports, talk shows, television series, movies, novels, and textbooks present a diffuse, sometimes panicked sense of struggle against unknown forces – a deep worry that normality is not normal any more, that 'somebody' has done something to the way things used to be, that we have lost something, that we have – that we have been – changed (2003, 260).

In the case of vaccines, this anxiety surrounding changes in our very way of life connects closely to notions of bodies, permeability, and vulnerability. This recalls classic anthropological works on bodies and boundaries, such as Mary Douglas' *Purity and Danger* (1966) and Emily Martin's *Flexible Bodies* (1995). For vaccine skeptics, the body is not fighting off outside pathogens in the sense of viruses or disease, but rather it is in active tension with the nebulous risk posed by more amorphous toxins – the "environmental triggers" mentioned by the medical marijuana activist. Websites and blogs proliferate with advice for "detoxing" one's children, supposedly exposed to an already always toxic world unlike what we knew in the past. The ethnographic project here is to explore what emerges in the spaces between knowledge claims and action, anxieties about difference versus imagined futures of disability, science, and the normal.

Medical rumors about vaccines, like other fake news stemming from bad or made up data, implore us to decide between what we think we know versus what we feel, and the two are not always in sync. We are told to trust our intuition, but given no clear guidelines for distinguishing it from superstition, paranoia, or misinterpretation. We are asked to follow expert advice, yet we know full well that it sometimes fails. Boundaries are not always clear, thanks to the endless sources of information and competing knowledge claims.

As an example of disability fringe, vaccine fears connect closely to practices of information gathering, curation, and interpretation in a digital age. Parents comb available sources looking for answers, strategies, and possibilities that – for whatever reason – they have not been made privy to by clinical professionals. Fringe beliefs can be legitimated and take hold by exposure and repetition. We hear the stories again and again. Perhaps they plant seeds of

doubt; they become somewhat normalized; we recognize them. While dangerous and scientifically unsound, the anti-vaccine movement is an unflinching reminder that fake news and bad science permeate daily life. As Todd Sanders and Harry G. West write, such conspiracy theories are often regarded as fringe, but are actually quite common and widespread (2003, 4). These narratives reflect and emerge from "profound suspicions of power" (Sanders and West 2003, 7). They are not simply isolated beliefs, but rather fall under a "sensibility of conspiracy (Harding and Stewart 2003, 260). According to such logic: "We are the victims of hidden persuaders of consumerist culture, a far-reaching technogovernmental complex, a network of demonic forces, an endless swarm of sophisticated social controls and invasive influences" (Harding and Stewart 2003, 259).

In *Illness as Metaphor*, Susan Sontag famously argued that cancer was the emblematic disease (or condition) of the twentieth century (1978). If this role is currently filled by autism spectrum disorder, then vaccine skepticism is the disability conspiracy theory of our time. The outspoken fringe voices gesture toward collective uncertainty of disability, particularly autism, and what to do about it. What causes disabilities and how can they be prevented? Within existing gaps in understanding, what counts as responsible caregiving? Who has the authority to claim knowledge and power, or to challenge existing structures, such as relinquishing the decades-long practice of vaccinating children from infectious diseases like pertussis, measles, mumps, and rubella or demanding personal belief exceptions that allow un- or under-vaccinated child to attend public schools? The notion that certain types of parents have the right to decline vaccinations fits with contemporary trends in conspiracy theories, hinging on a perceived risk of social regulation at the expense of individual agency (Harding

and Stewart 2003, 262). Per this logic, following the rules of the collective is precisely what might do harm and, for anti-vaxxers, stepping outside of mainstream practice and into the fringe is the only way to safeguard one's children. Or so the story goes.

PRESUMING COMPETENCE:

COMMUNICATION, SEX, AND THE CASE OF ANNA STUBBLEFIELD

Disability fringe is a bipartisan effort, falling – albeit in different ways – along the political left and right. Part of the persistence of the anti-vaccine movement, discussed in detail above, is its ability to bridge different communities. While the reputation and demographic data suggest that most vaccine skeptics are white, educated, and more affluent, it is important to note that the fieldwork discussions described in this essay included women of various racial and class backgrounds, political parties, and both urban and suburban settings. That is, they broke the stereotype. This illustrates the emotional pull of anti-vaccine claims, which can connect parents in otherwise disparate or unconnected communities.

While vaccine fears are arguably the most prominent example of disability fringe today, there is no shortage of other beliefs and practices that push the boundaries of accepted approaches to and definitions of disability. For instance, it is increasingly common in some circles to send otherwise typical children to occupational therapists to give them a leg up on skills like handwriting in early elementary school (Harris 2015; Tyre 2010). Along similar lines, the U.S. Secretary of Education is a key investor in NeuroCore, a chain of strip mall "brain

performance centers" that claims to reduce the symptoms associated with autism and ADHD, as well as depression, anxiety, sleep disorders, migraines, and stress, and perhaps even increase the patient's IQ in the process. The so-called treatments use neurofeedback and individualized "brain maps," both of which are unproven, and the company has not published any findings in peer-reviewed journals. At a disability resource conference for parents in the Rio Grande Valley region of South Texas, I spoke with social workers and therapists who knew local families that traveled to Mexico for their children to receive experimental stem cell treatments. Since many local families already crossed the border for medical and dental care, disability "treatments" were just another element of cross-border medicine for some.

Facilitated communication (FC) is another example of a practice once hailed as a breakthrough for people with disabilities and subsequently relegated to fringe territory. Facilitated communication was developed in Australia during the 1970s when Rosemary Crossley, an assistant at a Melbourne residential center for children and youth with significant disabilities, began exploring new ways to connect with some of her seemingly non-communicative residents. She developed FC as a method to help them communicate by using her physical support as a facilitator to guide their motions. The approach centered on the notion that individuals who were unable to write or type independently might be able to do so with minor physical assistance. There were different ways to implement FC, which included facilitated pointing, typing, or even writing, involving varying degrees of support. For instance, the "speaker" might place her hand over the facilitator's, wrapping it around the bottom hand in order to gain the support and strength to form letters. The facilitator's task was not to move

their hand, but simply to aid the speaker and her movement. FC rested on a key principle of disability rights: assuming competence. There was no reason to believe that people who appeared initially to be unable to communicate would not be able to do so with appropriate techniques or technologies. It was simply a matter of developing them.

Syracuse University education professor Douglas Biklen was instrumental in bringing FC to the U.S. He visited Crossley's Melbourne clinic in 1988 and was struck by this new technique. Was it possible to uncover someone's dynamic inner world through something as simple as FC? His subsequent paper, "Communication Unbound: Autism and Praxis," was published in 1990 in *The Harvard Educational Review* and ushered FC into the disability mainstream in the U.S. Trainings in the technique, led by Biklen, boomed and, for a time, it appeared that FC might be nothing short of a miracle. The situation became increasingly complicated, however, when sexual abuse claims began to surface from practitioners of FC. This was a time of widespread anxiety about such abuse claims, as detailed extensively in Ian Hacking's (1995) study of Multiple Personality Disorder. By 1994, at least 60 such claims had been made by FC users, calling into question the reliability of this communication method. As in the case of recovered memories among people diagnosed with Multiple Personality Disorder, these accusations brought the seemingly clinical practices under heightened scrutiny. The sexual abuse claims had to be taken seriously, but their veracity hinged on the legitimacy of FC itself.

Howard Shane, a speech pathologist and professor at Harvard Medical School, began to investigate. In one experiment with a teenage FC user who alleged that her father was abusing her, Shane showed pictures to both the girl

and her facilitator and then asked the girl to spell the words. Sometimes, she and the facilitator were shown the same pictures; other times, they were not. The girl consistently spelled whatever picture her facilitator had been shown (Engber 2015). Moreover, when asked about personal information that her facilitator did not know, her answers were noticeably less accurate. Finally, if she was shown an object while her facilitator was not present, she could not subsequently spell it out using FC. Such studies raised significant questions about the promises of FC, and researchers turned to the concept of ideomotor effect to explain what had appeared to be breakthroughs in communication. What if the communication facilitated by FC was only the result of the ideomotor effect, or the unconscious movements of the facilitator's body? Was FC little more than a quasi-scientific Ouija board? In the classic childhood game, nobody knows who is moving the Ouija pointer – and perhaps the players are not pushing it intentionally – and yet, each time a question is posed, it moves. Upon closer inspection, it appeared that something similar was at work with FC.

Following the scientific fallout surrounding FC, it shifted to a fringe practice and, much like vaccine doubts, retained a surprising amount of force in certain circles. In an article published in *Disability Studies Quarterly*, philosophy professor and disability scholar Anna Stubblefield flatly dismissed concerns of sexual abuse as "fear-mongering," stating that the number of accusers was too small to warrant the method's dismissal. She lashed out at skeptics, equating their stance with ableism and oppression and even comparing their statements on FC with hate speech. Stubblefield had no doubt that FC enabled people to demonstrate their true intelligence. Its opponents sought intimidate and silence people who supported the method. As she wrote: "People who are labeled as

intellectually impaired experience crushing expression within our society, rationalized by the 'science' of medical, psychological, and educational orthodoxies" (2011). For Stubblefield, it was simple: "The debate over the validity of FC is fundamentally a debate about the freedom of expression of FC users" (2011).

Tellingly, this method returned to the national spotlight in 2015 during Stubblefield's widely publicized trial for alleged sexual assault of a man with disabilities whom she claimed to have taught to communicate using FC. A professor of philosophy at the Newark, New Jersey campus of Rutgers University, she was a recognized scholar on race, ethics, and disability, and a self-proclaimed civil rights activist. She was white, married, and had two children. Her accusers were the mother and brother of DJ, an African American man with cerebral palsy who was in his early-thirties. Court documents referred to him as John Roe, to protect anonymity. Multiple professional evaluations placed his developmental abilities on par with those of a child younger than two years. Stubblefield claimed they were in love and enjoyed a consensual sexual relationship, all unlocked by the power of FC to reveal DJ's inner world and thoughts. His family argued it was nothing but exploitation, manipulation, and rape.

The case garnered significant attention in the disability studies community, multiple ongoing listserve discussions about "presuming competence" as a cornerstone of disability rights, popular views of alternative communication methods, and sexual ableism, or the notion that people with disabilities are asexual or unable to consent to sex acts. Stubblefield claimed to have engaged in a mutually loving, consensual, sexual and emotional relationship with D.J. His

family and experts in the trial, however, asserted that this was impossible (Engber 2015). Had Stubblefield successfully used FC to bring D.J.'s inner world, thoughts, and feelings to the surface, as she claimed? How could this even be determined? In relation to contemporary disability fringe, what was the ethnographic significance of her claim, which was supported to varying degrees by the disability rights community? And how did this group's insistence on the potential of FC, despite significant scientific evidence to the contrary, intersect or diverge from the underlying fringe logics of the anti-vaccine movement or other non-mainstream disability communities?

Their story began a few years earlier. In the spring of 2008, DJ's brother – known in court documents as Richard Roe – was completing his doctorate at Rutgers-Newark and took a course with Anna. After she showed a documentary on facilitated communication and disability, he approached her to ask if these techniques might benefit his brother. Anna began working regularly with DJ as his facilitator, and his progress appeared to be almost miraculous. At the age of 32, DJ was suddenly able to use symbolic communication – although only with Anna's help. His family's attempts to use FC failed consistently.

With Anna's guidance as a facilitator, DJ made incredible strides. He went from seemingly having no symbolic communication to crafting original essays for presentation at and publication in disability studies conferences and journals. He enrolled in an upper-level undergraduate literature course at Rutgers. As Anna later wrote from her jail cell, in a letter penned to a judge prior to her sentencing hearing: "…as his skill at communicating increased and as it became apparent through objective evidence that he was the author of his words and a very

intelligent man, we did become friends. And then something happened that took me by surprise – we fell in love" (Wichert 2016).

Anna began telling D.J. that she loved him. He supposedly followed by asking if she was "physically attracted" to him, which led to their first kiss (Engber 2015). The relationship soon became sexual. As detailed in court documents and trial coverage (Engber 2015), they used his keyboard and FC throughout. She assured that they would proceed at his pace and she would not pressure him. At the trial, she described asking if he would like to watch pornography with her, but he supposedly replied that the female actresses in such films were exploited and were not as beautiful as Stubblefield (Engber 2015). After they became sexually involved, Anna went to DJ's house and, sitting with him on the sofa, confessed their relationship in May 2011. This was approximately three years after she began working with him. DJ's mother – referred to as Jane Roe – immediately barred Anna from seeing her son. Anna, in turn, said that she would leave her husband for DJ, that she loved him and needed to be with him. The family took legal action after Anna contacted the director of DJ's daytime activity program, explaining that the family had forbidden contact and asking if there was some way to arrange a meeting with him. The program director immediately alerted DJ's family, who filed a formal complaint with Rutgers alleging that Stubblefield was harassing DJ.

Stubblefield's trial took place in the fall of 2015. She pleaded not guilty to two counts of aggravated sexual assault, arguing that DJ was, in fact, able to communicate. His family maintained that he was unable to consent to sex, given consistent estimates of his mental capacity. The judge ruled that FC was not admissible as a form of evidence, essentially closing the door on Stubblefield's

defense. The trial gained significant attention in the disability studies community, with scholars calling out on listservs to show their support, whether by attending the courtroom proceedings of by speaking out about the value of FC and the insistence on assuming competence. They cited the role of sexual ableism and argued that the jury, like society in general, was biased against viewing DF as a full person capable of consenting to, wanting, or enjoying sex (Perry 2016).

Nevertheless, the jury deliberated for only a few hours before finding Stubblefield guilty of both counts. Speaking anonymously with a New Jersey reporter, one juror explained that she simply did not believe DJ could communicate using words (Wichert 2015). The jury reportedly did not believe that FC worked – at least not in DJ's case – and without it there could be no means of consent. While the juror allowed that perhaps Stubblefield believed she had fallen in love with DJ, she maintained that manipulation and coercion had occurred. Her view was reinforced by DJ's only appearance in court on the first day of the trial. Supporting him physically, DJ's mother led him around the courtroom for the judge and jury to see, saying "Your honor, this is my son." The move was widely condemned as ableist by disability activists, who viewed at as DJ being objectified as little more that a person with visible physical disabilities. Nonetheless, it left its mark on the jury.

Stubblefield was sent to the Essex County Correctional Facility in Newark to await her sentencing hearing in January 2016. During her time there, she penned a handwritten letter to her sentencing judge, later published online by a New Jersey media group. In the letter, she repeated some of the key arguments of her defense and reiterated her love for DJ. As she wrote: "I believed that he

and I were intellectual equals and that our romantic relationship was consensual and mutually loving" (Stubblefield, cited by Wichert 2016).

She connected her relationship with D.J. with her broader commitment to civil rights, particularly in the disability community. Per this logic, her writings on FC and work with DJ were a continuation of her past scholarship on issues of racial justice and civil rights. She cited her lifelong commitment to the full realization of civil rights. As she explained: "I was raised by parents who are committed to the cause of equal rights for people with disabilities," going on to detail her mother's work as a professor of special education in Michigan (Wichert 2016). She went on to detail her involvement in the disability rights movement beginning in the 1980s, participating in marches and collaborating with fellow activists and allies. Through this lens, her relationship with DJ both emerged from and was indicative of her commitment to radial inclusion and disability rights. She expressed concern about DJ's future, saying that he had no lost access to communication, education, and a path to independence. Anna had provided all of these and, it appeared to her, the ableist refusal to acknowledge DJ's inner communicative world had now left him stranded.

Stubblefield expressed surprise that this view was not shared by DJ's family. As she explained to the judge, had she anticipated his family's negative response to the news of their relationship, she would have remained silent. They could have used the time for him to pursue emancipation from his mother and brother, who were his legal guardians, and she would have been able to leave her husband. "I believed that they would be happy that [D.J.] and I had fallen in love. I never intended to cause them pain" (Wichert 2016). Stubblefield closed her five-page letter with this:

> I am writing this letter from my cell in the Essex County Correctional Facility, where I am spending my first holiday season apart from my family. Thank you for taking the time to read it. I hope that it has helped you to understand that my actions were motivated by love, and my love was grounded in my belief in [D.J.'s] intelligence and humanity. I cannot adequately express my dismay, and sorry, and regret that my actions have led to so much distress for so many people. All I can do is extend my heartfelt apology – I am sorry for the pain I caused you (Wichert, 2016).

FIGURING PERSONHOOD: ETHNOGRAPHIES OF DISABILITY FRINGE

Disability fringe loomed large in the national media in recent years, as illustrated by widespread attention to the anti-vaccine movement and the Stubblefield case. While the two examples might appear initially to have little in common, they raise multiple overlapping questions that relate to disability anthropology – particularly in the U.S. Both cases resonate by provoking emotional responses. They throw into high relief the problem of legitimacy, knowledge claims, and sharing information in a digital age. They crystallize fears of political overreach and systems run amok, of a biomedicine that sometimes falls short, of the need to protect one's children. They embody a fundamental tension in contemporary views of and responses to disability: is disability itself a form of diversity, a medicalized deficiency, or something in the middle?

The key question is how to reconcile the rights-based push to ensure the legal – and, indeed, human – rights of people with disabilities while also reckoning with the ongoing role of stigma. From the widely cited, but statistically unsupported, belief that the vast majority pregnancies that receive a prenatal diagnosis of Down syndrome in the U.S. end in abortion to the critiques of autism organizations that stress finding a cure, rather than acceptance of neurodiversity,

the fundamental place of disability in today's social order and cultural imaginary remains fraught.

Anti-vaxxers and FC proponents lie at opposite ends of two examples of disability fringe. The anti-vaxxers presume the undesirability or, in some way, incompetence of an imagined vaccine-damaged child with autism. Conversely, FC proponents assert a radical commitment to presuming competence, and leave no space to grapple with profound intellectual disabilities. What is the distinction between acknowledging the personhood of an individual who cannot speak or, indeed, might appear largely unresponsive, and the desire to actively imbue that person with thoughts, emotions, and preferences? Where might this take us ethnographically? There are documented cases of people who learned to communicate symbolically with FC and later transitioned to independent typing. Similarly, it is well documented that a very small number of children will suffer major side effects from vaccines, sometimes resulting in life-long disabilities. These are the exceptions and not the rule, yet the stories provide a grain of truth for their corresponding fringe worlds. Indeed, both vaccine skepticism and the Stubblefield case are both animated by the very emotions they provoke.

In the two cases analyzed in this essay, there was a clear break between the persuasive power of anecdotal versus scientific evidence. Anna Stubblefield argued that "objective evidence" led her to believe – to know, even – that DJ's abilities with facilitated communication far surpassed experts' assessments of his capacities. The words, the way she experienced their bond firsthand, the radical commitment to assuming competence – a decisive break from the problematic history of assumed incompetence in this population. Similarly, the marijuana activist and autism mom maintained that it was not possible for there to be

thousands of similar stories of parents who traced their children's autism to their early childhood vaccines if there was no truth to their fears. Notably, both FC and the vaccine-autism link spread initially through research articles published in reputable academic journals. Anna Stubblefield published multiple articles on disability, race, and ethics, and *Disability Studies Quarterly*, the journal of the Society for Disability Studies, has not retracted the article supposedly penned by DJ, with Anna as his facilitator, "The Role of Communication in Thought." Even now, the byline for DJ directs any inquiries "c/o Anna Stubblefield" (2011). The article states:

> I believe my knowledge of language lies in listening to people talk. I learned to use language in my head before I began communicating. But having communication helps me think clearly. I might not be making sense in my head. Communication means I get feedback. I got my means of communication later than most people. But people know how to think in their heads before they learn how to talk (Johnson 2011).

One important distinction of today's disability fringe is the accessibility of information. The article above remains available in an open-access, online journal; anyone who searches for it can read it. Similarly, while Andrew Wakefield's original article linking autism to vaccines was subsequently removed from *The Lancet*, it remains widely cited in online communities. As Sobo et. al explained, today's information ecologies are simply different – fringe or otherwise. For amateur researchers in vast digital spaces, what does it mean when the comments section following an article gain as much attention as the findings in the article itself (Sobo et. al 2015, 531)? Ethnographic studies of vaccine skeptics shows that parents take pride in their research, asserting that part of responsible parenting was to acknowledge the multiple voices and

standpoints in the debate over vaccine safety (Sobo et. al. 2015). Despite the seemingly scientific tone with which they discussed vaccines, as illustrated in my previous example of the medical marijuana advocate mother, their approach in action was more in line with typical social media practices than clinical research. As Sobo explained:

> Parent narratives were not progressions but collections. Many resembled Storify or Pinterest boards – self-curated assemblages of ideas drawn from multiple sources using diverse criteria, held together only by connections envisioned by the individual curator (2015, 537).

That is, these narratives reflect a collage or assemblage, a curated and likely biased portrait of information, anecdotes, and knowledge claims gathered to support or refute a particular point. This trend is alive and well on the broader national scene, as evidenced clearly by the disparities in news coverage – and even in what is regarded as a news source – when it comes to current events. By facilitating increasingly curated, self-interested collages of information claims, fringe interpretations can strengthen and perpetuate themselves in new and newly public ways. Disability worlds are only one example.

As a disability anthropology topic, such trends highlight fundamentally shared affects and preoccupations that warrant further analysis. What animates our current anxieties, fears, and suspicions? At the heart of both cases is the question of what disability is, does, and can and should be. Is disability – such as seen in the rise of neurodevelopmental disorders – something to be prevented? Is it, as disability activists accuse anti-vaxxers of thinking, “worse” to have a child with autism than to subject your child or another community member to vaccine-preventable infectious diseases? Can we imagine a world in which people who

appear unable to function beyond the level of a small child do, in fact, have dynamic and almost literary inner worlds? And are able to consent to and perhaps even enjoy sexual relations? Such questions rest fundamentally on the definition of personhood, which is central to contemporary debates on everything from abortion to human rights, mass incarceration, police violence, and access to health care. Which bodies are real, preservable, prioritized, salvageable, or disposable. Better left unseen. Ethnographically, it points to the well-intentioned ways in which people attempt to reckon with this ambiguity by imbuing individuals with preferences and tastes.

A therapist I met, who was extremely active in the undiagnosed community, marveled at families' insistence on attributing meaning and emotion to children with extremely significant disabilities. She recalled going to a restaurant with one client and her mother, and the mom sitting down in the booth and announcing "She just loves it here! It's her favorite restaurant!" The child had no symbolic communication, showed no signs of awareness of her surroundings, and was fed through a G-tube directly into her stomach. She could not even eat the food. And yet this was real. Perhaps it was her favorite restaurant, after all.

A Closing Scene: Television

The television blares, sending the sounds of children's songs through the first floor of the house again. The girl loves *Sesame Street* videos. Or perhaps she used to. The parents' story doesn't make sense at first, but perhaps I'm just looking for the wrong type of sensory logic. The girl has no hearing and is legally blind, yet they swear she loves Sesame Street. The old stuff, especially the compilations of the show's music videos from the late-1980s and early-1990s.

Beatle puppets singing “Letter B.” Ernie playing the saxophone. These are the classics, I’m told, and the girl’s family and staff know every word.

In the case of a woman who cannot hear, see from a distance, or communicate her experience of the world, what does it mean to watch television? Why and through what textures has this practice taken on such importance in her daily life? A few times each day, she signs “TV” and heads for the sofa. Once there, she places her glasses on a nearby table – always the same one, front corner, next to the rocking chair. She lies down on the sofa, pulls a blanket over her long body, often covering her head, and just rests their in silence while her parents grab the remote control, hit the play button, and turn up the volume. Then, they leave the room. Sometimes, she makes an ‘L’ with her thumb and index finger, folding them into the creases of her closed eyes, shielding them from any residual light. The reverie lasts thirty minutes to an hour; she does not sleep, although sometimes it looks that way.

It is tempting to dismiss the girl’s love of television as a ritual. Perhaps the videos give structure to the act of resting - normalizing the separation from the family, understood through the archetype of an adolescent who just wants to be left alone.

But what if this is just a different way of watching? What if we approach the girl’s “watching” as a different sensory world within a particular saturated space? What potential might we find in this reimagining of an action? Pause. She’s in the room, the volume rises, buzzing and bouncing lightly to the bass. Footsteps trail away as her parents leave her in privacy to watch her show. The dog watches from a nearby chair – panting lightly, smelling that damp terrier musk. Perhaps the mother is cooking, smells sneaking through the sprawling

home, darting around corners and waiting to take hold. The curtains are drawn, lights low. Skin rests on worn cushions, the body wrapped in cheap, synthetic blankets. A silence of the body – washing over the senses, teasing out different attentions amidst the blast of the glaring TV. Here, watching is an openly multi-sensory engagement with surprisingly little to do with sight.

Every now and then, the family will try to trick her by putting on something else when she asks for Sesame Street. She'll sign "TV," wait on the sofa, take off her glasses (which supposedly only enable minor sight in her one working eye), lie down, and wait. And yet, somehow, if they put on anything else she knows. She will yell, jump, smack. Insist with her body and repetitive signs of "TV, TV, TV" that they turn on the correct show. It makes no sense, should be impossible. And yet it happens every time.

Interlude:

Lock and Key

"Let's go see the natives!" she exclaimed as we made our way to Division Street, the quintessential college town drag, lined with a café, Indian restaurant, smoke shop, and a handful of vintage stores. T. refers to my roommates collectively as "the natives," which I encourage shamelessly. Ours is a typical student house, full of old records, hand-me-down furniture, books, booze, and mildew, which we try to ameliorate by adorning walls and surfaces with swathes of bright cloth and various tchotchkes, relics from various travels and shopping trips. The first time I brought T. over, she saw the West African tapestries and exclaimed, "Where are the natives?" I stumbled, unsure of how to proceed as she crouched low in a combat position, stalking through the living room. A roommate walked in, T. yelled "Native!" and thus a new category was born.

Click. I try to turn the handle and, just as I thought, it remains stubbornly fixed in place. The door is locked and she is silent on the other side.

"Hello? Did you lock the door? T.?" I call to her, knowing she's far beyond my voice in the bathroom. I use her last name, as always. The poor fit of her first name – so feminine and old-fashioned – was evident upon meeting T.

Of all the possible bathrooms to lock yourself in, ours is not a bad one. Perhaps T. picked up on this prior to sprinting inside and slamming the door tightly. My college house has four women, one guy, all in the emerging stages of early-twenties vanity. Five deodorants, a sampling of different toothpastes, toothbrushes tossed in a plastic cup from a local bar, a box of tissues with Japanese lettering, the moldy smell of a house that will be condemned a few

years later. There are two hairdryers (one broken) and a stack of magazines (the *New Yorker*, *Spin*, and back-issues of *Vogue*) bought used at a nearby convenience store. The makeup collection is lacking and on the cheap side from the grocery, but the bath products make up for it. We had to buy extra shower holders for all the washes, creams, shampoos, treatments, gels, and puffs. Someone's boyfriend fixed the falling mirror on the medicine cabinet, so you can gaze at your reflection if you happen to lock yourself inside just for kicks, just because you can – just as T. has done. Click. The wind chill is below zero outside and, frankly, there are worse ways to spend the day. I imagine her looking at herself like this before taking in the objects that mark the space. Appraising her short, unwieldy brown hair and long hook nose, contemplating the freckles that dot her pale skin, turning side to side, grasping all angles of the possible portrait.

T. lives in the J.M. School, a residential facility for adults with disabilities. More dormitory than educational center, the School sits at the edge of my neighborhood, nestled between 1920s family homes, the college, and a public golf course that is open maybe three months of the year. I've been spending my afternoons working at the School, mainly just hanging out and getting to know people. I show up, clock in, find a resident (normally T.), and we head for a walk to the center of our small town. Today, we were headed downtown for coffee (me) and hot chocolate (her) before we stopped off at the house, which led to the bathroom situation. I wonder briefly if I'm allowed to take clients to my house, much less how to explain to my supervisors that one has locked herself in my bathroom just for the hell of it, and opt to hold off on the over-thinking. I pour

myself a glass of orange juice and fall into the overstuffed telephone chair that sits in the kitchen, gearing up to wait until I hear the lock click back.

On days like this, everyone knows to punctuate such a walk with stops – in shops, the grocery, schools, or anywhere else you can sneak into for a brief thaw before moving on – which is how we wound up at my place. The wind cut through our clothes, bathing the skin in burning shivers and freezing tears on our lashes as we made our way down silent streets. We walked arm in arm, as usual, because T. is sporadically terrified of falling on the neighborhood sidewalks, which would remain wrapped in ice until April.

We raced to my drafty house and hadn't even removed our jackets before T. saw the bathroom and ran for it, closing the door without a word. Her expression – plus an impish "See ya later!" – tipped me off that something was about to go down, but what could I do? Click. T.'s inside, door's locked, and I begin to suspect she wants a rain check on the coffee. After all, everyone knows she's prone to sudden shifts, the more absurd the better. On more than one of our walks, she has taken me on secret strolls through the neighbors' snow-covered gardens to examine their vast collections of yard art. Cement sculptures of squirrels, pairs of doves, and birdbaths were particular favorites. I played along, reasonably confident that people were still away at work and wouldn't catch us sneaking through the corners of their yards. All was well until the day a cement rooster, perhaps two feet tall, suddenly came alive for T. She bent down to stare into its neatly carved eyes and suddenly jumped up, screaming, and took off running down the street, dragging me behind her. I caught myself shrieking along with her as we ran, dangerously close to believing.

T. and I became good friends that year. She lived in the School, which was maybe a five-minute bike ride away or, in the winter, a 15 minute walk through snow that stretched over the tops of even the most determined boots. T.'s "cottage," as they called it, housed 10 or so adults of varied ages. Most of them were diagnosed with Prader-Willi syndrome, something I'd never heard of prior to working there. People with Prader-Willi, I was told by the School's young managers, will eat until they die. They will scour trash cans, bins in back alleys, eat the inedible – rotten food, plastic, even glass – although I'm not sure how much of this is fact or embellishment. I try to imagine the feeling of starving, of deprivation, that marks part of their sensory world. I looked for more information and paused at the slogan of the Prader-Willi Association, displayed proudly on their website: "Still hungry for a cure."

All of the food in T.'s cottage is kept under lock and key. The cottage has a kitchen where clients' meals are prepared. It is situated awkwardly in the center of the space, serving as a seemingly natural gathering spot for clients, staff, and visitors alike. We congregate around the 10-seat wooden table, clients drinking waxy paper cups filled with Crystal Light, staff casually flipping through the local newspaper, which arrives daily, half-listening to the television on in the adjoining living room.

The kitchen looks like any other in a group living situation – the aging cream-toned fixtures lined in cheap, pecan wood with a smooth matte finish – except that locks are installed on everything. The ample cabinets (such space!) share a single lock that is kept by the manager on any given shift. I recall a similar setup on a corner cabinet in my parents' kitchen, designated by the previous owners as the sacred spot for liquor in a house full of teenagers. (I

imagine they got in a time or two.) The Cottage's refrigerator has a more elaborate system, with individual locks securing both the fridge and the freezer, as well as an ominously oversized padlock ensuring that the two doors cannot be pried apart. It makes me wonder what's inside. The wastebasket is hidden away in a closet – the same place where we store household cleaners and other bottles of various toxicity. We remove it only at meals so that clients can throw away their trash when they finish eating.

T. does not have Prader-Willi, but her file reveals a laundry-list of other fancy names that dazzle. During my shift one day, a manager brought me to the dining room table – amidst the hum of Oprah Winfrey and an older client, who was engaged in a hushed conversation with imaginary people who stood eight inches tall – and suggested that I read the clients' files. I jumped in gleefully, marveling at line after line of terms (the longer the better!) used to describe the residents. The words restricted them, shaped their inconsistencies and aberrations into neatly folded edges, diluting the incomprehensible with soothing syllables that I pretended to understand. Each definition cut away at excess dough until the silhouette of partially understandable difference emerged. Descriptions tried to fill in the details. "Client enjoys music." "Client allergic to milk." "Client prone to outbursts." The language was so sterile and distant, it struck me as odd that this peek into their files was supposed to bring me closer, to push me inside of their realities.

Click.

T. emerges from the bathroom in her trademark high-waisted acid-wash jeans and colorsplash sweatshirt with an impromptu popped collar. She looks

positively refreshed and glows from her secret adventure. It has been almost an hour and I was just contemplating whether to start looking for a screwdriver.

On the day of the bathroom incident, T. is invigorated by her hour of solitude and is particularly eager to see the Natives. Two of my roommates have just arrived and are waiting at the end of the front hall for the usual greeting. T. sees them and quickly raises both her index fingers to the side of her temples, like a child mimicking horns. Her feet dance just barely, shaking from side to side. Her hair, spikey and soft, looked fantastic.

"Natives!" she hollers, fingers pointed straight to the ceiling like horns, and charges toward my friends like a bull. They are not surprised, although one gives a nervous laugh that I can't help but catch. The other gamely grabs her jacket from a nearby chair and holds it out to her side for T. to run through. The material flies up and T. doubles back, all smiles. "Hey native!" We all chat briefly and then T. and I head back to her Cottage. There is no time for the coffee shop today.

This is our routine. T. has intellectual disabilities, and I assume somewhere in her files there's an estimated developmental age to contrast her actual one. They tell me T. is schizophrenic, but I'm not sure what this means for her or me. I am assured that she was really crazy in the double sense of really/actually and also really/truly. I see that she has multiple personalities – some male, some female – which come out during our afternoons together. Sometimes she turns surprisingly salacious, speaking to me in her Elvis voice. *Hey baby-baby*, all low and a tad menacing. Other days she falls silent and delicate, and wants only to sit with me on the sofa in her cottage, just being there. One most afternoons, however, T. and I walk around town burdened by

nothing but our heavy coats and the layers underneath, and get into only a bit of trouble.

Chapter 6

Making Sense: A Place for Undiagnosis[3]

This chapter examines the themes of enclosure and fit as they relate to complex diagnostic cases, building from a single ethnographic account that shaped my thinking throughout the project. The notion of enclosures – of closets, cages, and locked doors – appeared repeatedly during my fieldwork and became a key analytic for making sense of the ongoing marginalization of the disability community, particularly with respect to the rare and undiagnosed population. From the physical enclosures of residential institutions to the figurative walls pushing these individuals and families outside of recognized disability groups, the concept stuck.

The case that follows illustrates an ethnographic flashpoint in my work on disability. Here, I offer an account of one morning during my preliminary research in Guatemala. The day marked my only visit to this particular institution (or shelter) for children and adults with disabilities. I learned later that the scenes depicted below were not necessarily representative of other shelters in the country.

Still, several years later, this case – this single morning – continues to shape my thinking on the making and unmaking of disability personhood in everyday life. I use it not to highlight the plight of an individual or probe the lived experience of disability in certain economic and sociopolitical contexts. Rather, I approach it as the first of several encounters that prompted me to examine my

[3] A portion of this chapter was published previously: Lewis, Elizabeth. "The Enclosed Case." *Somatosphere,* February 29, 2016. http://somatosphere.net/2016/02/the-enclosed-case.html

preconceptions of disability outliers – cases that originally struck me as so extreme they could not possibly happen closer to home, back in the U.S. People kept in closets? Surely not. Children abandoned to live in nursing homes? Impossible. A suspicion that disability was contagious? Come on. Having spent my entire life immersed in the disability community, whether personally, as an ally, or through my research, I naively assumed that I knew better.

Yet I heard such stories again and again as I moved forward with my work on family experiences with rare and undiagnosed disabilities, those confusing puzzles of sensory, physical, and intellectual difference that do not correspond to a clear label – the bodies that fall outside of diagnostic common sense. The themes persisted long after I transitioned to fieldwork in the U.S. They were not discussed as openly, yet simmered below the surface in many of my ethnographic encounters.

I have continuously revisited this case as a cautionary reminder of the materiality of bodily difference and enclosure, and of an ethnographic caution about attributing exceptionalism to an encounter. Each case tells a story, and this one is no different. But the story of a single morning has continued to reverberate through multiple years of a single project, despite my efforts to leave it behind.

THE CENTRO

The Centro was a clumsily crowded institution housing people of all ages with disabilities. Locals spoke of the kindness and generosity of the Church-run facility, noting its constantly changing international cadre of mission groups and gap-year volunteers. After all, where else could the Centro's abandoned disabled residents live and who would care for them otherwise? The building's facade

stood in typical colonial splendor, layers of sharply flowing lines doused in cheerful hues overlooking food vendors in the adjacent plaza. Anyone who has been to this well-traveled city has most likely passed by.

I met my local contact, V., a physical therapist based in the capital, outside of the facility. She worked there twice weekly through an innovative program developed by a well-connected national disability nonprofit (with significant international backing). The program brought experts from the capital city to other areas within a day's travel that lacked specialized disability service providers. Her formal job was to provide basic therapies to a handful of the residents, but there was more to her work – the simple act of attention, sitting with a person and communicating with them however possible, whether using sign language, speech, gesture, or touch. In this space, where residents far outnumbered staff and volunteers, such encounters were a luxury.

Leading me through the maze of partially locked gates, V. narrated the space as we walked. Hundreds of people lived between these walls, hidden from the humming city life outside. The Centro's residents appeared to have a dizzying array of disabilities, and according to V., many did not have a concrete diagnosis – an under-examined, yet quite common, occurrence in global disability. I saw wheelchairs, straitjackets, the whole bit. The children's quarters stretched around a standard open-air courtyard, a deceptively beautiful by-product of the architecture. There were flowers, grass, and a small jungle gym. A swing designed for kids in wheelchairs sat vacant and a collection of multicolored beach balls rested under a small tree.

V. and I stopped to greet clients as we walked, shaking hands and patting arms along the way. Almost all were in wheelchairs. She said this was a

requirement for residents, including those without mobility challenges. We walked toward a structure the size of a walk-in closet, a small wooden shed in yet another courtyard. My companion knocked. Tok. Tok. Tok. Without waiting for a response, she opened the door. A woman in her early-twenties was curled on a wooden plank bed lined with a foam mattress. I will call her Maria. She had cropped black hair that stood straight up. V. had told me that she was blind, presumably since birth. I believe her eyes were closed when we arrived.

Maria had lived at the Centro since she was 15. She had quite a reputation and was widely feared by staff. She was said to be uncontrollable, unhinged, and full of rage. She was violent, I was told, and took her wrath out quite physically on anyone who dared to come too close, especially when she was younger. Having heard all of this, I struggled to make sense of her small frame resting silently in this darkened closet. V. told me that Maria spent most of her days in this position.

Maria's room had no windows, but light slipped in through the uneven cracks where the rough wooden walls reached up toward the flat ceiling. The heat wasn't as oppressive as I expected. I noticed a small latch on the outside of the door. With force, Maria could have pushed her way out. The room was almost empty. A single light bulb hung from the ceiling and the bed sat next to a toilet with no lid or seat.

V. first met Maria the previous year, and had visited her weekly ever since, following her brief therapy sessions in the children's wing. Her other clients were primarily young kids with multiple disabilities – mostly combined sensory, intellectual, and physical impairments – but Maria was different. First, she was a young adult. Second, she lacked the diagnostic ambiguity of V's other patients.

On paper, Maria sounded misleadingly clear cut: she was blind. As with the other Centro residents, however, Maria's impairment was enmeshed in a personal history of neglect and isolation that could not be separated from her lived experience with disability. Blindness, as a diagnosis, flattened her everyday. Maria's disability had become inextricably linked to life in the closet, rumors (or truths) about aggressive behaviors, and an inability to communicate verbally.

As V. had learned from the staff at the Centro, Maria had been abandoned by her parents as a small child. She somehow made her way from town to town, and ended up in the main market of a small city. From there, she was sent to the Centro, where she had lived since she was around five. I had heard similar stories elsewhere – the disabled child found in a market stall or public bathroom. V. had not heard Maria speak and she did not utter a sound during our visit that day. V. had been told she spoke a Mayan language when she arrived at the Centro as a girl, but never learned to speak Spanish. Again, I do not know. With us, she communicated through gesture, bodily movements, and facial expression. And, yet, I could see that she listened to every word we said.

After sitting in her room for a while, Maria stood up. She and I walked outside, slowly making our way across the courtyard. V. trailed behind. The nurses stared openly. When V. started to visit Maria, Centro staff uniformly warned her to be careful. "She'll hurt you," they said. "She's like an animal, biting and clawing." Behaviors were individualized as nameless and decontextualized, yet fixed. Maria was just like that, the logic held, and we were all to be careful.

I sat with Maria on the concrete patio. The sun snuck out from rainy season clouds for a few moments. I recall Maria breathing slowly, in and out, always silent. I did the same, not wanting to make additional noise. One of her

hands rested softly on my arm, physically keeping tabs on my presence in the space.

I met a man several weeks after this visit, a physical therapy student who interned previously at the Centro. He immediately asked if I had met Maria. He snickered as he spoke, recalling the stories of the notoriously wild and uncontrollable patient – this grown man with children of his own. He told me that everyone was afraid of Maria, that she was capable of anything. I asked if he had ever seen one of her rumored explosions. He said no.

Maria and I moved to the grass as she relished the rare moments of sunlight. When she was ready, she stood to return to her room. V. and I accompanied her, and we sat on her bed. Maria lowered herself down onto one side, curling into the same position in which I sometimes sleep. V. took out her cell phone and began to play music. I recognized the song instantly, a South American band with soft compositions full of emotion and weight, lots of lost loves and what if's. The singer pondered the smells that linger once someone departs – of perfume, cigarette smoke, coffee breath, skin. Maria rested motionless, just breathing slowly and rhythmically with the music.

The three of us stayed like this for five minutes, maybe more, sitting there in stillness as the songs wrapped themselves around the small, dark space. Maria's open door caught any breeze it could find and the air shifted slightly. Maria rested her head on my companion's lap and her hand on my arm. After a few songs, she shifted her weight away from us, creeping closer to the edge of her bed to signal that she was ready to be alone. V. asked softly if she wanted us to leave, telling me that Maria's lack of acknowledgment indicated that it was time. We stood and walked slowly from the space.

“This is always the most difficult part,” V. said to me, looking down. I watched as she slowly closed and latched the door, and we left Maria inside of her closet.

I did not return to the Centro.

ENCLOSURES

While it was only a single morning in a multi-year project, my encounter with Maria continues to loom large in my thinking. In my early work in Guatemala and later in the U.S., including extensive digital ethnography, such outlying or seemingly extreme cases edged closer and closer to the center of my analysis.

The similarities between this case and the bulk of my fieldwork, which took place in the U.S., were uncanny. This was most visible in the convergence of spatial isolation in the crafting of differential modes of personhood. I returned to these themes repeatedly during later iterations of my fieldwork in Texas, which houses more citizens in large state institutions than any other state, as discussed earlier. Enclosure helped me understand the response of local Austin news outlets, which staunchly covered protestors opposing the closure of large residential institutions for adults with disabilities. The logic was familiar: “Where else will these people go? Who will care for them?” The media coverage curiously left out any significant discussion of legal precedent, the ongoing federal involvement, the Americans with Disabilities Act, or the simple fact that many other states had already phased out institutions in favor of community-based alternatives.

I recalled my morning with Maria as I struggled to make sense of these renewed calls in favor of disability segregation. I began to think about disability

through the lens of Elizabeth Povinelli's (2011) writings on the ordinariness of abandonment and isolation, and Kathleen Stewart's (2010) work on worlding and the everyday. Abandonment not as a jolt, but as the nagging hum of that single bulb in a darkened room, the murmurs of others told to keep away, or the lulling song we played from V.'s cell phone on the day of our visit.

Disability segregation, in this framing, became an ongoing process of bodies and moments, an everyday experience of life in the closet. The slow burn of almost but not quite forgetting a woman made to live apart, and a collective public denial that such cases are not necessarily extreme or, if they are, might somehow be justified. Here, isolation becomes a work in progress, always unfinished, available to the ethnographic lens in snapshots. It is both a process and an act, highlighting disability worlds that are both singular and widely shared, frozen in scenes yet necessarily ongoing.

But the theme of enclosure went beyond the actual walls of an institution, room, or home. The analytic of enclosure applied, too, to the realm of undiagnosis. The notion of a child cordoned off and individualized based on the lack of a name, of parents excluded from mainstream participation in specific disability communities that almost fit, but not quite. Of not having access to a diagnosis or, alternatively, finally receiving one but having no community because it did not (yet) exist. In my framing, enclosure encompassed the physical, practical, and affective dimensions of isolation in the case of disability. Stigma was no longer allowed and ableism – like all –isms – was shunned, at least in its overt forms, yet enclosure persisted.

Enclosure, in this chapter, is an affective social zone rooted in physical space. My thinking is informed by disability studies scholar Rosemary Garland-

Thomson's concept of misfit (2011). For Garland-Thomson, disability is both material and social; it is the mis-fitting of a certain body or mind to the environment. Garland-Thomson wants to bring bodily experience into the conversation to avoid the generic and perhaps misleadingly unifying designator of disability. As she explains: "The discrepancy between body and world, between that which is expected and that which is, produces fits and misfits (2011, 593). Disability is material and social. It is also an arrangement or a set of relations. This framing is particularly useful for probing the singularities of family experiences with rare and undiagnosed disabilities within the broader field of disability.

As Garland-Thomson states: "To mis-fit renders one a misfit" (2011, 593). To have a rare or undiagnosed disability is, by definition, to mis-fit. This is what parents meant when they lamented that their children did not "just" have autism or Down syndrome. Mis-fitting captures the disjuncture of medical visits, the roller coaster of repeated misdiagnoses during a diagnostic journey. Misfitting highlights the relations between different bodies in different spaces. It adds theoretical depth to the fact that interpretations and experiences of embodied difference fluctuate, that the qualitative experience of being undiagnosed or having an extremely rare disorder today is meaningfully – and also practically – distinctive from receiving a vague "multiple handicapped" label in a previous generation. Misfitting, too, places experiences of spatial isolation in dialog with the lack of opportunities for affective or logistical supports, such as in medical settings, through social recognition, or when left with a disability community that can only partly relate to a particularly diagnostic world.

Parents often used the concept of not fitting in to describe their experiences. One mother remarked casually that all the other moms in her so-called special needs support group had kids with autism; they were empathic and welcoming, yet they could not fully understand her experience. Another recalled receiving a preliminary diagnosis for her daughter as a baby. “I found the online support group for Charge syndrome…I found that group and I talked with other families, but there was always that, ‘Well, we don’t fit.’” Her daughter was re-categorized as undiagnosed at age four, and the mother went on to found Syndromes Without A Name (or SWAN), a national nonprofit dedicated to children and teens with undiagnosis. The girl was a teenager when I spoke with her mother, and they had recently discovered the source of her disabilities: a highly unusual gene mutation. Only nine patients had been identified worldwide.

Anthropology seeks to make sense of the relationship between the individual and the aggregate, but cases like this bring distinct challenges. The odds of having a particular genetic mutation – a certain diagnostic and clinical profile – are, in these instances, staggeringly low. One mother, speaking on a panel of parents with children who were or had been undiagnosed, riffed on the possibility that her son was a singular case. “We’re pretty sure he has the Aiden Syndrome,” she told a crowded room of parents, caregivers, and clinicians, echoing a sentiment I had heard elsewhere. Perhaps she was right. As the founder of SWAN USA explained: “A lot of times in diagnostic odyssey, it’s so difficult that once families get a diagnosis – whether it’s rare or not – they tend to leave that diagnostic odyssey behind.” Conversely, while in the midst of it, they tended to be quite isolated.

Nick and Crystal, two filmmakers working on a documentary about undiagnosis in the U.S., said that they had encountered similar sentiments from parents. When I asked what common themes they saw in people's experiences with undiagnosis, Nick explained: "The unknown is something you hear commonly. And being alone in that unknown." Crystal elaborated: "Undiagnosis is such an ill-defined term as a population that it's not considered a diagnosis, because it's not a diagnosis. But it's not really considered anything…There needs to be a stepping stone to get you to the next point, because otherwise you're just floating." But what if undiagnosis is an end in itself? Or, conversely, if learning the underlying root of a child's disabilities yields no additional information because the condition is so rare?

Such questions suggest that the power of a diagnosis is not so much the answer itself, as a question of fit. Indeed, this is precisely the power of rare and undiagnosed disabilities with respect to illuminating new understandings of what disability is and does. Rather than viewing undiagnosis as a liminal state or waiting game – and, conversely, seeing a rare diagnosis as a success – what if these are fundamentally reframed as emergent disability worlds that fall outside of existing norms, expectations, and systems?

There are critical temporal elements at play in this reconceptualization of undiagnosis. Disability experiences, like many diagnostic labels, are fundamentally different now than in previous eras in the U.S. Americans with disabilities are living longer and, increasingly, reside in their local communities. Disability rights are guaranteed by federal law. Hit television shows like *Speechless* and *Parenthood* feature lead characters with disabilities. There are huge gaps in services and ongoing unmet needs, to be sure, but the basic

concept of disability rights is firmly established and recognized, if not fully implemented.

This is a stark break from previous eras. It is important, for instance, to remember that institutionalization was a way of life for individuals with disabilities for much of the twentieth century. This was due primarily to a segregationist tendency built on stigma and fear. It was taken for granted that children with disabilities were bad for their families and would cause serious distress for parents and siblings alike. In addition, families could not count on today's federally mandated protections, such as early intervention programs and the Individuals with Disabilities Education Act, raising practical questions of the role of these children in daily life. Thus, the thinking followed, there was little doubt that families would be better off without the assumed burden of a child with disabilities.

Such logic reached its apex in the form of physician infanticide. The key figure in this sidelined, relatively little-known past was Dr. Harry Haiseldon, better known as the Black Stork. Haiseldon was a Chicago doctor who, in the nineteen-teens, went public with his practice of allowing newborns with disabilities to die. He believed that disability in a family would bring unavoidable degeneracy, poverty, and misery. For him, to save the lives of such babies was tantamount to ignoring divine will. A July 1917 *New York Times* piece described a typical Haiseldon case:

> The day-old daughter of Mr. and Mrs. William Meter of 121 North Cicero Avenue, died today at the German-American Hospital, where Dr. Harry J. Haiselden refused to perform an operation which he acknowledged probably would save the child's life. He declared the infant, if it lived, would be an imbecile, and that its parents and humanity would be better served by its death than by the prolonging of its life.

Such stories, along with the practice of institutionalization, are central to understanding the social history of disability in the U.S. Today, debates about disability eugenics often invoke prenatal testing and selective abortion. I spoke with only one parent, a father, who reported learning of his child's disabilities in utero, although many others said they suspected something was different with the pregnancy in question. The father recounted the story, with an ultrasound revealing around 19-20 weeks gestation that the fetus had an extra finger and distended stomach. After additional testing, they received a tentative (and ultimately incorrect) diagnosis of Trisomy 13, and were told that the fetus likely would not make it to term or, if born, she would live only a few days.

They were approaching the cutoff for legal abortion in Texas and doctors pushed them to make a decision. His wife remembers the perinatologist recommending abortion, but he thinks he has blocked that out. As he recalled: "It wasn't presented like 'Go home and talk about it,' just 'Okay, what do you want to do?' My response was 'I don't have the authority to make that decision.'" Although he said he would have described himself as a social Conservative prior to this experience, his views have shifted: "I've met parents that chose to terminate and my response to them without making it political or religious is, 'If you chose to terminate, you are the mom and the dad and y'all made the best decision you could in the situation you were in." He was, however, critical in one respect:

> My issue is, for a Republican Senator…for me personally you can't limit the ability to abort a baby but also make a headache for people after they're born. If you want to limit the abortions – hey, that's fine – but you need to do something on the other side and give the right support to the

> families who want to keep the baby and not leave them high and dry, because that's long-term care.

Selective termination is so deeply connected to contemporary discourses of women's rights and reproductive choice, however, that it is a difficult proxy for parsing out the value of or disregard for disabled lives. A more fruitful illustration of the tenuous place of disability personhood can be found in the occasional, but widely publicized, cases in which parents murder their adult children with disabilities. One such case involved Bonnie Lutz, a suburban Chicago mother who was sentenced to only four years of prison for poisoning her 28-year-old daughter in 2016 (Houde 2016). Such cases tend to be met with relative sympathy by the media and parents typically receive relatively minor punishments for their crime. This is a significant source of outrage among disability rights activists – particularly self-advocates with disabilities – as it implies a disparity in the perceived weight of death for certain types of bodies and minds over others. As a cultural event, it stands out because the public response focuses on the tragedy, not horror, at the murder of an offspring by a parent. The object of attention is the parent's assumed desperation, not the death of the victim.

Yet, parents often spoke of intense social pressure to focus exclusively on their child with disabilities. As one father explained: "We live in these layers. Yes, we have a child with special needs and we have these struggles, but we also went to the coast [for vacation]." He continued:

> I don't get this as much as a dad, but for [my wife], if there are people from her work who are her Facebook friends, then it becomes a challenge because they're trying to figure out what they can ask her to do…Can [they] ask her to come in and work if one day she's saying on her

> Facebook page that it's so awful but the next she's swimming in the ocean? These are the geographies of complexity that we live in.

They were, one might say, over-determined from the outside by the question of disability. Diagnostic complexity simply complicated things further. Without social recognition for their family's predicament, parents found themselves in a cycle of ongoing explanation and investigation. Nick, one of the documentary filmmakers, believed that public understanding of undiagnosed disabilities were almost wholly absent: "It's definitely not the word [undiagnosis] and one sentence. It's the word and six paragraphs." He related to the undiagnosed community in part through his experience as a cancer survivor. As he explained:

> Even people who have no personal experience with it can still really understand if you approach it the right way. Everybody's sat worried in a doctor's office at some point, whether for five minutes or 15 years. And if you can contextualize that, then it opens the floodgates of understanding.

MAKING A SPACE FOR DIAGNOSTIC MISFITS

What does it mean to have a child with undiagnosed, but known, disabilities in an age of public disability rights discourses, rising rates of disability, and new diagnostic technologies? Similarly, what are the implications – both affective and practical – of receiving an extremely rare diagnosis about which little to nothing is known? The essays in this dissertation show clearly that such experiences are relatively common, yet parents typically report feeling isolated, unacknowledged within the broader disability community, and abandoned by the medical system.

These disability communities are distinct in that they are intelligible through their shared lack of diagnostic recognition. As parents often said, their children do not “just” have Down syndrome or autism; they do not fit with expectations of what disability is and does, how it is described. Rather, they fall outside of diagnostic common sense, resulting in a disability world that emerges through a unique social and embodied experience. These individuals were often marked quite visibly different – often physically, intellectually, and sensorially – yet remained unintelligible. They were, one might say, too different.

This raises key theoretical and practical questions about the limitations of current understandings of disability. What might it mean to radically rethink fitting in with respect to the normal and pathological, pushing the limits of the really different and bringing the outlying cases to the center? Again, it is useful here to revisit Rosemarie Garland-Thomson’s theory of misfits and misfittings, particularly as expanded by disability studies scholar Aimi Hamraie through the notion of the normate template. As Hamraie writes: “In order to sustain itself, the normate template relies upon the impression that normates are normal, average, and majority bodies. Misfitting shatters this illusion, marking the failure of the normate template to accommodate human diversity” (2013). Therein lies the key: in the cases analyzed in this dissertation, the normate slot was filled by the mainstream disability population, as imagined and enacted through diagnosis-specific advocacy and support groups, popular culture imagery of what it looks like to be x or y, or simply the likelihood of encountering certain forms of visible and recognizable difference in daily life. The children and families with undiagnosed disabilities, past or present, were the misfits, failing to fall within the parameters of diagnostic common sense.

As demonstrated throughout this study, the rare and undiagnosed communities constitute a potentially seismic shift in thinking about what disability is, means, and does. Families have begun to carve new spaces of possibility, knowledge production, and support, increasingly through digital media. Scholars and researchers, too, can contribute to this effort by producing publicly accessible works that destabilize dominant and perhaps myopic frameworks of disability. Ultimately, the question of undiagnosis is part of a broader social project on difference, and ethnography is perhaps uniquely well suited to probe the boundaries of diagnostic ambiguity in everyday scenes, intimate spaces, and revisited recollections. This dissertation offers a first step in that direction.

Closing:

A Story

WHAT'S WRONG WITH HER?

"What's wrong with her?"

Of course, the boy who lived down the street has to be walking by our house right now. Here I am, standing at the end of the driveway with a freshly delivered newspaper in hand. My dad is backing our station wagon into the street and my sister in full tantrum mode in the backseat. At eight years old and tall for her age, anyone can tell she's too old for this kind of toddler-style display.

"Is she okay? What's going on?"

He's still talking. I almost never talk to the other kids in the neighborhood, so I should be excited. Between going to private school and staying busy with way too many after-school activities, I rarely see anyone from the neighborhood. I don't even know their names. I'm sure they think I'm the weird girl from the oversized house that keeps its curtains drawn. These things stand out around here.

"She's fine," I say. I look down and walk around the car, and the boy shrugs and passes by with a final glance at Chloe.

My dad unlocks the doors and I hop in the backseat next to her. Her body snaps like a mousetrap, leaning forward and then crashing back to the gray cloth seats. She's jumping as best she can with her seatbelt on, which can't be easy. She bites the meaty part of her left hand between her thumb and pointer finger, and smacks the inside of the door with her other hand. She's definitely pissed.

Was she mad that it was nearly lunchtime and there was no sign of her usual Saturday fast food? That I'd slept in again and caused the late start? She keeps smacking away, my dad turns on the oldies radio station, and I settle in and watch Neighbor Guy walking down the sidewalk as we pass him.

None of this is new to me, although that doesn't mean I don't notice. Of course I do. It's just that this is our everyday. It's what I know.

SIBLING STATUS

My sister has disabilities, which could mean almost anything these days. When people hear "disabilities" they think easily digestible categories like Down syndrome or maybe CP. Blindness is a good one. It seems straightforward enough.

Chloe's situation is much more complicated. Her disabilities don't have a name yet, although I'm convinced I'll find it one day. I've been able to rattle off the list ever since she was born: Chloe had auditory and visual impairments, but she still has some hearing in one ear. She was born premature and with a small heart problem, but it's okay. She has colobomas in her eyes, so her pupils are wide ovals instead of circles and she can't see as much as we can. [At this point, I place my flat hand against both eyebrows to show her range of vision. People appreciate the demonstration.]She has OCD tendencies and can't talk. She knows a little sign language. Basically, Chloe has a bunch of different impairments and a few medical issues, and we don't know why.

My dad calls this our elevator speech, but it's definitely a mouthful. People get uncomfortable hearing so much medical information in a casual conversation.

I know it catches them off guard to hear it coming from me, since I'm supposed to be talking about things like the World Cup or my dance team or boys.

We recently learned that Chloe is undiagnosed. Well, okay, I guess we knew that. But we didn't know there was a word for it until the geneticist told us. Undiagnosed. Part of me had always felt ashamed that we didn't know what Chloe had. When people asked "What's wrong with her?" I could only remember that I was supposed to say "Nothing is wrong, she just has disabilities!"

But that wasn't what they wanted to hear. They weren't looking for identity politics, just an easy term to explain the slanted facial features we pretended weren't part of a broader syndrome, her strange refusal to run or jump like other kids, the awkward gait or slightly too long arms. No, this wasn't just a case of needing eyeglasses, hearing aids, and a little speech therapy. There was more to Chloe. We just didn't know that we didn't know it.

I'm 14 and my sister was born when I was six. Adults sometimes say things like "So you don't really remember anything before she came along." It's almost a question, but not quite. I think they're trying to make themselves feel better or find a silver lining in what they think is a tragedy. I always wonder if they don't remember anything from childhood. I have lots of memories from before Chloe was born. Too many, perhaps. Does that make me weird?

My first memory is from around age two. I woke up one night in my crib and was sure there was someone outside of my window, yet I was too small to get away. I cried and cried until I mom came and scooped me up, bringing me into my parents' bed with the old cat who always scratched me.

I remember when my Grandpa died one spring. I took a clear, plastic umbrella with drawings of rainbows and clouds and gleamingly jagged suns, and

walked around the front yard in the rain singing songs my mom used to play. Peter, Paul, and Mary. Simon and Garfunkel. Those were always on in the house back then.

I remember driving across the country to live in Oregon for a while. I remember the day I threw up all over my favorite red patent leather shoes at preschool, and how I haven't had apple juice since. I remember going to a restaurant on the coast and eating chowder, which I didn't like at all. I remember pretending the algae growing in our fishpond out back was a school of microscopic fish. My fish.

People who know about Chloe treat me differently. Not my friends, but definitely adults. They act almost like I have superpowers. They say I'm "precocious" and that I talk like a grownup. They remark how I must have to help out so much at home, and ask how my parents are doing. Friends' parents and teachers offer to let me stay with them if my folks need to drive to see specialists, therapists, or other experts out of town. They give silent, knowing smiles and act like there's nothing else to say. But I see them looking at me, just a little extra – a little longer.

LABELS

Undiagnosed. It's a fancy way of saying we don't know why Chloe is the way she is. Different. Different is okay, my parents remind me. But she's not normal like my friends and me, I tell them. Don't say normal, they say – a little too quickly. You mean she's not typical. Typical is the word we use.

There are lots of rules about what we can and can't say. Some of them are obvious (like the R-word, which is never to be uttered), but a lot of it is more

confusing. I don't know why I'm not allowed to say "normal." It comes up in conversation all the time – normal kids, lives, behavior. That's not normal. Act normal. People say it all the time. But my parents tell me it's a bad word. If it's so forbidden, why do I hear it everywhere?

My mom usually takes me to the Family Disability Resource Center when she goes. It's an organization for a bunch of other parents who have kids – some grown – with different disabilities. It's usually all moms. They go and tell their stories, drink coffee, talk about different therapists, which teachers or school principles they hate the most. They also answer calls, meet with parents, and give trainings on things like disability rights and special ed. Everyone there has a child like Chloe, my parents tell me, although we all know they don't. I've never met anyone like my sister.

Sometimes the moms at the Center try to talk to me about being a sibling. They tell me that I'm doing such a great job and I'm so grown-up. They reassure me that I can't "catch" what Chloe has. (Apparently, the books on disability and families say siblings are worry about this, but it's never occurred to me. Adults are obsessed about this one.) They ask if I'm staying busy with school and activities. I get a lot of knowing smiles and Hallmark-style commentary, plus the occasional "If you ever want to talk to my other son about your experience I'm sure he's willing." Sure, I'd love to talk to a total stranger about having a sister who's undiagnosed. What teenage girl could say no to that offer?

But I guess they're trying. When I was 10, my mom sent me to a support group for siblings. She promised ice cream afterward, so I begrudgingly agreed to give it a try. Every single kid in that room had a brother or sister with autism. Every single one! And not the new kind of autism you see on TV shows like

Parenthood and hear about on the news, but the old kind – the serious kind that doesn't show up in one in sixty-something kids. And you know what? I was jealous.

Sure, the siblings seemed totally miserable and uncomfortable at the support group, just like me, but they had a common ground that I didn't even know I was missing. They could relate. And then, of course, I went and ruined it all during my intro: *my sister has visual and auditory impairments, and colobomas in her eyes, and possibly intellectual disabilities but that might be due to communication deficits…*Their eyes glazed over and I became, without a doubt, the outcast in the room.

Over ice cream afterward, I told my mom I wished Chloe had autism. That was my last trip to the support group.

But it's everywhere, this obsession with a diagnosis. A name. It reminds me of school. We all have labels in high school. Jocks, stoners, cheerleaders, art kids, theater people, band nerds. My yearbook tells everyone that I made honor roll both semesters, was on student council, wrote for the school paper, played the trumpet, and ran track. Those are my labels. They give an idea of who I hung out with, how my days were structured, what types of activities interested me and kept me busy.

It's not that different than the posters displayed at the Center of some of the staff members' kids. Big, proud professionally photographed portraits of the different kids, complete with brief biographies and then, in bold letters, the name of their diagnosis and a short description. My mom said they're from the website. I guess the posters are supposed to make the space seem more personal.

> Brianna's family has been active with the Family Disability Resource Center since she was a baby. They all love attending our annual conference and special events, and meeting other families. Brianna enjoys swimming, music, and spending time with her pets. She is seven and has lots of friends at school.
>
> *Diagnosis: Spina Bifida.* Spina Bifida (SB) is a birth defect in which the spinal column does not close completely. It begins in the womb and is a lifelong condition. It is associated with mobility impairments, as well as multiple other conditions. Mothers should begin taking folic acid supplements at least three months prior to pregnancy to help prevent SB.

I ask my mom why Brianna's mother didn't just take vitamins. She tells me it's more complicated than that and we shouldn't always believe what we read. I wonder what would we put on a poster for my sister?

> Chloe likes swimming, French fries, and watching Sesame Street on repeat. She loves animals and enjoys swinging on her backyard swing set for hours at a time.
>
> *Diagnosis: Unknown.* We've never met anyone who looks, acts, or has the same set of impairments and conditions as Chloe. If you come across anyone who does, please contact us via email or telephone. We don't know how often her undiagnosed diagnosis happens or what it means for the future.

A doctor once told my mom it was because she drank wine before she knew she was pregnant, and my parents think there was chemical dumping near a park we used to visit before Chloe was born. Maybe that's it? But why would she be the only one?

REGISTRY

After years of tossing around different possible diagnoses, my parents finally took Chloe in for genetic testing last summer. They even got insurance to

pay for it, which had been a big worry. I was away at camp when they did it, but they said it was just a blood draw. A few months later, they met with a geneticist and learned that Chloe's disabilities were caused by a genetic mutation. They even know which gene. She has a mutation on the SETD4 gene. And it's *de novo*, which means they don't know why it happened and there's no reason to think it could happen again in the family. But that was as far as they got. The mutation she has doesn't have a name and no one else is known to have it. Just Chloe.

My parents added Chloe's genetic testing results to a registry, which is basically just big storage place for people's genetic testing results. It's coordinated by the main teaching hospital in our state and falls under a bigger government-run program for undiagnosed disorders. In theory, we'll be contacted if someone else shows up with my sister's same genetic mutation. Good old SETD4.

I know my mom is waiting for the phone to ring. Do they even contact us that way? Who's *they*? I picture a geneticist showing up at the front door, like the *Publisher's Clearinghouse* guys on TV. Or what if it's an email that goes to our spam folder and we never find it? A letter that gets lost in the mail? An automated text message or voicemail that we fail to check? My parents are awful about checking their phones.

My mom talks about the genetic registry daily now. She says that I should be thankful to live in a time with this technology. She reminds me that 10 years ago this kind of genetic testing would have cost millions of dollars and been completely out of reach. Now, it's a few thousand bucks and insurance covered most of it. I haven't seen any real payoff yet, though.

I talk about the registry with teachers and other adults sometimes, but to be honest I can only explain it in abstract terms. The elevator speech again. I have no idea how it works or what it looks like. I picture a small man with a mustache turning a handle on a cage, like at a bingo tournament. SETD4. SETD4. SETD4. Chloe's genetic profile is displayed on an overhead projector, and the little man just pulls out number after number from his endlessly turning stash. "No match." "No match." No match yet.

My mom is convinced there must be others out there. *There's no such thing as a singular case!* she declares. Can Chloe really be the only one? Are we the only family like ours? My dad isn't so sure. While my mom spends her nights with a glass of wine combing over Google for any possible lead about Chloe's genetic mutation, my dad focuses more on our troubles with the local school system. They want to say that Chloe has intellectual or developmental disabilities, and this makes my dad furious. "It's a lack of communication, not her brain!" he yells. His voice is low and thick, especially after a drink or two, and carries throughout the house. It's one of the few voices that Chloe can still hear.

He gets so angry on the subject that I have to leave the room. He starts thundering about the ignorant, heartless people at school and the principle who's just a big nobody and wants to feel important. He says he hopes they get cancer or their husbands leave them, that their lives fall apart. I've never heard him talk like this. I'm supposed to hate the school people – I can tell from my parents– but I don't even know them. It seems strange that adults would be out to get my little sister, but my parents are convinced. We spend a lot of time talking about this. Sometimes I help them organize binders of special ed case law for when things get more serious with Chloe. I might be the only student in my grade who knows

what case law means, much less least-restrictive environment, reasonable accommodations, and low-incidence population. I'm still not clear on due process, but it's a term that's been coming up more and more.

HOSPITAL

My first memory of my sister probably isn't real.

After my mom went into labor, my parents left me at home with my grandmother. A day or two later, my dad came by the house to bring me to the hospital. They walked me down to the nursery so that I could meet my sister.

"She looks different than the other babies in the nursery," they cautioned. "She has a cleft lip, so there's a gap in the middle of her mouth." Armed with this knowledge, I was able to spot her immediately amidst the sea of wriggling, seemingly identical little pink newborns in the room. I loved that Chloe was different. She stood out and she was mine.

In my memory, my mom notices some stickers on Chloe's bassinet that the other babies don't have. She sends my dad off to ask the nurses, and, for me, this is when everything began. It is the moment that leads in a direct line to the present. But I don't think it actually happened. How could it? I now know that Chloe had to be in the NICU after birth, which is where they send the newborns with health problems. I wasn't allowed inside, since kids were too germy. So how did I make this memory?

The doctors didn't think Chloe would survive. My parents didn't name her, since someone told my mom it would be easier to lose a child if it hadn't yet been named. I have a vivid – and very real – memory of explaining all of this to a shocked teaching assistant on the playground at my school that week.

I remember the house filling up with bouquets. Everyone sent flowers, but not many people came by. My sister was premature, but not by much. My mom says she knew something was “wrong” with the pregnancy. I think she just means different than with me. She mentions that her belly got bigger earlier in her pregnancy with Chloe than with me, and a family member said that’s a surefire sign. Her doctor said it was nothing unusual, but she still holds onto it.

“Don’t all pregnant women have big bellies?” I asked the first time she shared this with me. “This was different,” she responded.

Even eight years later, she still spits with anger – literally – when she talks about the doctor who delivered Chloe. Her regular doctor was on vacation that night. This guy made it clear he wanted to be anywhere but the hospital. She never forgot it. I wonder if she believes things would have turned out differently had he been available. I’ve heard similar stories from the other moms at the Center.

After Chloe’s birth, we traveled to hospitals and specialists all around the country to find answers. My dad says this is why I do so well in school now. I learned the language of doctors when I was young. He tells me there are lots of studies showing that young kids who learn more words end up smarter and do better on tests, and I definitely heard more words than regular kids. I would go into the offices with my family and be the cute little girl who asked grown-up questions and helped with her disabled sister. The doctors loved me, the therapists got a kick out of asking me to be their special helper. I probably shouldn’t have been there at all, but what else could my parents do?

When I was in second grade, I learned about cells and atoms at a summer science camp and became completely convinced that I could see them. I told my

parents that my eyes were so strong I could make out cells moving through the air. They were just paranoid enough that they mentioned this to my sister's ophthalmologist, one of the best around. I remember hopping into his exam chair at the massive hospital with the adjoining hotel and floating walkways suspended between buildings. He did a quick exam, told me I was seeing nothing more than tears and goo in my eyes, and proudly proclaimed that my eyes were so good I would never need glasses.

Three years later, I couldn't see the board in school and had to get my first pair. My eyes have gotten worse by the year ever since.

SCREEN TIME

It seems silly to say that we found out Chloe was undiagnosed, but that's how I see it. My parents don't seem to care about this at all. Ever since they got the genetic testing last year, they've been obsessed with finding out what Chloe "has." My dad hopes a diagnosis can help us make her better, although disabilities don't have cures. They aren't sicknesses.

Anyway, we all secretly know mystery cures are a thing of the past. We tried them all. Special mouthpieces to help her talk (glorified retainers, if you ask me), facilitated communication, keyboard attachments for the home computer, speech therapies, psychologists, medications, different teachers, pictograms, weighted blankets, therapeutic horseback riding. You name it, we gave it a shot. Some of the experiments were more fun than others, but none were free, easy, or convenient. I don't complain, though. What's the point?

When we learned Chloe was undiagnosed and not just a mutt (a terms I'm definitely not allowed to use), I realized that there were millions of other kids like her and families like ours. Not just like us in terms of Chloe's box-shaped face, flat nose, refusal to play with kids her age, or curious habit of dipping all food in her drink before eating it. There were other families who also didn't know. Who were undiagnosed. Everybody else didn't have Down syndrome or autism or Angelman syndrome or whatever else my moms' friends' kids had. We weren't lacking something. Science just hadn't caught up with us yet.

I'd always felt embarrassed that we didn't have a diagnosis for Chloe. I saw people's eyes glaze over as I described her laundry list of impairments and conditions. I worried that I owed them an easy label so they could smile, nod, and not have to listen to me rattle off the elevator speech again. Instead, they would give me these looks of intrigued, mildly bored pity, and I'd respond by being so optimistic and chipper about the whole thing that that my parents were always reminding me that I didn't have to "hold it all in." But isn't growing up about holding things in? Feelings, knowledge, jealousy, anger? About learning to control ourselves and put on a good public face? I often wished my parents could hold it all in a little more. Or at least not share every little thing about Chloe with me. I've watched my friends with their families and I know it's weird for my parents to treat me like an equal partner. *But I'm 14 now*, I have to remind myself. I'm not a kid anymore.

My parents weren't as excited as I was about the undiagnosis angle. They didn't think it was a revelation at all and had no interest in connecting with undiagnosed families, unless they could find a kid like Chloe. My mom was getting increasingly obsessed with the computer and would run to it as soon as

Chloe went to sleep at night. Facebook groups, listservs, message boards, parent blogs – she read it all. The doctors always told us not to do internet searches about Chloe's disability or health, saying it would scare us and give us bad information, but my parents never listened. Not my mom, at least. She just parked herself in front of the glowing desktop, often forgetting to turn on an actual light. Hunched over, legal pad and multi-colored pens to the right, wine glass to the left. I usually left her alone like that.

She'd been talking about it more and more recently. It was hard to discuss anything else at dinner, between my mom's internet investigations and Chloe's increasingly epic tantrums – her chair slamming up and down so hard that the lights flickered. I hardly ever got to talk about school or friends anymore with my parents. We seemed to be having more and more fights, although I couldn't tell you about what. Sometimes my parents remarked that I'd started acting like a teenager.

"So I found this mom in the U.K.," Mom was telling us one night over tacos. "Her son's background is similar to Chloe's, but we emailed each other pictures and they don't look anything alike."

Code words like background, condition, symptoms, experience, history. So many attempts to explain Chloe, who was sitting directly across from me. I listened, looking down and hoping the meal would end soon so I could go to my room and start my homework. We always looked down these days. No one made eye contact at home anymore. I hadn't noticed until a friend at school pointed out that I was doing it, too.

"And she thinks she knows another mom in Canada whose kid has similar facial features!" My mom is still talking.

“Oh, okay,” I managed to say. I wasn’t going to get my hopes up. I spent most of my childhood getting excited about whatever new therapy that was going to make Chloe like the rest of us, and nothing panned out. As a kid, it does something when you hear enough grownups say they’re going to make something happen and then nothing changes. Chloe never talked. We never really learned anything, but just moved onto the next possibility. At some point, I started to get exhausted by it all. I started saving my excitement for things I could control: grades, improving my running times, that sort of thing.

“Can I get up?” I asked. “I have an algebra test tomorrow.”

DIY

I’m in my room doing my social studies homework, memorizing the branches of the government.

“James!” My mom yells my father’s name suddenly from the office. Even though Chloe can’t hear, we never yell after bedtime. It’s rude.

“James! Come here now!” She’s yelling again, perhaps more forcefully than usual. I hear my dad make his way upstairs to the office. He takes his time. My mom’s kind of a yeller. It’s hard to know when to hurry.

“My God!” I hear him exclaim. What is going on out there? Uninvited, I open my door and walk down the hall. My parents are huddled over the computer. My mom is on Facebook. This is why they’re yelling?

“That’s her,” my dad keeps saying. “Dear god, that’s Chloe!”

They don’t even hear me. I peek between their shoulders and there she is. It’s not Chloe, but I have to pause. I’ve never mistaken my sister for anyone else in her entire life. She’s never looked like anyone else. But there it is on the

screen: another girl, probably a few years younger, longer hair, slimmer eyebrows, but otherwise the resemblance is striking, right down to the coloring. That could be Chloe.

My mom fills us in. It's been a week since my mom first mentioned swapping photos with the woman in Britain, who then put her in touch with the mom in Canada. She and my mom started Facebook messaging each other – questions, descriptions, medical details. Sharing the personal stuff doctors have to keep secret, the things I could recite in my sleep.

"This is how the other mom did it, too!" my mom is saying. "This is how she found her daughter's diagnosis! She told me about the message boards, how she met a mom over her blog and that mom put her in touch with a woman in Ireland…"

I'm staring at the screen. Who is that? SETD4. SEDT4.

"It's all so DIY," my mom says. "That's what the mom said and she was right! Do-it-yourself, I swear. After all these years, all the doctors and tests! Facebook! Can you believe it?"

I can't stop looking at the picture. That's Chloe. It's not, but it is.

We're suspended in this moment of change. The air is gone from the room. My mom is still in front of the screen, her face inches from the monitor as she clicks through photos of the girl. My father leans over her balancing his weight on the back of the old wooden chair, just staring at the screen.

"I never imagined…" he starts to say, more a whisper to himself than anything, but then he trails off.

SETD4. SETD4. Undiagnosed, but not on our own. We are not the anomaly. Not the only ones. There is at least one other Chloe. And that means there are more.

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