

Anatomy of Care

Exploring Direct Support Work through Autoethnographic Fiction

by

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Abstract

In this project, I present a novella, which is constructed as a piece of autoethnographic fiction rooted in my experience working in a waiver home in rural Indiana. A waiver home is a kind of residential setting with twenty-four-hour staffing, in which one to five people live who have intellectual disabilities, and, in some cases, physical disabilities as well. The purpose of this project is twofold. The first purpose is to produce a piece of fiction that portrays honestly the experience of people who work in waiver homes in rural Indiana. The second purpose is to provide a close reading of parts of the fiction using preexisting theory, in order to demonstrate the role power plays in the dynamics of waiver home life.

The structure of this project is as follows. I discuss how I came to write this piece of fiction, first in a “General Background” section, then in more detail in the literature review, where I also introduce the texts I utilize in the analysis. Following the literature review, I discuss my personal positioning in relation to the issues and topics I discuss and explore in this project. Then, I present the piece of fiction. Following the piece of fiction, I analyze the role of bio-power, risk, and emotion in the fiction. Following the analysis, I present a reflection on notable issues not explored by this project.

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Dedication

This work is dedicated to my two siblings, without whom I would not be who I am.

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General Background

The idea for this project came about after months of reading about inclusion and because of a desire to write about the experience of people who provide direct support to people with intellectual disabilities. It was not until I read Michael Angrosino's book, *Opportunity house: Ethnographic stories of mental retardation*, that the idea of the project began to take shape. Within the realm of disability research, I have found nothing like Angrosino's book. In it, he uses the experience of spending years observing a group home as a researcher and volunteer to offer up a fictional account that is also "an ethnographic portrait of life in the OH [abbreviation of 'Opportunity House,' the pseudonym Angrosino gives to the group home] community" (Angrosino, 1998, p. 41). He accomplishes this through "the creation of composite characters, the invention of situations in which those characters can act and interact," which, without revealing "specific details that might tie the story to any one identifiable" person, enable Angrosino "to get at the truth of [his] experience with the OH clients, as well as the truth about their own experiences in the world" (Angrosino, 1998, p. 41). This is why his work constitutes 'ethnographic fiction.' In "Telling Tales? Using Ethnographic Fictions to speak embodied 'truth,'" Kay Inckle describes "'ethnographic fictions' as a strategy of representation," enabling one to re-write real "experiences, and real people...into carefully crafted themed vignettes each of which deals with a specific issue" (Inckle, 2010, p. 37). This method allows Angrosino to "cover all the traditional ethnographic

bases” of saying “something about the setting, how people earn a living, how they structure their familial and friendship networks, how they relate to the wider society, how they seek meaning in their lives,” and while the fictionalization does provide privacy for the people Angrosino worked with, it also pulls the reader into intimate engagement with people perceived as an ‘other,’ namely those living in a specific kind of setting, i.e. a group home in the early 1990s in Florida, who have been systematically ‘other-ized’ both in their physical separation from other communities and by narratives and assumptions about people with intellectual disabilities (Angrosino, 1998, p. 41).

Angrosino’s book was published in 1998, and the experience of people with intellectual disabilities is now, in many ways, very different. One can even see from the title of his book that it comes from a different era, with its use of the word, “retardation,” a word once commonly used as a diagnostic term, which is now, in 2020, a slur associated with dismissal of a person’s value or personhood, with bullying, and even with emotional and physical violence.

With this thesis, defended in 2020, I aim to follow in Angrosino’s footsteps, providing readers with an intimate engagement with people who are still often perceived as ‘other,’ and with those who support them. Like Angrosino’s book, the core of my work here is a piece of fiction. However, my relationship to the fiction-writing and the form of the fiction diverges in the following ways: (1) my fiction is written from my experience, which is more intimately connected to my subject matter than Angrosino’s was; (2) my fiction takes the form of a novella, rather than a collection of short stories; and, (3) I focus more than Angrosino does on the people who work with people with intellectual disabilities.

While Angrosino collected data by going into the realm of support environments for people labelled with intellectual disabilities as a researcher, with the aim of producing ‘research,’ I draw from my experience with and adjacent to the same support environments. I worked as a direct support professional (DSP) in an array of environments both before and after I began my Master’s studies. In fact, I currently work as an independent contractor providing DSP services to two individuals, with my work overseen by a service provider. Likewise, there is an even more personal component for me than my work experience. My two siblings are people with intellectual disabilities and they both receive support services. To clarify, “Direct Support Professional” is the title most commonly used to describe those who work with people with intellectual disabilities, and from here on out I will be referring to this position by its acronym, “DSP” (The Arc, 2020).

Certainly, as I have direct connections to this field as a worker and family member, I am arguably at a disadvantage when compared to Angrosino, in that I do not see the lives of people connected to support work from an exterior, observational view, that is to say, a strictly anthropological view. While, on the one hand, this is a disadvantage, it is, on the other hand, an advantage, because I can offer a more intimate view of someone affected as a worker and as a family member of individuals supported by DSPs. I know the way lips are sealed and attitudes adjust when someone from the outside—be they a researcher, government official, or medical professional—comes to observe a support work environment, and with confidence, I can guess the sort of cop-out, by-the-book public relations answers I would be given if I went and interviewed people who work as DSPs. I can “guess” about these answers, because in every setting I

have worked in, I have seen the shift in mood inside a room of DSPs and managers when ‘someone from the outside’ comes in to observe or ask questions. To be clear, in most cases, this response is rooted in DSPs and managers feeling intimidated or fearful that something unpredictable will occur in the presence of such a person, whose opinion might impact the career security of DSPs and managers. Drawing on my experience, I can report extensively on the state of things in these settings when there is no one asking questions or observing. I can offer insight by re-constructing my experiences in the field and conversations with co-workers into fiction that conceals identities while communicating truth in an affecting way.

The methodology I turn to is thus not ethnographic fiction, like Angrosino, but autoethnographic fiction, the autoethnographic aspect being “an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno)” (Ellis et al., 2011, p. 273).

Autoethnography seems especially useful to turn to since it is a methodology that acknowledges that “people occupy multiple roles and interact in diverse social spaces” (Jensen-Hart & Williams, 2010, p. 451). My experience as a DSP span multiple organizations and settings—group home, personal homes, waiver homes, day programs—so it is imperative that I utilize a flexible methodology that is responsive to elucidating various sorts of interactions across many spaces and roles, while still remaining coherent. Since autoethnography “accommodates subjectivity, emotionality, and the researcher’s influence on research, rather than hiding from these matters” it seemed a fitting methodology to couple with fiction, as Angrosino couples ethnography with fiction (Ellis et al., 2011, p. 274).

My approach to engaging theory and fiction together is grounded by the stance Stacy Holman Jones takes in her piece, “Living bodies of thought: The ‘critical’ in critical autoethnography.” She writes:

Theory asks about and explains the nuances of an experience and the happenings of a culture; story is the mechanism for illustrating and embodying these nuances and happenings. Because theory and story exist in a mutually influential relationship, theory is *not* an add-on to story. We cannot write our stories and then begin the search for a theory to “fit” them, outside of cultures and politics and contexts. Instead, theory is a language for thinking with and through, asking questions about, and acting on—the experiences and happenings in our stories.

(Holman Jones, 2016, p. 229)

As I formulated the basis for this thesis as a whole and developed the ideas that ground the novella, I did so while interacting with theory, the specifics of which will be outlined in the literature review below. As I journeyed through various theoretical works about inclusion, this project solidified, and as I wrote my fiction, I did not seek out theory to “fit,” but instead let the fiction arise from a conversation between the theory I was reading and my experiences.

Just as selves are complex blends of identities, writing itself is “a complex blending of various voices and is always partial and situated,” so it is vital I provide the context of who I am and from where it is that I come to be writing (Jensen-Hart & Williams, 2010, p. 452). This is why I present my positioning in relation to the topics covered in this project in the section directly before the novella. Before I do that,

however, it is important to continue discussing the methodological and theoretical backdrop of this project in increased detail with a literature review.

Literature Review

This is a detailed walkthrough of the literature that serves as the methodological and theoretical background of the project. It is a map of my intellectual journey, which is to say a demonstration of how the literature responded to the questions I initially asked, as well as how the literature re-oriented my direction throughout this project's development. Not included are the articles and books I read along the way that, while likely of some, less traceable influence, do not make up any substantial part of the theoretical or methodological basis of the project. This literature review is in eight segments: (1) Notes on dismodernism; (2) notes on normalization; (3) thinking with theory about inclusion; (4) thinking with theory about power; (5) thinking with relational geography; (6) thinking with other research about people with intellectual disabilities; (7) thinking with autoethnography as methodology; and, (8) thinking with fiction in an ethnographic context.

Notes on Dismodernism

I wish to start with a theory I encountered before I began formulating the idea of this project, because it guided me throughout the research process. I approach my memories, experience, research and analysis with Lennard Davis' theory of

dismodernism always floating somewhere in my mind. This theory positions all subjects as “disabled, only completed by technology and by interventions” (Davis, 2013, p. 275). The argument behind this claim is rather intuitive once one starts to think of all the supports in the world individuals require, whether they have a disability or not. Davis’ insight extends the concept of disability to include everyone by recognising that all people are intertwined with supports, pointing out that, “as the quadriplegic is incomplete without the motorized wheelchair and the controls manipulated by the mouth or tongue, so the citizen is incomplete without information technology, protective legislation, and globalized forms of securing order and peace” (Davis, 2013, p. 275). I do want to step back from this to comment on his use of “incomplete,” though, with a note. This view he puts forth is not an argument regarding human value, in that, this ‘incompleteness’ is not meant to devalue any aspect of being human, but rather to call attention to the situation of humanness, which is in fact, always in relation to supports. There are many ways to call attention to this. Certainly, it can be done in broad strokes like Davis does in terms of relating the experience of being quadriplegic to the experience of a citizen more generally, but it can also be done in smaller ways that might more clearly evince his point. For instance, in the way that a sighted person might use a flashlight or overhead light to navigate a dark room and a person who does not see visually might use a service dog or cane to navigate the same room. Fundamentally, Dismodernism is a call to be conscious that support is support, and everyone’s need for it is a fact of living. Being conscious of those supports enables one to see how measuring human value hierarchically in terms differing needs is misguided. Dismodernism asks everyone to de-

couple the idea of differing needs and human value, and instead recognise that human value is inherent to every person equally.

Dismodernism flows throughout my thinking and this project, opening the space for it in some sense, because it serves as the beginning of breaking down lines of demarcation, in its case, between ability and disability, need and (imagined) lack of need. This project arose out of a desire to speak from as close to an un-demarcated space as possible, to write a novella that blurs categories in the same way that lived experience always blurs the categories that are imposed on it. One way this desire directly influenced the novella is in how I approach portraying the DSPs. A huge component of my depiction of DSPs in *Anatomy of Care* concerns how much they need support, and how often they fail to receive it. Additionally, how these DSPs' needs affect the quality of the support they can provide, especially when that need is inadequately met, or not met at all.

From dismodernism, I move to address inclusion, which, through theory, I find to be dependent on a maintenance of demarcations, namely, 'inside' and 'outside.' These demarcations reinforce the separateness of spaces of intellectual disability—like waiver homes, group homes, and special education classrooms—from the rest of a community. Wanting to avoid reinforcing such separateness, I turn to my own experience related to spaces of intellectual disability, which spans several contexts. I take my experience as an in-between node that has floated throughout several kinds of spaces of intellectual disability. I call on the help of articles about methods of autoethnography to think through the validity and mechanics of conceptualizing the 'data' of my experience. However, ultimately, it was the existence of Angrosino's *Opportunity house: Ethnographic stories of mental retardation* that afforded me the initial permission to

delve into the realm of fiction, when I was still deciding on what methodology to utilize. The detailed reasoning for the utilization of fiction is fully fleshed out in the fifth section of this literature review, “Thinking with fiction in an ethnographic context,” but I can offer here a brief summation of the reasoning here. First, that there are ethical concerns with writing explicitly about past experiences involving other, real individuals, from whom I could not, in this present day, request consent. Secondly, that much of what I want to communicate about my experience of spaces of intellectual disability is served by fiction’s ability to place the reader in a visceral and nuanced relationship with an issue.

Notes on Normalization

A key facet of theory about people labelled with intellectual disabilities is the concept of ‘normalization.’ The seminal work on ‘normalization’ is *The principle of normalization in human services* by Wolf Wolfensberger. Wolfensberger defines ‘normalization’ as the “utilization of means which are as culturally normative as possible, in order to establish and/or maintain person behaviors and characteristics which are as culturally normative as possible” (Wolfensberger, 1972, p. 28). This, in my experience, takes many forms in a direct support context, but most explicitly in behaviour tracking and goal-setting. For instance, in Indiana, where I worked, every ‘client,’ no matter whether they live independently, with family, in a group home, or in a waiver home, has a goal related to money that the DSP who works with them is supposed to facilitate their progress in. The goals take many forms, but often have something to do with buying an item at a store or being able to acknowledge different values of currency. This gets at

Wolfensberger's another key point: that "the normalization principle is culture-specific" (Wolfensberger, 1972, p. 28). This is to say that often the way that normalization manifests in care and support settings reflects the values and ideologies of a culture. In the Midwestern United States, the prevalence of money-related goals set for clients reflects the high value the Midwestern United States places on the exchange of currency and participation in a capitalist marketplace. This also speaks to Wolfensberger's claim that normalization itself is a "neutral" concept, since it can function in any societal and cultural context (Wolfensberger, 1972, p. 28).

It is important to note that a society's values are reflected not only in the type of action in which a service provider is attempting to include a person labelled with intellectual disabilities, but also in the way this is actually practiced. This is to say that a society may in some cases offer "normalizing measures," but in other cases *impose* measures, and where, how, and why these are imposed, or offered, speaks volumes about a society's values (Wolfensberger, 1972, p. 28). This rings true as I recall my experience working as a DSP and my siblings' interactions with their DSP, and how different "normalization measures" manifest.

Thinking with Theory about Inclusion

I began this project with an interest in understanding something about inclusion. Specifically, I wanted to understand what an experience of inclusion or exclusion was like for adults with intellectual disabilities who receive support from DSPs. This was motivated by my experiences as a DSP as well as having siblings with intellectual

disabilities, who are adults now. Despite spending my whole life in the company of people with intellectual disabilities, I did not feel I understood the contents of the experience of being included or not included in “society,” at large. What took one over the edge, from feeling excluded to included? Defining this for any population is exceedingly difficult. The language that I had as I tried to parse my lack of understanding was shaped by hearing the word “inclusion” used in public, private, corporate, political, and philanthropic contexts. This word shows up in daily life often, even if one does not spend a great deal of time amongst people with intellectual disabilities. To be clear, I was not interested in directly looking at ways to increase or decrease inclusion, but rather, I wanted to know what it *felt* like for someone with an intellectual disability to move from a feeling of *being* excluded to a feeling of *being* included. From that sort of knowledge, I figured policy endeavours aiming to increase inclusion would flow more naturally and easily than they do now. But first, I had to set about figuring out what inclusion *is* in order to even find a place to start to look at what it felt like to be held within it. This is where I encountered the contentious, cobbled-together centre that exists where I thought I would find definitive meaning.

As I sifted through journal articles and books about inclusion, I came across a piece that shook my assumption that inclusion was, ipso facto, something good. Fiona Kumari Campbell’s “Re-cognising disability: Cross-examining social inclusion through the prism of queer anti-sociality” links “inclusion” to “ableist norms” by arguing that “the working model of inclusion is really only successful to the extent that people with disabilities are able to ‘opt in’ or be assimilated through being countable, categorisable, rehabilitatable and employable” (Campbell, 2013, p. 213). Given this, Campbell

advocates for something more radical than an attempt at changing culture and society to make them more inclusive, instead arguing for “a focus on anti-sociality” in order to “expose and rupture the discursive effects of disability toleration,” which would promote a “terrain that is anti-social” and a “reclaiming of a disability style” (Campbell, 2013, p. 238).

Campbell’s Anti-sociality is an overt expression of frustration with the underlying and unwavering nature of the manifestations of ableism in cultural, social and political systems. Campbell argues that “the project of inclusion has become conditional and normatively vacuous,” because over and over the project manifests in society being obsessed with “the capacity of disabled people to morph abledness” (Campbell, 2013, p. 237). With anti-sociality, Campbell is engaged in calling out the project of inclusion for valuing the assimilation of people with disabilities into an ableist society more than it values actual people with disabilities. Anti-sociality is both the stance from which that calling-out takes place as well as the response to the project of inclusion, which is to be “conscientious objectors” who “refuse complicity with a system that creates a permanent underclass of the excluded and exacerbates secondary and corrosive forms of impairment” (Campbell, 2013, p. 238). The force of Campbell’s rejection of inclusion is striking here, but perhaps even more striking is the way that she links a rejection of it with powerfully positive language, from the creation of “a disability style,” to, even more sweeping, opening up the possibility of “an outlaw flowering of beingness” amidst an anti-social stance (Campbell, 2013, p. 224).

Being that her article is a theoretical piece engaged in a radical re-framing of the project of inclusion, Campbell is in new, vague territory, for anti-sociality is

fundamentally the life people with disabilities might have by utterly rejecting ableist society. This amounts to an expression of a possible reality manifested out of resistance, rather than a concrete idea. Campbell's position is a radical theoretical stance constructed in a negative space oriented against the project of inclusion, however, at the very least, it forces one to consider potentially serious pitfalls of inclusion as a concept and project.

Before reading this piece, even amidst my confusion about the nature of inclusion, I thought that if nothing else, striving for inclusion, whatever it is, was an unequivocally good thing to do, even if only as an idealistic pursuit. But in encountering Campbell's rejection of inclusion and furthermore her suggestion that the rejection of it could be so forcefully positive as to have an almost world-creating force, I called entirely into question whether, even in some ideal form, inclusion was something I should view as positive. Having been introduced to this foundational line of questioning, I set about to read more pieces that unpack the concept of inclusion, hoping to figure *something* out definitively about inclusion. Instead, what I found was that cutting deep into the concept of inclusion reveals a hollow interior.

The work that introduced me to inclusion as having a hollow interior—that is to say, being a vacuous concept—is the essay “An illusory interiority: interrogating the discourse/s of inclusion” by Linda J. Graham and Roger Slee. This piece is grounded by an intuitive revelation “that the term inclusion...presupposes a whole into which something (or someone) can be incorporated” (Graham & Slee, 2008, p. 278). To the extent to which inclusion assumes this interior that is whole, it implies “centred-ness” that “discursively privileges notions of the pre-existing by seeking to include the Other into a prefabricated, naturalised space” (Graham & Slee, 2008, p. 278). This brings up

questions, then, about how this “centred-ness” gets constructed, and what does this construction *do*?

Graham and Slee point out that, first, individuals, types of individuals, and aspects of individuals that are exterior to the presumed interior are marked “through normative practices that identify and make visible differences as forms of alterity,” namely, “through the *normalisation* of culturally specific performances as particular expressions of academic, physical, creative ability; and the *naturalization* of particular ways of being which are characterised by whiteness, maleness, ablebodiedness and so on” (Graham & Slee, 2008, p. 285 emphasis in original). Graham and Slee then go on to argue that the concept of inclusion and the enactment of policies rooted in it serve to maintain the lines between what is constructed as normalised ways of being and non-normalised ways of being. They describe the process of this maintenance by citing Derridian ideas about how “the desire for a centre...leads to the supplementation of a central signifier which is played off against other signifiers in a system of differences” (Graham & Slee, 2008, p. 285). Their point here is that everything to do with inclusion starts with a desire for that centred space, which is implied by the term, and without that space, the term is hollow, and because the space is not a priori present, it must be manufactured. In order for the manufacturing of the centre to happen, everything flows from the desire to constantly reaffirm the binary of inclusion/exclusion. What flows from this is a web of solidifications of binaries that act to privilege one side of the binary, e.g. ablebodiedness/non-ablebodiedness, maleness/non-maleness, whiteness/non-whiteness, etc. Part of what is at play here is that the privileged side of the binary is specific, and thus constructing, implicitly or explicitly, the inside of inclusion—an inside which is

supposedly “the norm”—as a narrow space, where even an effort to move someone into the inside is an act that reaffirms the privilege of that specific, narrow space of “the norm.” In this way, the desire for inclusion is part of a broader metaphorical machine at work in culture and society that maintains the lines of difference as real and legitimate, reinforcing those lines over and over again. The fact that such a vast machine is required to maintain these lines speaks to how arbitrary the lines themselves are, in that they take natural human diversity and attempt to map hierarchies of value on top of that diversity via those lines.

The idea that inclusion is bound up in “the norm,” its centre manufactured *and* bound up in the maintenance of that centre, reveals that inclusion is something like a closed system, or as Graham and Slee refer to it, “a man-made grid” (Graham & Slee, 2008, p. 281). This is made clear through recognition that “the norm” is a system of binaries born out of the desire for a centre for inclusion that then presumes to justify the existence of the term and concept of inclusion, because having a centre enables a ‘call to action’ to draw individuals into that centre. The obvious circularity of this is why I use the term “closed system;” one could just as easily call it tautological, circular reasoning, a snake-eating-its-own-tail situation. This closed system should have no bearing on reality because it is utterly manufactured (and perpetually re-manufactured), and utterly unhinged from any fixed principles or materiality. The concept of inclusion is instead a chaotic force of governance embedded so deeply in the fabric of society, one imagines it almost as omnipotent in its diffuseness. Graham and Slee refer to the idea of the “norm” being “a fiction,” yet still functioning as “a man-made grid of intelligibility that attributes value to culturally specific performances and in doing so, privileges particular ways of

being” (Graham & Slee, 2008, p. 281). What this all comes down to for Graham and Slee is that “normalised ways of being” are “naturalised” through the “naming of the other” and through a performance of facilitating their inclusion toward the inside of those more normalised ways of being (Graham & Slee, 2008, p. 279). The conceptual fragility of “the norm” should be quite clear by now since it is, in fact, a vacuous concept, held in place only through an active dance of signifiers explicitly and implicitly acting upon and through individuals, sustained in the signifiers’ relation to one another rather than by actual attributes of those individuals. This dance is the “maintenance of notions of normalcy” (Graham & Slee, 2008, p. 289).

After their visceral deconstruction of inclusion, Graham and Slee argue that instead of continuing to aim for inclusion as any sort of goal, there should be a redirection “to disrupt the construction of centre from which exclusion derives” (Graham & Slee, 2008, p. 279). However, they make the point that this cannot be in the form most often taken of looking to “the excluded,” because that makes “visible the conditions of exclusion by pointing to exceptional characteristics as markers of difference” and this results in what they refer to as going “around in circles,” in that it trades on characteristics of difference that have had superimposed upon them a positioning of different to an intangible, unreachable, “ideal” and the vacuous “norm”.

Graham, in another piece, entitled “Caught in the net: A Foucaultian interrogation of the incidental effects of limited notions of inclusion,” elucidates the relational aspect of the maintenance of the norm via policies and rhetoric about inclusion by noting that “policy and discourses act as interdependent domains of intelligibility” (Graham, 2006, p. 5). In this piece, Graham suggests what can be done with the knowledge that the norm is

maintained through the interaction between discourse and policy, and how to dig deeper into what the significance of that is. She argues that, ultimately, given the “innumerable separate localizations” of inclusion policy and rhetoric, it first comes down to studying *practice*, and what happens as a result of practice (quoting Dreyfus & Rabinow, 1982, p. 187 Graham, 2006, p. 5). This is to say that it is of no use to engage in a “witch-hunt,” for it is unproductive to locate in individuals the issues that come about through cultural discourses and the “disciplinary technologies derived from complex power relations” (Graham, 2006, p. 5). Rather than focusing on individuals or intentions, Graham suggests focusing on what the incidental effects are of practices aimed towards inclusion (Graham, 2006, p. 5).

An important point to note in the critical discussion about inclusion is one made by Roger Slee and Julie Allan in “Excluding the included: A reconsideration of inclusive education.” In it, they write that there is “a tendency to mythologise the present as progressing towards some idealised inclusive state, with statements like ‘not yet there’ or simply moving ‘towards inclusion’” (Slee & Allan, 2001, p. 180). This is a significant point because it highlights the way that rhetoric and policy rooted in issues of inclusion are self-perpetuating. The present is positioned as the precursor to something ideal, *if* current policies and rhetoric are taken to their end in an imagined future, there is justification for a continuation along the paths we are presently on, the policies and rhetoric we currently live with. In a sense, it is a veiled threat against questioning the status quo of current ideologies and practices linked to what we call inclusion.

Graham’s piece, the piece by Graham and Slee, and Slee and Allan’s piece were written with the context of education in mind, but I found their points almost entirely

translatable to spaces that DSPs occupy, i.e. group homes, waiver homes, day programs, and ‘out in the community.’ Graham calls for a nuanced look on the ground as to the effects of policies linked to inclusion in educational contexts, but a look at residential contexts, like waiver home is important, too, if only for the simple reason that many people with intellectual disabilities who go through the education system eventually end up in residential settings.

When I read these pieces, I thought about the issues of visibility, awareness, and access, and how they relate to both special education and residential settings. With their call to take an on-the-ground, nuanced look at spaces governed by policies that use the language of inclusion, it becomes clear that commencing such a ‘look’ is a matter of looking at those lives governed by such policies, inside and outside of those spaces, as well as looking at the lives adjacent to them, including those of staff and family members.

Thinking with Theory about Power

I ended the previous section of the literature review by discussing what Graham suggests researchers do about the idea that inclusion—the principle that presently undergirds most policies and practices regarding people with intellectual disabilities—is fundamentally flawed. Fundamentally, Graham suggests ‘looking,’ to see what effects the policies and practices have, but it is incredibly important to know *how* to look. The rest of this literature review is dedicated to thinking through theory and methodology to help us

understand how to do the looking. The piece of theory to look at to help us is theory about power.

In Gilles Deleuze's text on Foucault, aptly titled, *Foucault*, he writes that "centres of power and disciplinary techniques form multiple segments, linked to one another which the individuals...traverse or inhabit" (Deleuze & Hand, 1988, p. 27). The important point here is that an individual does *not* possess power; rather power is something an individual moves through or walks inside of, almost like clothing. It is an odd metaphor, I admit, but think about how an outfit carries with it a force to affect those who see it or feel its fabric. An outfit is more than the sum of its parts and more than the sum of its wearer's parts. The individual is also not simply a vessel walking about with a static, transcendent signifier of a *kind* of outfit that happens to have picked their body. Rather, the individual is in a relationship with that outfit, though the summation of the outfit and the individual. The effect of them together is irreducible. Just as the individual with an outfit on is an utterly individual, irreducible series of strata of relations, so power, too, is "without transcendent unification, continuity of line without global centralization, and contiguity of parts without distinct totalization" (Deleuze & Hand, 1988, p. 27). Power is more than the sum of its parts—those individuals who perpetuate its structures—yet articulating a wholeness or "unification" of power also eludes the researcher or theorist. This elusiveness and lack of unification sends one looking at individual interactions for the functions of power.

Thinking with Relational Geography

It is not only power that functions in a relational way. Space itself, according to relational geography, as it is outlined in Edward Hall and Robert Wilton's piece, "Towards a relational geography of disability," is "made up of relations" with "bodies (both impaired and non-impaired), objects and spaces engaged in shifting relations that have the capacity to produce both exclusionary and/or enabling arrangements" (Hall & Wilton, 2016, p. 728). This is the case both at the structural level and at the level of interactions between individual people. Hall and Wilton express this, specifically, through "the shifting nature of formal care assemblages in...Western countries," of which waiver homes are a part (Hall & Wilton, 2016, p. 734).

They point to the fact that "outsourcing and downgrading of publicly funded care provision...has shaped relational contexts in ways that limit what bodies—both those of recipient and provider—can do" (Hall & Wilton, 2016, p. 734). Specifically, they point to "limited support hours" for people with disabilities in need of services and note that the work done by DSPs is "precarious work" (Hall & Wilton, 2016, p. 734). The precariousness is due to many things: inconsistent hours; physically intensive work, such as assisting in moving someone's position in bed; and poor access to healthcare in the context of contract DSP work in the United States. Thus, one can see how these structural issues directly affect the opportunities of individuals in the context of direct support work, both for the workers and those receiving support.

A granular way of looking at issues through a relational geography lens is with what Deborah Lupton describes as the "emotion-risk assemblage" in her article, "Risk

and emotion: Towards an alternative theoretical approach.” Lupton takes a cultural geography perspective on emotion, proposing that emotions are “produced through shared understandings and past experiences” and demonstrates how this way of discussing emotion is interwoven with the idea of risk (Lupton, 2013, p. 636). The way emotion is interwoven with risk reveals itself when the mechanics of risk are unpacked. “Rather than a realised threat or danger,” the mechanics of risk are “about projecting ideas into the future, about imagining the consequences of an action or event” (Lupton, 2013, p. 638). Thus, rather than risk involving an interaction with a fixed and certain reality, this imaginative element pins risks as “always virtual, in the process of becoming” (Lupton, 2013, p. 638). This leaves risk in a highly subjective space where what gets labelled “risk” is “influenced by the social and cultural context and by personal experience, including the embodied sensations that are defined as ‘emotions’” (Lupton, 2013, p. 638). This interweaving of risk and emotion leads to Lupton’s “terminology of the ‘emotion-risk assemblage,’” which allows for “a productive way of thinking through the complexities of risk and emotion” (Lupton, 2013, p. 639).

Lupton most directly pulls in aspects of relational geography when she explicitly connects this emotion-risk assemblage to embodiment. For Lupton, and others involved in projects of relational geography, “embodiment is never individual” (Lupton, 2013, p. 639). Rather, emotion, which is an aspect of embodiment, takes “place within and around the body as it moves through space and interacts with other bodies and with objects” (Lupton, 2013, p. 639). Given the emotion-risk assemblage, for Lupton, “just as emotion is both embodied and interembodied, so too is risk” (Lupton, 2013, p. 639). The easiest example I can think of to demonstrate this assemblage is the experience of a dog running

towards someone. To a person with a history of positive associations and relations with dogs, this is an experience where the person *feels* no risk. Whereas to another person, who perhaps as a child was attacked by a dog and has never lived with a dog, the dog running toward them causes them to *feel* risk. They project themselves into the future in an emotive and imaginative mode, seeing and feeling the possibilities of being attacked, and weighing those possibilities with the possibilities for a positive result. This stark contrast in felt reactions demonstrates how bound up risk is in emotion.

Thinking with Pre-existing Research about People with Intellectual Disabilities

Jack Levinson's book on group home life, *Making life work: Freedom and disability in a community group home*, details several specific points about the way life is governed in residential settings that helped me think through my experiences in and adjacent to residential settings and ultimately aided in synthesizing those experiences into *Anatomy of Care*. An overarching idea in Levinson's book is that residential settings for people with intellectual disabilities are structured in a way to construct selves. This is expressed through residents being sometimes subtly and sometimes not so subtly directed to "govern themselves according to an ethic of autonomy that requires them to take their own selves actively as objects of work" (Levinson, 2010, p. 246). Understanding this shines light on the way authority functions in a residential setting through "work," since "authority is not simply exercised in opposition to the autonomy of individual residents," but rather is exercised in the service of creating "conditions in which individuals may conduct themselves freely in particular ways" (Levinson, 2010, pp. 246, 39). Levinson

refers to this as the setting and authorities structuring “the possibilities for action” (Levinson, 2010, p. 39). Here, Levinson is using Foucault’s concept of “bio-power,” to distinguish between different ways power functions, bio-power being the indirect mechanisms through which a person, system, or cultural ideas of well-being are deployed to exert control over “the actions of others... through the protection and enhancement of individual health, happiness,” with more direct forms of power deployment being “crushing” the individual through overtly “compromising the aspirations and ideals of individuals” (Levinson, 2010, p. 39). At play in the very construction of the residential setting as a valid entity and in much of the way it is governed is bio-power, for its justifications are, for example, often that this is the ‘best place’ for so and so, or that its existence is in response to the awful treatment once deployed at a now defunct institution.

The book that further solidified for me why my experience should be the starting point for examining any of these issues is *Living otherwise: Students with profound and multiple learning disabilities as agents in educational contexts* by Duncan P. Mercieca. In responding to the deconstruction of inclusion by Slee, Graham, and others—which I have already referred to—Mercieca writes of inclusion in a different, but, I think, productive and positive way: specifically, in terms of locating inclusion within oneself. With the constructed-ness of exclusion and inclusion in mind, Mercieca re-writes a metaphor for inclusion originally conceived of by Deleuze, but in his re-writing, Mercieca refocuses it in relation to disability. This “metaphor is that of someone who starts learning how to swim,” where the water is “a system of different relationships” (Mercieca, 2013, p. 153).

In learning to swim, “does one practise on the side of the pool and mimic arm strokes and feet movements rather than jump into water?” ; of course, the answer is that, at some point, this is of no use (Mercieca, 2013, p. 153). Eventually, one must “jump into the water without knowing how to swim in order to learn how to swim,” and the metaphor unfolds as this being “the only way one learns about the unfolding other of the other,” the “other” here being *any* other consciousness outside of one’s own, and that “this is how one learns about inclusion of the self” (Mercieca, 2013, p. 153). One jumps into the presence of other selves as one jumps into the sea “and the body movements of the sea form an interactive system of motion, a different relation and singular points that extend across swimmer and sea” (Mercieca, 2013, p. 153). Mercieca collects these descriptions of learning to swim into the sentiment that the learner in the water “becomes an apprentice in the process of learning how to swim” (Mercieca, 2013, p. 153). This marks learning how to swim as “a creative act” that is interactive, between the learner and the water (Mercieca, 2013, p. 153). In relating it to a person jumping into a place constructed as Other place, he describes the experience of working for the “inclusion of the self” as being an “apprentice of experiences,” attending to other selves as well as ways they are constructed in terms of location and types of categorization, but also focusing as much as possible on fostering a relationship of self meeting another self, and that done in earnest there is a possibility for “a shared deterritorialization,” where what is constructed, i.e. that which marks territories of place and types of being, can fall away as much as possible, and two or more beings can be somewhere, responsive, together (Mercieca, 2013, p. 153).

Reading Mercieca, I am convinced of the value of becoming an “apprentice of experiences” that I had in residential, home, and day program settings I worked in with people labelled with intellectual disability as well as the experiences I had in my personal life, living with and intimately connected by familial bonds with my siblings. Being true to that apprenticeship means synthesizing those experiences in some way. Furthermore, it is important to remark on Mercieca’s emphasis on resistance to “majoritarian discourse,” about people with intellectual disabilities. One way to do this is to openly situate oneself in relation to specific experiences of specific people and places, without claiming the possibility of generalizability (Mercieca, 2013, p. 140). After encountering Mercieca’s ideas, I found myself drawn to autoethnography as a way of openly unpacking my experience, yet not claiming it as generalizable. To say that in describing one residential setting, day program setting, or family setting where one or more members is a person with an intellectual disability, one *knows* anything about these settings generally is assumptive, for it neglects the uniqueness of people and circumstances. However, in deeply looking at settings from one vantage point one *can* unveil lines of questioning.

Thinking with Autoethnography as Methodology

It became clear in reading work on autoethnography and ethnography that I could not merely describe what I saw or experienced coldly, as a detached observer floating through my memories, taking and relaying notes. Rather, I needed to think and write with the words of Brett Smith and Andrew C. Sparkes in mind, that in disability studies there is a need for an “artful, poetic, evocative, empathetic, multi-voiced social science in

which meanings stay open and writers and readers know not just the ‘facts’ in their heads, but can keep in their minds and feel in their bodies the complexities of culture, society and concrete moments of lived experience” (Smith & Sparkes, 2008, p. 24). It is of great importance to communicate the complexity of lives lived with intellectual disabilities, since often those lives are defined in terms of their relation only to services they receive or, more simply, being ‘helped,’ all the while their lives are as textured with complex emotional and physical states as anyone else’s. Narrative has a way of moving beyond categories, instead delving into lives, communicating the complex substances and “texture of people’s lives,” and thus is an invaluable “psycho-socio-cultural shared resource” (Smith & Sparkes, 2008, p. 18). Not shying away from the messiness of my experiences is essential.

Taking the words of Smith and Sparkes seriously, I considered the value of writing in a narrative form. Through “From living bodies of thought: The ‘critical’ in critical autoethnography,” I came to understand how theory and narrative can work together. In that text, Stacy Holman Jones writes that “theory and story exist in a mutually influential relationship,” and that neither is an “add-on” to the other, for “theory asks about and explains the nuances of an experience and the happenings of culture” and “story is the mechanism for illustrating and embodying these nuances and happenings” (Holman Jones, 2016, p. 229). It is rather fitting that I came to decide to write a novella rooted in my experiences while reading theory, because, as Holman Jones writes, “we cannot write our stories and then begin to search for theory to ‘fit’ them...instead, theory is a language for thinking with and through, asking questions about, and acting on—the experiences and happenings in our stories” (Holman Jones, 2016, p. 229).

In more broad theoretical terms, autoethnography carries substantial weight in its contribution to ethnographic literature. It is essentially a response to a movement in social sciences referred to as the “crisis of confidence” (Ellis et al., 2011, p. 273). In “Autoethnography: An overview,” Carolyn Ellis, Tony E. Adams, and Arthur P. Bochner detail how not only does autoethnography respond to the crisis of confidence that led to a questioning of objectivity in social sciences with an affirmation of the “complex, constitutive” aspects of human experience not served by broad, generalization-seeking social sciences, but also that the focus on individual, highly contextualised representations in autoethnography could be a resistance to an ever-present “exploiting” of “cultural members” to reinforce broad narratives that neglected to fully respect and represent the nuances of those individuals’ personal experience (Ellis et al., 2011, p. 274). Autoethnography responds to these issues by disrupting “the binary of science and art,” by being many things at once: “rigorous, theoretical, and analytical and emotional, therapeutic, and inclusive of personal and social phenomena” (Ellis et al., 2011, p. 283). These points by Ellis, et al., solidified for me that it was possible to rigorously engage in something that follows through with resisting the “majoritarian discourses” Mercieca refers to as the overwhelming societal and cultural representations of people with intellectual disabilities, by moving away from the generalizable folding of many individuals into statements about a category of people, and instead moving to writing about the intimate levels of their experience, through the researcher’s experience, so as to not claim to speak from *their* experience (Mercieca, 2013, p. 140).

Autoethnography runs into potential ethical issues that are similar to those of other ethnographic methods, since researchers “do not exist in isolation,” but instead are

“connected to social networks that include friends and relatives, partners and children, co-workers and students.” Thus, when writing explicitly about oneself, the work produced can implicate others (Ellis et al., 2011, p. 281). It is then necessary to alter “identifying characteristics such as circumstance, topics discussed, or characteristics like race, gender, name, place, or appearance” (Ellis et al., 2011, pp. 281, 282). However, with autoethnography generally, and my project, “the essence and meaningfulness of the research story is more important than the precise recounting of detail” (Ellis et al., 2011, p. 282). Given this, and the concern for privacy that leads to altering details, I move further into fiction.

Methodologically, within autoethnography, I look to narrative, presenting my project in the form of a story “that incorporate[s] [my] experiences into the ethnographic descriptions and analysis” (Ellis et al., 2011, p. 278). There are two primary reasons for this: (1) narrative serves well for creating an “accessible text,” increasing the possibility of reaching a “wider and more diverse mass audience that traditional research usually disregards;” (2) with narrative there is more room for creating a text that is “evocative by altering authorial points of view.” What I want to communicate about the structure of the spaces of intellectual disability that I have worked and lived within is well-served by pulling-out from exclusively reporting on experience of individuals to instead reflect on how aspects of the structure of these spaces affect individuals’ lives (Ellis et al., 2011, p. 277).

Thinking with Fiction in an Ethnographic Context

The first text I encountered that argued for using fiction in an ethnographic (or autoethnographic context) was “Telling tales? Using ethnographic fictions to speak embodied ‘truth’” by Kay Inckle, a text about seeking a methodology to “represent experiences of body-marking practices” that is both accurate and ethical (Inckle, 2010, p. 27). Two ideas ground Inckle’s reasoning to move beyond traditional social science methodologies into the realm of fiction: (1) “radical temporality” as it fits under “queer ethical practice[s]” in research; and, (2) her issues with representation and “the structures of knowledge which sustain them” (Inckle, 2010, p. 29). This first idea comes from the notion that much of social sciences works with the presumption that it is research engaged in setting the stage “for a future,” which more often than not, “ultimately, will never arrive,” and so queer ethics demands a shift into a “present-time responsibility” (Inckle, 2010, p. 29). This takes shape in a shift away from “abstract categories and the ideals of analytical tidiness,” to research that engages “the messy, complex and contradictory factors at play in human experience, as well as the essentially emotive, corporeal and intersubjective, visceral, sentient nature of our being” (Inckle, 2010, p. 35). Thus, “radical temporality” is essentially a move to write the complex present instead of writing in service of a potential future. Partly, this is due to research that deals in abstract categories being impoverished in its ability to represent anyone. Often, in trying to represent large groups of people, no one’s circumstance is individually well-represented. Likewise, her issue with representation is also that the structures of knowledge that undergirds representational research methodologies came to exist within “hierarchies of

knowledge which privilege hyper-rational, exclusively cognitive, and disembodied ways of knowing,” and the result of this is that these methodologies do not do well at examining or representing “the complexity and multilayeredness of...visceral, lived reality” and “bodily experiences” (Inckle, 2010, pp. 29, 30).

Inckle, then, argues that “‘ethnographic fictions’ as a strategy of representation” circumvents many issues with standard representational research methodologies as well as issues with “the entire, well-worn social sciences debates around ‘truth’, validity and objectivity” (Inckle, 2010, p. 37, 38). This is done in ethnographic fiction by stories that “draw on multiple ‘real’ experiences, and real people, but are re-written...[and] made up of “composite” “characters and events” so as to portray lived experience “without revealing any one particular identity or experience” (Inckle, 2010, p. 37).

Michael Angrosino goes into more detail about the merits and methods of ethnographic fiction in the “prefatory dialogue” sections of his book, *Opportunity house: Ethnographic stories of mental retardation* (Angrosino, 1998, p. 11). Angrosino’s book is a collection of short ethnographic fictions written in reference to a community of people with intellectual disabilities. Between his stories, he inserts sections of a dialogue between himself and one of his doctoral students, discussing the merits and methods of his work and of ethnographic fiction more generally. He follows similar logic to Inckle in decrying traditional methods of social science research as inadequate in their representation of large groups, describing it as “a fantasy,” that “we can step out of the picture and thus present a wholly objective portrait of culture-in-the-raw, culture-as-it-is-lived” (Angrosino, 1998, p. 32). However, as may be evident, his reasoning for why these broad, “objective” pictures are inadequate, is different from Inckle’s, who has a

fundamental issue with the structures of knowledge behind representational research methodologies. Instead, Angrosino is arguing that the researcher—the “we” in the previous quotation—cannot fully avoid influencing the research they do, in portraying a group of individuals who fall under a category and/or culture. Angrosino digs further into his critique of traditional social sciences methods by arguing that “academics tend to give more credence to the artificial boundaries they have set up to define disciplinary turf than they do to manifest content or intent of a piece of writing” (Angrosino, 1998, p. 98).

While this is certainly a critique of the methodological merits of traditional social sciences, he also argues that these traditional methods can do harm by going “overboard in ‘other-izing’ culture—treating it as an objective catalogue of traits that we need to discover, sort, analyze, and interpret” (Angrosino, 1998, p. 31). This going ‘overboard’ has the effect of focusing more on the lines of demarcation within culture(s) than actually delving into raw experience of individuals. Likewise, Angrosino recognises that these disciplinary demarcations are an “act of greater artifice” than speaking and writing in ‘literary’ styles, since, in fact, it is a ‘literary’ or narrative mode that defines “much of our ability to talk about ourselves” in life, in general (Angrosino, 1998, p. 98).

Moving beyond critiques of traditional social science methods, Angrosino offers substantial arguments for why ethnographic fiction is a valid way of commencing the ethnographic project of elucidating experience. The power of fictional literature is, Angrosino, points out, that it ‘rings true’ even when it is certainly not factual,” and has the effect of “enlargement of understanding” of a person or people (Angrosino, 1998, p. 97). This “enlargement of understanding” is the same goal as that of ethnographic literature, generally. Likewise, any literature, ethnographic or otherwise, is “successful to

the extent that we get the reader to stop asking, ‘Did this really happen?’ and start saying, ‘I understand what these characters are going through’” (Angrosino, 1998, p. 97). What Angrosino communicates with his collection, and what I wish to communicate with my project, is that people with intellectual disabilities “are a diverse lot with a full range of attitudes, values and outlooks on life” (Angrosino, 1998, p. 101). Angrosino pointedly notes that one can *say* or *write* that idea itself, but that as an idea “it hangs in the air or sits on the page like so much ‘data’” and that it is better to “*show*...the diversity of how people react to situations drawn from, but that are not exactly a photographic representation of, ‘real life’” (Angrosino, 1998, p. 101).

Situating Myself

Following other autoethnographers, ethnographers and storytellers writing with queer and feminist ethics in mind, I situate myself and provide relevant background information about myself to speak to how who I am shapes my writing (Ellis et al., 2011, p. 274; Jensen-Hart & Williams, 2010, p. 452; Zingaro, 2009, p. 108). Some aspects of my personal history and identities will be clearly present in the novella, but others only in the shadows of text, in ways that might not be clear on the surface, as writing itself is always “a complex blending of various voices and is always partial and situated” (Jensen-Hart & Williams, 2010, p. 452). As such, I present myself here, as thoroughly as I can.

I am white. Currently, I live in Indianapolis, Indiana, which is also the city in which I lived the first eighteen years of my life. I identify as bisexual. Since I was ten years old, I have experienced persistent gender dysphoria, though I have only in the last

year begun to come out to people close to me as nonbinary. I grew up in an evangelical Christian household, though I no longer identify as a Christian, nor do I hold any other religious affiliation. If pressed, I identify as agnostic.

I was never labelled explicitly with a disability, but when I was seven I was picked out as having ‘difficulties’ in school, a picking-out that manifested itself in different ways over the years, including my receiving instruction in segregated classrooms for five years and sitting in the gaze of psychologists during the early years of my elementary education. A couple years ago, my parents gave me the document from that psychologist that led to me receiving part of my education in a segregated setting. It is remarkable how vague it is, referring to me only as being “prone to distraction,” and as having some “learning difficulties.”

Members of my immediate family have had many labels attached to them. Psychiatric illness, schizophrenia, depression, vaguely defined mental disabilities, autism, “mental retardation” (usually appearing on documents as “MR”), as well as what are perceived as ‘concrete,’ ‘physical’ labels, like cancer, chronic pain, seizure disorder, diabetes, and obesity, which have manifested in experiences of physical, economic, and structural barriers.

My experience in relation to intellectual disability is diverse. There is the familial connection, with my two siblings having intellectual disabilities. Then, there is the professional connection. I have worked as a DSP in a group home for adults, a day program, and a waiver home for adults. I also worked at a middle school as a ‘special education aide’ for a school year. The only job I have held outside of Indiana was also as a special education aide in Fairbanks, Alaska, at an elementary school, a job I held for six

months, before family circumstance required I move back to Indiana. I have also worked as a DSP for adults who still live with their families. Currently, I do contract work as a DSP, primarily through a service provider. At this present moment of writing, due to the pandemic, I only provide direct support to my sibling who lives with my parents. This blurs the lines between familial and professional experience, since a service provider pays me for a portioned amount of the time I spend supporting my sibling.

Anatomy of Care takes place in a waiver home in Indiana. A waiver home is a house where people with intellectual and/or developmental disabilities reside. Those living in a waiver home receive services through a Community Integration and Habilitation (abbreviated to CIH) waiver (FSSA, 2020). “Waiver home” is not an official term, though, because sometimes the same kind of services are deployed in an apartment environment. However, colloquially, amongst all DSPs in the state I have interacted with, “waiver home” is the term used for a place someone receiving CIH waiver services lives, if they are not living with their family, and if the physical structure they live in is a house, rather than an apartment. Individuals on the CIH waiver experience a different structure of service provision when compared to those living in group homes. On the CIH waiver, individuals or their guardians pick and choose each set of services, i.e. day program services, occupational therapy, recreational therapy, behaviour interventions (FSSA, 2020). Individuals or their guardians also have the option to have different providers providing different services, i.e. one could live in a house run by provider X, have a behaviourist from provider Y, and go to a day program run by provider Z. However, not every area of the state where there are waiver homes has a plethora of these kinds of services and providers. Likewise, in my experience working in a rural waiver home,

waiver home staff are often relied upon to transport individuals long distances to get to services. This means if there are not enough DSPs working to send one off to do transport, while maintaining staff at the house, a person could *technically* have the funding to utilize a certain waiver service, yet if there are not enough staff to transport them to that service, they cannot utilize it. In group home settings, a resident only has access to the services provided by the service provider for the group home in which the resident lives (BDDS, 2020). The other significant difference between group homes and waiver homes is that group homes are bound by more state regulations than waiver homes (BDDS, 2020). It is one thing, however, to *discuss* the nuances of access and quality of life issues in waiver homes, it is another to *show* those issues, which is what I have done with *Anatomy of Care*.

Anatomy of Care

Summer

A long and tall white van pulled into the driveway of a small white house whose age showed in cracked layers of paint. The front yard lacked any accents or colour besides the greens of the grass and the young dogwood's leaves, but there were no dead spots and it was mowed often enough, thanks to regular lawn service. A single wiry green chair sat on the concrete porch, which overlooked a small, mulched area. Nothing grew there, but someone clearly intended something to grow there—someday, if someone got around to it.

The twenty-two year old man who sat in the driver's seat of the long and tall white van was named James. As he straightened the wheel and clicked the remote to open the garage door, James shivered. His shivering beard tickled his neck as he tried to keep the wheel steady while gently pressing the gas pedal. When James wore a beard, he passed for early thirties. His beard was thick and such a deep brown it looked black. He didn't like how awkward it looked against his pale skin, but he had grown it out, because looking older made life easier. After putting the van in park, James pulled down the sun visor from above the windshield and opened the mirror. The reflection confirmed that despite his shivering, beads of sweat covered his forehead.

It was late June in Indiana, and the beginning of a heat wave. Some people sweat when they're anxious, but James shivers. He worried the officer would ask him if he had been using drugs. James had not been using drugs, but the possibility of the question intensified his shivering. He wore a gray tee shirt and green cargo shorts that stopped just above his kneecap, where goose pimples were now forming. Before he worked at West Park, he would not be caught dead wearing cargo shorts, preferring slim-fitting pants and jeans in all seasons. Enough time had passed, however, that he no longer thought twice when slipping into a pair of cargo shorts, basketball shorts, or sweatpants, all of which he had purchased at a Goodwill a couple towns over when he moved back to Hawley. James had a sturdy, rectangular frame; the kind that looked like you could hurl a bowling ball at without knocking it over. Yet people who did not know him well were always a little taken aback when they realized he carried an overwhelming supply of nervous energy. He was a concrete slab built on a fault line.

James was a direct support professional who worked at the house he was pulling into. A direct support professional is the long title that appears on job descriptions, but inside the houses and at the offices, everyone refers to them as “staff” or “DSPs.” When James first saw the title scrolling through job search results, he looked up the phrase “Direct Support Professional” on Wikipedia and read, “A direct support professional is a person who assists an individual with a disability to lead a self-directed life and contribute to the community, assists with activities of daily living if needed, and encourages attitudes and behaviours that enhance community inclusion.” It sounded so noble and he needed a job with virtually no experience required, and he needed it right away, so he applied. He didn’t even have to send in a resume, just a brief online application form, a background check, and then someone called and said, “Mr. James Ray, when can you start?”

It had been about six months since he started, and maybe once or twice he felt noble doing his job, but mostly he just felt tired. He started working there after he dropped out of college to move back in with his mom who got sick and started chemo and then got sicker. Through all the ups and downs of his childhood, his mom had never moved, so he was moving back into his childhood home. That was six months ago.

When he wasn’t at work, James got groceries, took care of his mom’s house and yard, prepared her meals, drove her to chemo, and slept. His childhood home sits in a quiet corner of a town in Indiana called Hawley. In Hawley, there are two stoplights and not one Starbucks. James left Indianapolis while in his second year of college. That was six months ago. Though his college experience itself was aimless, since he couldn’t decide on a major, he enjoyed Indianapolis, which to most is just a minor Midwestern

metropolis, but to him was a beacon of culture. Hawley was only three hours from Indianapolis, but it may as well have been on the other end of the continent, because as soon as he moved back, he had no time to leave.

Up until the early 1990s there were two factories operating in Hawley. One produced the moving parts of a now-obsolete piece of technology, and the other factory put all the pieces together into a shining product that can now only be found in second-hand stores and the sheds and garages of collectors of forgotten technologies. At one time animated with bodies undulating with production lines, the buildings now sat abandoned, decaying. In the wake of the death of an industry, the shadows cast by these cavernous structures have grown long and expansive. Many of the same workers who once moved palettes and machinery and levers in repetitive motions inside those factories now sold or used fentanyl-laced drugs in the same buildings. And in this way, the buildings are now the hub of a new booming industry in Hawley, except this one offers no false promise of a vibrant community. The wages at the jobs still left in the town couldn't hold a candle to those of the now-dead industry, even without adjusting for inflation, and behind closed doors people who used to work in the factories would disparage anyone who mentioned open positions at the Dollar Tree or one of the three restaurants in town, as they would disparage any of their former factory co-workers who stooped to the level of cashier, line cook or server. In sharp-edged phrases, they wrapped up the decline of the town with the decline of the industry that once propped it up as a small town people moved to, instead of away from.

There was of course, Open Doors, the company James worked for, which ran three Medicaid waiver houses in Hawley, where people with intellectual and developmental disabilities lived. Open Doors operated just three houses in Hawley. Mostly, the company's houses were concentrated in four of Indiana's more sizable cities: Indianapolis, Fort Wayne, Evansville, and South Bend. But Open Doors did have a handful of houses, like the three houses in Hawley, peppered along the state road system in small towns and rural areas.

Despite Hawley only having three houses, there were always positions available. The turnover rate at the Hawley houses ensured that there was always at least one job opening at each of the houses, and on top of that there was a constant need for more substitute staff. But the jobs at those houses paid no better than the service industry jobs, and often, when a frustrated spouse would ask their unemployed spouse about applying to Open Doors, the reply often had something to do with not wanting to "change adult diapers," phrasing that demeaned a whole population to excrement.

There were other reasons besides turnover and people belittling that kind of work that led to the three houses in Hawley being chronically understaffed. Open Doors only hired people who came back clean on a strict background check and a drug test, so many people in Hawley who wanted to work for them were turned away: people who said they'd never done this kind of work, but suddenly felt called by God to do so; people whose kids had moved away and wanted to express care in some way; people who had family members with disabilities and felt like working at Open Doors would be participating in "a cause;" people who had decided to draw a line between their past and

present, concluding their past was contemptible and that working for this population would solidify some kind of goodness within themselves.

Lots of good people in Hawley had minor misdemeanours in their past, and even more used an assortment of drugs to cope with the ways labour had eroded their body and spirit. Between all that and the theoretically perfect workforce pool of the young people with clean records moving far from Hawley as soon as they turned eighteen, the people who worked in staffing at the Open Doors main offices took it for granted that the houses in Hawley would never and could never be completely staffed.

Even with subs filling in gaps here and there, the DSPs that worked permanent positions at the houses in Hawley worked far more than the thirty-five or forty hours that had appeared on the listings for their jobs when they applied. This is why people didn't stay long. It was too much for most people, even when factoring in overtime being time and a half pay.

James had applied for a thirty-five hour a week job, working ten in the morning to five at night. And yet, James could count the number of hours he had slept in the last two days on one hand. He had more responsibilities at home than most twenty-two year olds, but it was his job that left him sleepless. The weekend overnight DSP had quit suddenly—a no-call-no-show situation, and with the other staff filling in other gaps and subs working the other two houses, it was either him or no one, and no one wasn't an option. And now it was one in the afternoon on Monday and he was waiting for the garage door to open. The driveway, the lawn to his right, and the porch all appeared to move, like the scenery does when one has driven hundreds of miles in one day, though he

had only driven five or six. He wiped his eyes wondering if this was another symptom of his anxiety about the cop parked outside the house, like the shivering, or if he was just that tired.

James turned to look at Will, who was asleep in the passenger seat of the van, and muttered to himself, “thank God,” under his breath, since he knew Will had “a thing” about cops. He couldn’t remember what that “thing” was, but James could only handle one person’s anxiety about cops at a time, and at the moment that anxiety was his own. So, he had no intention of waking Will up if the cop got out of his car. He’d let the interaction unfold while Will slept peacefully and then wake him up when it was all over.

The garage door finished opening, and James watched Will out of the corner of his right eye to make sure the slight acceleration required to enter the garage did not wake him. But as he pulled in, James could see the police car door open. James decided to pretend he didn’t notice. So, he closed the garage door, cut the engine and breathed deeply, trying to decide how to go about the next few moments, while also trying to get his body to stop shivering in the ninety-degree heat of the garage.

Will was diagnosed with “Autism Spectrum Disorder” at four, and though his parents had never sat him down to talk to him about what that meant, he heard the word “Autism” rattled around a lot during the time when he moved out of his parents’ house. Now, he lived with two housemates and a rotating cast of staff. He had lived at West Park for four years, and while he never asked his parents to take him back, that didn’t mean he was happy there. Even though he had his own room at the house, it didn’t feel like his. He never knew when his door would be opened and someone would pop their head in.

Someone opened his bedroom door nearly every thirty minutes and asked him to do something in a tone like it was the most fun thing in the world—things like, “wanna help do the house laundry,” or “how about you and me scrubadub some dirty dishes.” Though the worst was when they looked around his room, then at him, and after a moment said, “just checking in.” The real problem to him was a feeling that even if he went over every inch of the house with a toothbrush, they’d still bother him, which made him never want to help with anything. There were other things about living at West Park that Will disliked, but not ever being truly left alone was the one that cast a shadow over everything when he was home, which was why he loved taking walks outside by himself so much. His most private space was strangely outside of any room, where all the people on sidewalks and by their windows could see him, but none of them ever tried to say anything to him, so he could easily pretend that during his walks he was the only person outside in the entire town.

James climbed down from the driver’s seat, letting his feet gently meet the floor of the garage. He slowed his breathing, and sneaked over to the thin long windows that ran across the top of the garage door, stepping onto a dusty stool to peak out and get a better look at the police car parked by the West Park mailbox. In the few seconds that had elapsed since he left the van, James’ mind had raced through a series of things he might do in the event that Will woke up. If the officer was inside the house, James would flip through his phone to find the first piece of classical music he saw on his downloaded music list, pull out his ear buds and tell Will “hey, you’ve got to check out this song,” praying it would enrapture Will, who had discerning ears, preferring very specific pieces

of classical music—what made a piece one that Will liked or disliked, still remained a mystery to James. Then, he would tell Will to go straight to his room to wait for a surprise while James desperately hoped there was something deep in his backpack he had forgotten about, like a pack of gum or something that Will might like, and if not, he would just dump out his backpack and give it to Will. James knew Will liked collecting bags and backpacks and James could always start carrying his snacks and water bottle in a grocery bag to work, if it came to that. If the officer was still in the police car, James would rattle off the list of sweets and junk food the staff were supposed to be discouraging Will from eating, and say, “if you get to the kitchen fast enough, you can have one of each!” As he was thinking that last plan was the best for avoiding an interaction between the officer and Will—though also the most manipulative—James saw the top of the officer’s hat through the dirty garage window from his perch on the stool. From the hat’s movement, James could tell the officer was looking from side to side. After a few swivels of his hat, the officer knocked on the garage door. Shockwaves shot through James’ bones and a rattling sound throughout the garage that jolted Will awake.

All James’ ideas and strategies fell out of his mind as his finger clicked the garage door remote, sending the door up and up. James muttered “it’s okay, Will,” without looking back to see if he was heard. The words “he’s got a thing about cops” floated around in James’ head like they did whenever he saw police when he was out with Will. If they were out driving somewhere and James spotted a police car, he always took the next turn. Or if they were walking in the Dollar Tree and James saw an officer, he would make up some reason for him and Will to turn around and head towards an aisle at the opposite end of the store. But the garage door was rising, revealing the unavoidable

presence of a police officer, boots first, While James thought about how “a thing about cops” could mean anything, and what if it meant Will became aggressive? Against the cops? Against himself? Against staff? James had never seen Will aggressive in any way, and the door continued rising, revealing the officer’s pants, and James considered how he had heard from other DSPs of clients being dangerously aggressive to staff, leaving themselves and staff with concussions and cuts and bruises.

James pulled himself out of the anxiety loop of these what-ifs enough to realize he was shivering even more uncontrollably now, and as this awareness hit him, so did an awareness of a reverberating thump. The garage door had stopped just above the officer’s belt buckle.

“Looks like your door’s a dud, bud,” the officer said flatly while bending over so that he could see inside the garage. The officer saw James clearly, but Will stood directly behind James, about five feet. The officer could not make out Will’s face.

“Uh, yeah,” was all James could get out.

“Can it go any higher?”

The officer’s sarcasm lost on him, James gave himself a pat down to relocate the remote.

“It was just—let me—sorry—thank God,” James mumbled, then squeezed out a laugh, adding, “I must have dropped it.”

After the door jerked up and down a few times, it finally rose unobstructed, revealing the officer in his entirety. He was a spindly man, his belt buckle broader than his knees. The officer stood on the threshold between the garage and the driveway, apparently taking care not to step inside as he looked past James while saying, “Sir, it’s

okay, I just have a few questions, for your, uhm...” James followed the officer’s gaze, looking back, and saw Will had his hands over his eyes. Lips held tight, it looked like Will was doing everything he could to hold in a scream. Never having seen him this way, James realized just how little he knew about Will. This terror didn’t come from some unspecific fear of a uniform or even something seen on TV. It wasn’t just “Will has a thing about cops;” a statement outside time and place; a fact of uniform plus Will equals bad news; there was a story. And though nobody had told James that story and Will was not able to tell it directly, James felt he had received a small piece of it just now, and this also made James feel embarrassed for ever thinking he knew Will, because six months of working with Will did not mean he knew Will at all, or even what larger story that small piece went to, and maybe he didn’t deserve to know.

But James’ face didn’t have time to twist itself around all those thoughts. His face still had fear and anticipation of unknown aggression smeared across it, which is what Will saw when he took his hands away from his wet eyes. The re-remembered trauma of whatever the uniform triggered turned into a fear of James’ fear. Will bit his wrist, funnelling the fear through a physical sting. Then Will ran into the house, into his room, put on a pair of noise-cancelling headphones and laid on his back in bed, staring at a spot on the ceiling where a cob-web hung loose like a frayed string.

The officer’s black-booted toes touched the edge of the garage floor. James thought better than to go in for a handshake, so he adjusted himself out of his surprise, straightening his back and shoulders.

“I’m James Ray, how may I help you, officer?”

While he spoke, James resisted scratching an itch on his left ankle.

“Officer Bream,” a hand extended to James, “how are we today, Mr. Ray?”

James took the hand, but the word “we” made him dizzy. Officer Bream seemed unfazed by James’ quivering hand, and went on without waiting for an answer.

“We’ve gotten some complaints from folks in Brent Woods, the neighbourhood down a bit off State Street, you know the one?”

James nodded, though Officer Bream’s flat tone made it hard to hear the question.

“That man who was just standing out here with you, we have reason to believe the complaints are about him,” and he asked for Will’s name.

“Will Tinley,” James offered.

“Right. People have been reporting a man who matches Mr. Tinley’s description, climbing their trees,” Officer Bream emphasized, “cliiimbing” and “trees,” then added, “Obviously, this can’t happen.”

It took James a moment before catching on that Officer Bream wanted a reply. He tried assembling a smile, but James’ face warped into a grimace by the sun, instead.

“Well, uh, we’ll take care of that. It won’t happen again. Thank you, sir. Is that all, sir?”

“Yes, thank you, and have a good evening,” Officer Bream said, as his gaze darted around the over-large garage, before walking back to the patrol car.

As Nolan Bream reached out to open his driver’s side door, he called out to James, who was still frozen in place.

“Hey, by the way, if I needed to call the people that run this group home, who would I call?”

When someone wants something to be over badly enough, they say too much, which is what James did.

“It’s Open Doors, you can find their number if you Google ‘Open Doors’ and ‘Indiana,’ and this house is called ‘West Park,’ but it’s not a group home, it’s called a waiver home, which is, uhm, different, though I’m not really sure how. Some people say waiver homes are way nicer than group homes, but I’ve never been to a group home so I couldn’t say.”

He was rambling, and still shivering. Part of him wished the officer *had* asked him about the shivering, because he knew it was obvious. Him *not* asking was somehow more nerve-wracking, which then made James shiver more.

“Thanks. Hopefully you don’t hear from me again,” Nolan Bream said, tipping his hat and smiling. On his way back to the car, Nolan Bream hollered back without looking, “by the way, the beard looks good, bud.” The compliment sounded genuine. James wished it hadn’t.

He stared in the direction of the police car as it drove off, as it slowly dawned on James that he would have to report that entire interaction: what Nolan Bream said, what James said, how Will reacted, and how James did or did not respond to Will’s reaction.

In the “med room” sat a binder labelled “Will Tinley’s Individualized Support Plan (ISP), and on page five was written:

Goal: Will will engage independently with his community regularly.

Proposed Strategies: Will will take a forty-five minute walk in the neighbourhood surrounding his residence every weekday by himself. This will be referred to in documentation as “private neighbourhood walking time.”

Ten days before officer Nolan Bream appeared in front of West Park, Will took a walk to the edge of his neighbourhood. There was the big road (labelled “State Street” on maps of Hawley), with a faded “20.5 Acres For Sale” sign across the street. The sign had a phone number on it, but he could only make out four of the digits, it was so faded. Behind the sign was an expanse of tall grasses, bright and wavy in the sunny breeze. Bees jumped in slow motion from one flowering tip of tall grass to another. Beyond the field, in the distance, he saw a line of cars and houses like the Micro Machines he collected before someone threw them out, and across that more fields, and again and again, until his eyes couldn’t see any further. To the left more of the same shade-less expanse, but to the right just one walk-around-the-block’s worth of footsteps, tall trees gathered together making real-looking woods. His neighbourhood had trees, sure, but little ones that he thought looked more like big plants than trees. The trees down the road were like the ones at the house he used to live in with his mom and dad, tall, with branches like giants’ arms, big enough to sit on comfortably.

This was his “private neighbourhood walking time” and where the trees were looked like a neighbourhood, so he walked fast, keenly aware of his forty-five minutes counting down. Soon enough he saw a sign, fittingly, painted with green pines around the words, “Brent Woods.” The houses there looked as beautiful as the trees. There were vines crawling up brick exteriors, white pillars, bay windows, and deep yards filled with

trees like the ones at his parents' house. He moved out of that house four years ago, but he still missed waking up to the daybreak sun broken apart by branches.

Most places he wasn't allowed to go: other people's houses, cars, trucks and garages, but anywhere with a sidewalk seemed okay since nobody had ever yelled at him for walking on a sidewalk. Now that it was hot and sunny out, and he saw Brent Woods had many streets to explore, he decided right there that this summer he'd dedicate his "private neighbourhood walking time" to exploring this neighbourhood, looking at every tree from the roots to highest leaf, he'd scan his eyes over every single one. He liked making goals, knowing how his days and months would be spent. Will felt thankful he already had a plan for how to spend his summer.

The next few days that he returned to Brent Woods he noticed little spots of color on the branches of several trees. The spots were mostly green, but some were yellow. More and more spots appeared on more and more trees every day. Over the next week, he inched closer and closer to the spots, walking up to every tree. One red maple tree he came across had loads of spots, but they were high up in the branches. This tree was only a few feet away from the sidewalk, barely inside a yard. It had a few thick, low branches bunched closely together, beckoning him to climb. He knew trouble would find him if he fell out. The most trouble he ever got in was when he got hurt. But this tree didn't seem to come with a risk of falling.

Once he hoisted himself up above the first level of branches, he looked up and the rest of the tree presented itself like a ladder. As he climbed he was rewarded with closer and closer views of the spots. At what felt like twenty feet up, he realized the spots were not really spots, but pods, like escape pods from a sci-fi transport ship, though small and

green and yellow instead of person-sized and space-gray. They were pretty, each smooth and about as big as his thumb. The tops were round, like little domes, the bottoms pointy and sharp. The yellow ones looked like someone had painted them like Easter eggs and the green ones had gold halfway around what he thought of as the ridge if it were a mountain. It was as if someone had climbed up the tree and sewn gold-studded thread into the pod, like someone wanted to mark the front of the pod, but in the most beautiful way one could say, “this is the front.” Will enjoyed how when he was on the ground they looked like spots on the tree, but up in the tree’s world, he could see they were hanging off the branches by something delicate and sticky-looking. The thought occurred to him, though, that this might have more to do with needing glasses. He once overheard a doctor telling his parents he needed glasses, but his parents told the doctor, “Will would break them.” So, Will never got glasses.

When his eye was inches from each pod, drawing his sight over each, he saw how they differed slightly in construction and size like fingernails. They were all the same kind of thing, but each still vastly different from the any other. He thought about how up close they could fit into his imagination as huge green and yellow mountains plucked from the ground and hung like a fern. Then his watch beeped, which meant his “private neighbourhood walking time” was over in ten minutes.

After scurrying down most of the tree, Will jumped down with a thud from about four feet up, landing on his butt. He sat in place praying for a few seconds that he hadn’t gotten a bruise, but that if he had, staff wouldn’t see his butt, since they were always so mad about having to “report bruises.” When Will opened his eyes from praying, he saw a man across the street standing on a porch. He looked like he was waiting for something

important, given he wasn't sitting in the comfortable-looking rocking chair that was right at the man's side. Will waved, but the man didn't move, so Will checked his watch and ran so he could make it to the house before his "private neighbourhood walking time" was over.

James closed the garage door and took several deep breaths before going inside the house. A few steps after walking inside, he gasped as his feet did an awkward dance to avoid stepping on Lily, whom he had not seen, because she was so close to the ground, and because the light was off in the hallway, and not much natural light reached this part of the house. James flipped on the light switch, and saw Lily clearly, sitting on her knees as she faced the wall opposite the rumbling washer and dryer. A dull fluorescent light bathed them. The hominess of the ridged frosted glass of the light fixture was betrayed by the bulb inside, which emitted the kind of cold cheap light more suited to a garage or warehouse break room than the hallway of a home.

James watched as the backside of Lily's hands touched the wall. Slowly, Lily moved her hands down the wall, towards the floor, her wrinkled knuckles and thin fingers contemplating the minute textures of the wood paneling. Then, her knuckles met the floor, a shift from warm and grainy wood to cool, slick tile. Lily's hands soaked up the waves of vibrations in the tile, which emanated from the washer and dryer. A wide smile appeared on her face.

James was surprised to see Lily wide-awake in the hallway when he walked in. It was unlike her to not be asleep in her recliner in the middle of the afternoon. Seeing Lily out and about lifted James' spirits enough that he briefly forgot about his and Will's

encounter with the police officer. He considered putting his hand under Lily's hand so she could show him exactly what textures she was smiling at, but instead was struck by a sudden concern with excrement, so he looked down at her backside. "Bet Val hasn't changed you all day," he whispered, though he knew Lily didn't hear him, since her eardrums did not function. Without first considering Lily's privacy, he bent down on one knee, lifted up the large shirt she was wearing and peaked inside her pants to see if her Depends were wet. "Thank God," he said to no one, putting her shirt back down, shaking his head at what he thought was a ridiculous thing for Val to put Lily in.

James hated that oversized hunting-orange shirt, with "DON'T TREAD ON ME" written in forest camouflage-coloured letters, the shirt so large it covered her blue gym shorts and scratched-up-white kneepads. The shirt was how James knew Val was working, because she always put Lily in that shirt, which annoyed him, though he had never asked Val about it. Val would have told him it was the only shirt that covered her kneepads, which she didn't want anyone visiting the house to see, because they were awfully banged up. Medicaid wouldn't pay for new ones just because they looked bad, and Val didn't want to be put in the position of explaining all that to someone. Val knew if anybody came from the state unannounced to evaluate West Park, she would be too flustered to justify why Lily wore scuffed-up kneepads. The "DON'T TREAD ON ME" shirt prevented that from ever happening.

The story of how Lily came to be at West Park was murky and incomplete. People who worked at West Park knew her mother had died a long time ago, and judging from a dusty photograph in Lily's bedroom, of Lily holding her mother's hand extended out

from a hospital bed, all sorts of wiry objects poking into her mother's arms, Lily had been there when she died. At least that was the impression the photograph left in the minds of the staff who took notice of it.

Before coming to West Park, no one knew exactly where she had been. It was a gap in her history filled in by rumours. Some said she stayed with neglectful family. Some said she stayed with loving family that died off. Some said she was recovering in a hospital from an illness that nearly killed her, while some said it wasn't an illness, but an "accident." But before that gap and long before coming to live at West Park, they knew she was at an institution. Lily was in her sixties and had lived through the days before group homes and waiver homes existed, sharing a bedroom with thirty people being "cared for" by one or two staff at a time.

Just last week, a sub named Miriam asked about Lily's story, so Val told her what she knew.

"My goodness," Miriam said, looking shocked.

Miriam had seemed genuinely interested, so Val didn't leave out that Lily was at an institution where ankle and wrist restraints were regularly used, or that there was rampant sexual abuse, or that the clients were forced to shower huddled together like cattle.

"Well," Miriam said with her hand on her heart and a sigh, "she is blessed to be here now."

Val was taken aback. It didn't take much to be a better place than an institution. Val thought West Park was passable, as a place to live, but to call Lily "blessed" to be

there seemed a bit much. She tried to think of a nice way to contradict Miriam, but couldn't come up with anything.

Sometimes Val imagined Lily's mother visiting Lily in the institution, and what her mother might do to show love to Lily. She tried to imagine, so that maybe she could make similar motions, and though there was no way for Val to do any more than imagine, she would occasionally, when nobody was around, embrace Lily, sometimes for several minutes at a time, hugging her and stroking her hair. Val knew if she were Lily's mother, this is what she would have done. This violated Open Doors' policy about appropriate professional contact. Val knew this.

Lily neither saw nor heard, in the ways that most bodies do, but she knew each DSP by touch and the vibrations of their footsteps. There were DSPs who danced with her and put their hand under hers as she pored over her favourite surfaces in the house, and there were DSPs who only engaged with her to feed her and take her to the bathroom.

Nobody had figured out why, but she recoiled each and every time her anus and vagina were wiped, no matter who was doing it. There was no access to a history of this response, since every person who currently worked at West Park had never known Lily to react any differently. Val and a few others had their suspicions as to why, but never voiced them, because they knew there was no hope in finding answers to the painful questions that welled up in them when Lily recoiled.

The police encounter and the un-typed report reclaimed James' mind with force. James patted Lily's head as he walked away. He had to get to the house computer. Lily

pressed her fingertips onto the tile floor, and she felt the vibrations of James' footsteps get softer and softer.

West Park's computer was in a corner of the dining room. To get to the dining room, James had to walk through a hallway, passing Lily and the laundry facilities, then a bathroom, and then the bedrooms, which were spaced out two on the right and one on the left side of the hallway. Will's was on the left and as he passed by, he instinctively reached out to turn the doorknob to check in on Will, but stopped himself before turning the knob. The report James was about to type up about what happened with Will would look better if he could include a line about "checking in with Will," after the incident, but James decided it was not worth it. James had never seen Will so distraught, and if he had wanted to talk it over, Will would not have shut himself in his room. Giving Will some extra privacy was worth sitting through a rant about protocol from his manager.

The hallway ended at a door that led to the kitchen. The kitchen looked and felt prefabricated. Lining the upper regions of the kitchen were light brown cabinets whose texture and weight called to mind balsa wood spit-shined with glaze. The fridge and stove appeared to be from different centuries, the fridge large, matte gray with a digital display, while the stove's crooked metal coiled burners stuck out of the off-white base like four broken Slinkys. On the opposite side of the kitchen from the doorway that led to the hallway, there was another doorway that led to the rest of the house. These two doors that connected—or, separated—the kitchen to the east and west ends of the house were added after the house became a waiver home. The kitchen was the centre of the house, but this had nothing to do with why the doors were added. They were added because at some point there was an issue with a resident and the kitchen, but James did not know the

details. All he knew was it was not an issue now, because on James' first day, he was instructed to always leave the kitchen doors open. The doors were now a relic of an old restriction that no longer applied. On the rare occasion when James took notice of the doors, he found himself thankful that he and the current DSPs did not have to worry about whatever issue led to the doors' installation.

Every single time Will walked through the kitchen doorways, he felt a visceral sense of relief that the doors were not shut and locked. For Will, the threat of being locked out of the rest of the house was ever-present as long as those doors existed, whether they were open or closed.

Beyond the other kitchen doorway was the dining room, where the house's computer sat in the corner, and next to that a sliding glass door that led to the small flat brown-green back yard, which nobody set foot upon, apart from the DSPs who smoked cigarettes. The sliding glass door's purpose was less to be a door than to be a large window, the natural light collaborating with the off-white tile of the dining room floor to make it the brightest room in the house.

A line manifested through the meeting of the off-white tile of the dining room and the brown carpet of the dim living room. This line was all that separated the dining room and living room, though the only person who ever took notice of it was Lily. Everyone else felt the separation of the rooms through light and its absence, since the dark carpet and furniture of the living room swallowed up the light, while the dining room's floor let the light be free and bright.

On the south end of the living room was the front door, and on the west end was another bathroom that belonged, unofficially, to Lily and the DSPs. This was partially the

result of the simple fact that it was the closest bathroom to the living room, where Lily and the DSPs spent most of their time. But the main reason was that there was a time when Will could not access that bathroom after nine in the evening, and the bathroom in the hallway, by his room, was the one he could count on if he needed to go during the night. To this day, if Will is sitting in the living room watching TV or eating at the dining room table and has to use the bathroom, he walks all the way through the kitchen and uses the bathroom in the hallway.

James walked directly to the computer and sat down in front of it. The computer was in sleep mode, but he made no attempt to wake it up. If thoughts could hyperventilate, James' were. In the time since he saw Lily in the hallway to now, he had been playing and replaying in his mind the series of events with the police officer. He had to in order to ensure accuracy in his report, but the recollections had taken a life of their own, gripping his mind like a vice. He waited to touch the mouse, staring at the black nothing on the computer's display. The nothing grounded him, loosening the vice grip. He exhaled the contents of his lungs and poked the mouse with his pinkie, causing the quiet purr of the sleeping machine to awaken with metallic whines and plastic crackling. Val sat at the dining room table, and was less than ten feet away from James, but he had not noticed her.

Val was fifty-three, but it was only last month that the bags appeared under her eyes. These badges of weariness were long overdue, but she welcomed their arrival nonetheless. Her hair was pulled up in a ponytail. It was gray with dark brown speckles. Back when it was dark brown with speckles of gray, her mom had told Val to colour it, but Val refused and shot back that, "it's no use fighting nature."

She wore a bright yellow T-shirt that had no images or lettering except across the upper back, where it said, “VOLUNTEER” in large bold black letters that threatened to swallow her shoulders. The tattered jean shorts she wore made her legs look even thinner and her knees knobbier than they actually were. Truthfully, Val liked looking frail, and had sought out clothes to exacerbate that quality since she was very young. She had always been physically strong and there was something about moving through the world with people wrongly assuming weakness that brought Val a certain satisfaction. Up until everything with her mom, she followed an intense workout routine four days a week. She told herself at the beginning of every week that she would start up her old regimen again, but, without fail, some new soreness appeared and prevented her from inhabiting that memory of peak fitness.

Most people who had worked at West Park found it changed their relationship to clothes. Pants became tattered jeans or gym shorts. White button down collared shirts became T-shirts or the denim shirt normally reserved for working in the garage. Most people started out wearing clothes they associated with “going to work,” but by their third or fourth shift were wearing clothes they would have thrown on to scrub their own toilet. For most, this was an adjustment. For Val, it was not.

Val angled her arm to scratch the part of her back covered by the “T” in “VOLUNTEER,” and then returned her hand to her phone. Despite having heard all the commotion earlier when Will stormed into the house, Val made no effort to get James’ attention to ask about it. Like James, Val hungered for a hollowed out mind. She hunched over her phone, cradling it in her hands, which were cracked from all the hand washing.

Her thin thumbs did not reach for the phone's touch screen. The static menu icons offered solace in their backlit stasis.

Val had just finished in the bathroom with Lily when James came inside. It took Val forty-five minutes to wipe the feces off Lily. The whole time Lily fought hard to get away from Val. Eventually, Val gripped Lily's right thigh with one hand and used her other hand to clean her with wipes. Val's grip was a calculation: how tightly to hold so Lily couldn't get away, while ensuring she left no bruises. Leaving her with feces caked back there would be neglect. But bruises amounted to abuse. This was the saddest kind of calculation, and it especially got to Val, since it reminded her of visiting her mom in the Alzheimer's unit of the hospital. There, Val saw people in scrubs walking around a little too fast with faces a little too blank, clearly doing the same kind of calculations behind the closed doors of bathrooms, the sound of moaning protests reaching out into the hallways of the unit as she walked with her arm around her mom. Val couldn't help but imagine her mom making similar sounds when she was "assisted with toileting." The phrase sounded so pristine when Val wrote it in her notes about Lily at the end of her shift, but in the moment, it didn't feel like "assisting" at all. Sometimes she wished she could write, "Lily protested being cleaned by crawling away from staff," but interpreting Lily crawling away from Val's "assistance" as protest would be twisted around as neglect; she just knew it. Val knew that reporting a client "protesting" would open her up to the question, "how do you know that's what she meant by crawling away," and to that she had no answer, because the real answer was, "I just know." And telling a company like Open Doors, "I just know," as a defense against neglect charges was a terrifying

prospect. Fire-able? Maybe. She did not want to find out, so as Lily squirmed more and more, Val held tighter and tighter.

Val's memories of her mom's last few months made this job painful for her, but those memories also motivated her to do the job. After her mom died, Val could have picked up her old job at the Dollar Tree, which she had left to help her mom when her Alzheimer's started to get bad. But the idea of wearing her old uniform and badge like nothing had happened was too much. She wanted a job that would mean *something* even if it paid less. She wanted a job that allowed her to peek inside the world her mom lived in those last few months. Not being qualified as a CNA to work in a nursing home, she figured working at Open Doors could afford her a similar opportunity. In her mind, both involved "taking care of people," so she figured the experience of working at an Open Doors house couldn't be far off from working at a nursing home. So, she took a DSP job at West Park. That was six months ago, the same time James started, and two months after her mom passed.

As she worked more and more at West Park, the connection between her mom and her job grew messy and confusing. Sometimes, she felt no connection and sometimes that was nice for Val, since her job could be her own experience, a new chapter, where she supported the people at West Park just because that's what she wanted to be doing. Sometimes, it made her wonder why she was even there. And sometimes she felt the connection like a train barreling towards her heart—like when she was in the bathroom with Lily. And now she was trying to forget about it, because it was too much.

The sound of fingers typing a little too hard finally reached her ears. “You okay, James?” Val asked, but James did not hear her. She remembered it had been awhile since she checked on Scott. Thankful for a straightforward task to force her out of her head, she got up and headed to Scott’s room. James ignored her as she walked by, and Val ignored him.

Scott was in bed. Except when he was in the shower, Scott was always in bed. “Are you wet?” Val asked.

“I’m dry,” Scott replied.

Val immediately regretted asking. She remembered the email from the house’s nurse that said they were supposed to say things like, “I am going to check and see if you’re wet now,” instead of asking. This was because Scott said he was dry, even when he was wet to avoid being changed.

Scott was diagnosed with Cerebral Palsy and the broad, IDD—intellectual development disorder. He could make small movements with his arms and legs. To get Scott out of bed, staff used a Hoyer lift, a piece of equipment attached to the ceiling that hooked up to a harness, and was operated by remote. Though he rarely wanted to get out of bed. According to those who had worked at the house longer than James or Val, Scott often used to sit in his wheelchair and hang out chatting with staff in the living room well into the night. They said everything changed when Scott’s brother Kent all but disappeared. One day he just didn’t show up for his regular Sunday afternoon visit with Scott. Kent didn’t call or text any of the DSPs or the house manager that he wasn’t coming, which he had always done in the past when he had missed visits.

Being Scott's guardian, Kent had to maintain a certain communication with West Park. So, the house manager Dawn was nervous when Scott's case manager asked Dawn for Kent's signature on some documents. Dawn texted Kent about needing signatures and to her surprise he replied immediately with a "sure," then followed by another text asking Dawn to send the case manager to his house. Kent included his address in his text. Since that day Dawn has often thought about showing up at Kent's house to try and get a glimpse into the reason why he disappeared from Scott's life. But she never got beyond typing Kent's address into Google Maps.

Before Scott moved into West Park five years ago he had been living with his brother. Apparently, Kent said it had become too much work "to take care of Scott in addition to his family," or something along those lines. The words varied slightly depending on which staff recounted the recounting of what some former staff had said. Not even Dawn was around back when Scott moved in, so no one *really* knew. And no one asked Scott about it either. No one asked him about why he moved to West Park. And no one asked Scott how he felt when his brother disappeared. Some didn't ask him about any of this for fear of upsetting him further, while others just didn't think to ask.

Val was about to say, "I'm just going to check and see if you're wet," when she thought about being in the bathroom with Lily not too long ago, and how she wished in that moment she could have just left Lily alone. Because Scott said he was dry, she could always say, "he said he was dry," if someone found him wet with cold urine and asked Val why she didn't change him. Still, Val felt good about this, like she really gave him a choice for once. But on her way back to the dining room table she almost turned back,

cringing at the thought of him laying in his own urine until the next time someone checked on him. Her weariness crushed that thought.

The truth was that Scott *was* wet, but Val was wrong about being worried someone would ask her about it. Nobody would say a word or make a special note about Scott laying in cold urine. Sammy would change him several hours later and be too busy to think twice about it.

Val returned to her spot at the kitchen table, saying nothing in reply to James' long exhale as he finished typing up the email about Will and the police officer. He hit send. Dawn—who was filling in as a sub at another house—would sit down to read the email. She would have to notify Will's case manager and behaviourist and this would set into motion what was always set into motion when things like this happened. Invisible walls built with words.

Still with his headphones on, Will sat up on his bed, rocking his body backwards and forwards as a series of people uttered his name over and over, across phone lines and network cables.

Ten days later

In the “med room” sat a binder labelled “Will Tinley's Individualized Support Plan (ISP), and on a freshly printed page five was written:

Goal: Will will build community safety skills while engaging with his community regularly with staff present.

Proposed strategies: Will will go out into the community with staff three times a week.

*Will will take walks in **his** neighbourhood only if accompanied by staff.*

A head poked itself into Will's room to tell him the news.

Winter

Part I

Val was in West Park, but the house was empty. The walls, windows, and doors were covered in papers, but she couldn't read what they said. Though the papers looked official, with letterheads and signatures. She tried to open the front door, the garage door, then the windows, but they were all locked. A breeze entered the house and all the papers fluttered. Val found this grotesque, because the fluttering papers made the house look like it had undulating gills or feathers. So, she retreated into the dark bathroom and shut the door. When she flipped on the light switch and looked in the mirror, it was not her face looking back at her. It was her mother's. She was equal parts mesmerized and horrified, drawing closer and closer, nearly touching her nose to the glass.

"Val? Va—aal!?" Val woke up to Dawn's voice saying in a whisper yell.

Val saw her phone next to her pillow. She didn't remember answering Dawn's call.

"Yeah, hey Dawn, sorry," Val said in a frenzied tone, adrenaline still pumping from the dream. Dawn continued, noticing nothing, "No worries. I was just trying to whisper to not wake Scott. He finally went down about twenty minutes ago. I know this is awful timing, really I do. And I know you still haven't had time off for the holidays, but I wouldn't be calling to wake you up, if it wasn't important. I texted you, but didn't hear back, so..."

"Oh no, no," Val cut in, feeling a need to absolve Dawn for interrupting her sleep.

"I mean, I did just wake up, but I was having an awful dream anyway, so no harm done," replying as if Dawn had apologized for the interruption, even though she hadn't. But it

was true that Val felt immense relief being pulled out of her dream by Dawn's call.

"Can you come in, Val?"

"As in now? To the house?"

"I'm afraid so. Sammy had an issue with her diabetes and fainted, so I'm here picking up the pieces. I called James first, since I know you didn't get off yesterday, but he's out drunk at Tilly's. His friends from high school are in town, I think. I can't blame him with all he's got goin' with his mom, and he's so young, you know."

Dawn trailed off and the line grew quiet. When she started again her tone was even more disjointed.

"I would stay, but it's my weekend with Caleb, so he's with me here at the house, and I just—if he can't tie his shoes or say full sentences, I don't think he's ready to meet Lily or—Scott, or—you know, I'm just not ready for my kid to see all this, so it would be a huge help. I'll re-jigger the hours so everything lines up—may even be able to get you paid for the two hours I've been here already, but that stays between us obviously. Sound okay?"

Val could barely process the ending of her bizarre dream, let alone all the layers to whatever Dawn was talking about, so without much thought, she spat out, "Sure, yeah, I can be there in twenty."

"You're a life-saver, Val," and Dawn hung up.

It was 1 a.m., barely the day after Christmas. Immediately after Dawn hung up, Val wished she had said no. Yesterday, she had worked both the day and evening shifts. She was supposed to get Christmas off, but there was no one to fill the day shift—the shift she usually worked Monday to Friday—which was from 6:30 a.m. to 2:30 p.m. Then the sub

who was supposed come in for evening shift at 2:30 p.m. no-call, no-showed. So, Val worked through the evening shift, to 10:30 p.m. With only two hours of sleep after all that, she felt half-dead, like her body was a corpse she was dragging around. All the same, it didn't seem like turning Dawn down was an option, and Val lacked the energy to be angry about it.

She began getting dressed in the dark bedroom. Val lived in her mom's old house. She hadn't moved anything out of the bedroom since her mom passed last May. There were ten tall stacks of audio and video cassettes arranged neatly in a line from the door to the window that could be mistaken for model skyscrapers when the lights were on, since they came up to Val's waist. A large tube TV sat in the corner. A few stacks of newspapers wrapped with string leaned against the bed. A dusty treadmill was barely recognizable in the corner. It was covered in at least five feet of stuff spanning well over five decades: everything from old board games and boxes of polaroids to Hawley High newsletters and yearbooks dating back fifty-four years, to 1961, the year Val was born, which was also the year Val's mom took a job as Hawley High's assistant principal. Some of the things in the room were marked with sticky notes, the names of nieces and nephews written on the sticky notes. Each sticky note had its own layer of powdery dust covering a name, written in sharpie.

After fastening the clasps of her bra, Val ran her hand across the headboard of the bed feeling for her dark blue denim button up shirt. In the winter it was cold in West Park, so having the heft of denim around her was nice. After buttoning the shirt, she felt her way to the desk and found her old jeans, the ones with the white stars sewn into the back pockets. The jeans were draped over the desk chair's back, where they always were

when she wasn't at work. She kept just one or two sets of clothes per season as her “West Park clothes.”

She pulled her right leg through the jeans, then her left, and swayed left and right to pull them over her hips, and as she did this her hip bumped the desk. The sound of broken pottery made Val freeze, pants still unbuttoned. Stepping over where she imagined the broken vase to be, she flipped on the light switch.

A knot appeared in her chest. Sharp shards of yellows, browns, greens, and blue were splattered on the carpet. A deep black circular stain remained on the desk, as if the vase had been on the cusp of fusing with the desk. The vase had occupied an outsized role in her life and even after it was gone it refused to be forgotten. Seeing it broken so easily, by a stray hip shimmying into work jeans, Val wanted to burst into tears and roar with laughter all at once. Instead she just looked at the shards of clay on the ground and nodded, as if agreeing with the shards that they, indeed, were no longer a vase.

Her great grandmother had hand-painted the sunflowers that wrapped their stems around the vase. Her great grandmother's name was Ruth. The story went that Val was born in Ruth's living room. Outside the living room, visible from two broad windows, were four sunflowers, which Ruth planted around the time Val was conceived. The day she was born in that living room, instead of the sunflowers facing the sun, they faced inside, towards Val, as she left her mother's womb and entered this world. Ruth spent the next several days painting the vase to commemorate Val's birth. When Val was ten, Ruth gave her the vase. Val felt it watched over her, especially after Ruth's death four years later. Val didn't think the story that came with the vase was literally true, but that didn't

matter. She still loved it for whatever truth prompted her great grandmother to paint it. Not once did Val put flowers in the vase.

The vase remained an uncomplicated and warm presence until the day Val set in motion her mother's move to the Alzheimer's unit. That day, her mother draped a sheet of uncertainty over the vase. After that day, when Val raked through her mind to unearth what the vase meant to her, the thoughts slipped through her fingers. But that was before the vase was a collection of shards scattered on the floor of her mother's old bedroom, which had become Val's bedroom. Now, she hoped it could just be trash, plain and simple.

Val's mother, who went by Essie, approached having Alzheimer's the same way she approached the rest of her life: methodically, relentlessly. The day she forgot whether Shirley Caldwell, one of her many "dear old friends from school," liked red or white wine, Essie scheduled an appointment with her doctor about her "mind going sour."

She had bought a red and a white, strategizing how she would read Shirley's face to determine which bottle Shirley assumed was for the guests of the birthday party and which bottle was her present, and Essie would maneuver the bottles accordingly. Essie plotted these wine bottle maneuvers in her mind as she looked for her car. She thought she parked on the west side of the liquor store's lot. Her red 2008 Honda Fit was in the Dollar Tree's lot across the street from the liquor store, following an old habit she picked up while she was principal at Hawley High.

"You alright, ma'am?" The liquor store clerk popped his head out into the lot to ask. Essie turned red, embarrassed and a little annoyed. The unwelcome interaction

jogged Essie's memory, though. "Yes, I'd forgotten something, but now I remember."

The clerk watched with skepticism as she crossed the street to the Dollar Tree's lot and got into a red Honda Fit.

Given that she had been principal of the school for twenty years, and for twenty years before that she had been assistant principal, she could have forgiven herself for a brief slip into her old sneaky parking habit. But she did not forgive herself. She called the doctor as soon as she got home. After she hung up, Essie chuckled and muttered to herself, "oh Doc, what hath you wrought?"

"Doc" referred to a deal she struck with herself and her family the day she turned sixty: If she forgot two important things in the span of three hours, she would call the doctor. Alzheimer's hung over her heavily since her "daddy died of a sour mind," as her mother put it. Essie was born when her father was sixty-five and at seventy-five he was institutionalized somewhere in Indianapolis. She remembered her father being gone suddenly, along with some white-coated man explaining that, "the thin line between his mind and body had become the size of a football field," and so if she was with him, she was really, "a football field away from him," so "no, I'm afraid you won't be able to visit him."

Essie suspected her mother had sent him away as soon as he started acting strangely, even though she "couldn't remember a single strange thing that man had ever done in the ten years" she'd known him, "not one damned thing!" And this being the crux of her last and biggest argument with her mother, she yearned to figure out how to avoid the same fate as her father, if she ever came down with a "sour mind."

The struggle was balancing continued connection with her loved ones, while

ensuring they wouldn't lock her up somewhere too soon. So, when she turned sixty in 1991, Essie created a document that was the fruit of this struggle. She titled the document, "The Doc," thinking it gave the whole thing a lighthearted touch, in hopes of lessening the somberness for her kids' sake, even though they were both in their thirties at the time and already well-acquainted with loss.

"The Doc" laid out detailed instructions and rules for her kids, Valerie and Kenneth, in case she was diagnosed with Alzheimer's, or began "exhibiting symptoms." She finished writing the document and printed it out just before sundown on her sixtieth birthday, before Val came over for cake and hot cocoa.

"Mom, this won't be necessary at all."

"It is absolutely necessary."

"Mom, come on, it's not like we were going to *not* take care of you."

"That is *not* the point, Valerie."

Essie's tone cut the air, leaving her daughter startled and silent. Val almost added that it was a ridiculous idea to withhold all the stuff in her house from Valerie and Kenneth *unless* they followed The Doc's instructions. Val almost added that times were not like those when her father was diagnosed, that people couldn't get locked up for showing minor symptoms anymore—at least she was pretty sure they couldn't. Val almost added that she wouldn't dream of walking away from her mother, the woman who held not only the history of a school, but the history of a whole town inside her. Val was going to add that after all Essie had given of herself to Val, Kenneth, their whole community, all while being a single mother, Val couldn't imagine walking away from her. But instead of saying any of that, Val just nodded in affirmation.

Essie reached into the pocket of her slacks, pulled out a pen, and handed it to Val to sign the document. Kenneth was out of town and Val told Essie to “tell him yourself,” after Essie asked if Val could “inform him of the arrangement.” Essie broke the silence that followed with a joke that had something to do with the death of a turkey vulture on Thanksgiving. “Shut it, mom, that’s an awful joke,” Val said while laughing so hard she nearly choked on her hot cocoa.

Twenty years later, in 2011, Essie was officially diagnosed with Alzheimer’s and The Doc came alive like a magistrate. First, Essie saw her friends less often. The Doc laid out a plan for seeing her friends one less day a month, until she didn’t see them at all. Before her diagnosis, she went to Hawley Family Diner to meet her friends every week—fellow retirees of Hawley High and other former public servants who vividly remembered the town’s bygone era of prosperity. Essie figured she could disappear from her group of friends without much trouble, as it was typical for people to fade away from the diner due to declining health. Her heart warmed at the concern they showed when she was only coming to the diner once a month, but she brushed them off saying her car had been acting up on her. She felt bad lying, but it was so deeply ingrained in her that divulging her Alzheimer’s diagnosis was a social death sentence.

As per The Doc, as soon as she forgot the way to Hawley Family Diner, she turned back to head home, never to set foot inside again. It was not lost on Essie that she was isolating herself. It pained her immensely. But she still thought it was better than leaving the isolating up to others, letting others dictate when they determined she was not the same Essie, not the Essie they wanted to be around anymore. That thought pained her

much more than slowly fading away on her own terms.

Then Val moved in with her mother. According to The Doc she should have waited until Essie needed help with cooking and bathing, but Val saw the isolation unraveling her mother. Following a mandate from The Doc, Val had been going over to Essie's once a week to organize her mother's valuables so family members could easily claim them. But it just wasn't enough time. Essie yearned for time with others, real presence that Val was unable to give by coming over only once a week. Even though Val was overstepping the timeline laid out in The Doc by moving in before Essie *technically* needed it, Essie never said a word about it. She knew it was exactly what she needed for her emotional health. The version of Essie that wrote The Doc twenty years ago missed that.

Once her mother did need help cooking and bathing, Val found out she could get a little money through a Medicaid program for people who cared for the physical needs of family members. With that money and no rent to pay, she was able to quit her job as manager at the Dollar Tree, and support her mother full time.

Three months later The Doc spoke up again—its final mandate. Val became Essie's sister, cousin, mother, her college roommate. While she was thankful that her mother wasn't threatened by her presence, Val felt an isolation deeper than any she had ever experienced. She didn't expect it to feel like that. Years earlier, when Val first read the line in The Doc about a "failure to accurately recognize my loved ones," it may as well have been a line in a psychiatry textbook. It had nothing to do with her. Now, she moved through her mom's house as a ghost of her mother's past. For Val, it was like looking into the absence of herself when her and her mom's eyes would meet and her mom saw no daughter, no one named Valerie.

Val neglected to follow through with The Doc's last command when the time came. If she were following it as Essie intended, she should have made the phone call to the Alzheimer's unit a week earlier than she did. For that week, though, Val toyed with disregarding The Doc altogether, because, she felt entirely capable of supporting her mother regardless of whether she recognized Val. If she had dug deeper into this toying, she would have found its root in an assumption that Essie was "basically not present anymore," because she assumed that with the departure of Essie's recognition of Val also came the departure of Essie—or, at least the departure of the Essie who wrote The Doc. So, if she broke that contract now, who would stop her? Val believed she was the only one in the entire world aware that Essie had stopped recognizing her loved ones.

These thoughts sat just below Val's consciousness, because in her consciousness the calculation was simply that she wanted her mother to live as long as possible in her own home. But the next Sunday swallowed up Val's confidence and ended with Val making the phone call to the Alzheimer's unit.

Val was in the kitchen that day, trying to sort out what was worth saving and what wasn't: which knives were dull beyond hope, which glasses were chipped or cracked. Her mother had just woken up from a nap. It was early March and the sky was dark above Hawley, threatening snow, so even though it was only five, the light outside was a deep gray-blue over the brownish late-winter grass.

That evening Val noticed sticky notes on the corners of the two china cabinets in the dining room with her niece's name written on them. She texted her brother, "does she want any of the stuff inside the cabinets? Did they look through it? Did you look through it?"

It was a text prompted by the chance sighting of the sticky notes followed by a random thought that popped into her mind. Val expected he would either not reply or it would take days, but to her surprise within seconds her phone buzzed with a text from her brother saying, "no, you can pitch that stuff. Thanks."

The cabinets held some china, several Japanese tea pots, little ceramic figurines in fancy clothes, taking off their hats, taking bows and curtsies, their paint dusty, and set of hand carved wooden animals, apparently from the same artist: a turtle, cow, and an elk. These were gifts given by her mother's friends, some of them handmade especially for Essie. Val wondered where these friends were now, who had given these gifts to her mother, whether any of her friends at the diner would know, though Val would never go and ask. Val would never pitch any of these gifts, and neither her niece nor her brother would pick up the cabinets.

As Val drafted a curt reply to her brother's text asking her to throw away "that stuff," she heard a scream from her mother's bedroom. The exchange with her brother had unsettled her usual calm demeanor, so she rushed toward the bedroom with unkind eyes.

"What's wrong, mom!?" Val hollered on her way through the hallway. Since Essie had stopped recognizing Val earlier that week, Val had been careful to not use words that identified their relationship, letting Essie define it moment to moment. But she was reacting faster than her thoughts could keep up, so the word "mom" just fell out.

Essie had her hands wrapped around the sunflower vase. Her arms pulsed with flexing muscle tissue, swollen veins, and the heaving of Essie's lungs caused the vase to rise and fall. An image of the vase succumbing to the pressure and popping like a balloon struck Val, as she exclaimed, "What on earth?!"

Val lost control of herself. With that control went her ability to *see* her mom, instead seeing only a looming threat to a precious object. Val had every intention of leaping toward her mom and grabbing her wrist and the vase. But before Val could make a single movement, Essie released her grip on the vase. It was Essie who fell to her knees weeping, exclaiming, “it’s ruined,” as tears began to stream down her face. During those moments that Val’s gaze traced the length of Essie’s arms to the vase, Val had seen Essie as a volcano whose core was rage threatening to erupt and destroy. But that was wrong. Val saw now that her mother’s movements were not angry, but sorrowful, as if Essie were trying to undo a tragedy by destroying the vase. Val was suddenly struck with horror at what she had been so ready to do, at how she could have easily injured her mother, how she would have made her mother fearful for her safety in her own home.

Beginning unprompted, Essie tearfully explained, her eyes still pointed at the floor. “This was my grandma’s vase. She built her own kiln out of bricks. She fired the vase herself. She gave it to dad and he took it with him when they locked him up. It was sky blue. When I was little, I imagined that he could see me grow up by touching the vase. It let him float into the sky and see me from above, because when I first saw the vase, it looked like someone had caught a piece of sky and brought it to the ground. But now someone has painted tacky flowers on it. Was it you?” Essie turned her head back toward the corner of the room to look Val right in the eyes as she said this. Val shook her head, ‘no.’

That night Val decided to cook a three-cheese macaroni casserole. She wanted to enjoy at least one moment that day. Essie was still on her knees in the bedroom when Val walked silently out into the hallway and into the kitchen to begin prepping the casserole.

It wasn't conscious, but whenever she was fed up with an interaction with her mother or, later, with someone at West Park, she went into the kitchen to escape, either to clean or cook.

As Val sprinkled the second layer of cheese over the casserole, Essie appeared in the doorway to the kitchen.

"I need a shower."

"Can it wait?"

"No, I'm all itchy."

So Val washed her hands of cheesy residue in the kitchen sink and followed Essie into the bathroom. Val was still deeply unnerved by the scene in Essie's bedroom. Her hands and arms were compelled to move a little too briskly, scrubbing Essie's legs with a little too much pressure, maneuvering Essie's limbs with rigid starts and stops rather than gently gliding them into place as she usually did. Essie's eyes followed the starts, the stops, the just-a-little-too-hard scrubbing, taking notice of the feelings Val's hands wrote into Essie's skin, the sponge a pen whose ink was just faint enough to not be read aloud. If Essie protested, Val could say, "what are you talking about?" With the ink of Val's violence so faint, Essie would have nowhere to point and say, "this, here."

None of this was lost on Val. She knew her hands moved with violence and with every moment she decided to stop, but the deciding had no power over her arms and hands, as if they had been colonized by all the anger and confusion she was trying not to feel in the moment. Her mind had slipped onto unsteady ground after hearing what Essie said about the vase. She didn't totally believe Essie, but she couldn't find a way to totally disbelieve her either. What Val was left with was a history as muddy as the clay before it

formed into the vase. The vase *did* have sky blue peaking out behind the sunflowers. But Val had never thought of it as any more than the background, a canvas to make the sunflowers shine more brightly. Now the sky blue cried out to her, but she was unsure whether there was any truth inside its cries.

“Ow, that hur—” Essie stopped short of making an explicit accusation as Val stopped, lifted the sponge, and looked down at her mother’s leg. Essie knew that an accusation would be like accusing a baby of sadness while it shed tears: the words would be sucked up, processed, and released as further secretions, evermore salty, evermore dense with resentment. Essie did not need to recognize Val to see that in her eyes.

A red spot shown bright on Essie’s thigh, but it began fading under the shadow of the sponge in Val’s right hand. Val was stiff, her left hand held the detachable showerhead pointing the water at the shower wall, her body arched over Essie’s as she watched the red spot disappear.

Val waited until Essie was asleep before making the call. A pre-recorded voice message on the other end instructed Val to type in a web address to finalize Essie’s admission. She followed the instructions on the website, wishing there were other options for her mother. They were doing what Medicare would cover. And even without The Doc, it felt untenable to Val to keep Essie in the house with a home health aide popping in every now and again. Val thought if Essie stayed at home, she would have to put locks on doors and hide fragile and dangerous items. All that sounded like more than Val could handle. Val imagined Essie asking her who she was and what she was doing as she installed locks throughout the house. The image alone was too much for Val to bear.

Essie had foreseen all this and already made the hard calls in The Doc so nobody

else had too, and Val was grateful to her mother for that. Val wondered in this moment if this last stage in The Doc's timeline was more for her than for Essie. There was probably a way they could have prepared enough to keep Essie at home, but this was just like the diner. Just like Essie orchestrated a pulling-away from her friends, she orchestrated it for her loved ones as well, because that was what she wanted. Even conceding this final point—that this was what her mom wanted—making this last hard call her mother had made twenty years earlier come to life in the present still felt to Val like welcoming a monster into their lives. Val finished the forms and clicked “Submit and Finish,” and then she began to cry.

Val swept the shards of the sunflower vase into a dustpan, wondering whether it would be easier or harder to wake up in the morning every day without the sunflowers staring back at her. She tipped the dustpan into a grocery bag, which filled with the ceramic shards. As she walked out to her truck, she realized she was still holding the bag of shards in her left hand, so she threw it in the back before climbing into the driver's seat. She texted Dawn, “heading over.”

“Let's put you on your side now,” Val said, as she forced her hands between Scott's back and the bed. She was proud of herself for remembering the nurse's instructions to not “ask,” but instead, “tell him what you're about to do.” As she repositioned Scott from his back to his side, a dull pain shot through Val's wrists, wrapped around her forearms, her elbows, then her shoulders before swallowing her back whole. For weeks now, sharp pains shot through her wrists and back whenever she adjusted Scott's position in bed. The

pain always dissipated quickly, but she told herself if it began to linger she would see a doctor. Until then, it seemed more worthwhile to spend her days off resting.

"Hold on," Val said in a strained whisper, as she took her hands away from his bare back. Scott's bed frame had guardrails on both sides, consisting of four parallel bars on each side. Before Val took her hands away from Scott's back, his fingers and palms wrapped around one of the bars. His nose peaked through a gap between two of the bars. As Scott grasped the bar to keep himself from rolling onto his back, Val looked through the closet for spare blankets or pillows, but there were none. She needed either blankets or pillows or a comforter to prop him up with, so he could lay on his side. His position had to be changed every few hours, so there was usually something on hand next to his bed, but Dawn must have mistaken it for dirty laundry.

"One sec," Val said as she tried to walk quickly and quietly to the laundry room on the other side of the house. "Hey, hey, wait!" he yelled after her, quivering as he held the bars. This made Val wince as she glided through the living room, hoping the yelling didn't wake Will, who was a light sleeper.

She could have guided Scott onto his back again as soon as she realized she would have to run to the dryer for something clean. She could have asked, "hey Scott, you okay like that while I run and grab a clean blanket for you?" She could have even just told him what she was about to do—a simple, "gonna go grab a blanket real quick!" Instead her, "one sec" left him suspended with no idea what would happen next as his fingers grew whiter and his palms redder, holding onto the bars.

On her way back from the dryer, Val broke into a jog with a blanket squished under her armpit, her own "one sec" comment rattling around her mind. She had her suspicions

about Scott's brother, Kent. The fact that he rarely returned their calls made her doubt the quality of care he gave Scott before Scott moved to West Park. How many times had Kent neglected to reposition him in bed, leaving Scott to collect sores? How many times did Kent leave Scott in soiled clothing? How many times did his brother say, "one sec," when that really meant one hour? Val began to wonder if there were times the nurse's assistants at the Alzheimer's unit moved or touched or didn't touch Essie in ways that reminded Essie of Val's missteps in caring for her mother. Did a nurse's assistant scrub too hard one night in the shower? Did Essie relive that night with Val over and over, or was it forgotten immediately? There was no way for her to know, and seeing herself and Scott's brother in similar roles—as family, as former caretakers who gave up for one reason or another—Val felt a rush of sympathy with Scott's brother, who—who knows—maybe Kent was a single dad with a backbreaking job who just couldn't support Scott and sent him to the waiver home for Scott's own good. Maybe he didn't call back because it was too painful, a reminder of his inability to support a sibling whom he loved.

Val got to the threshold of Scott's open door and saw every muscle in his face straining, his grip loosening on the bars. Val's visions of Scott's brother and herself as protagonists in similar tragedies collapsed as she ran to Scott's backside, one hand pushing his back to support him, while the other stuffed the blanket between his body and the mattress. Then Val gently eased him onto the compressed blanket's support, so that he could lay on his side with no effort. The movement of Scott's body corresponded with a searing pain that snaked through her wrist and then took up residence in her upper back.

Although only he would be aware of it, this episode would make Scott's arms and palms sore for nearly twenty-four hours. The muscles in Scott's hands and arms were not

always this weak and tender. A person who worked at the house a couple years back used to give him stress balls to squeeze. Her name was Kris, and she could have been fifty or thirty-five. It was hard to tell, because she moved with an aura of both wisdom and child-like wonder. She would bring him a stress ball to squeeze in the evenings and sit with him while he watched *Everybody Loves Raymond*. That show made her laugh with her whole body. In general, Kris carried herself with laughter, but nothing got her going like Ray Romano. When her shift was over, Kris would take the stress ball with her, so he only got to squeeze them when she was around. She brought him stress balls of all shapes. Once, she brought him one that looked like a hamburger, which made him laugh. One time she brought him two—one in the shape of a pink frog and one shaped like Winnie the Pooh, one for each of his hands. When Kris stopped coming to the house, Dawn came. Scott knew something bad had happened with Kris, but he never figured out what, and nobody told him.

Scott's hands were about to lose their grip when Val came back and bunched up a blanket and shoved it into the crease between his body and the bed, tucking it into the crease with the tips of her fingers. The blanket was warm, fresh out of the dryer and it felt good against his back. He faced the window. It was snowing. "Do you like the snow?" Val asked in a whisper. Scott shook his head, 'no.' "Aw, that's too bad; I think it's beautiful," She said while stroking his hair, which was a dark gray speckled with white. "Do you prefer warm weather?" Scott was silent as he continued looking out at the falling snow. Val took her hand off his hair. Scott looked relieved. It had been nearly six months since she began working at the house and Val wondered if she would ever connect with him.

In the med room, Val checked the box next to “1 am” and under it in an empty space wrote “from laying on back to laying on right side.” She closed the three-ringed binder labeled, “Scott Donovan's Reposition Chart” and pulled out a binder from the shelf labeled, “Night Shift Checklist” and opened it to December 26th, 2015, bringing it out into the kitchen to check tasks off as she worked. Val stuck close to the checklist, because this was Val’s first overnight shift.

Sammy had been doing overnight shifts seven nights a week for four months straight. There had been no permanent weekend overnight staff since June. So, for all intents and purposes, since September, Sammy filled that role. Val thought it set a bad precedent for Sammy to work so much, that it made anyone who wasn’t willing to work any and all open shifts look weak or like they didn’t care about West Park. It *was* a point of pride for Sammy how much of herself she gave to the house, but really her work ethic had more to do with trying to climb out of medical debt. And now she was in the hospital.

Val swept the floors in the kitchen and living room, wiped the kitchen counters and the stovetop with a dishrag, afterward making three checks in the “Night Shift Checklist” binder, when she saw she had forgotten one kitchen task. Val dumped out the ambiguous slimy contents of the sink strainer, washed her hands and made another check. The heavy silence of a spin cycle ending came over the house as Val remembered to check on Will.

She cracked Will’s door open trying to squint to see through the darkness. He sat up abruptly with a loud inhale through his nostrils, and looked directly at Val with bleary eyes. “Sorry!” she whispered with a start, “you can go back to sleep,” and as if seeing someone peer into his room at his sleeping body were the most ordinary thing in the world, he laid back down and fell back to sleep immediately.

Val went to the laundry room and moved clothes from the washer to the dryer, others from the dryer to a hamper. Then she transferred a pile of dirty towels from the floor to the washer and added detergent. She stared at the ceiling wondering what she had meant to do after laundry. She peeked at the checklist, and it sent her to the bathroom to mop the floor, clean the toilet seat, and then to sanitize all the doorknobs. Then to take Lily to the bathroom. It unsettled Val that “Assist Lily with toileting” was on a list next to “Sanitize doorknobs,” but her exhaustion made it impossible to hold that concern in her mind for long.

After checking the rest of the boxes in the “Night Shift Checklist,” she put the binder up on a shelf in the med room, she saw Scott's reposition chart out of the corner of her eye. She let out a “shit”—before she could stop herself—because the chart reminded her that she'd forgotten to keep up on his repositioning. She checked the clock in the med room and it read 4 a.m. In the reposition binder, 3 a.m. had an unchecked box next to it, and after a moment's consideration as to whether she should just check the box and move on, she went into Scott's room. Val took the blanket out from his side, and with one hand gently ushered him onto his back. He opened his eyes briefly to see what was being done to him and by whom, then closed them again, falling back into sleep.

Val sat down for the first time at 4:30 a.m. As soon as her body relaxed and sank into the couch, her eye-lids began drooping, threatening to shut entirely. She had heard about overnight staff being fired after being found in the morning passed out on the couch. Her eyes closed for a few seconds and an entire scene played out in a half-waking dream of her getting fired, having to sell her truck and crawl back to her job at the Dollar Tree. She assumed if you got fired for negligence like that, you'd be shut out from any

work with people with intellectual disabilities forever in every state and city. But she was wrong about that.

Val got up after only a couple minutes on the couch, found her thermos with yesterday's cold, half-drunk coffee in her bag and gulped down all of the soggy tree bark taste. Giving 6 a.m. meds was the next thing she knew she had to do, but 6 a.m. was over an hour away. Still, she needed something to do to stay awake, so she began prepping everyone's morning meds, anyway. Having never done morning meds, it took Val nearly thirty minutes to go through and check the med documents and the pill containers.

While prepping meds, Val saw that Will was overdue for a shower, according to the bathing tracker in his med book—each person who lived here had a spot for tracking the last time they'd showered. So she knocked on his door while cracking it open, "Hey Will, time to get up for a shower." Her voice grew in volume with each word. He turned to face away from her. She went deeper into his room. It was still dark out, but the outlines of objects were discernable by the light from a History Channel documentary about Roman warships. In the corner was a dorm room style desk and chair. DVD cases were scattered on the desk, but she could not discern the text or images on them. In another corner was a pile of backpacks and messenger bags—Will's collection. The one on the top of the pile was made with reflective material. Val saw her distorted reflection peppered with zippers and buckles every time a bright image shown on the TV. She made her way to the foot of his bed, stepping over the outline of an empty laundry hamper.

"Will, Wi—ill," she said in a loud whisper while checking her phone for the time. Val inched closer until she was next to Will's head, then she tapped his shoulder with one

finger, then two, then five, patting his shoulder, then shaking it. He sucked in a large breath through his nose as his torso shot straight up, relieving his shoulder from her wobbling grasp. “Time to shower Will,” Val said. “Don’t want to,” Will said bluntly. “But you need to,” Val retorted, “it’s been almost five days, Will.” Will looked up at the ceiling, then lay back down. She checked her phone again for the time, and it set her heart racing. She knew her job was to sit there and convince him, it was almost time for everyone’s morning meds. The meds, the shower tracking, the possibility of having to talk with the behaviorist or Dawn about how Val “*didn’t* succeed in getting Will in the shower,” about his “apparent strong feelings about not taking a shower”—it was too much. “If you take a shower, you can go out to breakfast Monday, when you see me next,” Val finally blurted out, and immediately Will sat up and looked at Val in the eyes, measuring, Val assumed, how much truth he could see her eyes. No staff had ever taken him out to breakfast. Lunch, sure—he had been taken out to lunch tons of times. But they always had breakfast at the house, and it was always mediocre at best—oatmeal, bland grainy cereals, or sad pale sausages and frozen Wal-Mart hash browns on a good day. Five or six more seconds passed of eye contact before Will quietly put his feet to the floor, stood up and walked to the bathroom. Val emptied her lungs, ashamed and relieved.

Bribing, power struggles, coercion. Open Doors trained its DSPs to never engage in these, but most did at some point. For most, it was a reflex to being trapped. A DSP is trapped when a document says a client must do or not do something and then that client refuses. A refusal here and there is easy enough to move on from but if they pile on,

parents and behaviorists and caseworkers start asking questions and the DSP is in the middle of it. Those who oversee the DSPs are pressured and transmit that pressure to the DSPs who transmit it to the clients. But, if the DSP makes a bribe, the issue is papered over. The boxes get checked and the only person affected is the client. Their world transforms into one where at any point, something they wish to do is held hostage by something they wish not to do. Their world transforms into one where their will or wishes could be undermined at any moment. But because bribes, power struggles, and coercion are never documented, it is as though they only exist in their effects on clients. And a client's word is only ever given, at best, lip service when colliding with a DSP's word. Bribes, power struggles, and coercion will continue undermining everything Open Doors and organizations like it stand for, unless clients are treated as humans with the capacity of witnessing.

The door to the bathroom was slightly ajar. Val stood in the hallway waiting for the sound of the shower to begin. As she waited, she leaned against the wall, looking away from the bathroom toward the living room. Snow fell outside the window. The shards of the sunflower vase in her truck came into her mind. Pretty soon the shards of the vase would be covered with snow. A worry sprouted that when she got off work they would go unseen and forgotten, invisible under snow. She held them in her mind so she would not forget they were there. Val unstuck her gaze from the window down the hall and checked her phone. It had been almost five minutes now and the bathroom was still silent.

“Hey Will, you okay?” Val whispered to the sliver of light between the bathroom

door and the doorframe. There was no answer. In one motion she knocked on the door with her left hand, while opening it slowly with her right hand. The knock was an announcement that the door was opening rather than a knock that asked whether she could come into the bathroom. She was caught off guard by how relieved she was to find him still clothed.

Will stood in the middle of the bathroom, not moving, facing Val. He leaned forward like he needed her to demonstrate her willingness to help him, before he could say what he needed. She wished she had read Will's Individualized Support Plan more closely when she began working at the house, because surely there was something in there about showering. Her first day on the job, she just sat in the kitchen reading all the clients' ISPs. This was how everyone's first day working at West Park went, but not knowing the people referred to in the documents made very little stick in anyone's mind. She had felt even less incentive to pay attention when Dawn handed her the ISPs and said, "you may as well skim, mostly you'll just learn by doing and seeing as others do." But Val had never been at the house when Will took a shower, so she was lost in that bathroom with Will. Regardless, there was no time to run to the med room, grab his ISP and sift through it. Not to mention that the whole image of her leaving him in the bathroom and running off to grab his ISP struck her as someone, in a pinch, consulting a manual for a person, and that rubbed her the wrong way. As much as Val worried about being by the book, that was too much.

"Do you need help taking a shower?" And as soon as the words left Val's mouth, she felt her body cringe, as if bracing for a blow. "I need help," Will replied. "With undressing?" And as she asked this, she remembered James telling her about a guy at

another Open Doors waiver home, a guy diagnosed with autism, who would ask for more help than he needed bathing, because he got off on being touched while showering. She remembered James saying that this guy targeted women who worked there, especially. This memory spread fear through her whole body. As far as Val knew, Will had done nothing inappropriate or violent to her or anyone else and she was pretty sure he never would. If something like that had happened, she assumed it would be gossiped about, eventually making it to her ears.

This had happened with Scott, even though she didn't think his offense deserved the scathing gossip. She actually felt quite sorry for Scott. He apparently had reached out to touch a DSP's hip several years ago, and the story still spread. Maybe because she thought of Scott as so gloomy, she found the image of him reaching out for human touch an especially sweet one. Or maybe because Val herself did not follow Open Doors' strict rules about staff and client touching, with a history of embracing Lily and stroking Scott's hair behind closed doors. Though she would never admit that she did these things let alone that they influenced her view of Scott's actions.

But there was no gossip about Will, so she felt ashamed that every bone in her body was telling her she would be wise to turn and run out of the bathroom, then out of the house, then keep running until she couldn't. She caught a glimpse of her face in the mirror and was filled with relief that it was utterly blank, like a mask.

"No," Will answered, while Val struggled to remember what her question was, since her mind had wandered so far, so quickly. "I can take my own clothes off," Will added, flatly. "So what exactly do you need?" Val asked after a minute of staring blankly at Will, realizing she had yet to ask what he actually needed, because she had been so

concerned about touching him. “Unlock the soap,” Will answered while pointing at a cabinet in the bathroom with a metal keyhole next to the handle. Then he extended his arms straight out towards her, palms open to the ceiling, ready to receive the shampoo and body wash as Val jangled her keys in front of the cabinet.

Part II

When Val got home Saturday morning at 6:45 a.m. she immediately went to bed. Apart from making herself microwave meals and using the toilet, she stayed in bed until twenty minutes before her shift on Monday at 6:30 a.m. She had hoped staying in bed would make the pain stop, but it didn't. A threatening dull ache lingered, floating around her back, though focused most sharply in her upper back and shoulders. Her nearly forty-eight hour stay in bed had also not rejuvenated her energy. She was still exhausted, except not in a sleepy kind of way anymore. Instead, it felt like someone had attached ten-pound weights to each of her limbs.

When Val got to West Park, James was in the kitchen making breakfast. The house smelled like sausage, and this made Val queasy. She saw Lily wasn't wearing the

“Don’t Tread on Me” shirt. So she grabbed it from Lily’s room. Lily was in her usual spot in her chair in the living room, asleep. After waking Lily up, Val changed her shirt right in the living room. Val was so out of it with exhaustion and pain, it did not occur to her that she violated Lily’s privacy. And only after she changed Lily’s shirt did it occur to her that she needed to clock in.

At the computer Val noticed a sticky note on the monitor, “Val, please do shift notes for your overnight.” There was no signature. Val remembered almost nothing of the last couple hours of her overnight shift, so it didn’t surprise her she had forgotten to do notes. After setting up Will with his shower, an exhaustion set in so deep it felt like the conscious part of her brain mostly shut off. Something about that interaction with Will in the bathroom completely drained her, and while she knew it was probably significant and rooted in some kind of past trauma bubbling up, there was no way she could dig into that right now. To crack that surface would release a torrent that would consume her. She just knew it.

Val clocked in with the Time Clock program on the computer. Then, she opened the program where they input shift notes and began typing one or two sentences for each hour she was there during the wee hours of Saturday. When she got to the last hour, without thinking she typed, “the vase,” and caught herself. She hit backspace and a panic welled up in her. What had she done with the bag of shards? She couldn’t remember at all. But also why was it on her mind? Did she care that much? She didn’t know. It was basically a bag of trash. She picked up a pen from the computer desk and wrote on the back of her hand, “check truck for bag after shift,” and tried to put it out of her mind.

After finishing the hourly notes, she moved on to filling out Scott's urination and bowel movement charts. He hadn't gone at all the whole night, so it didn't take long to fill out the chart. Val's body still felt heavy. She didn't want to get up yet, so she decided to scroll through Scott's last few days of charts. It took her reading the urination and bowel movement charts five times to believe that what she saw was actually what was on the screen. Val yelled towards the kitchen.

"James, come here!"

As James appeared behind Val, he spoke abruptly and awkwardly, "Hey Val! I didn't hear you come in. How's it going? I heard you did your first overnight. How was—"

"We might have a situation," Val said, cutting him off. She was far too focused on the issue at hand to sense James' nervousness.

James peered over Val's shoulder at the screen, taking it in for ten seconds, his eyes scanning over the chart over and over. Finally, he whispered, "holy shit."

"Right? James, if this is accurate, it means Scott hasn't peed in three days."

"We have to call Dawn," James said.

Dawn's reaction surprised Val. She sounded angry, not worried like James and Val. "That pain in my—" Dawn began, but stopped herself, lowering her voice and continuing, "he's done this kind of thing before. I'll be right there."

Val wondered if calling Dawn was the wrong move. If Dawn came in upset with Scott, Val couldn't see how that helped anything. James began to panic. His face reddened as he paced back and forth, muttering under his breath. Val was worried, too, but James' reaction seemed a bit extreme to her. So now, Val needed to keep James away

from Scott, and keep an eye out for Dawn, so Val could try calming her down before she went into Scott's room. Having a panicked James and angry Dawn hovering over Scott sounded like a sure-fire way to make things worse.

"James, can you tell Will to get ready to go out for breakfast and set out Scott's breakfast, and help Lily with hers," Val asked, and James scurried off to Will's room without question.

James didn't process the words "get ready to go out to breakfast" even as he spoke them to Will, because he was still panicking about the situation with Scott. Will heard the words loud and clear, though, and was so excited to experience breakfast out with James. He raced around his room, and back and forth to the bathroom, getting ready faster than he ever had before at West Park. It didn't occur to Will that Val might take him out, because Val had never driven him anywhere.

James was still pureeing Lily's food when Val picked up the plate of non-pureed sausage and hash browns and went to Scott's room.

"You hungry, Scott?" She asked, poised to press the remote control for Scott's bed that shifted him into an upright position.

Scott shook his head, 'no.'

Val let go of the remote, sat his plate of food on his bedside table and got a chair from the kitchen. She placed the chair next to Scott's bed and sat down.

"Did you hear what we were talking about out there?"

Scott nodded his head, 'yes.'

"Yeah," Val paused and looked down at her hands, then added, "so what do you think?" Val asked in a gentle tone.

“I need to pee.”

“I’m sure you do. It’s been several days since you’ve gone,” Val said, trying to avoid any accusatory language. “Do you have any idea why you haven’t gone?” She added.

Scott’s eyes drifted from hers to the ceiling, and after nearly a minute of silence, Val said, “So are you having trouble peeing?”

Scott nodded, ‘yes.’

“Do you want some water or juice? Cranberry might help.”

Scott’s brows furrowed.

“I don’t want a drink,” he said firmly, as if she had offered him a foul-tasting medicine. Val was taken aback by this, and she had an impulse to tell him Dawn was angry with him and on her way, but she crushed the impulse. She did wonder if asking him if he was having trouble urinating was putting words in his mouth, or giving him an out, but she also knew he had a hard time processing questions, so it felt wrong to not throw some reasoning out there to help him think through what he was feeling. Val cleared her throat to prepare the gentlest tone she could manufacture.

“Is there anything I can do for you or get you that might help you pee?”

Scott paused, appearing to mull the question over. Finally, he shook his head, ‘no.’

“Do you want me to sit in your room with you?” Immediately, Scott nodded and spoke up, “yes,” in a cracked voice.

“Okay, I’ll stay for awhile.”

During the next twenty minutes she sat with him, Scott did not look at Val or acknowledge her in any way. But Val watched him intently. She had never seen him look so calm. Usually some bit of his face was strained, but for once, he looked genuinely relaxed. For the first ten minutes, she felt honoured, like it had to do with her presence, but as she sat there longer, she realized that was unlikely. He did not particularly like Val—that was obvious—and he looked at a spot at the ceiling the whole time she sat with him. Maybe it was that he actually got to decide how a moment unfolded. Or, maybe he just wanted *someone's* attention and that's what this whole not urinating thing was all about. For a little while Val flipped between reasons: whether he was manipulating her, merely exercising control over his environment—or if he genuinely wanted her there for comfort. But then she decided to just try and enjoy the quiet moment they shared, accepting that she did not know what any of this was about. As she sank into the moment, she forgot that Will was expecting to be taken out to breakfast, and she forgot Dawn was coming.

As Dawn entered Scott's room, she bellowed, "For Christ's sake, are you putting one over on this woman?"

Val got up from the kitchen chair she had dragged into Scott's room.

"At ease, Val!" Dawn said puffing out her cheeks.

"I was just-" Val started.

"Oh come on, Val, I was just joshing with ya," Dawn interrupted, deflating her posture and softening her face. "Joshing" was not what Dawn was doing, but it was all she could think of to say to wipe away Val's caught-in-headlights look. Dawn grabbed

the chair by its shoulders and pulled it out into the hallway. Val saw flashes of elementary school kids squirming in chairs outside classrooms. When Dawn walked back into Scott's room, there was no room for Val to squeeze out and was forced to shuffle to the other side of Scott's bed.

In Scott's small room, the three of them made for a crowd. Val sandwiched between Scott's bed and the window, Dawn standing between piles of four feet by four feet pads, used for soaking up urine, and Scott, who lay in bed staring at the TV, which was playing a Tim Allen movie on mute. The tiny walkway between Scott's TV and the foot of his bed was the only standing room not occupied. Scott's face remained pointed at the TV, but when Dawn entered he pushed out his chin and tightened his lips.

Dawn was the largest and strongest person who worked at West Park. Whenever Scott or Lily ended up in an awkward position or one of the lifts broke, the responsibility of lifting them defaulted to Dawn. James was a close second in strength, but he lacked the experience in lifting other people, so because of his poor technique, even if both James and Dawn were present, lifting always fell to Dawn. She meant to teach James the specifics of lifting Scott and Lily, but they were all spread far too thin to take the time necessary to work on that. In the back of her mind, she also recoiled at the idea of having to subject both Scott and Lily to endless inadequate trial lifts in order for James to get the technique down.

Incidentally, Scott's Hoyer lift was broken just the week prior for three days. Over just the course of those three days, Dawn lifted Scott by hand more times than she could count. Dawn knew Scott hated being lifted by human hands. It crossed her mind that this might be the root of Scott's refusal to pee—a retroactive resistance. But she

pushed that idea out of her mind as soon as it entered. Dawn was the designated crane of West Park, and she did not want to dwell on holding that role anymore than she absolutely had to.

Bowing her head and sighing, Dawn put her hands in the front pocket of her black hoodie, which had a graphic of a basketball in a wolf's mouth on the back and read in bold yellow letters, "1998 State Champions."

"What are we gonna do with you, Mr. Scottie?" Dawn meant this to be playful, but Val did not take it this way. While Val wracked her brain for something to say that would eject Dawn from the room, Dawn asked, "I hear you're taking Will out for breakfast today. Shouldn't you be leaving soon?"

"Oh," was all Val could say, since her train of thought had been all focused on Scott, she forgot about her promise to Will.

"Will came up to me as soon as I got in the door and asked, 'is James taking me to breakfast?' and I told him that it would be you taking him, if it was anyone."

"I'm sorry. Friday night—er, Saturday morning I guess—I promised him he could go out for breakfast today. I know I shouldn't have." Val took a moment to draw herself out of an apologetic mindset and began protesting, "but you *know* he likes James better than me. And technically, don't I need to be trained to go out with Will before doing it alone?"

Dawn knew Val's concern *was* technically legitimate, but ignored her question, replying, "Will needs to get used to people other than James, since he won't be here much longer to take Will anywhere." Pre-empting Val's shock, Dawn added flatly, "I'll tell you about it all later. Will is waiting for you."

This new revelation about James washed over Val. She walked out of Scott's room in a daze.

James appeared in front of Val, as she put on her coat. He could tell that Dawn told Val. He had expected Dawn would call a meeting to break the news, taking time to go through the gory details of why he was leaving, where he was leaving to, and all the possible ramifications for West Park. James tried to ignore what he knew Val was thinking about.

"So, Will is ready, but as you might have guessed," James paused, manufacturing a sigh before continuing, "he doesn't really wanna go with you—no offence. He'll probably be super quiet and maybe a little sour, but I promised him that next time I'd take him, so hopefully that helps."

"Is that a promise you can keep?" Val asked coolly.

Flustered, James replied in a rapid whisper, "I'll tell you everything later, but just so you know, this is all way over my head. It's an administration level thing." Then he muttered something about laundry and scampered off.

Val felt like an alternate reality had swooped in and swallowed her whole in the last few minutes, because nothing made sense and everything was wrong. Scott was in whatever kind of pain comes from not peeing in three days. James was leaving West Park and *administration* had something to do with it. And to Val it seemed like Dawn was taking her feelings out about this news on Scott. Val couldn't decide if that was better or worse than her being callous with Scott for no reason at all. Or if it mattered either way.

But Will was still in the living room ready to go to breakfast, even if he would rather it not be with her, so, Val took a deep breath, applied positivity to her face as best

she could and walked up to him, letting him know it was time to leave for lunch, that is, if he still wanted to go out. He did.

The server at Hawley Family Diner lit up when she saw Will.

“Your name’s Will, right?”

Will’s attention snapped to her face, and he stopped rocking forward and backward. He stared at her, his body rigid. Val’s attention snapped to Will.

“Do you remember me?” The server asked as she poured water into their glasses.

“I remember you. You’re Linda,” Will said while pointing at the server.

“Yeah!” Linda said like she’d won something.

“Linda was my neighbour,” Will said.

“I sure was. I don’t live in the neighbourhood anymore, though. Do you live in the neighbourhood?”

“I don’t live in the neighbourhood.”

Val felt an urge to speed up the talk about where Will lived. She worried it might upset him to be reminded that he no longer lived with his parents. But she resisted jumping into the conversation. Him having an uninterrupted interaction with someone outside of West Park was more important.

Her urge to jump into the conversation forced Val to confront the fact that she had no idea how Will *actually* felt about living at West Park. She had assumed he missed living with his parents, but, then again, she had no idea what his life looked like when he lived with his parents.

Val looked up from her thoughts and realized Linda had been trying to ask her something.

“Pardon?”

“How do you know Will?”

“Oh...”

After a few moments searching for the words, Val said, “I work at the house that Will lives in.” Linda nodded and said, “awe, that’s so great, it must be so fulfilling to work with, uhm,” and she trailed off and looked at Will, then back at Val. “People,” Linda finally added.

Whenever her job comes up, Val usually gets a version of this response. She hates it because it doesn’t leave her any room to talk about all the hard things. She hates it because it doesn’t leave her any room to talk about how her job being “fulfilling” is great, but “fulfilling” doesn’t pay her bills, and the eight dollars an hour she makes only allows her to scrape by because she works so much overtime, but also the amount of overtime she’s roped into working has pushed her body and mind to the limit. People asking her if the work is fulfilling is the easiest way for someone to avoid learning about any of the complexity of her work. Every time, Val feels pinned into a nod and a smile by that response.

“It’s the most fulfilling job I’ve ever had,” Val said with a nod and a smile. Then she abruptly shifted the conversation away from her job, saying, “I’d like a coffee, what would you like Will?”

After taking their drink orders, Linda stood still for a moment, her mind either wandering or focusing, Val could not tell. Will’s focus shifted to the menu in front of

him, and with his left hand, he straightened the menu, so its bottom edge was parallel with the table's edge. After watching Will make this adjustment, Val turned back to Linda, about to ask if there was something wrong or something else they needed to do in order to free Linda from their table. The awkwardness of the moment made Val nervous, and just as Val had mustered the confidence to address it, a smile washed over Linda's face, and then, with new warmth in her voice, she said, "okay, I'll be back with your drinks in a moment."

Linda had been looking at Will's left hand, specifically his thumb. She saw he had some faint red marks on his wrist and other parts of his hand, but on his thumb she saw what looked like a callous—a slightly raised, rough-looking spot. This was nothing compared to the perpetually raw-looking spot in her memories of riding the school bus with Will. Truthfully, she almost never actually saw him biting his thumb when they were neighbours. It was only from the visible raw spot that she deduced that Will bit his thumb often, and hard. They went to the same public schools, but Linda had no recollection of seeing Will *at* school.

From elementary through high school, she remembered that Will enjoyed his time on the school bus, despite always having to sit next to a bus aide, who often looked vaguely annoyed, though Linda never knew why. On the bus Will would rock back and forth, clap periodically, and over the years rotated through a series of sounds that sounded happy, at least to Linda's ears. But as soon as Will would step off the bus a teacher's aide would whisk him away to the special education classroom. Linda knew where his classroom was, but never set foot inside it. It was a mystery to her what went on in there.

She wondered if it was something or someone in that classroom that caused him to bite his hand.

When Linda was younger, Will actually made her a little nervous. No one had ever showed her how to interact with people “like him”—she had never been clear what the right term was, and was too afraid to ask. No one in her TV shows, movies, or books moved like him. As a young child, the closest Linda ever came to knowing how to think about Will was overhearing one of her parents speak of that “poor boy.”

By the time she got to high school, she was no longer nervous around Will, but she still rarely interacted with him, except for occasionally waving, ‘hello,’ in the morning as she passed him and his bus aide to find a seat. Somewhere inside her was an urge to interact with him more deeply. Maybe it was just curiosity about people “like him”—she had never been clear what the right term was, and was too afraid to ask. Maybe it was simply because they were neighbours. Or maybe she just wanted to be his friend. It did not matter, though, because she never approached him in any meaningful way.

She told herself that maybe if there was not a bus aide that sat next to him every day she might have sat next to him, but deep down, she knew that was not why. Talking to Will was opening up an unknown like no other she could have opened, and that scared her. It was different than the nervousness she felt as a child, which was vague yet all-encompassing. As she got older, it was a fear that she would screw up, that she might say something that would confuse or upset him, or that breaking the norm of nobody talking to him might freak him out, and cause him to—she assumed—bite himself. So instead of crossing the borders of their two yards or stepping into his classroom to interact with him,

she watched him—sometimes from her bedroom window, which overlooked the Tinley’s yard, and sometimes from her own porch. She would watch Will walk around his yard, usually flapping his arms in a way that looked happy, or, during the winter, when he would gather snow in his gloved hands then make his fingers flutter, and whatever snow remained in his palm, he would lick. Witnessing Will’s joys from this distance made her happy and feel like she knew him a little.

Occasionally, she witnessed him biting his hand, which, by the time Linda was in high school, she assumed to be his universal expression of negative emotion. Once, while Linda sat on the porch watching Will, who was in his yard biting his thumb and making a groaning noise, she heard a knock on the sliding door behind her. It was her mom, waving angrily for Linda to come inside. Once Linda came inside, her mom told her she must “respect the Tinley’s privacy.” She spoke in an exasperated tone, the kind a parent uses with a child when the parent is saying something they believe they should not have to say aloud. Linda was sixteen at the time, and though she was not the kind to talk back, she couldn’t help herself and blurted out that, “everyone can see his thumb, mom. It’s obvious he bites himself, and has tantrums or whatever. And how’s privacy gonna help him?”

Linda walked away before her mom could reply, though if she had stayed, her mom would not have known what to say. While Linda thought privacy was no help, judging from the glimpses of his thumb she got on the bus every few days, she had no idea what could actually help him. She had not known then, but looking at his thumb now, in the diner, and how the raw, perpetually open wound she remembered had turned into a callous, she smiled at the idea that someone must have figured it out. It never

occurred to Linda that it might be wrong to reduce Will's entire being down to the condition of a wound.

The clicking of Linda's footsteps grew feint as Val and Will sat in silence. Will stared off at some spot outside the window next to their booth, his body rigid, his nose rhythmically exhaling. Val tried to think of something to say. She knew tiredness and discomfort were written on her face, so Val felt she should make up for it with conversation.

"Is this diner where you usually eat lunch with James?" It was the only thing she could come up with to ask. But Will continued looking out the window. She tried again.

"Will, is this diner where you usually eat lunch with James?"

"Yes," he said, without turning back to her.

"It's a nice place, that's for sure."

This was the first time Val went to Hawley Family Diner since her mom stopped going. When Val and Will had walked in, Val lowered her eyes to avoid welcoming any conversation from a regular who might have known Val and Essie. Now, while trying to think about what to talk about with Will as they waited for their drinks, Val's eyes drifted around the diner. She breathed a sigh of relief. Nobody looked familiar. Once that anxiety about running into someone washed away, an unshakable sadness revealed itself. Essie belonged in this diner, and Val existed there only ever as Essie's daughter. Being there without Essie, Val felt a question in the pit of her stomach: how much of a daughter am I when my mom is gone? It felt like an utterly ridiculous and crucial question all at once. Her coffee and Will's iced tea appeared in front of them.

Val asked Linda for more time to look at the menu in a voice that sounded like she hadn't talked in days. Trying to smooth over the awkwardness, Val's eyes darted around the room and then she asked, "is that Christmas tree in the corner real?"

"Uhm, I can check."

"No, that's okay—it's not important," Val pleaded, her face turning crimson.

"No, no, it's no problem, now you got me interested," Linda said as she jogged over to look closely at the branches and down at the base to see if it was in water.

"Looks real to me," Linda reported with a smile.

Val thanked Linda for indulging her, and said they would be ready to order in two minutes. Deciding to take the topic of Christmas and run with it, Val asked Will if he liked the Christmas decorations, while methodically pointing them all out.

"They have a stuffed Santa by the register, big reindeer stickers on the windows, colourful lights inside and white lights outside—"

Will cut her off. He pointed his index finger at her and asked, "Were you having a hard time Saturday?"

She was taken aback. It frightened her that he remembered that time on Saturday around six in the morning, while her memory of it was so spotty. How had she appeared? Were there bags under her eyes? Did she look angry? She had no idea. But clearly Will had noticed something off about her. Val *was* having a hard time Saturday morning. And she was having a hard time now. It struck her all at once that Will was empathizing with her in this moment. She nearly let fear overpower her ability to sense his empathy.

“You know what, Will, I *was* having a hard time—Saturday morning and today. I am so tired, because I didn’t really sleep Friday night, and that same night I broke something very special to me.”

“What did you break?”

“I broke a very old vase that was important to my family.”

After a few seconds of eye contact, Will said, “It’s sad.”

“You’re right, Will. It is sad.”

Val wanted to climb over the table and hug Will. The lack of her mom’s presence hung about her so heavily, she wanted living human pressure to drown it out. But she couldn’t just hug Will like that in public. Even with her loose interpretation of Open Doors’ policies about clients and staff interaction, *that* was over the line to Val.

Will shifted his gaze to his menu, running his finger down the lists of items. As he did this, his torso rocked forwards and backwards, and he hummed a scale. Val quieted the noise in her head by focusing on the scale, “up, up, up, up, up, up, up, uuup, downn, down, down, down, downdowndowndownn”

“Hey Will,” Val spoke up, causing Will to pause his movement and sound, though he continued looking at the menu, “thank you for asking about my hard time.”

“You’re welcome.”

Halfway through their lunch, a man’s head popped up behind Will from the booth next to theirs. Startled by someone’s head suddenly inches from his own, Will scooted to the edge of the booth, arching his neck and back away from the stranger. Before Val could even process this invasion of space and privacy, the man started talking at her.

“Did you say you work at a group home, ma’am?” he asked. She was so startled, she answered honestly, explaining in a rush that, no, actually she worked at a waiver home, which was different, but similar, and that she didn’t know much about group homes, except that sometimes people who lived in group homes had to share rooms, or maybe most of the time, she wasn’t sure. Mostly, what she knew was that people who had worked in both said group homes were terrible and waiver homes were okay sometimes. She immediately felt embarrassed for spewing all this to a stranger, but more than that she was annoyed that this man had put her in the position of saying things that might confuse Will.

The man stared blankly at her for a moment too long, before sidestepping the whole distinction by asking, “So, is this one of your clients?” He waved at Will as he asked this, and Will waved back at him. Val did not respond. She had already said too much to this guy, and saying Will was her client was probably crossing the line into a HIPPA violation. But the man continued talking anyway.

“I used to do that kind of work for Open Doors at a couple houses they have in Indianapolis—or had maybe, I dunno if they’re still around. They were group homes, though. You work for Open Doors, I assume? That’s the only provider with houses in Hawley, right?”

Desperately hoping a silent cold stare would spook him off, Val didn’t respond to this question either. She just kept looking at him as though he were a giraffe, who had suddenly begun speaking English—awkward and just plain wrong. If he used to work for Open Doors, he knew exactly how inappropriate it was for them to be having this conversation.

“Well anyway,” he added, brushing off her icy demeanour, “It *is* ‘fulfilling’ work, no doubt.” He draped air quotes with his fingers around “fulfilling.” “I heard the waitress layin’ it on thick with that. People on the outside think we’re a bunch of mother Teresa’s or something. Don’t you get sick of that?”

While she was sure her view was less dark than this guy’s, she hated that she couldn’t deny that last bit. She said, “sure,” flatly, maintaining her blank expression.

“Nobody talks about the toll on us—the bruises, the bites. I had a client once shove me into a wall, and the impact dislocated my shoulder.” The caustic delight in his voice made it sound like someone gloating about a street fight. Val squirmed in the booth. Will sat stone still, still arched away from the man. If Will hadn’t been with her she would have told this guy off already.

The man went on, “I finally quit. I just couldn’t take it anymore. I loved those kids, but they took it all out me, you know?” Val wrinkled her forehead and looked up at him when he said, “kids,” hoping to convey her objection to that term being used for adults with intellectual disabilities.

The man went on to share another anecdote about a “violent episode.” As he got into it, Val pulled out her phone, blatantly putting it in front of her face.

He appeared to get the hint. But before the man’s head disappeared behind the booth, his expression drooped, eyes sunken, and, without acknowledging Will, he said, “sorry for bothering you, ma’am.” After he was completely out of their space, Val hit send on a text to James and silently mouthed the words, “thank you.”

“Is the man gone?” Will asked.

Val was glad Will asked loudly enough that the man could have heard.

James was washing dishes from breakfast when he felt the buzz of a text in his pocket. He turned off the water, dried his hands, and saw that the text was from Val.

How's Scott? What's Dawn doing???

Scott's door was closed, so James knocked, and hollered "Everything alright in there? Need any help?" James looked at his phone as he waited. He hadn't realized a half hour had gone by since Val left and Dawn had been in there with Scott. Now he was a little concerned, too.

After fifteen or twenty seconds, Dawn opened the door. Scott lay in the same position he had been in before Dawn had gone in there—on his back. To James' surprise, Dawn seemed calm.

"We're good," Dawn said confidently, "I just told him I'd wait here with him 'till he peed and if he didn't pee by tonight, I'd take him to the hospital."

Then Dawn turned her head toward Scott and said, "because it's not safe to hold it for so long, is it?" To this, Scott craned his neck in the direction of Dawn and James, and said, "but I don't want to go to the hospital." An exaggerated smile appeared on Dawn's face, as she replied, "Great! Me neither, Scottie, so pee for us and I can be on my merry way and leave you alone." At this, Scott sighed and went back to facing the ceiling. Dawn turned back to James and spoke in a hushed tone, "look, it's obviously really unhealthy for him to hold it so long. And last time he did this I just sat with him for three hours and then boom, he went. I think he just got sick of me, which was my plan. I know it sounds bad, but it worked."

"I guess you have a point, but don't you think you should call the nurse?"

“I did,” Dawn said deadpan, adding, “just let me take care of this, Mr. Manager.”

“Okie dokie,” James said trying and failing to ease the tension he accidentally created.

As soon as James walked out of Scott’s room, Dawn regretted snapping at him. But she was still raw from the email he sent her early that morning. She couldn’t repress her weariness and frustration with the situation, even though none of it was his fault.

They hadn’t talked about the email yet. Dawn didn’t *want* to talk about the email, yet. But Dawn read it over and over as she sat with Scott, digging herself deeper into a trench of helplessness.

Hi Dawn,

According to Open Doors, I shouldn’t tell you any of this, but personally, I think you should know. I’ve been offered the position of house manager for another house. Lemon Grove. I’m taking the position. But there’s more bad news. When they called and offered me the position they told me something else.

Open Doors will be pushing all the DSPs to contract. And not just the ones in Hawley, but at every house and day program in Indiana. They’re all going to lose their health insurance, overtime pay, and PTO. I knew if they told you that you would tell us, so that’s why I’m telling you.

Anyway, they made it seem like this “take the promotion or get pushed to contract” thing wasn’t just

with me, but I don't know how many DSPs they can afford to promote. They're already so short staffed, and they obviously wouldn't be throwing people on contract if they had the money to promote a bunch of DSPs.

It all happens February first. That's when I start at Lemon Grove and when all DSPs become contractors. I'm so sorry you had to hear all this from me.

Best,

James

The call from Open Doors came the day before Christmas Eve. James typed out the email within an hour of receiving the call, but no time felt like the right time to send it. He was angry with Open Doors for the shockwave they were about to set in motion. Staff would leave, for sure. They might have to shut houses down. He wasn't sure what happened to people living in a waiver home once it shut down, but he couldn't imagine it was anything good. Or maybe they would loosen their requirements for new hires, to keep the houses staffed. But James didn't know how they could make their requirements any looser, unless they loosened background check requirements.

He sat on the email three days without sending it. He had been drinking the night he sent it.

Rarely did James drink these days, and more rare still did he allow himself to get drunk. He drank well whiskey and Coke, while his friends drank beer. As empty glasses

multiplied around him, more and more details of his “work shit show” spilled out of James’ mouth.

James’ friends lived in Indianapolis now and were all in their senior year of college. These days, he rarely saw them. And this year, since he was putting in so many hours at West Park, this one night at Tilly’s was likely the only time he would see them for six or more months. It was the evening of Christmas day when they met up, but James talked at them into the early hours of December 26th. Many former Hawleyans visiting for Christmas filled the bar, which was decked out in Christmas lights, tiny plastic pine trees scattered about the tables, many knocked over by 11 p.m., others bent in fidgeting hands. On the floor, bluish tinsel mixed with peanut shells. Many who used to live in Hawley found “the vibe” “quaint” or “quirky,” while those who still lived in Hawley wavered between ashamed and proud of the town watering hole.

James’ friends listened with patience while he outlined all the ways this situation made him feel “complicit in Open Doors’ backhanded slap of the DSPs.” Since they had only a vague idea of what his job even was, everything James said overwhelmed them.

James worked for people with disabilities, his friends knew that much. Their grasp of what this meant was simple: James did one of those jobs where you “help people.” “People,” to them, could be filled in with any group that generally experiences hardship or “needs help:” poor people, kids, refugees, people living under oppressive governments, or in war zones, and people with disabilities. But it was a two-way street. On the infrequent occasions he saw his friends or texted them, he didn’t want to talk about work. He found his work was too emotionally demanding to talk about. But now that a work situation was all he could think or talk about, he regretted never explaining

what he did at West Park to his friends. He hadn't even told them enough to know what DSP stood for, and as he spilled his feelings, somewhere in the back of his mind, he knew he was overwhelming them, but he couldn't stop himself.

After walking home at three in the morning, James lay in his bed thinking about how he just wasted a precious evening with his friends. He had sucked up all the air of the night. He should have anticipated how little his situation would resonate with them. Replaying the night in his head, he saw their squirms and shifting eyes clearly, even as they tried to throw generic phrases of support and advice his way. Their world, the world of term papers, class presentations, summer internships, and study groups was so far from being a DSP.

James replayed the night's events in a loop until he was no longer tired and it was five in the morning. He thought he might feel better about the night out at Tilly's if he just sent the email. Then, maybe, his unraveling in front of his friends would not have been a total waste. He could redeem the night by knowing it led him to take action.

So, he got out of bed and grabbed his phone. He opened up the email draft and sent it to Dawn's personal email address. His dread about wasting a night with his friends' vanished, now replaced with the dread of awaiting Dawn's reply.

Dawn couldn't decide what was worse: The news or how she found out. She knew her existence was a blip on the map for Open Doors, but not hearing this from administration felt like Will, Lily, and Scott were all blips on the map for them, too. She could handle being disposable, but confronting how little they cared for her clients was

too much. How could the DSPs *not* quit in droves after losing their benefits and overtime pay? People in administration or HR would have to drive four hours from the main offices to come out and fill shifts in Hawley. They'd done that before—a shift here and there—but never on the scale that would be required once the DSPs left or got promoted. Dawn was afraid. The future of the house looked untenable. But she couldn't imagine leaving. To leave the house in the hands of random substitute staff and a hodgepodge of white collars...no, that would put the house on a fast track to being shut down. It made her head spin.

When James left Scott's room and shut the door, Dawn slumped into the chair by Scott's bed, buried her head in her hands. She cried. Not tears of sadness, but the kind that come from a weight so great smashing you down that you just can't help but leak. Dawn was thankful Scott was facing the ceiling, and not her.

James stood over the kitchen sink, but with his hands wrapped around his phone instead of the dishes. He was finishing a reply to Val's text.

Everything seems fine. Dawn's sitting with him. Don't even think she's talking to him. Just waiting for him to pee. I think she's hoping he'll realize if he wants her to leave he just has to pee. Dawn said it's worked before. Said the nurse knows about this strategy. I guess it's okay. I dunno... Hope all is well at lunch.

Val responded right away.

Even if the nurse approves, that's pretty messed up.

James thought so too deep down, but he didn't feel like he could stand up to Dawn—especially now, before they talked about the email he had sent her. So he couldn't let himself dwell on whether what Dawn was doing with Scott was okay. Dawn was sure hers was the only way, and that was that. In his reply to Val he changed the subject.

You know Will has day program today right?

Shoot. No, I forgot cuz you always take him. I've never taken him there. Idk even what to do.

Just follow him to his classroom. He knows the way. Will's supposed to be there by 9 a.m.

And James texted Val the address.

Val apologized to Will for interacting with her phone instead of him. But Will still looked uncomfortable, or upset, or depressed—Val couldn't tell, but she knew something was off.

“Is James gonna take me to school?”

Val took a moment to process that “school” must be what Will calls the day program.

“No, sorry, I'm taking you today.”

Will stared into her eyes and leaned forward, intensifying his eye contact, like he was asking her to ask him something.

“Is that okay, Will?”

“Nope,” Will said without hesitation, like he was waiting for her question.

Val's face flushed with frustration. If she wasn't so tired, she could keep her body from displaying this feeling.

A countdown from ten, deep breaths, long enough for Will to think the matter was settled, that his "nope" stood—after all this, Val finally composed herself enough to explain to Will that his opinion held no sway in the matter.

"So, we don't have time to go back to the house before you go to—uh—school, so I have to take you today."

"Don't want to," Will replied, matter-of-factly.

"Which don't you want? For me to drive you or do you just not want to go to school at all?"

"Don't want to go to school."

Val struck an 'I'm thinking' pose with her fingers stroking her chin. She was quiet, so she wanted to demonstrate to Will that she heard him, even if the thing she was thinking about was how to coerce him into agreeing to go to day program. But before she could figure out what to say, Val's heart sank to her toes, because that awful man's head popped up again.

"It sounds like you got some trouble brewing here," he chuckled, then continued, "I'm pretty good at dealing with autistic kids, and I know CPI, too—any hold and restraint in the book, I've done it in the field, with kids of all sizes, at all levels of aggression. But I am also good at talking these kiddos down. So, what's the issue here?"

The man directed all these remarks towards Val without even so much as glancing in Will's direction, as if he wasn't there.

Will bit his left thumb. If he did not have thick callouses there, his teeth would have drawn blood. But the man paid no mind to this. Val tried to glare at the man to communicate that he was making things worse. But the man continued, either unaware or unconcerned.

“You gotta be firm. Be the authority. Don’t leave him any wiggle room. Taking the dominant position is key. I hate to say it, but the best analogy is like training a dog. Give it an inch, it takes a mile.”

She snapped. It was one thing for him to be bumbling and wrong, but the dog thing sent her over the edge. She broke into a whisper yell.

“I don’t know when you worked at an Open Doors house, or when you were trained, but it was either back in the God damn stone age before people like Will were treated like people *or*, you didn’t absorb one bit of your training, and are incapable of relating to someone who processes the world differently from the way you do.”

And then Val turned her attention to Will.

“Will, I am *deeply* sorry that you were not treated like a person by this man.”

The man appeared completely shocked by this rebuke.

“I—I don’t know wha—“ is all he could get out before Val cut him off, “uh uh, nope, no, you’ve said enough. E—nuff!”

The man’s head descended slowly behind the booth. Val breathed like she had just run a hundred meter dash and her face was bright red. The contrast between the diner’s stillness and the adrenaline coursing through her was deeply uncomfortable. She regretted her anger and resented him for triggering it. Val was also terrified another patron might have complained.

Linda slipped into Val's field of vision, "one check?" Reflexively, Val said, "yes." After she said this, she realized her mistake, but figured paying for one of Will's meals could not hurt, though if Dawn were more on top of Will's budgeting, it would have been a problem, for certain.

Nothing in Linda's expression indicated she had heard Val's interaction with the man. So, when Linda walked away and Val noticed the man's head slinking down, completely out of sight, a fire lit inside her. She called out to him.

"Nope, you stay and listen to this, because you may need to hear this more than Will."

She continued as the man slowly raised his head back up to be completely visible.

"First of all, Will, what you do is your decision. That's the most important thing. So if you really don't want to go to day program—er, school—that's up to you. But, lemme make the case for going.

"If you don't go, you'd just be cooped up at the house. And we don't have you scheduled for another outing until three days from now, when you go to lunch and then to work at Goodwill. Anyway, if you're not at school you'll just be at home. When you go places outside of the house you can meet people, maybe make new friends, even. If you don't leave the house, though, who will know you exist at all?"

Will stared at Val without moving a muscle, not allowing her to see an iota of what he was feeling in this moment.

"So, let's go to school once we pay the bill. Is that okay, Will?"

"Okay," he said in a tone Val could not discern.

Val thought about asking him more about how he was, whether he *really* wanted to go to the day program, or whether he just wanted all this tension at the diner to go away and that was why he was suddenly agreeable, but Val worried if she delved into all this any deeper, she would not only confuse Will, but would probably confuse herself, not knowing where a desire to end an interaction and a desire to do something began and ended.

While Val considered the impact of her rant on Will, the man had gotten up without her noticing and slipped into the restroom. And as soon as Val realized he was out of sight and earshot, she decided it was best to get out of the diner before he came back to his booth next to them. So, she paid the bill in cash and told Will, simply, that they were leaving now.

Val climbed into the driver's seat of the van, and the pain struck again. Val bent forward, then tried to sit up as straight as possible, but neither position helped. The pain had a depth to it that made Val want to crawl out of her body. It was as though a cannonball had teleported into the space between her shoulder blades.

Val had only clicked the unlock button for the van once, meaning only her door had unlocked, not the passenger door. Val's mind and body were stuck inside the pain, so she didn't notice that Will was still outside the van, standing in the parking lot, by the passenger side door. A woman appeared next to Will, trying to squeeze by him to get inside the car parked next to the van. She shot annoyed glances at him as she muttered, "excuse me, sir." Then Will bit his hand, and the woman jumped backward away from him. And then her face softened. Once Will had become a person with intellectual

disabilities in her mind as a result of him biting his hand, the woman forgave his socially awkward behaviour. He went from being an aloof jerk to being a helpless person in her mind. The woman looked in the van, knocked on the window, and gave Val a ‘how *could* you?’ look.

“Oh my God, I’m so sorry, Will!” Val exclaimed as she reached through her pain to unlock the door, even though he could not hear her from outside the van.

“Are you okay, honey?” Val asked, exasperated, after Will climbed in.

“I’m okay,” Will said.

Val nodded, and took thirty seconds to concentrate on forcing the pain out of her mind, at least enough that she could get through the rest of the day. She muttered, “I do not have a back,” “I do not have a back,” “I do not have a back,” over and over, until the thirty seconds were up. Then she took a deep breath and put the van in reverse.

James was carrying a hamper of clean laundry for Lily. Dawn stood in the middle of the living room. James walked with his head down, eyes pointed at the laundry he carried. He nearly bumped into Dawn before noticing her. He could immediately tell she had something to tell him, so James put down the laundry where he was.

“The deed is done,” Dawn said, “the man peed and peed and peed some more.”

“That’s great!” James forced a toothy smile.

“Don’t take this the wrong way, but you look awful, James. Sit your butt down on the couch! There’s nothing urgent that needs done before lunch, so you can take it easy for awhile,” Dawn said.

James sat down and exhaled.

“I couldn’t sleep after I got back from Tilly’s Friday night, and I haven’t really slept since.”

“I wondered, when I saw that you sent that email at five in the morning. But, you know, it’s going to be okay. Sure, I’m pissed. But not at *you*. There’s nothing I can do, not when Open Doors doesn’t respect me enough to tell me anything. Hell, I bet they haven’t even told any parents of these guys yet, and who knows if they ever will. I know for a fact if Will’s parents knew we’d be hearing about it. They’re some of the good ones.”

James had met Will’s parents several times. They made monthly visits and called once a week. They seemed to genuinely care for him, and would talk on the phone with Will for at least an hour each time. Will’s face lit up whenever they called. When James would hand the phone to Will, he only ever said, “yes” or “no” in response to them. But that didn’t seem to matter. Their questions about his life held the call in a loving space, no matter how little he said in reply. James could see that after they hung up. He could see it in Will’s forehead, which held an ambiguous tension most of the time. When he handed the phone back to James, whatever held the skin on Will’s forehead in that uncomfortable crinkle lost its gravity. This only ever lasted a couple hours until gravity returned.

James peeled his head off the back of the couch, his eyes off the ceiling, and turned to face Dawn.

“So why do you think Open Doors picked me? Not just for the promotion, but why do you think they told me their plans about pushing everyone to contract? I told you, after all. So they clearly didn’t pick someone who could even keep it secret. But also

Val's a better candidate, anyway. Why not promote her? She was a manager at the Dollar Tree. We started about the same time here and have the same DSP experience, but she has years of management and—probably more importantly—way more life experience.”

“Well, we don't actually know that you're the only one. They could be promoting lots of people. And they did *ask* you to stay quiet about it, after all.” Dawn said this bluntly, and James blushed, responding with a meek, “yeah.”

“Hey, there's no shame in what you did—I'm glad you told me. Otherwise, I'd be in the dark right until all this blew up in my face in a month.”

“But if they promote a bunch of people, wouldn't you and the house be screwed,” James said.

“We *may* be screwed.” Dawn said, feeling the hope in her voice dissipate as she said it. “But, we don't know *how* screwed. At the end of the day, they still gotta have someone in these houses, and if a bunch of DSPs quit once that contract stuff happens, that's gonna mean admins gotta roll up their sleeves and come in to work shifts. If that happens they might get an education real fast on how much they need DSPs. Sure, if their issue is budget stuff, maybe they can't afford to pay benefits, but they sure as hell can't afford to have the state shutting down their houses, either, so who knows. Maybe they bite the bullet, go in the red, and treat their DSPs like they deserve.”

“Dawn, I honestly can't tell if that's optimistic or pessimistic,” James said, laughing. They had never talked this openly. Their intangible aversion to one another was fading, the way it does when two employees of differing ranks speak frankly with one another. Or when those employees no longer have differing ranks.

Dawn laughed too. “What can I say, James, instead of being a glass half full or glass half empty sorta girl, I’m the kind that picks up the glass and chucks it.” Dawn held up an invisible glass to her mouth like she were struggling to get a drop or two of water from it, then threw the invisible glass on the floor. Her face was red from straining to throw the glass. She smiled, breathing a little harder than normal.

Taken aback by the performance and realizing his fake laughter sounded like fake laughter, James broke the silence as quick as he could come up with new topic of conversation.

“Hey, are you even supposed to be working right now?”

The red in Dawn’s face faded.

“No, but that’s how it goes. You’ll see soon enough. Once you’re managing a house, you’ll find out you’re the end of the line. The DSPs have a problem they can’t solve, they call you, and whether you know how to fix it or not, you have to come in there like you could stop the sky from falling.

“Take this stuff with Scott. About two years ago—way, way before you and Val—there was a period where it was just me, Sammy, and a bunch of subs. Back then, this same thing happened. Sammy realized Scott hadn’t peed in three or four days. We didn’t know what to do. And the nurse we had at the time didn’t know what to do either. She basically said to just tell him that holding it was bad for his health. She thought he would see reason or be scared into peeing. Well, that didn’t work. And I knew it wouldn’t. A few days before that, Scott had stopped talking to us. He used to talk a lot; told us what he wanted to watch on TV, told us if he wanted to sit outside, told us if he was mad and why he was mad. The nurse didn’t know him like I knew him. Scott was

making a point—taking a stand. That pee thing was his *last* stand. But to this day I have no idea what that protest of his was about, so I had to just approach it like he was being defiant for no reason.

“Even though I didn’t know why he was taking a stand, let alone how to reason with him, I had to act like I had a plan. Sammy and the subs were scared, so I had to pretend not to be, even when I had no clue what to do. If I didn’t act like I had it under control, I would look incompetent. And if I freaked out, so would everyone else.

“I just told them to let me handle it, and shut myself in Scott’s room with him, so no one could see me not having a clue. That bought me time away from the subs and Sammy, so I could try and figure out what to *actually* do. I mean, there’s no roadmap for getting someone to pee.”

“Anyway, I sat in that room with him, burning through my phone’s data, looking up how to induce urination and at what point he was in serious danger if he kept holding it.

“But after sitting in there for four hours, fretting and researching till my phone died, he peed. He soaked through his Depends and two layers of pads. He was dead silent while I cleaned him up.

“After I finished helping him slide on clean pants and threw all the wet stuff in the wash, I asked him what that was all about and he just said, ‘I couldn’t hold it anymore.’ So I asked him if he was mad about something and he nodded, ‘yes.’ But he wouldn’t tell me what he was mad about.”

James wondered if Scott had been mad at Dawn. The thought dissolved as quickly as it came. He needed to stop making assumptions, he had made so many about Dawn

and Val, and about Lily, Scott and Will. Half the time he realized he was wrong, the other half he realized he had no access to the truth. James had to come to terms with the unexplainable, and that jumping to conclusions would cause him to act on assumptions. As much as James wanted to dive into Scott's mind and find out what he thought and why he was upset, pretending to be able to guess just papered over the reality that he did not really know Scott. As painful as it was he had to accept that Scott was not a puzzle to be solved, but a person who either could not or chose not to communicate his motives.

“But yeah,” Dawn went on, “that’s all to say, you’re gonna have to figure out ways to convince everyone around you that you know what you’re doing even when you don’t. Consider that your first lesson in how to manage a waiver home. I’ll give you that one for free, but from here on out it’ll cost you twelve hours overtime.” Dawn held a straight face for a few seconds, taking in James’ inability to hear the joke, then burst out laughing. “I’m joking,” she finally spat out, laughing. James forced a smile that Dawn saw through, but she didn’t say anything. She just kept laughing. James couldn’t figure out how Dawn managed to do what she was describing. And he certainly couldn’t figure out how he could do that at Lemon Grove.

Dawn got up from the couch and walked over to Lily, who was in the recliner across from them. Lily was completely covered by a thick flannel blanket the colours of Christmas, so that she appeared as a soft bump swept up and down in the tides of breath. Dawn slowly pulled the blanket off of her. Dawn said, “let’s go to the bathroom,” more as an announcement to the air than to Lily, who did not hear or read lips, because she did not see either. Dawn’s hands moved gently as she transformed the reclining Lily into a

Lily who used Dawn's presence as a walker made of organic, human matter. Dawn's movements were a reply to the slightest inclination of Lily's muscles.

James watched their dance to the bathroom in awe. For a moment he was annoyed and distracted by that awful "DON'T TREAD ON ME" shirt Lily wore, because Val insisted on it. But in his new resolution to not assume things he pushed away his annoyance. He soaked up the way they moved together. Dawn was air for Lily to flow through. And then James looked up at Dawn's face for the first time during their dance. In this moment he saw that Dawn had a super power. Dawn's face was utterly blank. The only phrase he could put to it in his head was, 'Dawn doesn't care.' She trained herself not too. This dance is a job. Dawn takes the part of herself that cares and checks it at the door when she walks into West Park. It's not that she doesn't care in a general sense. He had seen in other moments that in a general sense, she wants what is best for everyone living in West Park. In a general sense, he had heard her say, "I would die for any one of these clients," and he knew it to be true. In a day-to-day sense, she turned off all that to move her body for other bodies, without a care.

Two years earlier, back when it was just Sammy, Dawn and a rotating cast of subs who worked at West Park, back before Dawn checked the part of herself that cared at the door, she failed Lily.

As far as Sammy, Val, James, Dawn, and any of the subs that passed through West Park knew, Lily had always spent every day the same way. Staff woke her up for breakfast. She ate a pureed version of whatever was cooked for Will and Scott. Staff escorted her to a recliner in the living room. Staff pulled her flannel, Christmas coloured

blanket over her entire body. At lunchtime, staff helped her out of her chair to eat a pureed version of whatever was cooked for Will and Scott. After lunch, staff escorted her back to the recliner and pulled the blanket over her. At some point before dinner, Lily crawled out from under the blanket and investigated the sensations of various surfaces throughout the house: baseboards, the cracks between closed doors and doorways, where two floorboards met, the points where the legs of furniture became the floor. Lily excavated the sensations of the lower regions of the house. Then staff escorted her to the table in the evening for dinner, then escorted her to bed after she finished eating.

When Sammy came in for her overnights at 10 p.m., she went to Lily's room first to escort her to the toilet. Sammy did this as a precautionary measure, to limit the chances of Lily urinating in her sleep. Every night, Sammy found Lily wide-awake. Then Sammy would come in for a second time at 4 a.m. to escort Lily to the toilet again. Every night, when Sammy came in again at 4 a.m., she would find Lily just as wide-awake as she was at 10 p.m.

At some point, Sammy told Dawn about Lily's sleepless nights. Dawn had had no idea. She was flooded with sadness. Dawn had thought Lily was just tired all of the time and slept constantly, apart from when her spurt of energy hit her before dinner. It never occurred to her that Lily's sleeping rhythms were just out of sync with daytime hours.

Dawn had tried enrolling Lily in a day program months before Sammy told her about Lily's sleepless nights. This was back when Dawn started at West Park as house manager, back before she knew much about Lily—it had just seemed like the thing to do, to try and enrol Scott, Will and Lily in a day program, since none of them were enrolled

when Dawn started there. This is how Dawn understood how to realize Open Doors' mission of "inclusion in the community." There was no way they could have steady enough staff to go out and spend time with the clients in town, so it made sense to Dawn to drive them forty-five minutes away, three towns over to the day program, where they would have staff provided for Scott, Will and Lily. Dawn could even finish off all the paperwork she never had time for while they were gone. She got Will enrolled, but he only agreed to go once a week, and after Scott's first day of day program he explicitly told Dawn that he "didn't wanna go back there," but she figured since there was no way to communicate with Lily, she may as well enrol her for every weekday.

For awhile, the subs were consistent enough to get Lily there five days a week. And when the West Park van broke down and Open Doors said they had to wait a month for a replacement, Dawn began taking Lily in her 1994 Toyota 4runner, which meant Dawn lifted Lily up into the passenger seat for each trip out to the day program. When Dawn lifted Lily like this, Lily dug her nails into Dawn's neck. Dawn believed this was just because Lily didn't like being lifted by hand.

These 4runner trips to the day program went on for two weeks before it all fell apart. Shifts stopped getting filled by subs. Dawn didn't have the time or energy to investigate why. Staffing said, "No one was available" one day, then it was for two days, then days became weeks. When there were no subs, it was just Dawn, Sammy, and the occasional person from the main offices. Twelve and sixteen hour shifts were the norm for days on end for Dawn and Sammy. With only one staff at the house at a time, there was no way to take anyone anywhere. Lily went back to spending her days in her recliner and her nights awake. Will stayed in his room watching TV. Scott did the same. There

was no word from staffing. Dawn got the feeling that because nobody was dying at West Park, because between Sammy and Dawn, everyone was getting food and meds, Open Doors wasn't out hunting for subs or permanent DSPs for the Hawley houses. And at eight dollars an hour, Dawn didn't blame the people of Hawley or the surrounding towns for not applying.

But the problems didn't end there. It turned out one of the subs who had worked at West Park while Dawn was taking Lily in her 4runner had moved away and started dating a woman who worked in HR at the Open Doors main offices. Without knowing Dawn's actions were against any rules, the former sub casually mentioned what Dawn was doing to the woman.

Dawn was reduced to begging to keep her job. She had no infractions prior to this one with Lily. She tried to plead her case, that she took Lily in her private car, because there was no other option and "wasn't it the right thing to do, you know, morally?"

The woman from the main offices of Open Doors had been sitting right where James sat now, on the couch. She'd driven three hours just to tell Dawn she'd be fired under any other circumstances, except that right now they needed her. If they fired Dawn, Open Doors knew West Park would be shut down, and "that would make us look terrible." "If you give us two squeaky clean years, we'll give you a clean slate. We'll pretend this never happened. But if you *do* screw up in that time, even in the tiniest way, you are gone. But we don't want that to happen. And I know you don't either."

Dawn was afraid if she spoke she would start crying. So, she just nodded. But as the woman from the main office opened the front door to leave, she turned back to Dawn.

"I'll need verbal confirmation."

“I understand,” Dawn said in a small voice she barely recognized as her own.

And as soon as the woman from the main office closed the door, Dawn broke down.

Dawn never told anyone about all this. But once the two years were up, she had planned to re-enrol Lily in the day program. In ten days the two years were up. She had toyed with the idea of opening up about this to Val and James. When she got the email from James, and Sammy fell ill, all those plans shattered before her.

“Everything okay?” James asked, waving at Dawn, trying to get her attention.

Dawn had been staring down at Lily for almost a minute. When she heard James and looked up at him, her bewildered look suggested she had just been plucked out of space and dropped into the room with him.

Her face settled into that blank look James had just come to understand and Dawn spoke flatly, “this last month that you’re here, things are gonna be different.”

“What do you mean?”

“We’re gonna take Lily somewhere that’s not here while we still have the staff to do it. We’ll work twenty-four hour shifts to get her out if we have to.”

James started to say something, then stopped himself.

“What?” Dawn snapped.

“Do you think she really wants to go anywhere?” He asked hesitantly.

“James.”

She paused to make him think about his question.

“It isn’t about that, James. It’s about doing the right thing. Do you think it’s the right thing for her to be in this house 24/7 like this?”

“I uh—I guess not.”

But James remembered how he wanted to be more receptive and honest to the reality of not knowing what clients want by never assuming what they want. So, he mustered something like courage and added, “but we can’t know that there is somewhere Lily would want to go, or really if she wants to go anywhere. Look at her face when she lays down in that chair, that big smile that washes over her.”

The way Dawn’s face looked as he said this made him feel like he was throwing words at a wall. And despite feeling the same way about James’ stance being both hopelessly wrong and hopelessly unwavering, Dawn retorted, “But what if she could establish a new routine? What if she could be pushed to be more active, and yeah, maybe she’d hate it at first, but what if she became *happier* than she is now. Happier than she’s *ever* been. And if she became more active, she might *live* longer. How could you argue with that, James?”

“Dawn,” his tone shaky but determined, “it should be obvious. If you and I ate salads and nuts and berries all the time and never drank pop or beer, we would live longer too. What if someone followed you around and forced you to eat that way, telling you it was so you could live longer? Wouldn’t that be terrible?”

“It’s not that simple,” Dawn said, staring down at floor, still standing next to Lily. “Doing nothing *is* doing something. Doing nothing assumes Lily wants to do nothing. Who the hell do you think wants to do nothing, James?” She didn’t wait for an answer. “I don’t know what else to do. I have to try stuff, and unfortunately, the only stuff I can try

is stuff we either have staff for or stuff that her Medicaid waiver will pay for. That pretty much leaves us with the day program. You don't think I know that place sucks? My cousin works at the day program at Open Doors' main office, and there they have a greenhouse, an art studio, a whole room of fancy sensory stuff for people like Lily who love to feel things, and exercise equipment, and there, staff actually stick around for more than a couple months. I could go on and on about how it's better. I know that the day program we have isn't that. I know that it's in an old elementary school building where on their best day they do shitty art projects with shitty materials, because they have no money, no staff, and even the people who care about the clients have less training than you and I. But at least there we give Lily the chance of experiencing more than just this house. She might not like it at first, but what if she finds something there—anything—that she does like, or even love. Could be an object, a room, or maybe a staff or other client. Who knows? And even if she doesn't find something there she loves, that day program is at least *something*, and isn't *something* better than nothing?"

Again, she did not wait for an answer.

"One more thing, James."

"Yeah?"

They both looked up at each other. Dawn could see she had rattled him, and even though James could not see it in Dawn, he had rattled her too.

"I have another piece of free advice for you," Dawn said as she picked up her bag, put it on her shoulder, and continued looking into James' eyes from across the living room. Her face softened for the first time that evening. "Be ready to be wrong. Be ready to do something that causes your clients pain and your staff to hate you, because even if

you act with the best intentions, you will still mess everything up. Don't let that stop you from trying. I'm not ignorant. I know the status quo here sucks. That's why I tried two years ago to make some changes, and it almost got me fired. I've basically been on probation with Open Doors the last two years, James. I messed up things in a big way. But I don't regret trying for a second. I know I carry myself like I'm hard or whatever. I can see that you see that. I can see that Val sees that too. But that's my 'I'm trying' face. Because even with stuff like Scott not peeing, I don't have any idea what I'm doing, really. There's no manual for any kind of person, ever; no matter what a training session might tell you about people with intellectual disabilities. I go into a situation not knowing how it'll play out and that means I have to approach it as though I've already failed and I'm okay with it. If I go in worried, that worry spills out of me, makes me screw up more, makes my client worried. It's not bracing for failure, it's accepting that failure is part of your job.

“When you walk into Lemon Grove, you should imagine you've already let everyone there down a hundred times, but that you're already okay with it. If you do that, you'll be a good manager. It's hard as hell to do, but if you care enough about the people you work for, you can do it. And I know you care, James.”

Val sat in the van staring at the steering wheel. She was still in the day program parking lot. She now understood why Will hadn't wanted to go. When she walked with Will to his day program room and opened the door, she wanted to ask Will, “is it always like this.” She refrained when she noticed the staff look up from their phones, in her direction. She waved at them, but didn't say anything. They nodded at her as Will took a

seat by a TV. Non-descript ambient music came out of the TV while the screen showed colourful shapes moving around and transforming into other shapes. Other than the soft music, the room was quiet. The overhead lights were dim, but there were a few lamps around with blue and green bulbs in them. A few people worked on a puzzle at a table in the corner. Other than the puzzle, nobody was doing anything. It looked like Will was settling in to do nothing, staring at the DVD player underneath the TV. Val almost settled for assuming they were just between activities, on their way to do *something*, but as she walked out, she realized she couldn't leave that room without knowing. She turned, standing at the doorway, surveying the DSPs, eyes buried deep in phones.

“Hey,” she called out to one of the DSPs.

“Sir,” she asked again, and he looked up with a ‘who me?’ kind of face.

“I work for Open Doors—they run the house where Will lives—and they’re asking us to take more detailed notes for when our clients are out during the day. What do you all have planned while Will is here?”

The DSP looked blankly at her. An immense wave of pain overtook her. She used her whole body's strength to stay composed, to speak without her voice quivering.

“Like, what can I write down about what you guys will be doing? I’m off soon, so I won’t be picking him up, and I want to make sure we get all our notes right.”

“Oh, yeah, of course,” the man said, striking a thoughtful pose, with his thumb and index finger to his chin.

“Honestly, we’re probably just gonna chill.”

The man had a goatee and looked to be in his late thirties. He leaned back with a stretch and smiled, then continued, “might show a movie after lunch. I may break out some colouring books for them, if they get antsy, but that’d be about it.”

“Okay, thanks,” Val said, flashing a half-second smile while turning to leave. She didn’t feel bad at all about lying.

The word “warehousing” kept floating around in her mind. She’d heard an instructor use that word during an Open Doors training session where they taught new DSPs about the history of Open Doors. The instructor spoke about how there used to be institutions, but that awful era of “warehousing people with intellectual disabilities was over” and now it was the era of places like Open Doors, an era where people with intellectual disabilities were “supported by DSPs so that they could fulfil their hopes and dreams.”

At the training session she learned that institutions were hellish places where people were sprayed with cold water, restrained, left for hours in soiled clothes. She learned that people slept in big rooms packed with beds, never having any privacy or space to call their own. She learned that first and foremost, the function of these institutions was to keep people with intellectual disabilities locked away from the rest of society. She knew the day program wasn’t an institution, but as she sat in the parking lot looking up at the drab gray building in front of her, she couldn’t shake the feeling that this place had echoes of that old era of setting aside people with intellectual disabilities. Nobody at the day program seemed tormented or badly treated as she walked through the halls and looked into the classroom. The outright cruelty of that era was gone—or at least

wasn't rampant enough to be visible. But all those people were still *stuck*. And even if there's pleasant music and coloured lights in the rooms where they're stuck, they're still stuck.

"Excuse me, ma'am, is everything okay?" a muffled voice came from outside the van. The voice came again, with a knock at the driver side window. Startled, Val looked around, trying to wrench her mind back to the present moment. She saw an older woman, probably in her seventies, staring back at her. The woman looked tiny to Val from up in the tall Van.

Lowering the window, Val said she was "fine." She felt her voice quivering, so she said it loudly to sound more self-assured.

"Okay, I just noticed you were staring off for going-on twenty minutes, and wanted to make sure you were alright."

Val was quiet. She became distracted by the realization that it was snowing. "How long has it been snowing?" She muttered. And then she became distracted by the woman's lack of a coat. The woman wore black slacks with a red sweater that said, "Santa's makin' a list!" in bold green letters. Her gray hair was wet from the snow. Val wondered how long she'd been standing out there by the van.

"I'm sorry, I wasn't trying to be nosey or nothing, I just work at the front desk, and could see you, and...well, truly I thought you might be having a seizure or something. We had someone working here last year who'd never had a seizure in his life, and poof, just like that one day he had a grand mal and—"

“Oh no, no, nothing like that. Thank you for checking on me though,” Val forced a laugh to try and paper over the fact that she intentionally cut the woman off, not wanting to hear her story. Not feeling able to hear her story.

“Well that’s good. I was worried. If you’re working with Will now, I guess I’ll be seeing you in and out a lot. I’m Joanne.”

“Nice to meet you, Joanne,” Val said, reaching her hand out of the van and down where Joanne could reach it comfortably. “I’m Val. Er—Valerie, but nobody calls me that.”

“Well Val, I hope to see you and Will again soon,” Joanne said as they shook hands. The motion triggered Val’s pain again, or rather an awareness of a pain that probably never left. She winced, but Joanne either didn’t notice or pretended not to.

Val nodded and rolled up the window. She hoped neither she nor Will would ever see Joanne again. But Val was powerless to make that hope a reality.

After putting the van in reverse, she looked down at the clock on the dash. Her eyes widened in shock as she saw 10 a.m. She should have been back at West Park forty minutes ago at the latest. As Val drove back to West Park, the snow turned to sleet.

Dawn sat in her car, which was still parked in the driveway of West Park when Val pulled in. Val assumed she was leaving, but when Val pressed the button to close the garage door, she heard, “Val!” and saw Dawn splashing through the wet snowy sludge towards her. Dawn waved her foot in front of the garage door sensor to stop it halfway down and crouched under it into the garage.

“Oh my God, Val, are you okay?” Dawn asked as soon as she saw Val up close.

“Yeah, Dawn, I’m doing fantastic, can’t you tell” Val said bitterly, but immediately felt bad for snapping, “I’m sorry, I just—”

“No, no, Val,” Dawn said holding up her hand to stop Val from continuing her apology.

“You deserve to be pissed, but you’ve been a superstar. I don’t know what we would have done without you Friday and Saturday, you doing that overnight saved my life. Seriously, thank you.”

Val stared back at Dawn blankly like she barely heard Dawn’s words, so Dawn quickly added, “But what I meant to say was how about you take a seat inside for a while before driving home?”

Val looked surprised, since her shift didn’t end until the evening and it was only 11 a.m.

“I’m serious Val, as soon as you’re up for driving, you’re heading home, and that’s final. I think you know you aren’t much help here until you get better.”

Val nodded. She did feel terrible. Every step she took sent a shockwave of pain to her back. As they walked out of the garage and into the house, Dawn wrapped her right arm around Val’s waist, pressed in and up. Without knowing exactly what ailed Val, Dawn improvised. Val had no idea how badly she needed the support of Dawn’s arm until it was there. The fullness of Val’s pain was only visible to her now, in its absence. Val blushed, feeling infantilized, needing this kind of support from her boss. But maybe the easy breaths her lungs could take without that pain were worth it, Val thought.

They walked passed James, who was sweeping the hallway floor. He was startled to see Dawn, because he had seen her leave through the front door earlier, and he was

even more startled to see Val being held up, the colour drained from her face. It occurred to Val as she saw James staring aghast at her that she had not told either James or Dawn about her ongoing back and shoulder pain. This was why, though. The way people looked at her when her hurt was visible, like they are disgusted to have to enter into negotiations with the reality of pain's existence; or, like they want to make her pain go away as quickly as possible and how it is never clear if that's because they want to just stop seeing her in pain or because they genuinely care. Hiding it was easier, that is until she couldn't.

"I'm not sure what's going on with you, but you should really have it checked out," Dawn said as she helped Val sink down into the couch.

Dawn continued, "I mean it. I know we aren't buddies or anything, but I care about my people. Take some time off. Hell, take a week off. I can wrangle some subs, call in some favours or something—we'll figure it out."

"What about overnights, though, with Sammy—"

But Dawn held her hand up to stop Val from continuing.

"That's not your problem. And Sammy's tough as nails. She'll be good soon. Probably just was overdue for a med adjustment. But as far as you're concerned West Park's got nothing to do with you starting when you go home today all the way to next Monday."

Out of the corner of her eye, Val could see James still sweeping, not looking up. Val knew he was thinking about how he will have to pick up the slack from her absence. Val knew he was wondering how he would pick up that slack, and still be able to do all the things he needed to for his mom. Val hated the thought of James running a calculus in

his head of how to fit his mom's needs in between shifts at West Park. But Val also knew she wasn't much use at West Park in this condition, and she needed to see a doctor.

"Okay, I'll take the time off. It'll be a long shot, but I'll try and get into to a doctor one of those days," Val said. And then she remembered seeing Dawn in her car in the driveway, and how Dawn had rushed out to talk to her.

"Wait, were you waiting out there for me?"

"Oh, I uh..." Dawn trailed off, looking at the floor. Until Val mentioned it, Dawn had forgotten what led up to them sitting there on the couch. She *had* been out there waiting for Val. She had been waiting to tell Val about James and Open Doors pushing everyone to contract. She had been waiting to give Val a pep talk about how no matter how much they were overworked, under-supported, and underpaid, it was still worth it to stay on at West Park. But seeing a glimpse into Val's pain wiped away Dawn's talking points.

In the following eternity-sized seconds Dawn put the pieces together that Val most likely needed serious long-term medical care, and how she wouldn't be able to get any medical care as soon as Open Doors cut her status down to contract. But all this cracked under the weight of Dawn's conviction that she owed it to Val to tell her everything. Dawn peeled her eyes from the floor and looked up at Val with a smile. She would delay and figure something out.

"Yeah actually, I was going to ask if you wanted to grab a beer, my treat—a thanks for working so hard all the time."

This was sort of true. She had planned on asking Val about getting drinks sometime. Dawn had had a hunch she couldn't explain that the two of them might make

good friends, despite lacking rapport in the work environment. Dawn also did not have any friends to speak of, and her and Val were roughly the same age. Even as she continued to talk, Dawn knew they would never get drinks. They would never be friends.

“But obviously some other time, not tonight when you should be going straight to bed,” Dawn added, realizing in this moment how clueless she had been to think Val would be up for drinks after working so much, even if she didn’t have this pain.

“Oh,” Val looked taken aback, but quickly course-corrected, “sure, let’s do it in a couple weeks or so!” Val tried to sound upbeat, even though she didn’t particularly like drinking, nor did she particularly like Dawn, but rejecting her boss’s request to socialize felt like a bad move.

Dawn did her absolute best to look excited, and then asked Val if her back was better enough now to walk to her truck and drive home. Val said it was and left out the front door, while Dawn stayed seated on the couch, exactly where James had sat only an hour ago.

Dawn pulled her phone out of her pocket, stared at the unlock screen. She knew what she had to do. The changes with Open Doors were coming too soon to wait around to tell Val over drinks in a week or two. Dawn knew Val needed to know as soon as possible so she could start searching for a job with benefits.

After copying the text of James’ email, Dawn pasted it into the text box, followed by, “I got this from James the other day. I’m so so sorry. I didn’t know.” She didn’t want to tell Val this way, but she didn’t know what else to do.

As Val walked outside towards her truck, she caught a glimpse of “check truck for bag after shift” written on her hand. She worried if she did not check now, she would forget again, and perhaps for a long, long time.

First she tried reaching over the edge of the truck bed to feel for the bag, but all she felt was slushy snow. A fresh wave of pain shot through her before she could dig into the wet snow. She brought her hand to her mouth and breathed hot air onto it, then waited a moment before opening the truck bed. The pain lingered, but she thought climbing into the truck would allow her lower body to do more of the work, if she positioned her feet right. She wiped snow and ice off the spot where she would plant her feet. She still couldn't see the bag of shards, even with the truck bed open, so she assumed it was somewhere in the middle, covered by the snow.

As her right foot bore the weight of her body, the rubber of her shoe slid. Her knee hit the edge of the truck, followed by her ribcage. Her phone fell out of her coat pocket. If her arms were not weak with pain she could have grabbed something to stop herself from hitting the pavement.

Arms outstretched, Val lay flat on the driveway, facing the gray sky. As the adrenaline wore off, the wet snow underneath her soaked through her coat, and shock turned to pain and despair. Tears warmed her face as she waited for Dawn to come back outside, so that she would see Val and run to her aid. Val's phone lay next to her. It lit up with a text message as melted snow and sleet slowly crawled inside to the circuit boards.

Part III

“Welcome home, love!” Caroline called out from down the hall of the apartment as Linda pulled her shoes off by the door.

“How was your first day?” Caroline added.

Linda settled into the couch next to Caroline before answering, “I am so tired—super not used to being on my feet so long.” Linda’s head nestled into Caroline’s shoulder. With a smiling exhale, Linda added, “but it was good—I mean, it’s a job and the tips were just okay, but everyone I know in town seemed happy to see me there. That part was nice.”

“I’m so glad. Any highlights of the day?”

Linda peeled her head away from Caroline’s shoulder.

“Yeah, actually. Remember Will Tinley, from high school?”

Caroline took a moment to dig through her foggy memory of high school.

“His name sounds familiar.”

She took another moment, finding the face for the name, “wait, was he in special ed?”

“Yeah, but he was actually my neighbour growing up, too. Ron—er, Ronnie was what he went by—is Will’s brother, quiet kid a couple years older than us.”

“Oh, I know Ronnie! Yeah, gotcha, I definitely remember Will. Just FYI, pretty sure Ronnie uses they/them pronouns now. Ronnie is out east doing an internship last I heard. But yeah, I can picture Will’s face, for sure.”

“Interesting about Ronnie,” Linda paused, modifying her conception of Ronnie to fit them to their pronouns, before catching her previous train of thought again.

“Well, anyway, I saw Will today at work.”

“Oh yeah?”

“Yeah, and it was just so nice to see him doing well.”

“That’s great!”

“Back when we were kids, he seemed to have lots of hard times, like his thumb was always real messed up—remember his thumb?”

“His thumb?”

“Oh yeah, it was real bad. He used to bite his thumb so hard it looked like he had a rotten grape attached to it.”

“Yikes,” Caroline said sucking her teeth.

“Yeah,” Linda said flatly, pausing for a moment to give some distance from that grisly imagery. Then she continued, “Anyway, he was out with someone from Open Doors, and get this. His thumb was fine. I mean, there was a callous there, but it was obvious he hadn’t bit himself there in a long time.” Linda decided against mentioning the other red marks on his arm and hand, since, she told herself, they were nothing compared to how she remembered his thumb when they were kids.

“That’s wonderful!” Caroline softly exclaimed while putting her hand on Linda’s back. A pensive air descended on Linda, and Caroline angled her head down to try and look into Linda’s eyes. She wanted to ask Linda if something was wrong, but decided against it. Linda looked at her hands like they had an answer to an unasked question.

“It made me think of Tim, though,” Linda said, finally, rotating her left wrist to look over her knuckles, which were cracked. Seeing the cracked skin reminded her that they hurt.

“I don’t know,” she continued, “I haven’t said much to you about him.”

“Yeah, I don’t remember you mentioning a Tim.”

“Tim’s my cousin. He’s also...” Linda’s face grew hot realizing she didn’t really know the right words. She marvelled at how she didn’t even know the words when she had a family member who... She wished someone had just sat her down and told her, ‘this is the appropriate and respectful way to refer to this person and people with similar—’ was ‘disability’ okay to say? She didn’t even know that much. It sounded negative to her. If she didn’t have any labels that sounded right, she would have to settle for description.

“Tim was in special ed, too.”

Caroline nodded, though Linda didn’t notice, since she was still looking down, but now her palms were open.

“But he stays home with my aunt and uncle.”

“Mhm,” Caroline nodded again.

Linda looked up at Caroline, “No, like I mean, they don’t take him *anywhere*. Ever. Well, I guess to the doctor sometimes, but they give him something to make him real groggy for that, so it’s like he may as well not be anywhere when he’s at the doctor.”

Caroline made a sound that meant, ‘awe, that’s too bad.’

“I just can’t believe I never thought about it before. How could I have not thought of it before?”

Caroline hesitated before asking, “thought of what?”

“That it didn’t have to be that way for Tim...” Linda’s eyes fell down to her palms again.

“Seeing Will today, it hit me, I just assumed it was normal for people with... you know, that situation—that it was normal to never see them in public. I guess I also thought if you brought Will or Tim out in the light, people would be super shitty to them. I think that’s why my aunt and uncle don’t take Tim out.”

“I guess I would have assumed the same. Just think back to high school. All the awful jokes people made at the expense of the special ed kids. You hope people grow out of whatever makes them think saying that stuff is okay, but then again, you see the stuff some people say in our town, especially on Facebook. All the people you see around that are so polite and homely when you run into them at the store, but some of their Facebook posts range from outright racism to outright homophobia. I dunno, I guess I get why your aunt and uncle wouldn’t want to take Tim out. People might get to complaining on Facebook or something and if they caught wind of people talking about their son like that, that’d be devastating for them.”

“Caroline, you’re missing the point,” Linda said without looking up, “I’m saying how seeing Will out at the diner made me think about how Tim could be out places, and if Tim got out places, more people like me would think about their cousin or whatever and then maybe the chain would keep going and people would stop thinking it was so weird to see people like them out, and then maybe eventually people wouldn’t even bat an eye at them being in public.”

“Hm. I guess that makes sense, in a way.” Caroline thought for a moment before asking, “so are you going to talk to your aunt and uncle about doing stuff with Tim?”

“I think so. I mean, it couldn’t hurt. They know the Tinleys, so hearing that Will is out doing stuff might be the nudge they need. And maybe they could figure out how to hire someone to take him out if they aren’t able.”

Caroline lit up, “Linda, this is a beautiful idea. This kind of hope you have in spreading acceptance almost has me thinking while you’re at it you should tell your family about us.” Caroline smiled mischievously while nudging Linda with her elbow.

The weight of things hit Linda in that moment. Her family still didn’t know her and Caroline were anything more than roommates living together to save money. There was more to changing people than being ‘out.’ If they were out with her family, Linda knew it wouldn’t be pretty. ‘You never know.’ ‘You might be surprised.’ ‘You’re their daughter, their niece, their granddaughter after all.’ Caroline would occasionally throw out these hopeful nothings, but Linda knew better. It wasn’t that her family would cut her off or try and exorcise her, or something off the wall like that. They would just be really, really sad and confused. And her parents were old already, so by the time they sorted everything out to where they could have a pleasant Christmas together, they might be

dead. She knew she was hiding an important part of herself, an important person, but she couldn't see a way out—a way to be out.

“What’s wrong?” Caroline asked while wrapping her arm around Linda’s shoulders. Linda looked like she was in the midst of grieving a loss.

“Maybe I shouldn’t say anything about Tim to my aunt and uncle.”

“What do you mean? Wouldn’t it be cool to actually be able to make a difference?”

“I probably just don’t have the whole story. I only see Tim once a year when they host my family for Christmas. I don’t even talk to him. I mean, he doesn’t talk at all anyway, but still, I haven’t even *tried* to learn how to communicate with him. Who the hell am I to just go suggesting they hire someone to completely change the structure of Tim’s life when if we’re being honest I don’t even know him?”

Linda breathed deeply to try and calm herself down, but it didn’t work. Caroline tried rubbing her back, but Linda lurched away.

A silence fell on the apartment. The moon—a crescent—was out now, and the pitter-patter of sleet made itself known by its absence, as it turned to silent snow. The same snow fell outside of Linda’s aunt and uncle’s house. As Tim slept, his parents were interviewing yet another potential DSP from Open Doors. Five minutes in, they knew it wouldn’t work out, but out of politeness, they ran through the rest of their questions anyway.

They wanted someone to come provide respite and after building rapport with Tim, take him out in the community, and eventually on trips around the state. They were picky, they’d be the first to admit that, but this was their son, and so far every DSP Open

Doors sent left a bad impression. Some clearly didn't respect people with intellectual disabilities; some clearly just didn't know anything about interacting with people with autism; some were unpleasant; and some talked about him as if he were a kid, even though Tim was twenty-two. There was so little hope. After Tim's parents interviewed and passed on one DSP, it would be months before Open Doors sent them another one.

The worst part was that it had taken two years to get to the point where Tim could even have a DSP. Tim's dad, Harry, had slogged through paperwork for two years to get Tim onto the Family Supports Waiver—the smaller Medicaid waiver that enables people with intellectual disabilities to receive twenty to forty hours of services a month, depending on what exactly they're utilizing their waiver budget for. And if they could find someone for Tim, they would have forty hours. Harry couldn't wait for the day to come when Tim got approved for the waiver. He thought this would change Tim's life, finally giving him the ability to not be imprisoned in their house. But after almost a year of interviewing duds, Harry was a wreck, and so was Tim's mom, Jennie.

Jennie was one of the few divorce lawyers with a practice in town. She spent most of the day working, so it was hard for her to make time for the interviews with potential DSPs. But she refused to miss an interview. More than once she had clients yell at her for not being available or answering her phone during an interview with a DSP.

Sometimes Harry's desperation made him less critical of the DSPs they interviewed, so Jennie knew it was of utmost importance to be present for all the interviews, to see and hear the DSPs for herself rather than rely on Harry's report. But she never begrudged him for his desperation. In fact, she had told him so many times she wouldn't begrudge him if he turned the search entirely over to her.

Harry had cancer, had had it a long time. It was held at bay by medication, but that medication caused him chronic pain. The pain was from inflamed nerves, so it was a raw pain like he had never felt before, like someone was scraping the insides of his limbs with sandpaper. When the pain first began, doctors prescribed an opioid, but he refused to get the prescription filled. Jennie and Harry had lost too many friends to heroin, and every one of these friends' stories began with a prescription. Once in awhile, Harry was tempted to fill it, but he told himself the same thing whenever he had the urge, "a dead dad is worth less than a dad in pain."

Harry had enough strength to fight the pain so he could make Tim's meals, play matching card games, video games, and pretty much anything that could be done sitting down with Tim. But going outside the house with Tim was not an option. If Harry was out with Tim and one of his big waves of pain hit, Harry would be useless. If Tim had a seizure, he would be useless. If Tim focused on something far off and wondered away, Harry would be useless. And when Jennie had vacation time to use, she had to use it to stay home with Tim while Harry took care of his medical appointments.

Every time another DSP walked through their door, both Jennie and Harry were filled with so much hope that their lives were about to change. And every time they were let down. This time was like every time. Harry and Jennie both knew before they walked him out the door that this DSP wouldn't fit Tim's needs at all. They didn't have to discuss it to know they agreed.

After Jennie turned the deadbolt, she heard Harry drop to the floor. Harry cried while slumped on the floor, a quivering lump. Jennie leaned down to him, reaching out to

touch his back, but freezing as she remembered that if she did, he might have a wave of pain.

“I’m so sorry, Harry.”

Finally, Caroline broke the silence.

“Well, it sounds like it’s time you get to know Tim.”

Linda wiped her wet cheeks with her palms, and looked out at the crescent moon.

“I guess he is my cousin after all. It’s kinda weird we’ve never hung out,” Linda said smiling.

What adds up to Power in *Anatomy of Care*?

In the literature review, I discussed "An illusory interiority: Interrogating the discourse/s of inclusion" by Linda J. Graham and Roger Slee. It is a conceptual unraveling of inclusion as a discourse and a concept. Its most fundamental stance is "that the term inclusion...presupposes a whole into which something (or someone) can be incorporated" (Graham & Slee, 2008, p. 278). Graham and Slee use this deconstruction of the term, "inclusion," to argue that employing inclusion for the sake of undoing ableism and the barriers that come along with it in society is a contradictory act. This is because the "centred-ness" that inclusion implies we should be pulling people with intellectual disabilities into, i.e. "the community," discursively privileges notions of the pre-existing" structures, which is to say structures built to serve able-bodied people (Graham & Slee, 2008, p. 278). To move away from discussing this in terms of categories, one can think of it in simpler terms, akin to the idea that we should question why we are focused on pushing a person with intellectual disabilities into social, political, and economic structures that have excluded them. Or, a simpler, more fundamental example that comes

to my mind has to do with sensory friendly showings of films. These are understood to be a good thing for many people with diverse sensory needs, allowing them to access an experience previously inaccessible to them. At the same time, one could, and I would argue should, ask what would it look like for a film industry to exist created, curated, and presented by people with intellectual disabilities and advocates for people with intellectual disabilities? One could go further down this line of thought, still, asking what it would mean to have people with intellectual disabilities and advocates create their own tools for sensory-based (sight and/or touch and/or aural and/or smell based) story-telling?

Graham and Slee, however, would likely not find this to be a complete shedding of the skin of the "norm"—which is one of the ways they refer to the aforementioned centre. My questions about film and storytelling, though, are more of a concrete example put forward to get one thinking in the direction of Graham and Slee. To be clear, they argue that the "norm" is far more engrained, writing that it is "a man-made grid of intelligibility that attributes value to culturally specific performances and in doing so, privileges particular ways of being" (Graham & Slee, 2008, p. 281). So, they suggest a turn away from inclusion would be a disruption of "the construction of centre from which exclusion derives" (Graham & Slee, 2008, p. 279).

It requires a bit of piecing-together to see how this might look in any kind of praxis. To begin that piecing-together, I turn to an article by Linda Graham called, "Caught in the net: A Foucaultian interrogation of the incidental effects of limited notions of inclusion." In that article, Graham writes about school-aged children in special education programs, and not about people who live in waiver homes, but her fundamental point about how to move beyond inclusion certainly resonates within the context of a waiver

home. It is that "practice...is where analysis must begin," as opposed to looking at "policy" (Graham, 2006, p. 5). Though policy is "oft regarded as an ultimate arbiter" in the function of a system of care or schooling, Graham argues it "is but one thread or aspect of a 'problem' and policy intent can be melded through interpretation and implementation" (Graham, 2006, p. 5). Looking at practice allows us to see barriers for people with intellectual disabilities at the level of "innumerable separate locations" (Graham, 2006, p. 5).

We can use Graham's quoting of Foucault to help orient us further:

Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target; they are also the elements of its articulation. (quoting Foucault, 1980, p. 78-108 Graham, 2006, p. 4)

This is the shape of things. Power acts upon individuals, but also they "are elements of its articulation;" they are binding agents for the threads, while the threads give their actions shape. However, what I especially want to call attention to in this quote is the language of movement and position. In this description of power as net-like, it is important to imagine a net, and that its relationship to its threads is that the threads are in relationship with one another, and the result of this connective tissue of threads is a net. "Individuals" are not simply wandering about these threads, either. The suggestion is they are in a relationship with the threads, manifesting their form as elements of these threads' expression.

By this point, it is clear that another step is needed to be able to see this “net-like organisation” of power ‘on the ground,’ as it were. For this, I turn to non-representational theory, which authors Edward Hall and Robert Wilton discuss in their article, “Towards a relational geography of disability.” Hall and Wilton describe “non-representational theory” having “had a broad impact across human geography in recent years, shaping debates in fields of study that overlap and intersect with disability geographies,” amongst others (Hall & Wilton, 2016, p. 729). Specifically, what drives home its usage for my purpose is that “a key element of this approach has been its emphasis on the importance of practice,” which is described basically as interaction, and is “the basis of social life, and...the source for conscious meaning and intent” (Hall & Wilton, 2016, p. 729). This rightly calls to mind Graham’s argument that understanding the experiences of people with intellectual disabilities requires a turn away from studying inclusion/exclusion, in favor of looking at *practice*. Within non-representational theory’s (NRT’s) approaches to geography, “practice is concerned with demonstrating the significance of seemingly mundane, habitual, non-reflexive practices for how we come to understand ourselves and the world” (Hall & Wilton, 2016, p. 729). To engage in NRT in this context of disability geography, one must take a relational approach, because, within NRT, “practice” is also “conceived in relational terms such that the making—and the making sense—of social life happens in and through relational connections between heterogeneous bodies, objects and environments” (Hall & Wilton, 2016, p. 729).

It is not just with Graham that NRT is philosophically aligned, however, but also with dismodernism. Dismodernism positions all subjects as “disabled, only completed by technology and by interventions” (Davis, 2013, p. 275). As a philosophical stance,

dismodernism sees all individuals as incomplete. All individuals are incomplete, because they need a vast spectrum of supports, which are as varied as individuals who utilize “a motorized wheelchair...the controls manipulated by the mouth or tongue” to individuals who utilize and rely on “information technology, protective legislation, and globalized forms of securing order and peace” (Davis, 2013, p. 275). NRT takes this same philosophical stance, making it useful as an argument for shifting away from an “epistemological emphasis on meaning and identity to an ontological concern with bodies and material doings” (Hall & Wilton, 2016, pp. 728, 729). Hall and Wilton argue NRT accomplishes this shift by “decentering” the idea “of a stable...disabled subject in favour of an emphasis on relational becomings” (Hall & Wilton, 2016, p. 729). The effect of this is an opportunity “to think differently about how *all* bodies become dis/abled in and through their everyday geographies and how such becomings might be made otherwise” (Hall & Wilton, 2016, p. 729).

What this all amounts to is a permission to analyze settings relationally, in a way that highlights moments of becoming, of enabling or disabling. Looking relationally enables one to pick apart interactions between people, as well as how certain policies, emotions, histories, structures, ideals, etc. relate to people within those interactions. However, interactions are often complex assemblages of these innumerable facets, and cataloguing them *all* would be a daunting and potentially impossible task, even with one interaction, let alone interactions across a novella. Narrowing the focus here is essential. Certainly, power is what I am interested in, but it is important to clarify the kind of power and the aspect of interactions I look to in order to illuminate the dynamics of power. The kind of power is bio-power, and the aspect of interactions is the inter-active role of

emotion and risk, identified by Deborah Lupton as the “emotion-risk assemblage” (Lupton, 2013, p. 634).

To reiterate what was discussed in the literature review, what Foucault refers to as “bio-power” is described by Jack Levinson as “acting” indirectly on “the actions of others...through the protection and enhancement of individual health, happiness, and wealth” in his book *Making life work: Freedom and disability in a community group home* (Levinson, 2010, p. 39). Bio-power is distinguished from other kinds of power in that it does not act through overtly “crushing” individuals or “the aspirations and ideals of individuals” (Levinson, 2010, p. 39). One of the ways bio-power manifests is through risk. It is in the name of “protection and enhancement of individual health, happiness” that risk can be deployed as a limiting force, an instantiation of power—bio-power, to be precise.

In turning to the issue risk, I turn to Deborah Lupton’s article, “Risk and emotion: Towards an alternative theoretical perspective,” in which she draws from “analyses of the relationship between risk and emotion” found in “cultural geography, cultural studies and affect studies” to argue for looking at risk and emotion together (Lupton, 2013, p. 635). In order to do this looking, Lupton applies the concept of “assemblage,” which “incorporates...a constellation of...elements: ideational and material, human and non-human, living and non-living,” and “affect” (Lupton, 2013, p. 640). The resulting assemblage for looking at risk and emotion together is the “emotion-risk assemblage,” and as an assemblage this allows for an acknowledgement of “the shifting dynamics that are inherent in the embodied nature of risk understandings” (Lupton, 2013, p. 640). More basically, this approach affirms the reality that “we interact with different others, whether

they are human or non-human, living or non-living, and [that] our senses are engaged differently, depending on the places we inhabit and the things with which we interact” (Lupton, 2013, p. 640). While it is important that the emotion-risk assemblage acknowledges this interactive element in the ontological plane—which is simply to say interaction in the world—it also acknowledges that “both emotion and risk interact with each other and in the process, configure each other” (Lupton, 2013, pp. 640, 641). Emotion and risk do this configuring of each other in that ontological plane, each being “produced through...material and non-material phenomena: individual and collective memories and experiences, discourses, practices, objects, space and place, flesh” (Lupton, 2013, p. 641).

The best way to see the usefulness of Lupton’s emotion-risk assemblage is simply to use it, which I will do, as mentioned before, with the aim of revealing functions bio-power in moments in *Anatomy of care*. This is a three-tiered approach: 1) unpacking interactions within certain scenes of the novella, which has the methodological backdrop of non-representational theory; 2) within those interactions, isolating the presence of instances that fit within the emotion-risk assemblage; 3) Discussing the role bio-power plays as it is revealed in the effects of the instantiations of emotion-risk.

I wish to begin with the scene where Will has just been up in a tree, examining chrysalises and then jumps down, landing with just enough gravity to force him into the sitting position, and “when Will opened his eyes,” he sees “a man across the street standing on a porch” (Maxwell, p. 55). This is the precursor to officer Nolan Bream standing in West Park’s garage asking James about Will, because people reported to the police that “a man by his description [was] ‘climbing their trees,’” adding that

“obviously, this can’t happen” (Maxwell, p. 51).

Between the man on the porch, who stands stone still watching Will even as Will waves at the man, and the presence of a police officer saying people called the police on Will, a disconnect arises. This man and ostensibly others—if others are also watching Will—behave as though Will is a physical threat by calling the police without engaging Will directly. All the while, Will is climbing trees in broad daylight, clearly not trying to hide his actions in the way someone engaged in unscrupulous behaviour might. This disconnect, then, is between Will’s actions and the response to his actions.

Lupton’s emotion-risk assemblage provides a way to unpack this disconnect. According to Lupton, “individuals’ and social groups’ desire to maintain social order,” and to do this they engage in continual maintenance and demarcation of “symbolic as well as literal boundaries” (Lupton, 2013, p. 639). This boundary maintenance is an outgrowth of hyperactively focusing “on the identification of Others...that are considered threatening to this order” of symbolic and literal boundaries (Lupton, 2013, p. 639). One kind of boundary at play in this scene is that of property lines, which Will challenges by his very presence. Lupton also points out another kind of boundary that Will challenges, which is the boundary that demarcates what counts as “accepted embodiment” (Lupton, 2013, p. 640). “Accepted embodiment” for an adult does not include climbing trees in a subdivision. These two forms of boundary-crossing mark Will as “risky,” because boundary-crossing marks individuals as “inhabiting a position of liminality or hybridity” (Lupton, 2013, p. 640). A reasonable course of action—either letting Will alone or calmly approaching Will and speaking directly to him—is thrown out, because people attach disproportionate levels of riskiness to bodies that inhabit liminal boundary-

crossing zones, even when there is no actual elevation of threat.

Bio-power has an interesting relationship to the goings-on in this scene and to the aspects of the emotion-risk assemblage that is at play. I referred earlier to bio-power as acting “through the protection and enhancement of individual health, happiness, and wealth” (Levinson, 2010, p. 39). Here, it is acting through the protection of wealth. The reaction to call the police is portrayed as at least partially a reaction to a perceived threat to private property, which is a kind of wealth. The result of this action to protect wealth is that Will definitively loses freedom, being no longer able to take walks on his own.

Next I will discuss a scene involving Lily and Val. It is the one where Val spends “forty-five minutes” wiping away the stool from Lily in the bathroom. While Val wipes Lily, she is confronted with the need to make “a calculation” (Maxwell, p. 63). The calculation Val makes is how to hold Lily tightly enough so that she can wipe away the stool, while not holding too tightly so that she leaves bruises on Lily's body. This is not a calculation that comes from Val, even though it flows through her, and she is governed by it. The root of the calculation is visible later on the same page: “Leaving her with feces caked back there would be neglect. But bruises amounted to abuse” (Maxwell, p. 63).

If Val does not hold Lily tightly enough or let her leave the bathroom not completely wiped, there is a risk Val could be charged with neglect, but if Val holds tightly, she risks bruising Lily. Val is deep inside an emotion-risk assemblage here. At play are discourses and policies of health and safety that mandate Lily to be supported in such a way that does not result in her being left with stool on her skin or anus. These discourses and policies are thus in a relationship with the science that tells us that skin

erosion is a possibility when stool is not fully removed from skin. But also at play is Val's memory of the Alzheimer's unit where her mother resided before her death.

In Val's memory she sees "people in scrubs walking around a little too fast with faces a little too blank, clearly doing the same kind of calculation behind the closed doors of bathrooms, the sound of moaning protests reaching out into the hallways" (Maxwell, p. 64).

Val is in a fluid space constructed through her physical relation to Lily—which is primarily a relation to Lily's resistance—through her relation to Open Doors policy, through her relation to her perception of risks related to stool's contact with skin, through her memory of the Alzheimer's unit. A node that acts in the text as a connective tissue between all of these aspects is the phrase "assisted with toileting" (Maxwell, p. 64).

In a passage where free indirect discourse gives the reader a glimpse into Val's mind, the reader learns that Val feels the dissonance between the way the phrase, "assisted with toileting" comes across in the text of her typed notes in contrast to how, "in the moment, it didn't feel like 'assisting' at all" (Maxwell, p. 64). Val even laments that she cannot report Lily as "protesting" (Maxwell, p. 64). If she did, she knows she would be questioned how she could know that, since Lily does not speak or sign. Val knows that Lily crawling away from her is a form of protesting, yet simultaneously Val knows that she would be unable to provide an answer satisfactory to Open Doors to the question of *how* she knew that is what Lily meant by crawling away.

These feelings Val has all speak to Lupton's description of emotions "as fluid, relational and highly contextual," and that "they have histories, building on previous experiences" (Lupton, 2013, p. 638). Likewise, all of these feelings involve some sort of

“if, then” aspect, e.g. if Val reports that Lily is protesting, she will not be believed; if she participates in this “calculation,” she becomes closer to the people who worked at the Alzheimer’s unit; certainly the “calculation” itself: if she holds too tightly, she risks bruising Lily, yet if she holds too loosely, she cannot wipe away the stool. This is the aspect of risk, which, as I have shown is interwoven with emotion, as Lupton would argue all risk is, to some degree.

These risks Val feels her way through fit neatly into Lupton’s description of risk as “potentialities, both ‘constructed realities’ and ‘real constructions’ that are comprised of complex networks of materialities, procedures, regulations, discourses and strategies—and emotions” (Lupton, 2013, p. 638). The materialities are the physical movements Val and Lily are making. The procedures are the hard fact that when Lily has stool on her and Val’s position demands she clean it off. The regulations are what manifest for Val as the threat of being charged with neglect or abuse. The discourse most prominently at play here is the idea that Lily’s actions cannot indicate agency, which Val has issue with, as evinced in her wish that she *could* report Lily as protesting, yet the discourse is powerful enough that even though Val goes so far as to feel she does “know” Lily is protesting, she fears she could not make a convincing argument if she were questioned. The strategy present here is clearly the “calculation.” The emotion is both interwoven through all of these aspects, but is also apparent in the way her memory of the Alzheimer’s unit comes into play. That couches this whole situation in a very emotive light, because Val is essentially establishing the point that she knows what it feels like to love someone subjected to this kind of calculation. This emotive light envelops the entire scene.

The last scene I would like to discuss is the one where Val, James, and Dawn take

issue with Scott not urinating for three days. Specifically, I want to focus on the moments Dawn interacts with Scott, as well as how Dawn communicates with other staff about this issue.

Shortly after Dawn enters the room, the reader learns that due to Dawn's strength, size, and skill at lifting Scott and Lily when the necessity arises, "the responsibility of lifting them defaulted to Dawn" (Maxwell, pp. 100, 101). The reader also learns that Scott hates "being lifted by human hands," and that just the week earlier Dawn had "lifted Scott by hand more times than she could count," because his mechanical lift was broken (Maxwell, p. 101). Thus, it crosses Dawn's "mind that this might be the root of Scott's refusal to pee," though the lack of certainty allows Dawn to push "that idea out of her mind as soon as it enter[s]" (Maxwell, p. 101). This speaks to the way Lupton describes the body as "the most intimately felt geography," which applies on an extreme level to Scott and Dawn, as that "geography" is constructed via "relating to and responding to other bodies" (Lupton, 2013, p. 639). "Embodiment," according to Lupton, "is never individual," but this is especially true for Scott and Dawn's interactions (Lupton, 2013, p. 639). Likewise, since "emotions take place within and around the body as it moves through space and interacts with other bodies and with objects," Scott's intense response to being lifted by Dawn should not surprise the reader. (Lupton, 2013, p. 639).

Before I continue, I want to note something key about this specific issue with Scott being lifted that points to a broader issue portrayed in *Anatomy of Care*. It is the issue of epistemological blockages regarding how a resident of West Park feels and how the people working at West Park feel about that lack of knowledge. This comes up especially

clearly in the long conversation James and Dawn have after Scott pees and Dawn considers the issue resolved. The issue comes up explicitly with regard to whether Lily really *wants* to go to a day program, but here, I am more interested in the way it comes up regarding Scott, because it demonstrates how deeply interwoven and relational emotion, risk, and bio-power can be.

Dawn brings up a time before James or Val worked at West Park when Scott refused to pee. Straight away, Dawn makes known that one of her primary goals in that moment was to appear like she “had it under control” (Maxwell, p. 128). It is important to acknowledge that Dawn is focused on the situation—the it—here, rather than the who—a person—which is Scott. This speaks incisively to Lupton’s point that “both emotion and risk interact with each other and in the process, configure each other,” for it is the fear that “Sammy and the subs” express that informs how Dawn perceives the risks at play, tipping the scales toward others’ perception of Dawn rather than toward Scott as a whole human being (Lupton, 2013, pp. 640, 641) (Maxwell, p. 128).

This emotion-risk assemblage of Dawn’s feelings about others’ perception of her, the risk of embarrassment, and the risk of something medically dangerous resulting from Scott’s refusal to pee all add up to an intense manifestation of bio-power. The nuances of the situation and Dawn’s response leads her to go into Scott’s room and sit in there “for four hours” (Maxwell, p.129). Once she is in Scott’s room, the weight of risk to Scott’s health appears to descend more heavily on Dawn, because she is described as “burning through” her “phone’s data, looking up how to induce urination and at what point he was in serious danger” (Maxwell, p. 129). The implication from earlier in the text is that Scott is not pleased to have Dawn in his room, so this is a significant instance of a

manifestation of bio-power as Dawn's actions are influenced by notions of health, in a way that results in the undesired limitation of Scott's privacy.

When Dawn interacts with this same risk to Scott's health again, as it is discovered this time by Val, Dawn inhabits an "embodied/material dimension" of emotion and risk that is "predicated on individual past experiences" (Lupton, 2013, p. 638). This time, Dawn appears callous as a result of feeling she has a sure-fire strategy of inducing Scott to pee, which is to blatantly tell Scott that she will wait with him until he pees, and if he does not she will "take him to the hospital," which Scott explicitly says he does not want to do (Maxwell, p. 113). The simple way to look at the function of bio-power here would be to only acknowledge the role of protection of health, but that is far from exclusively what is behind bio-power here, for which Lupton's emotion-risk assemblage enables an unpacking.

Lupton points out that frequently "public health workers" navigate mitigating "risk to the population" by "inspiring emotion," and that because the inspiring of emotion is perceived to be in service of a certain health outcome, this "is viewed as a rational action on the part of public health workers" (Lupton, 2013, p. 644). Certainly, Dawn is not in the position of interacting with a whole population, but the way she interacts with Scott by essentially threatening him into having such a strong emotional response that he speaks to her—something he rarely does—parallels the structure of the interaction between public health workers and populations to which Lupton refers. This interaction, then, not only involves Dawn's "individual past experiences," but also "collective memories" of the form public health's deployment of fear can and has taken.

While there are certainly more scenes in *Anatomy of Care* where Lupton's emotion-

risk assemblage or forces of bio-power play a role, the ones that I outlined above demonstrate waiver home dynamics that exhibit both of these at once. Beyond the analysis I provided above is the role this analysis serves, which is to demonstrate an analytical move beyond looking at residential services through the lens of inclusion/exclusion. As I showed at the beginning of this section, as well as in the literature review, the inclusion/exclusion binary is an inadequate lens through which to analyze *and* construct residential services. Lenses that deal with the on-the-ground realities of the experiences of people who live and work in residential settings provide more granular results that are not beholden to binaries. Certainly, the lens of bio-power combined with emotion-risk assemblage is only one way of going about this, but due to the granularities I was able to unearth in the dynamics of the fictional West Park, it appears to be useful lens.

Missing Pieces, a Reflection

Like every individual, I am a person with many intersecting identities and issues at play in my life. Despite the core of this project—the novella—being rooted in my experience, it cannot possibly cover every complex or intersectional issue at play in my histories with the settings I write about, let alone the issues that arise in these settings that are outside of my lived experienced. Humans are complex beings with interweaving and intersectional identities and histories, and I find it imperative for writers, theorists, and researchers to acknowledge that all representational work such as this is inherently limited. So to end this section on a note of humility, I wish to address some limitations of this project. Issues connected to race make virtually no appearance. There are several reasons for this. As a white person, living and working as a person of colour is obviously not an experience I can speak to with any kind of authority, especially in the specific context of this project, which is rural waiver home settings. Likewise, there is virtually no research out there to work from on this specific intersection of race, work and region. That lack should certainly be remedied. Collecting and developing such research was far outside of what I would have been able to accomplish within the scope of this project, however. There is much work to be done on the experience of people of colour working as DSPs in rural settings.

Something that does not appear to any significant extent that I do have experience with is being a part of the LGBTQIA community. Unlike my nonbinary gender identity, I have been varying degrees of “out” to co-workers and superiors about my bisexuality

over the years, including during my time working in residential services for people with intellectual disabilities. However, I decided to not include this aspect of my identity in the novella or discussions surrounding it, because I wanted to avoid the novella ballooning into a bigger project than I could handle. That being said, I find representation vital in fiction, and since I am a part of the LGBTQIA community, I felt comfortable attempting to honestly portray characters who belong to this community, even if those characters were not people who work in residential services—Linda and her partner, Caroline. It is important to point out that even though I do not engage the issue in this project, I do believe it is vital to produce further research on people in the LGBTQIA community who work and live in rural waiver home and other residential settings. Despite it being intentional to not include this in my project, for the sake of scope, it is an unfortunate gap I must acknowledge in the name of reflexivity.

Finally, to end this section and this project, I wish to pull the reader into the spring of 2020, which is when I am writing. No matter when this is read, the reader will be aware of SARS-CoV-2/COVID-19/the novel coronavirus that has grown into a global pandemic. It is vital that disability studies and disciplines adjacent to it begin researching the effects of this on the lives of people with intellectual disabilities, both because of the huge impact this virus has had, but also for the sake of understanding how to navigate a potential pandemic in the future. Even with no members of my family having contracted the virus as of now, we have struggled with the structural effects of this virus, like I am sure all families have in which there are one or more individuals with intellectual disabilities. That said, even the difference in experience between my sibling with intellectual disabilities who lives with my parents—and for whom I provide direct

support—and my sibling who lives in a group home has been vast. Each of them may be marked by the same category of “intellectual disability,” but no part of their experience has been the same. This microcosm of the vastness of varying experiences of the pandemic for people with intellectual disabilities calls to attention the importance of examining this issue from the angle of intellectual disability.

While I certainly never planned on ending this project on a current event note, to not address the fact that this disruptive event is not mentioned in the rest of this project would be a gaping hole in itself. It provides me with at least a small glimmer of hopeful purpose to know what work is left to be done in my corner of the world.

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