

‘I’M A JUGGLING ROBOT:’  
AN ETHNOGRAPHY OF THE ORGANIZATION AND  
CULTURE OF AUTISM-BASED APPLIED BEHAVIOUR  
THERAPIES IN ONTARIO, CANADA

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## **ABSTRACT**

This dissertation is an ethnographic study of the culture, social organization, and everyday practices of providers and recipients of autism-based applied behavior therapies in Ontario, Canada. Autism-based applied behavior therapies are highly controversial evidence-based autism interventions that have become the standard of care, and the only guaranteed-funded services, for autistic people in this province. These therapies are provided by teachers in public autism classrooms, by parents in the home, and by personal support workers in group homes with autistic residents. The lives of many autistic people in this province, whether at school, in the home, or the community, are structured through completing behaviour therapy activities.

The growing voices that resist and proliferate applied behaviour therapies, highlight the importance of critical scholarly attention to these therapies. This dissertation is situated within the fields of science studies, medical anthropology, and critical autism studies, and focuses on the experiences and practices of providers. Learning about what providers do, and how they make sense of what they do, helps to understand the professional culture in which they work, and the complex forces of power that govern both their activities and the everyday lives of autistic people in this province.

For this project, I completed an ethnography, which included participant observation activities and interviews with thirty-two providers and recipients of these therapies. To understand the complex power relations that constitute everyday enactments of behaviour therapies, I combined the governance-focused approach offered by Studies in the Social Organization of Knowledge, with anthropological approaches to ethnography that focus on meaning and description. The merger of these two methods of inquiry, where cultural analysis bolsters an organizational account, enables a rich and comprehensive analysis of behaviour therapy practices.

*In my work and thinking, I am committed to an actual world. A world of social relations and experience, of human practice and activities, of embodied joys, pleasures and pains.*

*In this world, texts are but a part of life, often for some people more than others.*

(Mykhalovskiy, 1996, p. 143).

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## INTRODUCTION

I met with Hailey, a high-profile clinician with an impressive research background, at the autism organization where she works. Hailey came down to meet me in the waiting room. She greeted me warmly with a boisterous handshake and, moving quickly, asked me to follow her upstairs to her big office, where her passion for her work emanated through stacks of paper messily strewn on every surface.

Hailey informed me that she might have to cut the interview short for an “important meeting.” She would know in twenty minutes when she had to make a phone call. With a short timeframe looming over the interview, I got right to the consent form. Hailey painstakingly went through each line, asking a series of questions: “What do you mean by governance? That’s an interesting word to put in your title.” “Why do you have committee members in Anthropology and Sociology?” “What happens in the Department of the History and Theory of Psychology?” After a few of these questions, I got the sense that Hailey was doing a dance, trying to figure out, through my language and affiliations, what my stance towards applied behaviour therapies is. I realized that she was doing this dance because she did not think she could directly ask me and because she did not feel that she could tell me her views without knowing mine. As I continued my ethnographic work, I got to know this dance well and I learnt a bit about how to lead it.

Getting a candid interview with Hailey depended on my own views, but what views did she want me to have? Did she not want to expose her work to a behaviour therapy critic? Or was she afraid of speaking critically of behaviour therapies to a proponent? Either answer reveals the heightened tension within current autism communities in North America, where the animosity between critics and proponents of these therapies has created a culture of secrecy, distrust, and fear around openly stating one’s views. While behaviour therapy proponents are ubiquitous in autism communities and often vocal about their positive appraisal of these therapies, they often do not like engaging with critics, except to vocally discount their views (Bagatell, 2010; Dawson, 2005; Devita-Raeburn

2016; Gruson-Wood, 2014; Morris, 2009; Orsini, 2009). As such, both proponents and critics police entry into their everyday worlds.

As I will describe throughout this dissertation, applied behaviour therapies govern the lives of autistic people and shape autism communities in Ontario. These therapies are referred to as “science-based” and “evidence-based” methods and practice, and have become widely adopted in healthcare for autistic people (particularly young autistic people) in North America, and increasingly beyond (Ontario Autism Program, 2018; Orsini, 2009; Ontario Ministry of Education 2007; Yergeau, 2018). Applied behaviour therapies are often also described as the “gold standards” of care for autism in Ontario (The Ontario Association for Behaviour Analysts, 2017, p.3): they are the only guaranteed government-funded autism services (Ontario Autism Program, 2018); they must be provided by teachers in all public autism classrooms (Ontario Ministry of Education, 2007; Perry, 2002), and in most group homes serving autistic and developmentally disabled adult populations.<sup>1</sup> Autism exists in North America as it does at this moment—diagnostically, discursively and socially—because of these therapies (See Eyal et al., 2010).

Ole Ivar Lovaas, a Norwegian-American clinical psychologist, pioneered autism-specific Applied Behaviour Analysis (ABA) in the 1960s, and later, an intensive scientific program based on the principles of ABA, called Early Intensive Behaviour Intervention (EIBI). He completed his work at the University of Los Angeles, California, in what would become *The Lovaas ABA Institute* (Smith & Eikeseth, 2011). As opposed to ABA which does not require a specific time-commitment or programmatic format, EIBI requires at least forty hours a week of structured one-on-one ABA work, which generally consists of proscriptive teaching methods to promote systematic incremental learning (Lovaas,

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<sup>1</sup> I could not find provincial data to confirm that applied behaviour therapies have become standard services within group homes and day programs for disabled adults. Yet in my ethnographic work, every group home and personal support worker working within this setting that I encountered discussed the use of ABA in their workplaces and described how care is structured through the Behaviour Support Plan (which I will describe in detail in Chapter Two). Further, the behaviour supervisors I spoke with who consult within group home spaces described the use of behaviour therapies as central within these spaces. Lastly, the relatively recent development of behaviour therapy companies specifically targeted to adult populations living in residential care facilities suggests the increasing ubiquity of behaviour therapies within these spaces (Behaviour Innovations, 2018; Behaviourprise Consultant Inc., 2018).

<sup>2</sup> As I discovered through my ethnographic work, the findings from this paper and its impressive results are still often quoted by clinicians and ABA experts at autism conferences and events, as evidence of the clinical success of applied behaviour therapies, yet there are also multiple clinical reviews that have claimed Lovaas’ pioneering work is methodologically and scientifically invalid (Bassett, K., Green, C.J., & Kazanjian, A,

1987). Discrete Trial Training (often referred to as “table work”) is a popular EIBI method, which includes completing a series of ten two-minute scripted teaching lessons, which are repeated until mastered, with a short break in between each (T. Smith, 2001). During these sessions, the behaviour therapist observes and collects data on the responses of their client and compiles this data over time to turn it into graphs and charts.

Lovaas’ and his behaviour therapy enterprise became a popular method for treating autism in North America through his landmark 1987 study “Behavioural Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children.” The results from this study (which continue to be both widely hailed and contested within autism communities) stated that receiving forty hours of EIBI over a two-to-three year period caused “47% of study participants in the control group” to achieve “normal intellectual and educational functioning, with normal-range IQ scores” and successful integration into a first grade mainstream school classroom (Lovaas, 1987, p.3). Lovaas claimed that another 40% of study participants improved to be “mildly retarded” and were “assigned to special classes for the language delay,” while “10% were profoundly retarded and assigned to classes for the autistic/retarded” (1987, p.3).<sup>2</sup> These findings, in which *eighty percent* of study participants were described as making substantial improvements to their IQ and behaviour (with forty percent of this total demonstrating normal functioning and full societal integration), were considered clinically revolutionary.

Up until the point of Lovaas’ 1987 study, autism was treated primarily by psychiatrists, and considered to be a chronic mental condition that could not be rehabilitated. While notable psychiatrists and psychologists tried to alter the cognitive and behaviour function of autistic people, these attempts did not yield substantive results. Accordingly, until Lovaas and his behaviour therapy treatments, most autistic people spent much of their lives languishing behind the brick walls of mental institutions, receiving only custodial forms of care (Eyal, Hart, Onculer, Oren, Rossi, 2010). With applied behaviour therapies, Lovaas showed that it was possible to intervene on autism and create extensive positive behaviour and intellectual change. By completing behaviour therapy

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work, the autistic person could even, according to Lovaas, approximate the ‘normal’ citizen. The effective potential of applied behaviour therapies changed everything for autistic people, professionals, and parents.

Lovaas, as well as governmental bodies and current ABA experts, classify applied behaviour therapies as an applied science. These therapies are based on B.F. Skinner’s radical behaviourism (1938, 1971) whereby the environment is understood as the variable that, through antecedents and consequences, determines behaviour.<sup>3</sup> With applied behaviour therapies, the human condition is understood as comprising a set of behaviours that are shaped by the environment and modified by applying scheduled reinforcements (in the form of positive and negative reinforcements, and less commonly now, aversives or punishment).<sup>4</sup> Further, because behaviours are considered empirically observable, they can be measured, analyzed and modified. With behaviour therapy programs, targeted behaviours can include: learning to speak and communicate needs, use the toilet, count, build social skills, make eye contact, stop tantrums, or reduce stimming (self-stimulation like hand flapping or rocking), and so on. Interventions may take the form of quick, short, proscriptive sessions that are repeated until mastered (Discrete Trial Training), while other common therapeutic interventions include natural environment (structured instructions carried out in the client’s natural environment or at moments of high interest and motivation) or incidental training (using naturally occurring opportunities to instruct), and

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<sup>3</sup> Don Baer and Sid Bijou, as well as others at the University of Washington were also highly influential for Lovaas’ development of systems of coding for direct observations, and Israel Goldiamond and Ted Ayllon’s work on antecedents and consequences was crucial to Lovaas’ ABA method (Lovaas, 1993; Smith & Eikeseth). Smith (2011) details how Lovaas was influenced by 19<sup>th</sup> century case studies of educators, particularly Jean Marc Gaspard Itard who completed immersive therapeutic work with “Victor,” who he referred to as the “Wild Boy or Aveyron.”

<sup>4</sup> An aversive or a punishment is the scheduled application of an unpleasant stimulus with the intent of stopping an undesirable or harmful behaviour that could not be changed through positive or negative reinforcements. There are a range of common aversives used in ABA, such as electrical shocks, slaps, pinches, taste aversives (such as hot sauce and lemon juice), or temperature aversives (such as making the therapy recipient fish pennies out of the bottom of a bucket of ice water). While many practitioners and parents are against the use of aversives, I found that highly educated behaviour science researchers had a more nuanced and sophisticated understanding of aversives. For instance, my participant, a behaviour science researcher named Ronnie, argued that an aversive, as any unpleasant stimulus, really depends on what is aversive to each therapy participant. An aversive could be a high-five, for instance, for some clients. Lovaas posited (1987) aversives as an effective part of the science of his behaviour analytic approach when dealing with extreme and harmful behaviours, such as when a child bangs their head repetitively against a wall. Yet Lovaas’ (Rekers & Lovaas, 1974) sense of an extreme or harmful behaviour becomes increasingly questionable as he applied aversives (such as slaps and electric shocks) to young “feminine boys” (when he used ABA to change “atypical” gender behaviour) when they exhibited feminine behaviours, such as walking with a “swish” or wearing a purse.

pivotal response therapy (targets specific areas of development rather than specific behaviours, is often play-based).

Despite the prevalence of applied behaviour therapies and their scientific status, they are highly controversial methods within autism and autistic communities. Although parents and clinicians are often strong proponents, having even launched human rights cases for ABA and EIBI to be classified as medical necessities, autistic self-advocates (some having received these therapies) are often very critical of these methods (*Auton vs British Columbia*, 2002-2003; Dawson, 2004; Gordon, 2012). This is evident from the legal and social media testimony provided by autistic people who have criticized these interventions as non-consensual, scientifically unethical and biased (Bagatell, 2010; Dawson, 2004, 2005; Schaber, 2014; Sequenzia, 2015, 2016; Solomon, 2008). Critics have also denounced applied behaviour therapies as being oppressive, disciplinary, normalizing, corrective methods with the intention to eradicate autism.<sup>5</sup> In addition to being innately harmful, critics argue that the use of overtly harmful punishments (such as taste aversives like lemon juice and hot sauce or fishing penny's out of ice buckets) are still being used in some behaviour therapy programs (five of my behavior therapy informants did confirm that they have witnessed the use of these punishments in their ABA workplace at some point).

On the other side of the coin, proponents tend to advocate for science and evidence-based clinical therapy treatments as life-giving and life-saving, and they view applied behaviour therapies as the best example of this. Proponents often further claim that critics are misinformed about current ABA practice, and are slanderous to the field when they state that old school Lovaasian methods like punishment are still being used on autistic children. For proponents then, applied behaviour therapies are positioned as the path to agency, productivity and the good life.<sup>6</sup>

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<sup>5</sup> It is clear how critics make these claims when reading through Lovaas' work. For example, consider this excerpt from, "Some Generalization and Follow-Up Measures on Autistic Children in Behavior Therapy" his multi-authored article with Robert Koegel, James Q. Simmons, and Judith Stevens Long:

Throughout [this study] there was an emphasis on making the child look as normal as possible, rewarding him for normal behaviour and punishing his psychotic behaviour, teaching him to please his parents and us, to be grateful for what we would do for him, to be afraid of us when we were angry, and pleased when we were happy. Adults were in control. In short, we attempted to teach these children what parents of the middle-class western world attempt to teach theirs. There are, of course, many questions that one may have about these values, but faced with primitive psychotic children, these seem rather secure and comforting as initial goals (1973, p.135-135).

<sup>6</sup> For instance, parents launched the *Auton vs. British Columbia* suit that made its way to the Supreme Court of Canada in 2004. These parents were fighting for ABA to be designated as a fully funded "medically

Critics often ban pro-ABA actors from entry into their social and political groups, via policing and monitoring content in chat rooms (Bagatell, 2010). In contrast many of the parent and clinician-run autism organizations that advocate for the use of applied behaviour therapies have also excluded anti-ABA autistic critics from their organizations and events. What I observed through fieldwork is that when proponents and critics do converse about the topic of behaviour therapies, these interactions are often hostile and combative. As I will examine in Chapter Four, there are many actors who do not fall neatly into either side of the binary, but these oppositional sides do exist, and their battles shape autism discourse and social relations.

For the reasons just outlined, applied behaviour therapies constitute a social and political fault-line within autism communities, and so seemingly banal words and statements are amplified, held in suspect, and used as code to communicate a particular political position relating to them. For instance, I used the word “politics” in my call out for study participants for this thesis, stating: “I am a social scientist and so my project aims to explore some of the social and political implications of applied behaviour therapies.” Tajman, a behaviour therapy clinician (and eventually one of my participants), asked to speak on the phone after seeing my call out, as she wanted to figure out whether or not to participate.<sup>7</sup> During our lengthy conversation, she affirmed: “I should let you know... that your use of the word politics turns practitioners off from participating in your study and

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necessary” service. When this case was lost, these parents took to the media claiming that this failure meant that: 1) the Canadian government was abandoning autistic children (Dawson, 2005); 2) parents would have to resort to institutionalizing or putting their autistic child into foster care (Dawson, 2005); and; 3) that some parents might have to resort to killing themselves and their autistic child (Dawson, 2005). Other parent’s involved in this case repeatedly compared autism to cancer: one parent stated that he would rather his child have cancer because at least then she would get appropriate treatment (Dawson 2005). In all of these statements, autism was articulated as a horrible illness, and ABA was articulated as: 1) the *only* valuable autism service; 2) lifesaving and curative, and; 3) as responsible for providing the means to actually create people out of blank autistic entities. As Lovaas often said (in different ways), the task of ABA was to “[build] a person where little had existed before” (Lovaas, 1989 *in* Dawson 2005).

Mainstream autism media coverage often reinforces this reification of applied behaviour therapies as lifesaving and self-giving, and this exposure works to intensify this culture of urgency around (early intervention) access to these services (Gordon, 2012; Hammer, 2008; Mallan, 2004; Talaga, 2012). Autism seems, for instance, to be the cause du jour of the *Toronto Star* newspaper (The Autism Project, 2012-2014), which publishes regularly on the dire state of publicly available ABA/IBI services with stories of children missing their curative early intervention “window,” parents spending their life savings on private treatment for their child, and families being ripped apart by autism.

<sup>7</sup> This participant also engaged in extended conversations with her employer about my study (where he warned her about participating in a study that might be “against” her) and required that I send her a list of my interview questions in order for her to decide about participating.



makes you seem suspicious. Maybe you should change that word in your call out.”<sup>8</sup> She further clarified: “My work is clinical. I don't care or think about politics. I just think about how, as a clinician, I can make people's lives better.” Like Tajman, many of the behaviour therapists I encountered during this study (though as will become evident, some clearly deviated from this model in striking and meaningful ways) and throughout my life (as the sibling of an autistic person), were keen to position behaviour therapies as outside of the muck of politics and culture: they viewed the political virtue of behaviour therapies as deriving from them being empirical, objective and value-free methods.

My original call out also referred to behaviour therapies as “evidence-based methods.” I sent my call out to “Josephine,” a prominent autistic critic of behaviour therapies. She viewed my wording as problematically *reinscribing* the evidence-based designation assigned (by government experts who make provincial autism policies) to behaviour therapies, and thus charged me with being both untrustworthy and uninformed. Josephine refused to participate in my study specifically because I used this phrasing.

Through my ethnographic work, I came to view both Tajman and Josephine’s reaction to my call out as a microcosm for just how fraught the topic of behaviour therapies is, and how larger discourses relating to science, power, and politics get roped into political debates regarding the value and nature of behaviour therapies. Said differently, conflicts about the ethical nature of behaviour therapies are intertwined with conflicts about scientific ideals and the social value of autism. In the debates about behaviour therapies that I have analyzed, the following queries are often all tangled up in shaping how people view these therapies: Are behaviour therapies ethical? Is autism a form of difference to be included or a disorder in need of normalization? Is un-situated objective evidence possible? Is standpoint knowledge a valid form of objectivity or is it merely anecdotal? Does clinical work exist within a citadel or is it shaped by social life and systems of power? Throughout this dissertation, I consider how autism, science, and the social, are knotted up, not only in stakeholders’ responses to, but also in everyday enactments of, applied behaviour therapies.

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<sup>8</sup> Tajman wanted me to correct this, I told her I could not, but assured her that my focus was not to degrade her work but to analyze the larger context in which it is situated.

*Hailey: the “quirky place” of ABA critique*

It was only after my phone conversation with Tajman that I understood that it was likely my controversial use of the word “politics” in my call out that first communicated to Hailey, the clinician who was so interested in my consent forms, that she might be able to share her views with me. I had my recorder out and was ready to begin the interview with her. I asked Hailey if I could turn it on and she asked: “Do you want the kind of interview you are going to get if you record me, or do you want the kind of interview you’re going to get if you don’t record me?” I was intrigued by her reluctance (no one else had turned down a recording), and reminded her that though she could choose not to be recorded, this interview, her identity, and her organization, would be confidential. Still, Hailey insisted that the recorder would result in a “really different interview” and she decided she wanted to speak to me candidly without it.<sup>9</sup>

During our conversation, Hailey shared her deeply critical views of applied behaviour therapies. Not only did she have a “philosophical bias” against them, she described them as often leading to “iatrogenic abuse.” From her clinical perspective, she considered behaviour therapies as methods that lend easily to traumatizing autistic people. She explained the high correlation between autism and PTSD, and that when you have sensory disturbance and overload, as many autistic people she knows do, you’re being re-traumatized all the time. Rather than address this, behaviour therapists, according to Hailey, often try to “correct” behavioural outbursts that happen in reaction to PTSD triggers, that they misidentify as “behavioural.” Hailey further described the behaviour therapy field as laden with “so much arrogance.” behaviour therapies might be beneficial to some, she confirmed, but they should not be the standard.

I recount Hailey’s position here, not to align with it, but to illustrate how, even with these *extremely* critical views, she will not publicly or professionally speak against behaviour therapies. It is important to consider the politics and culture that shape her tremendous hesitancy to be candid about her clinical assessment of these therapies.

After sharing all this information, Hailey said: “I’m just going to make this call about the thing I had to go to and tell them I’m going to be late.” She added: “You’re

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<sup>9</sup> Thankfully she allowed me to take jot notes, which I took furiously throughout our interview. After our interview I found an empty hallway and dictated all the dialogue I could recount from our conversation.

going to be really interested in this phone call, so just wait while I make it.” She picked up the phone and said: “Hey Jessica? Yes, it’s Hailey. I ordered a pizza to be ready for 4:10, but I’d like you to delay that till 4:45. But I want to make sure that you don’t make the pizza before I get there because I want it to be piping hot. It *has to be* piping hot.” Hailey, hung up the phone and laughed: “That was my really important meeting!”

What this phone call told me was that Hailey was expecting me to be a proponent of behaviour therapies, and if I was, she had an alibi in place to legitimize not giving me her time. It was also significant that Hailey *wanted me to know* that she was originally suspicious of me. With this phone call, Hailey showed me some of her techniques for dealing with proponents. The incident thus highlighted how Hailey, in her everyday interactions with autism professionals invested in behaviour therapies, has learnt to circle around her authentic views masterfully, like perfect figure eights. Her evasiveness is analytically important, signifying both the authority of behaviour therapies and the fear that even autism experts can have of speaking critically of them.

After the interview was complete, Hailey wanted me to clarify how I would refer to her in my study. I said I planned to name the geographical district she works in but she was uncomfortable with this, so I proposed: “clinician in Ontario,” which she agreed to. She asked for us to walk out of her workplace together while she grabbed her pizza. As we exited the building she warned me to be “very careful” about how I present my study, and to whom, because there is “a lot of resistance” to people who are critical of behaviour therapies, and most troublingly, to people who want to include the voices of autistic people in their autism research. I asked Hailey if she’s afraid to speak up about her views. She said she has to be “really careful” because she does not want to lose her “invitations to the parties.” Though Hailey jokingly described her views as placing her in a “quirky place,” I was left with the impression that she was actually quite terrified of losing much more than party invites for sharing her criticisms of behaviour therapies with her colleagues: I think she genuinely worries about losing her *credibility* as a clinician—maybe even her job. The dangerous stakes involved with countering the value of behaviour therapies is why, I think, Hailey refused being recorded, and why she was so concerned with being identified by my study.

A few years ago I met Annie, a fellow participant I happened to sit next to at a large autism summit. Annie said overtly what Hailey communicated less frankly. Annie has worked in the autism field as a sensory therapist—kind of like an occupational therapist—for twenty-five years, and shared her profound concern that she is seeing a level of anger, isolation and trauma in autistic children that she has not encountered before. She directly attributes these emotional responses to her clients going through intensive behaviour therapy programs at a young age. She informed me that the last presenter we listened to at the conference, who positioned his therapy program as an extension of Lovaas’ ABA enterprise, is actually secretly opposed to behaviour therapies, but he feels he *has to* frame his method in this way in order to assert his credibility as an autism expert. In fact, Annie explained that this presenter knew Lovaas, witnessed his work with autistic children, and thinks his “studies and science are horrible.” As Annie concluded telling me about the presenter’s views and her own encounters with kids who have been through behaviour therapy programs, she said, in a hushed tone so no one else could hear her:

I’m glad you’re doing this study. This is the study I want to do but I literally can’t. So I’m glad you’re doing it. I *have to be* friends with the behaviour therapy people. They are everywhere. They’re over there, over there, over there [She subtly pointed with her fingers to different tables in the conference room]: they’re everywhere. *You can’t be critical of behaviour therapies if you want to work in autism.*

I saw Hailey present at a conference a few months after our interview, and though she only said one, fairly rushed, line about applied behaviour therapies in her talk, she explicitly included them and affirmed their benefit.

## **Objective**

I felt compelled to conduct a critical ethnography of autism-based applied behaviour therapies because I am personally invested in them. As a sibling of an autistic person, and as an ally to disability rights movements, applied behaviour therapies have been important topics in the communities of which I am a part. Yet there is little social science literature studying the work and culture of behaviour therapists. Though I did not know the name for them when they were being applied to my sibling when she was a teenager, behaviour therapies have, for the past fifteen years, shaped my kin’s life, my home life and the autistic communities I care about.

The point of this thesis is not to provide a normative critique of applied behaviour therapies as good or bad, but rather to analyze them in relation to governance and everyday practice. Yet to understand how this study is situated, it is important, before I begin my analysis, to state my personal views regarding these therapies. Because in my own life, I have witnessed behaviour therapies being applied in ways that I would characterize as harmful, when I began this study, I was deeply critical of them. Yet the process of interviewing behaviour therapy providers has substantively altered my personal views. I appreciate now, that there are a wide range of activities that occur within behaviour therapy practices, and providers can each orient to their work quite differently. Providers also locate their work within various ethical, moral and political frameworks and some explicitly conduct their work to align with, what I would consider, a disability rights framework. In short, behaviour therapists and behaviour therapy practices are quite diverse, which is interesting because this counters the notion of behaviour therapies as clinically valuable because they are systematic and programmatic. I also found that behaviour therapy providers often hold a host of ambivalent feelings and attitudes towards both the therapeutic methods they apply and the larger institutional and professional infrastructure that governs their day-to-day work.

Yet what I observed through my study is that behaviour therapists are often taught to think of autism as an individual problem of dis/functionality to be worked on through intensive behaviour work. As I will analyze throughout this dissertation, viewing autism in this manner can constrain the scope of practices that the therapist completes in a variety of ways. I further found that behaviour therapists are often governed by larger bureaucratic, managerial, economic and political infrastructures that can structure and restrict how they complete their everyday work. For these reasons, I point my analytic arrows in two directions: towards analyzing everyday practice, as well as the techniques and systems of institutional healthcare governance that structure the culture of applied behaviour therapy providers in Ontario.

My dissertation is not objective in the positivist disinterested sense of the word, but this study constitutes an honest and comprehensive effort to learn and write about how behaviour therapies are applied on the ground to autistic people in everyday life. One of the goals of this dissertation is to produce a document that pushes beyond the culture of

fear about speaking critically of applied behaviour therapies, and that (by examining everyday practice) offers a path to move beyond, what has been called, “the autism wars.” The autism wars is a term that is used to describe the stalemate between critics and proponents of behaviour therapies. While both Michael Orsini (2009, 2012; Orsini and Smith, 2010) and Michelle’s Dawson’s (2004, 2005) scholarship has been vital for carving out the cultural discourse that shapes the autism wars, what is lacking in critical social science autism scholarship is an extended empirical analysis of *what actually goes on* in people’s everyday lives when they provide and receive applied behaviour therapies. As such, this thesis is focused on understanding: behaviour therapists as working within a distinct professional culture with specific cultural logics; how everyday practice is shaped by systems of power and modes of governance; how therapists resist and advance power/governance; and how autism communities are culturally shaped by behaviour therapies.

I am further committed to bringing to the surface, what Jo Anne Myers-Ceiko calls “shadow stories” (in MacDonald, 2010, p.23): stories of behaviour therapy providers being pushed out or constrained by different forms of institutional disciplinary power. To this point, autistic researcher Michelle Dawson (in the comment section in one of her blog postings) writes (2006):

I’ve participated in a discussion among a lot of people who work with autistic kids, about the problem of discrepancies between what is published in the literature about ABA [Applied Behaviour Analysis] programs, and what can be actually observed in the practice. Everyone was in agreement that these discrepancies are common (common enough that everyone had observed them). Nobody knew what to do about this.

Clinical ABA research studies present an important, but partial positivist account, of everyday behaviour therapy programs. Yet clinicians, government bodies, media and parents often orient to these accounts (because of the political capital of positivism as apolitical and acultural) as providing the whole story and the objective truth of what happens in ABA programs. As a result, other accounts of behaviour therapies get relegated to the status of being ‘anecdotal’ and biased. By understanding ABA as a cultural object, and behaviour therapists as constituting a distinct cultural group, I analyze the richness of everyday practice in a way that brings a multiplicity of stories to the surface. Including these stories comes from a place of considering the significance of applied behaviour

therapies as beyond the matter of clinical effectiveness, to address how they exist within, and are shaped by, our social fabric and social systems. I incorporate these stories, not primarily with the antagonistic motive of “serv[ing] as counterpoints” (MacDonald, 2010, p.24) to clinical hegemonic behaviour therapy narratives—though sometimes this is the case—but with the intention to breathe new life into clinical accounts. My study extends the science research discourse on ABA and autism by providing a complex situated empirical analysis of the range of activities, affects, feelings, practices, discourses, and institutional systems that constitute the everyday practices of local behaviour therapy work.

### **Behaviour Therapy Workforce in Ontario**

In Ontario, there are four main distinctions and levels of behaviour therapy providers (Ministry of Children and Youth Services, 2018). The first and most prestigious is Clinical Director or Clinical Supervisor. Clinical Supervisors are responsible for creating, evaluating and overseeing behaviour therapy programs. They direct the activities of therapists who conduct one-on-one or group work with autistic clients, often from a distance (sometimes off-site) and through periodically visiting therapy session work. In many settings, Clinical Supervisors must have a doctoral degree in psychology or behavioural science, but in some circumstances, only a master degree is required. Most Clinical Supervisors must also be certified with the Behaviour Analyst Certification Board (BACB), which is based in the United States (I provide a detailed description of the BACB in Chapter Two).

The second kind of provider is a Senior Therapist, who operates as a bridge between Instructor Therapist and Clinical Supervisor. The Senior Therapist carries out the directions from the Clinical Supervisor and oversees a smaller number of children receiving one-on-one work with an Instructor Therapist. Senior Therapists provide one-on-one work as needed. They also train parents to provide behaviour interventions in the home. Senior Therapists should have at least six months of clinical experience providing behaviour therapies to autistic children and ideally have a masters in psychology or behavioural science.

Instructor Therapists, often referred to as “Behaviour Therapists,” conduct one-on-one and small group instruction. They typically complete daily data sheets to track progress and they report to Clinical Supervisors and Senior Therapists. Instructor Therapists entering the field now often need a college or undergraduate university degree in psychology or behavioural science to practice. Instructor Therapists who have been working in the field for a long time may not have a post-secondary degree but are still allowed to practice because of their significant experience conducting front-line ABA work.

Lastly, Assistant Therapists aid with conducting one-on-one work and should be closely supervised by Instructor Therapists. The Assistant Therapists I interviewed were often teenagers or young adults and worked as one-on-one support workers at summer camps, ABA centres, or in home-based settings. While those working at summer camps and home-based settings described receiving little supervision when working one-on-one, Assistant Therapists at behaviour therapy centres often described being used as an extra hand for Instructor Therapists during front-line session work. No standard formal qualifications are required to work as an Assistant Therapist.

I cannot find aggregate data about the size of the behaviour therapy labour force, demographic composition, or salary range. There are a few reasons for this. The first is that while the province announced (on June 8 2017) its intentions to make ABA a regulated professional field, this has not yet come into fruition (Ministry of Children and Youth Services, 2017). Currently, anyone with any amount of training can call themselves a “behavioural expert” to work in a private home-based setting and charge whatever fee they would like (according to my informants, this could be up to a few hundred dollars an hour), though they might find it more difficult to acquire employment.

As I will discuss in Chapter Two, there is growing pressure within the field to become a certified ABA provider (there are different professional levels of certification, which I will also explain in Chapter two) through the BACB. There *is* some data available about the number of BACB certified providers in Ontario. Marchese, Perry, Walton-Allen, Ward, & Zorzos, (2017) explain that the rise of behaviour therapy services has created a large workforce of certified providers. In 2000, there were no certified providers in



Ontario, while there are now 50,000 registrants with more than 550 certified Behaviour Therapists and Clinical Supervisors (Marchese, et al., 2017).

A key reason why it is difficult to find data on the number of ABA providers is because of the crucial role para-practitioners play in carrying out everyday ABA work. These para-practitioners (I will describe the range of para-practitioners working in the field shortly) could be paid or unpaid, have little formal training, and this training could vary greatly. There is simply no way to account for all the para-practitioners working in the field.

Since ABA is not yet regulated, there are no distinct or clear salary levels for providers. Throughout my dissertation I include data from my participants that indicates behaviour therapy work often involves precarious non-unionized labour conditions yet Clinical Supervisors indicated job security and a higher-paying salary. Many Clinical Supervisors work in research institutions or as professors in academic university settings. Their salaries reflect those provided by these institutions. In my online searches for behaviour therapy jobs, Assistant Therapist job postings offered a salary of around \$15.00 per hour, Behaviour Therapist job postings offered a salary of \$20.00-29.00 per hour, whereas Senior Therapist job postings offered a salary between \$35.00-45.00 per hour.

### **Terminology and Definitions**

It is important to explain how I orient to autism in this study. I refer to those diagnosed with autism by using identity-first (“autistic person”), not person-first (“person with autism”) language. My language choice signifies my political affiliation with autistic self-advocacy movements. Self-advocates generally prefer identity-first language because it proposes autism as innate, central, and inseparable from the person—whereas person-first language communicates that the person can be separated from the autism (Sinclair, 1999). Identity-first language also situates autism as a political identity, not a medical condition. “Autistic person” is used by self-advocates similar to how “queer” is used by queer people: as a blunt political reclamation (Hoya, 2011). Further, by linguistically insisting on placing the person before the autism, as is the case with “person with autism,” personhood is tacitly construed as normative—as something that is first and foremost, *other than* autism (Hoya, 2011).

My terminology further indicates my conceptual understanding of autism, which undergirds this dissertation. Describing autism as something a person *has*, “person with autism” naturalizes autism as an innate medical condition that exists outside of politics, thus exemplifying, what Heidi Rimke (2010) refers to as a “psychocentric” orientation towards disability categories. Psychocentrism is characterized by the view that all human problems are individually rooted rather than socially constituted. In essence, I understand autism much like medical anthropologist Lochlann Jain understands cancer, as not exclusively a biological—or neurological—phenomenon “but a politics with which to engage and struggle” (2013, p. 14). Throughout this study I read the “personal, medical, economic, cultural, and epistemological together,” and consider “the fact” of autism as intrinsically produced through “its all-too-human interpretations” (Jain, 2013, p. 4). Viewing autism as shaped through politics is not the same as viewing autism as a social construction. Like Eyal, Hart, Oncular, Oren and Rossi (2010), I consider autism as both socially constructed and real—it emerges exclusively through specific temporal assemblages of institutional, social, biological, clinical and cultural forces.

Before moving on, it is important to clarify the terminology I use to refer to applied behaviour therapies in this dissertation. In my own thinking, I favour the term applied behaviour therapies because this indicates the multiplicity of practices and methods that constitute everyday behaviour therapy work. Yet ABA is the most popular method of behaviour therapy work and most of my lay and para-practitioner informants exclusively used this language to refer to applied behaviour therapies, unless they were specifically discussing EIBI programs. While ABA is still the most popular term used by expert providers, some providers also used other terms to refer to applied behaviour therapies (“intensive behaviour therapies,” “intensive behaviour analysis,” “applied behaviour technology”) which indicates how their expert knowledge leads to increased knowledge of the behavioural approaches that can be applied in behaviour therapy work. As this is an interdisciplinary science and technology studies text where I examine behaviour therapies as cultural objects, it is important to include the terminology used by all my participants, as their terminology indicates how they conceptualize these therapies. Accordingly, to indicate various conceptualizations, I primarily shift between referring to

applied behaviour therapies as “applied behaviour therapies,” “ABA,” “EIBI,” and “IBI” throughout this thesis.

Finally, behaviour therapy providers use the terms “individual,” “client,” “kid,” or “child,” to refer to the autistic people that they work with. I incorporate these terms when my participants use them. The language I most often use to refer to autistic people receiving behaviour therapy programs is “therapeutic recipient.” I favour this term because it reflects (in contrast to a world like “client”) the common dynamic of autistic people receiving, rather than asking for or actively constructing, their therapy programs.

### **Context and Background: Lovaas’ enterprise and the democratization of ABA**

Before moving on it is important to lay the contextual groundwork to explain current behaviour therapy practice. To do this, I will begin with a synthesis of the history of Lovaas’ relationship with parents and his investment in democratizing ABA work.

As I will detail in Chapter’s Three and Four, unlike the leading autism experts (like Bruno Bettelheim and Leo Kanner) who preceded him, from the beginning, Lovaas’ ABA enterprise was distinctly “generous” (Rose, 1994, 1998): lay people were invited to provide ABA to autistic people in a variety of non-clinical social spaces, such as the home, school, playground, hair salon, doctors office, etc. Lovaas considered the effectiveness of ABA as linked to how extensively it could be provided, and he advocated for ABA to be practiced “during every waking hour” by a range of clinical and lay actors (Lovaas, 1987, p.5). To this end, in 1993, his third decade of providing ABA to autistic people, Lovaas stated:

Effective treatment for severe behaviour disorders is seen to require early intervention carried out during all or most of the child’s waking hours, addressing all significant behaviours in all of the child’s environments, by all significant persons, for many years. (p. 617).

From the beginning of his ABA career, Lovaas stressed intensiveness and required there be continuity between the clinic and everyday life. Yet when he began his work, Lovaas did not centrally require the clinical contributions of lay practitioners, and found that their peripheral participation limited how immersive and thus effective, ABA could be. Lovaas claimed that without the help of lay practitioners, autistic children reverted back to their pre-therapeutic baseline (Lovaas, 1993). Thus, his UCLA ABA Institute programs required autistic children to be in a “total environment” setting to achieve substantive

behaviour change. Such a setting, “literally required the participation of parents in the therapeutic process, and the redesign of the home as a therapeutic environment...” (Silverman, 2013, p.123). As autism historian Chloe Silverman states, with ABA, families were essentially framed as “the targets of intervention” (2013, p.123). Thus, parents became key para-practitioners responsible for providing ABA to their children. Not only did Lovaas emphasize the importance of parent participation, he framed parental love as “caring enough to teach obedience” (Silverman, 2013, p.97).

Parents not only took on a central role in carrying out behaviour therapy programs, they were also powerful advocates primarily responsible for the institutionalization of ABA as a standard of care. Lovaas recognized both the clinical and political importance of parents in regards to applying behaviour therapies, stating: “Parents continue to be the leaders in disseminating behaviour interventions” (1993, p. 627). As I will examine, primarily in Chapter’s Three and Four, parent advocacy has, and continues to shape, behaviour therapy science, knowledge production, and methods in notable ways.

While Lovaas was incredibly generous with inviting parents to provide ABA with his UCLA ABA Institute work, this was only the beginning of the generosity and democratization of ABA. The expansion of ABA is indebted, not only to rising autism rates, deinstitutionalization, and the rational technocratization of healthcare, but to a larger employment economy characterized by precarity, scarcity, and a prioritization of pragmatic trades-knowledge over an intellectually-focused university degree. For example, in the last ten years there has been a proliferation of applied behaviour science programs in universities and (particularly) colleges in Ontario.

Adding to this landscape of precarity is the growing popularity of psychopharmacology and the proliferation of psy modalities and professionals. There are so many options for people to choose from when it comes to healing their maladies. Social workers and psychotherapists can have their own (not often insured) private practice, thus occupying the professional territory previously staked by psychologists, psychiatrists and psychoanalysts. Less formal but astoundingly popular avenues like yoga retreats, reiki treatments, and CBT workbooks further nudge into the space of traditional psy approaches to mental and emotional wellness.

In this context of psy proliferation and competition, ABA is *the* great success story for clinical psychologists and has become the main source of income for many clinicians in private practice.<sup>10</sup> In my interviews, many providers with a psychology background identified ABA as their best career option. In addition, when I asked my behaviour therapist informants how they came to work in the field, almost each of them had the same story: they finished their university degree, often in psychology, and couldn't find work, and then stumbled upon a flyer for a condensed behaviour therapy program which offered a flexible schedule (part-time or full-time enrolment options), promised steady after-graduation employment, and had few formal entry requirements. My participants often recounted finding their behaviour therapy program as “kismet,” and had no prior interest in specializing in autism. Alternately, my interviews with those working in the autism field in a support worker role told of how they had to learn to apply ABA to keep their jobs. The pre-eminence of ABA contributes to the professional ambivalence this ethnography uncovers, both in relation to autism and ABA.

Yet the generosity of behaviour therapies is much more expansive than a proliferation of training programs and behaviour therapists. It reaches into the organization of the public school system. In 2007, the Ministry of Children and Youth Services released a Policy Program Memorandum, which establishes ABA as an educational standard in the public school system, which has resulted in teachers being enrolled as ABA para-practitioners for their autistic students. For example, my participant Lydia, who works as a special education resource consultant, told me about how “these [ABA teaching] jobs didn't exist years ago.” Lydia did not even know what ABA was when she first started working in the autism field, yet she now describes it as a “booming business.” Lydia tells anyone looking to get into teaching: “You need to learn the word ‘autism,’ and you need to learn as much as you can about it and then you'll get a job teaching. Cause it's an

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<sup>10</sup> For example, in her illuminating ethnography of psychoanalysts, Kate Schechter (2014) demonstrates how the advent of psychopharmacology, the proliferation of psy-modalities (in addition to competing with psychiatrists, psychotherapists have become a licenced profession, social workers often have their private practice, and medical doctors can proscribe quick-fixed and insured cognitive behaviour therapy) and the current technocratic evidence-insurance-based managerial healthcare system, has lead to a situation of professional obsolescence. Contemporary psychoanalysts, Schechter argues, define their profession and conduct their everyday work in and through their professional obsolescence, finding ways to torque classic psychoanalytic methods and practices in order to continue to practice in a dying field. In this context of psychoanalytic obsolescence, ABA flourishes.

[ABA] explosion.” While there is no formal policy guideline for providing ABA in adult group homes and day programs for autistic and developmentally disabled adults, my fieldwork indicates that these therapies have become the standard organizational practice for these institutions too, meaning that individual support workers also primarily work as ABA para-practitioners. Further, behaviour therapists are often the first to discuss the importance of *conceptual* generosity and democratization: lay para-practitioners do not need to learn about or understand the scientific theories that they are using when applying behaviour therapies.<sup>11</sup>

Beyond the institutionalization of the para-practitioner role for paid professionals like teachers and support workers, some of my informants told stories about how they enrolled non-autistic family members—including their children and grandparents—to complete ABA methods on their autistic kin. As I learnt from my interview with a parent named Laurie, students in her autistic child’s classroom were also enrolled to help provide her child’s ABA program to him, they were even called upon to help restrain him when having a “meltdown” in the classroom. Finally, when interviewing another parent named Frances, I learnt how her autistic teenage son, who in addition to receiving his own ABA program at a public autism centre, was enrolled by his behaviour therapists to help assist conducting ABA programs for some of the younger autistic kids at this centre. In other words, part of an autistic persons ABA program might be to aid with carrying out another autistic persons ABA program. In essence, people from all walks of life, with varying degrees of familiarity and training, are integral to the production of ABA work in everyday life.

The generosity and democratization of applied behaviour therapies is an interesting topic to consider when adopting a science and technology studies (STS) analytic approach. In her important historical STS text about B.F. Skinner and his behaviour technology, Alexandra Rutherford (2009) discusses the importance of including lay accounts of clinical work and concepts to account for how clinical methods are reshaped in the lay-public sphere. For instance, traditional disciplinary histories of science and psychology “generally ignore the ways in which the terms, phenomena, procedures, and products of

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<sup>11</sup> Consider this statement by Donald, M. Baer, Montrose M. Wolf, & Todd R. Risley:

The past 20 years have shown us again and again that our audiences respond very negatively to our systematic explanations of our programs and their underlying assumptions, yet very positively to the total spectacle of our program—their procedures and their results—as long as they left ‘unexplained’ by us. (1987, p.316).

the laboratory both arise from and return to the lay culture of which they are, ultimately, part” (2009, p.13). Similar to the lay actors who took up Skinner’s work—who “did not use” behaviour technology “in the same way as formally trained practitioners did”—in this ethnography I deem it important to “intentionally fluctuate between account[s] of internal disciplinary developments and their external reception and appropriation to highlight the permeability of these two cultures” (Rutherford, 2009, p.13).

Yet with ABA, what is internal and external is difficult to pinpoint. While government actors and many clinical experts consider applied behaviour therapies to be a scientifically-validated clinically effective method, and while Lovaas once stated that “A major source of joy in my work has been to help narrow the distance between research and practice” (1993, p.618), lay actors who often have very little understanding of the science they are practicing comprise an enormous part of the everyday practice of these therapies. Behaviour scientists and researchers are well aware of the lack of scientific analytic knowledge some practitioners of behaviour analysis have, and recognize the disciplinary murkiness inherent within current ABA practice.<sup>12</sup> Even those completing paid therapy work may not understand the basic scientific principles of ABA. For instance, when I asked my informant Maya (who tellingly, did not know the difference between a negative reinforcement and an aversive)—an assistant behaviour therapist who is providing a one-on-one Intensive Behaviour Intervention program to an eighteen year old—if she has read up much about the ABA methods she applies, she said: “I haven’t read up on it and I don’t think I found it necessary to at this point, because any modification we have to make with the program...we just do it through experiential basis. Like it’s sort of like trial and error.” Maya has no sense of the science she is supposed to be applying.

One of the challenging parts of this dissertation has been figuring out where applied behaviour therapies sit in relation to science, as experts seem to want it both ways:

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<sup>12</sup> See, for instance, this statement by prominent behaviour scientist, Donald M. Baer, et al:

Twenty years ago, *analytic* meant a convincing experimental design, and *conceptual* meant relevance to a comprehensive theory about behavior. The two topics could be and often were discussed separately. Since then, it has become increasingly aversive to maintain that separation. Now, applied behaviour analysis is more often considered an analytic discipline only when it demonstrates convincingly how to make specified behaviour changes *and* when its behavior-change methods make systematic, conceptual sense. In the past 20 years, we have sometimes demonstrated convincingly that we had changed behavior as specified, but by methods that did not make systematic, conceptual sense- it was not clear *why* those methods had worked. Such cases let us see that we were sometimes convincingly applied and behavioral, yet even so, not sufficiently analytic. Similarly, we have sometimes changed behaviour without even a convincing demonstration of how we did that, and so did not know if our methods made systematic, conceptual sense because we did not know clearly what the responsible methods were; those cases let us see how not to be a discipline, let alone an applied, behavioral, or analytic one. (1987, p.318)

ABA is clinically validated and programmatic/ABA can be practiced by anyone with just a little expert guidance. In this ethnography I adopt an STS approach to consider how behaviour therapies *complicatedly subsist through both clinical and lay engagements* and the disciplinary contradictions that take shape through the sheer volume and diversity of providers.

### **Conceptual Framework**

The growing voices that both resist and support applied behaviour therapies, highlight the importance of critical scholarly attention to these therapies. Situated within the fields of science studies, medical anthropology, and critical autism studies (*see Davidson & Orsini, 2013*), my thesis seeks to analyze the behaviour therapy-dominated culture of autism services in Ontario. Following Foucauldian scholarship (1991, 2007), my study also analyzes the power and knowledge practices of experts and providers working within autism services. I further draw on Studies in the Social Organization of Knowledge (Diamond, 1995; Mykhalovskiy, 1997, 2001, 2003; Rankin & Campbell, 2006; D. Smith, 2005) to consider how local everyday behaviour therapy work is hooked into, coordinated by and translocally ruled by managerial institutional bodies. This area of scholarship considers how standardized text-based documents are used to govern and organize people's everyday work activities to line up with larger institutional objectives.

In my study, I adopt Dorothy Smith's (the founder of Institutional Ethnography, a feminist sociological method of inquiry within the social organization of knowledge) concept of "social relations" as a way to methodologically consider "how a particular someone's experience is organized by concerted human activity not experienced in its immediacy by that particular someone" (Mykhalovskiy, 1997, p.142). As Eric Mykhalovskiy writes, analysis of the "social organization of rule" focuses on how "a range of professional and managerial practices are carried out" and "discursively shaped and connected with one another" as well as how "they hook people's activities into extended social relations or chains of actions" (2001, p.273). In essence, researching the social organization of rule begins from the vantage point that "a whole social organization is needed to create each unique experience (Bannerji, 1991, p.85, in Mykhalovskiy 1995, p.142).



The reason I am focusing my analysis on the everyday work of behaviour therapy providers is because, until now, they have not been the focus of critical social scientific studies within the field of autism, which means they are an understudied group. The lack of research and discussion about what it is like to work as a behaviour therapy provider misses an important opportunity to analyze the everyday *clinical* practices that constitute this increasingly influential, applied scientific field. This is a significant gap, as STS scholars have demonstrated how scientific methods, disciplines, and those working within them, are situated in specific “epistemic cultures”: “machineries of knowing” comprised of specific social, political, and economic contexts that shape expert knowledge and evidence production (Knorr Cetina, 1999 p. 364). As Bruno Latour (1988) and others have advocated, one way for the epistemic culture of a scientific field to begin to be revealed is through empirical analyses of the everyday work conducted therein. I’ve worked to “get to” the everyday work of behaviour therapists in Ontario in a variety of ways, which I will explain in the methodological section of this Introduction. Another important point is that placing therapeutic recipients as the only objects of study misses a full apprehension of the complex forces of power that govern autistic people towards collective norms of optimization (Foucault, 1991, 2007). Said differently, providers need to be analyzed in order to piece together the anatomy of governance that is enacted when autistic people receive applied behaviour therapies.

My study did not begin with this focus on providers, but after speaking to both providers and recipients, the incredible exploratory nature of the ethnographic method led me to understand that the experiences of providers was a significant unexplored terrain. The providers I spoke with had rich and variable stories and perceptions about their work. I wanted to learn how applying behavioural therapy shapes how therapists think about themselves and others; what practices they complete in their every day work; what their workplaces are like; what scientific methods they learn and identify with; what policies and economies they are governed by; what texts they encounter and how they relate to them; and how they learn to relate to their bodies and emotions and the bodies and emotions of the autistic people they work with. Finally, I was also interested in knowing if there are specific clinical epistemological logics that govern their ethical framework for relating to the autistic people they provide therapy to.

### *Science and Technology Studies*

STS scholarship is focused on analyzing the processes of scientific knowledge production and considers science through the lens of power, culture, and social structure. Susan Leigh Star describes science studies scholars as engaged in a “heretical challenging of the biggest sacred cow of our times: The truthfulness of science as given from nature” and “the inevitability of scientific findings” (1990, p. 31). Star further writes that, in “talking of the central modern institutions of science and technology, we are talking of the moral and political order” (1990 p. 31). In her ethnographic work on the cancer industry, STS anthropologist Lochlainn Jain situates science as a “cultural project that takes place within political and ethical infrastructures” (2013, p. 24). Perceiving science as a cultural project does not discount the value and legitimacy of scientific theories and scientific work. In their landmark text, *Laboratory Life*, Bruno Latour and Steve Wolgar (1986) demonstrate that scientific methods take place within specific epistemic traditions that have ethical norms and are constrained or enabled by economic resources. In her ethnography about the culture of high-energy physicists, Sharon Traweek (1992), demonstrates how scientific work is created through particular social relations, and through adherence to managerial and institutional standards and policies. The analytic depth and focus of each of these STS texts has been instrumental for the conceptual foundation of my ethnographic project, where I consider the work of applied behaviour therapists as a cultural project which is shaped by ethical and political infrastructures, certain epistemic traditions, workplace and social relations, as well as larger institutional standards and policies. This project comes from a place of being deeply interested in analyzing the meaning, social structure, and institutional systems that shape the clinical and therapeutic work of behaviour therapy providers.

Nikolas Rose’s (1994, 1998) STS and Foucauldian approach to studying the *psy* sciences is particularly influential to my dissertation, especially in relation to his concept of the generosity of expertise as a form of *psy* governance. Rather than viewing expert power as deriving from exclusion, Rose considers expertise as a form of productive power generated through the democratization knowledge, where lay actors come to view themselves and the world around them through *psy* concepts, vocabulary and ways of

thinking. I consider the popularity of ABA as a salient example of the generosity of psy governance, as lay actors play a key role in forming and disseminating everyday therapeutic practices. Analyzing the dissemination of everyday ABA work thus becomes a way to understand key things about our wider cultural context. I further consider how ABA is not just an applied scientific method but indicates a particular conception of the autistic subject.

In addition to Rose, Alexandra Rutherford's (2009) historical STS text, *Beyond the Box: B.F. Skinner's Technology of Behaviour from Laboratory to Life, 1950s-1970s* provided the framework for thinking through how current autism-based ABA shaped and is shaped by various cultural discourses relating to parenting, autistic subjectivity, and the calculability of the psy human subject. Rutherford's comprehensive historical coverage of the scientific work and cultural impact of the legacy of B.F. Skinner's technology of behaviour, including recounting initial ABA research studies and their cultural reception, is key to understanding the controversies, activities, and methods that continue to circulate in current ABA discourse.

Finally, Gil Eyal's (2013; Eyal, et al., 2010) sociological STS scholarship on autism governance and expertise is crucial to my dissertation. Eyal considers how the deinstitutionalization movement and the rise of behaviour therapies has created "autism" as it exists today (both as a diagnostic category and in our social imagination) as an "epidemic." The relationship of autism and ABA is one of co-production. Eyal's genealogical analysis of shifting networks of autism expertise offered me a way to understand how current autism discourse is influenced by larger cultural factors and discourses as well as by different historical eras of autism care and advocacy. Learning about these different eras of governance provides the tools to understand power relations within autism communities and advocacy movements as they relate to ABA practice today.

### *Medical Anthropology*

Medical anthropologists situate health, illness and healing systems (in which biomedicine is one) as cultural artefacts linked to cultural orders and created through collective worldviews (David-Floyd 1992; Fadiman 1997). Medical anthropologists use an extended

ethnographic approach to understand these complex cultural systems. In this dissertation, I adopt a critical-interpretive approach, which situates “all knowledge relating to the body, health, and illness as culturally constructed, negotiated, and renegotiated in a dynamic process through time and space” (Lock and Scheper-Hughes 1990, p. 49, in MacDonald, 2010, p.9). I further incorporate Byron Good and Mary-Jo DelVecchio Good’s (1993) notion that “distinctive medical worlds are constructed experientially so that they appear singularly convincing, natural, objective, the only way to imagine the world” (p.103). I thus aim to denaturalize behaviour therapies as objective clinical methods and as constituting a distinctive clinical-cultural world. In addition, the effort within the field of medical anthropology to view biomedicalization as the instrumentalization and industrialization of health and illness is key to my contextual understanding of applied behaviour therapies. By viewing the autistic body in terms of function and dysfunction, and by viewing healing as observable and measurable, I consider applied behaviour therapies as existing within the instrumental rationalized and technocratic domain of biomedicalization. Lastly, I am interested in how ‘autism’ as a health category is mediated and shaped through engagement with applied behaviour therapy practice.

### *Critical Autism Studies*

Lastly, critical autism studies is a newly defined subfield of critical disability studies, concerned with producing non-positivist autism research that situates autism within culture and systems of power and oppression. Michael Orisini and Joyce Davidson define three criteria that constitute a critical autism studies approach:

1. Careful attention to the ways in which power relations shape the field of autism
2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy, and popular culture
3. Commitment to develop new analytical frameworks using inclusive and nonreductive methodological and theoretical approaches to study the nature and culture of autism. The interdisciplinary research required (particularly in the social sciences and humanities) demands sensitivity to the kaleidoscopic complexity of this highly individualized, relational (dis)order. (2013, p.12)

While the focus of my study is not primarily geared to producing enabling narratives of autism, the intent is that, by focusing on autism providers I avoid the legacy of

objectifying autistic people as research subjects and introduce a new way of understanding the systems of power that flow through autistic bodies. In other words, by decentering autism as the topic of analysis, and instead attending to the providers that govern the lives of autistic people, my work circuitously aims to have enabling effects for autistic people. By considering behaviour therapies as innately cultural topics that exist within the moral and political order, I further work against reductive positivist and ableist approaches which view autism as an innate individual medical disorder and applied behaviour therapies as outside of power and culture.

## **Methods**

My study relies on an ethnographic methodology for the intimate and extended opportunity it provides for empirical observation. Theoretically informed analysis of detailed empirical data is central to ethnography (Clifford, 1989; DeWalt & DeWalt, 2002), as is researching from a positionality within the culture being examined (Abu-Lughod, 1991). My fieldwork, conducted over the course of two years, from 2014-2016, included observation research at autism conferences, exhibits, and events, archival research at the *National Library and Archives of Canada*, and interviews with thirty-two providers and recipients of applied behavioural therapies. I further filled up two books with fieldwork notes where I described my informants, analysed our interviews, detailed the spaces we occupied, as well as the interactions that happened at conferences and in social situations.

I used a variety of methods to recruit my informants in order to understand the culture and social organization of behaviour therapies in Ontario. I focused on recruiting participants with experience providing, receiving, or working with behaviour therapies. To understand the breadth of everyday ABA practice, I recruited a range of providers and worked to interview a similar number of providers from different professional sub-groups (para-practitioners, assistants, instructors, clinical supervisors). It was also necessary to speak to other autism stakeholders (autistic adults, psychiatrists, social workers, occupational therapists) who encounter ABA in their everyday lives. These actors provided additional and important perspectives about the ABA activities they witness, and

the ABA-centric autism healthcare system they interact with in their everyday work and life.

I used various techniques to recruit. I created a study call out that I posted on: online autistic self-advocacy group forums; the Autism Ontario online newsletter; self-advocate blog-postings; and the walls of Psychology Departments in various Universities. I chose these sites as I wanted to spread a wide net to reach different autism stakeholders, and to ensure I was incorporating a wide spectrum of experiences and political views towards ABA. Some participants were recruited through sending my call out to my extended network of autism community members and professionals. I also sent targeted emails to specific behaviour therapy clinicians who are leaders in the local ABA autism research field, as well as key members of Ontario ABA autism organizations. After some of the ABA presentations I gave, a few attendees who work in the field offered to provide an interview. Often, my participants provided contacts for further interviews, which broadened my participant pool significantly. In the initial stages of my study it was important to speak to ABA providers willing to explain both foundational behaviour therapy methods and the basic structure of public behaviour therapy program delivery in Ontario, and so I relied here on targeting my participants. In the end, I recruit participants fairly evenly between my call out, the snowballing method and targeted emails. My exclusion criteria was quite minimal: all participants had to be adults and have knowledge of ABA. Of all the actors interested in participating, I only excluded one, as he was a parent of a child diagnosed with developmental disabilities but said he had no knowledge of or experiences with ABA.

My interview participants include: instructor therapists, assistant behaviour therapists, clinical supervisors, behaviour science researchers, autism-focused psychiatrists, a diagnostician, autistic people who have received behaviour therapies, parent and teacher para-practitioners, government policy workers, social workers, an occupational therapist, an educational behaviour consultant, and adult autistic self-advocates.<sup>13</sup> Notably, some of my informants occupied a few of these roles: for example, I

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<sup>13</sup> Here is more detailed breakdown of my participants: seven Instructor Therapists; four Clinical Supervisors (all were former behaviour therapists); three Clinical Behaviour Researchers (all former behaviour therapists); three Assistant Behaviour Therapists; two ABA-Teachers; one ABA Education Consultant; eight parent Para-practitioners; five autistic adults; two autism policymakers; two Social Workers; one

interviewed a few autistic self-advocates who have provided behaviour therapies to their autistic children as parent-para-practitioners.<sup>14</sup> With the exception of one informant who chose not to be recorded, all confidential interviews have been transcribed in full and all participants are referred to using a pseudonym. My shortest interview lasted twenty-five minutes and my longest, four and a half hours. Most interviews were about one hour long. Some of my informants kept in touch, sent articles, and we sometimes continued our dialogue after the interview. My informant Margot and I met on multiple occasions, where she showed me videos of her one-on-one behaviour therapy work, and taught me about the methods themselves.

The interviews themselves were exploratory and semi-structured. I deviated from using a structured set of questions in order to account for the diversity of subject positionalities. Since there is no standard informant, much can be lost by sticking to standardized questions. I did create a template of structured questions before beginning the interview process and would spend about an hour before each interview altering the template, sometimes only including one or two questions from it, and adding questions to match the areas and experiences relevant to the participant.

My interview methods were heavily informed by Studies in the Social Organization of Knowledge (Diamond, 1995; Smith, 2005; Mykhalovskiy, 1997, 2001, 2003; Rankin & Campbell, 2006). I considered the interview as a powerful practice of learning about another person's life so as to understand how their everyday lives are hooked up into larger organizations of rule. I was further influenced by scholarship in the area of feminist postcolonial thought, which insists that knowledge generated from interviews, as with all knowledge, is partial, meaning that the data created between my

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Occupational Therapist; one Psychiatrist; one Diagnostician; one Support worker; one sibling. Of these participants, eight identified as men, while twenty-two identified as women. Participants were between the ages of nineteen to-mid-60s.

<sup>14</sup> There are two reasons why I included interviews with autistic self-advocates. First, since the initial focus of my study was on the culture of behaviour therapies, though I specifically wanted to avoid studying autistic people, I wanted to hear from all the actors affected by behaviour therapies in order to understand how they are practiced in everyday life. This is why I also interviewed other autism providers, policy makers, and clinicians, such as diagnosticians, psychiatrists, educators, and occupational therapists. Once the ethnographic process led me to focus my topic on the work of behaviour therapists I still wanted to hear from autistic people, and others invested in autism, because their experiences interacting with or receiving behaviour therapies could provide important information of certain practices and activities that providers may not think to or wish to speak to. When studying any healthcare system or expert profession I think it is vital to speak to all the actors involved to form a comprehensive analysis of that system or profession.

informants and I was based on our situated bodies and how we felt while being with each other. In order to create a safe and open space and to build the rapport necessary for people to want to share their important stories with me, I oriented to the interview as a directed conversation, where I prioritized conversational flow over whether or not my participant answered every question on my list. In fact, not often looking at my question sheet, and instead building conversation based on my informants responses, was a key strategy for remaining present, creating trust, and opening up new areas of knowledge and experience.

I used a number of techniques to analyze interviews. First, I analyzed each transcript and looked for key words (“programmatic,” “effective,” “science,” “care,” etc.), phrases (“running a trial,” “table-work,” etc.), concepts (“hand-over-hand,” “chaining,” “aversives,” etc.) and themes (behavioural function, behaviour as communication). I also highlighted important passages and dialogue. I then coded the transcripts and my field notes, creating categories such as, “parent training,” “funding,” “reinforcement strategies,” “time,” “research,” “responsibility,” “organizations,” “documents and policies,” “metaphors,” “fear,” “public school system,” “ethical reflections,” (and so on), creating 47 different codes. I also created a separate document for critical excerpts that did not fit neatly into any distinct code. After this stage I had a clear idea of the structure of each chapter, with some chapters including data from multiple different codes.

*Ethnographic Knowledge Production: the problem of the ethnographic account when occupying a liminal situated space*

After undergoing a crisis of representation in relation to a deeply disturbing colonial and imperialistic past of Othering, exotizing, and objectifying racial, ethnic, and marginalized others, anthropology redefined its epistemological conventions (Asad, 1995; Fabian, 1990; Marcus & Fischer, 1996). No longer was anthropology a discipline that could portend to objectively learn about and describe a distant other. Instead “being in the field” became “more a matter of looking and listening in particular anthropological ways, rather than being in particular kinds of anthropological spaces” (MacDonald, 2010, p. 12). The anthropologist is not an objective masculine-coded subject “studying down,” but a subjective being whose own positionality centrally shapes how they interpret the empirical



world. The task of ethnography is now often to turn the gaze on one's own culture, to find the strange in the familiar, to parse the cultural logics that shape one's own life.

In her presentation on Indigenous human-fish relations at the York University *STS Seminar Series*, Indigenous anthropologist Zoe Todd (2017) proposed an embodied and sensual formulation of methodology. She asked the audience if we had ever held a fish and to consider the animate and unruly experience of holding this floppy, slippery, substantial being as central to the process of ethnographic knowledge-production. Knowledge, Todd insisted, exists, not through rational distance, but through the co-mingling of self-other, through sensory embodiment, through a textured closeness. To study something ethnographically is to apprehend it intimately, to *be with it*, to hold it in a deeply close and scarily alive way. By immersing ourselves in the lives we are studying we understand new important things about these lives, about their (our) culture, about power.

To this end, Joao Biehl writes of the political importance of ethnography as related to how a detail oriented, intimate approach, reveals the lives, struggles and occurrences that have been left out of “dominant theories and policies” (2010, p.216). Biehl writes:

Anthropologists bring back the everyday stories and writings of characters that might otherwise remain forgotten... Ethnographic details reveal nuanced fabrics of singularities and the worldliness, rather than the exceptionality, of people's afflictions and struggles; they make explicit the concreteness of processes and failed or foreclosed anticipations. Perhaps the creativity of ethnography arises from this effort to give form to people's own painstaking arts of living and the unexpected potentials they create, and from the descriptive work of giving these observed tensions an equally powerful force in our accounting” (2010, p.216).

I view the value of contemporary anthropology and the ethnographic method as deriving from attributing scholarly value to holding a fish: the ethnographer has to operate from this place to understand how the intimate and embodied relates to larger social structures.

In this dissertation, it was quite complex for me to find a way to hold the fish in a scholarly manner, and in such a way that I could share in my analysis. To acquire formal immersive insider knowledge to use as data for this study, my committee member, Michael Pettit, was kind enough to help me work through some of the complex ethical dimensions of my research plan during the ethics review stage of my study. At the time, I had planned to conduct participant observation at an ABA or EIBI centre, and in autism school classrooms, and he importantly cautioned me against this more traditional

ethnographic framework approach: did I really want to be another professional watching autistic children receive therapy and writing about their activities? I did not. As a result, my ethnography is methodologically unorthodox because I did not conduct sustained observational examination of applied behaviour therapy providers when they are completing their everyday work—at least not in a formal way that I can write and talk about in a public academic manner.

Yet through my own personal and professional life, I have held the fish I am reporting on here, though I have done so by occupying a liminal space between insider and outsider. My liminality interferes with how I can talk about my own experiences and professional knowledge. Professionally, I used to work with an autistic youth, “Claire,” and for two years I witnessed applied behaviour therapies being provided in an educational space she occupied. While far from participating in an ABA program, at the urging of my employer, I even applied some ABA-derived methods, such as the token economy system.<sup>15</sup> In this job, I worked on a team of former behaviour therapists and other autism professionals who shared stories about the ABA and EIBI centres they worked at. Claire also shared stories about her experiences receiving EIBI as a young child. But Claire was not a participant in this study, and I was working with her as a teacher, not ethnographer, so this cannot count as a fieldwork site that I can analyze publically. While this employment experience provided excellent ethnographic knowledge, there is nothing from my experiences with Claire beyond what I have just said, that I can share as data.

Another liminal aspect of my insider/outsider status relates to autism. I am not autistic, yet sharing an everyday life with, and being closely biologically connected to, an autistic person has meant that from a young age, I have been subjected, complicit and resistant to the powerful moral and epistemological matrices of curiosity, medicalization, pathologization and investigation that have governed my autistic kin’s life. I witnessed the often ABA-centric educational and rehabilitative spaces my sibling was and continues to be in. As a child my blood was taken for research studies trying to find the genetic links of autism, and the autism rates between siblings. I was interviewed for PhD dissertations interested in what it was like to be a sibling of an autistic person. My family was featured

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<sup>15</sup> Token economy is a systematic program where tokens are given to therapeutic recipients for correct behaviour performances, and once they are accumulated, can be exchanged for material goods or privileges such as treats, or outings

on a TV special for autism, and I still remember how weird I felt being filmed while putting my dinner in the microwave. I remember all the therapies, diets, and medicines; the stares, remarks, questions, violence; the prohibited visits and segregation; the blood tests and breaking research; the doctors, police, support workers, teachers, clinicians, naturopaths, psychiatrists, social workers, researchers, audiologists, speech therapists, occupational therapists, behaviour therapists, and reporters. I remember how confusing it all was and continually is.

I remember when I realized that I fit the clinical profile of what siblings of autistic people are supposed to be like and I understood then how deeply my identity is “made up” (see Hacking, 2006) through the systems of medicalization/oppression/power aimed at my sister. In the eyes of autism experts, my sibling and I are clinical kin. My self-understanding is inextricably shaped through my kinship with autism. I do not remember a life before the one where I’ve been intimately knotted to this autism matrix (Eyal et al., 2010) of cures, modifications and therapies. There is so much left to know, study, think about, when it comes to mine and my sisters’ life and this matrix we’ve been so tied up in. Yet in this study I won’t talk about her life or mine much at all. Because my stories are her stories and it feels wrong for me to tell them for us here.

So while I have been immersed in autism culture and the therapies I write about, all of this personal knowledge, while formative in the shaping of this ethnography, cannot be shared as data. But inside the writing of this dissertation is a world of feelings, memories, witnessing and doing. A world of bodies interacting in ways that heal and hurt. Behaviour therapies and institutional approaches to autism care live in the choke of my neck. I didn’t just hold the fish for this study; it flops in my stomach in my everyday life.

I’ve tried very hard to convey these fleshy forms of knowledge through descriptive writing of my scholarly ethnographic data. By analyzing translocal institutional forms of governance through the pulse of individual stories, I hope that the experiences I recount demonstrate how the aesthetic, emotional and relational aspects of applied behaviour analysis are central to how these therapies are enacted in the headiness and banality of the everyday. I do not just want to recount what I observed in ways that makes rational sense. I want you to *feel what I felt* so you too are tangled in the fleshy, slippery, aliveness of the lifeworld of applied behaviour therapies.

## **Chapter Outline**

In Chapter One I explore the everyday work of behaviour therapists through the topics of discipline, standardization, and worldview. I describe my concept of a behavioural worldview and argue that it not only governs the work behaviour therapists do, but guides how they understand what should be done to their therapeutic recipients. I further argue that linking empathy with functionality is a distinctive collective identity building experience that marks the process of becoming a behaviour therapist.

The second chapter moves away from an interior look at the subject formation of the behaviour therapist, to examine larger forms of governance that shape and constrain the everyday work of behaviour therapy providers. This chapter is concerned with examining “the text mediated ways in which managerial and clinical work come to be transformed as they are brought into relation with one another” (Mykhalovskiy, 2001, p. 274). I examine how practitioners are challenged by various institutional practices to do the work they want and are trained to do. Rather than the science of behaviour analysis governing therapist’s practices, I consider how managerial forms of rule, and self-regulatory forms of governance, fundamentally shape everyday behaviour therapy activities and methods and analyze how this occurs in different areas of practice.

In Chapter Three I analyze the complexity of the para-practitioner role, the involved relationships that form between para-practitioners and behaviour therapists, and how these affective relationships fundamentally shape the practices that constitute behaviour analysis as carried out in everyday life. My analysis of para-practitioners reveals that behaviour therapy providers do not always embody a technical instrument as articulated in my analysis in Chapter One. I further demonstrate how para-practitioners can work within constraints to manage and resist clinical knowledge to make behaviour therapies fit within their social fabric or their workplace.

In the final chapter, I stray farther away from an attention to clinical delivery and instead focus on how behaviour therapies shape discussions of autism advocacy and politics. This chapter is about rethinking the politics of autism advocacy movements and the role of behaviour therapies therein. As described in this Introduction, current social science literature on the political and social implications of behaviour therapies has

examined how autism communities are marked by a severe cleavage between critics and proponents. Yet my empirical work leads to different findings that indicate that actors within autism communities can have more nuanced political engagements with these therapies, especially as they relate to the topics of representation, political voice and advocacy. I argue that political formulations of applied behaviour therapies and issues of advocacy are actively shaped by larger scientific and social conversations, as well as by different historical responses to autism care. I further expand how the “autism wars” have been studied by considering how the fissure between critics and proponents is coordinated by gender and sexuality.

**CHAPTER ONE:**  
**“What Are We Doing? Like With Ourselves?”**  
**Adopting a behavioural worldview**

Margot, a former behaviour therapist in her mid-30s, recounted her experience of being trained as an instructor therapist at a public EIBI centre while in her mid-20s, describing her cohort as young and energetic, all of them eager to get their autistic subjects to respond to therapy work.<sup>16</sup> She stated:

My friends... they could hear each other over their partitions with their kids and we would talk about how crazy we would get to try and get the kids reinforced... socially reinforced... And one of them heard the other one being like ‘I’m a juggling robot!’ [*loudly and clownish with arms flailing around*] and then the child would laugh and then perform whatever it was... Like ‘match the cards!’ Or whatever. The kid would do it. But we were all like: ‘What are we doing? Like with ourselves?’

In describing attempts to get their “kids” to perform, Margot paints an almost frenetic picture of a therapist’s desire to incite specific responses in her kid. Margot’s description also vividly captures the intensive bodywork involved in being a behaviour therapist. When speaking to me, Margot had a low voice and calm demeanour, but when imitating her friends’ tone in speaking to her kid, she raised her voice an octave to a cartoonish, almost shrill tone, startling me so that my body instinctively moved away from hers. The tone and wild actions involved in becoming a juggling robot suggest the extent to which behaviour therapists modify themselves to work as malleable instruments for accomplishing targeted responses in their therapeutic subjects. The process of identity rupturing and formation was succinctly captured in the stunned reflection Margot and her friends shared: “What are we doing? Like with ourselves?” Margot and her friends had to learn to “do” themselves differently to be behaviour therapists. I suggest that to become behaviour therapists they had to learn to *embody and adopt* a behavioural way of relating to their own bodies and that of their “kids.” How does this occur? What is a behavioural way of relating?

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<sup>16</sup> I published a version of this chapter in article form called, “Autism, Expert Discourses, and Subjectification: A Critical Examination of Applied Behavioural Therapies” in the *Studies in Social Justice Journal* (2016).

Becky and I sat side by side on stools at a Starbucks. She sipped on a no sugar soy green tea latte and told me about her work experiences. Becky, a marathon runner, full-time public school teacher for autistic students and part-time private behaviour therapist, recounted the behaviour therapy interventions she completed with Sandy, an autistic teenager. Becky created an intervention program for Sandy that consisted of training to run a five-kilometer marathon race, which she wanted Sandy to be able to run regularly. Becky thought running would improve Sandy's mobility, build self-esteem, promote independence, and increase functionality. In this excerpt, Becky describes the first time she and Sandy ran a race and the resistance they encountered:

She [Sandy] knew that if she peed [while running the race], I would take her to go change... [or] so she thought... I didn't... a lot of people's eyes were open on that one: 'you made her... finish jogging in pee!' And I said: 'yes.' There's a reason. I have a rationale. And my rationale is: she will do it again the next time she doesn't want to run'... Paramedics came for us. Police came for us. Parents in the community came to yell. Let me tell you, it was a scene. I just kept going. So of course the child was crying. Anyways... We finished the race... with swears, people telling police... ten years later, we're running races and people see us in our 'pretty stage' because obviously there's no tantrums. She's laughing through the whole five-k. She loves it.

Here, Becky describes a process where compliance to a behaviour intervention program took precedence over compliance to policing authorities and social and bodily norms of conduct. Becky's actions indicate how, as a behaviour therapist, she follows a different set of rules, customs, and laws and, when on the job, is trained to operate as if existing inside the silo of her behavioural world. Becky also describes how defying norms to adhere to her ABA rationale led to the optimized outcome of Sandy enjoyably completing races. Becky's conviction that finishing the race was the right thing to do, despite causing a scene, elucidates the extent to which the exercise of discipline is required to work as a behaviour therapist and is formative in shaping a distinctive ethical framework for relating to autistic subjects. Not all behaviour therapists would complete the actions Becky did, and some would be highly opposed to Becky's work, but the excerpt is instructive for providing an account of the unique modes of conduct and the commitment often involved in applying behavioural therapies.

I see Becky and Margot's dissimilar stories as intimately connected, and here is how: though their actions and approaches were entirely different, both therapists

strategically conducted themselves through disciplining and modifying their own bodies and responses, to produce the targeted behavioural response in the autistic person they worked with. Both excerpts further indicate that there is a uniquely behavioural way of relating to their autistic therapeutic subjects that they had to *learn* to adopt. While Margot's story elucidates the transformational aspect of learning to *become* a behaviour therapist, Becky's account demonstrates the naturalization of a behavioural way of orienting to herself and therapeutic recipients through years of working as a therapist. For these reasons, I consider both of these excerpts as examples of what I define as a behavioural worldview.

In this chapter, I describe this worldview and argue that it not only governs the work behaviour therapists do, but guides how they understand what should be done to their therapeutic recipients. I consider the subject formation of the behaviour therapist as created through disciplinary exercises aimed at splintering and reconstructing her view towards herself and her therapeutic recipient. The subject formation process creates a distinctive clinical-ethical behavioural worldview that hinges on the science of behaviour functionality and structures therapists' daily actions, feelings, and beliefs. The central use of standardized documents in ABA work is another key piece of the formation of a behavioural worldview, as these texts are used to shape and govern therapists' consciousness and moment-to-moment work-activities in distinctive ways. There are specific work-activities essential to the formation of a behavioural worldview: intertwining the behavioural modification of the provider with the recipient; intensive exercises consisting of panoptic forms of audible, textual and video surveillance; and automation via becoming a technical instrument for producing optimized functional outcomes. Exercises of compliance and reliability, aimed at creating the disciplined therapist, work to objectify therapists' body and behaviour (i.e., use them as technical objects), so that they come to identify their professional and personal worth through the ability to incite specific so-called functional responses in their therapeutic subjects.



## Theoretical Framework and Outline

Before moving on to my ethnographic analysis, it is important to describe the theoretical framework and outline for this chapter, beginning with defining my orientation to the concept of “worldview.”

### *Worldview*

I orient to the concept and process of adopting a worldview primarily through Byron Good’s (1994) work on the formation of a medical worldview.<sup>17</sup> Good empirically demonstrates how standardized disciplinary practices reshape the clinical work and emotional life of medical students and leads to a particular way of relating to patients. Like Goffman’s (1961) work on the “total institution,” Good argues that training to be a doctor is a total process, like training for the army, that requires an unmaking and reconstructing of the medical students’ reality vis-a-vis the body, mind, time, care, language and ethics. As Good (1994, p. 72) observes, in medicine, “the body is newly constituted as a medical body, quite distinct from the bodies we interact with in everyday life.” Good (1994, p. 72) continues to explain how an “organized set of perceptions and emotional responses” arise with the “emergence of the body as a site of medical knowledge.”

In his collaborative work with Mary Jo DelVecchio, the authors ethnographically examine how “distinctive medical worlds” are “constructed experientially so that they appear singularly convincing, natural, objective, the only way to imagine a world” (Good & DelVecchio, 1993, p.103). To examine the “discursive practices through which such worlds are constructed” (Good & DelVecchio 1993, p.103), Good (1994) describes how

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<sup>17</sup>Here is more information about how I am orienting to the concept of worldview. Sociologist Jeffery Butler (2013) provides a comprehensive synthesis of “worldview” and, like him, I agree with Wodak and Meyer (2009) that worldview is essentially identical with “ideology.” Worldview constitutes how “particular social agents interpret the world and their role within it” (Butler p.74-75). Berger and Luckmann’s definition also resonates as they articulate worldview as a “coherent and relatively stable sets of beliefs and values” that are formed by certain “underlying assumptions” (Butler, 2013, p.74). Richard DeWitt (2010) further orients to the concept as composed by core beliefs and peripheral beliefs. Peripheral beliefs can change without changing a worldview, but core beliefs cannot be changed without threatening it.

In respect to the topic of ABA, the concept that all behaviours have a function that can be optimized through ABA work is a core belief that cannot be altered without threatening both the contemporary North ABA framework for responding to autism and the value of applied behavioural therapy itself. Which behaviours require targeting or what the function of a behaviour might be are peripheral beliefs that can deviate from provider to provider.

learning to conduct autopsies, perform standardized narratives of patients' cases during medical rounds, and write standardized documents of patient histories in medical notes fundamentally changes how medical students view others. Through completing these disciplinary practices, medical students began to see everyday people as anatomically fragmented bodies ready to be sliced open, and learned to sieve out any aspect of a patient case that could not be emplotted into standardized medical genres of writing and speaking. Good's text is highly informative for considering the exercises therapists complete, and their effects. Like Good's analysis of becoming a medical doctor, I argue that becoming a behaviour therapist involves intensive standardized work procedures that lead to breaking down and rebuilding the therapists' way of perceiving themselves and their autistic therapeutic recipients.

But my work departs from Good's in important ways, and this requires explanation. First, while my focus is how behaviour therapists principally learn to reimagine their own bodies and selves, Good describes how medical students learn to reimagine other people's bodies and stories. Second, I analyze how behaviour therapists, in reimaging and reconstituting their own bodies, learn to reimagine autistic bodies as capable of producing functionally optimal performances. Third, while there is a centralized qualification standard (in the form of a medical degree) that medical students must pass to become a medical doctor, this does not yet exist for behaviour therapists in Ontario (though the organization, Board Certified Behaviour Analysts, is working to standardize the qualifications for being an applied behaviour analyst), and so the training and exercises therapists complete *can* vary to a greater extent (variability is a topic I consider primarily in Chapter Three) than medical doctors.

My interest in understanding the formation of the behavioural worldview emerged when listening to the arguments launched by behaviour therapy critics about how autistic people are subjected to hyper-intensive disciplinary procedures when receiving applied behaviour therapies. It is important to study the impacts and responses to behaviour therapies as communicated by autistic people, since they are the (often non-consenting by virtue of their age or station in a institutional facility) recipients of the therapies. Yet, a research focus on autistic people has resulted in a lack of research and discussion about what it is like to work as a behaviour therapy provider. Exclusively studying the views of

autistic people who have received ABA limits the scope of analysis and the ability to understand the cultural logics and professional contexts that shape the everyday *clinical* practices that constitute this new, and increasingly influential, applied scientific field. As stated in my Introduction, situating autistic therapeutic recipients as the research subjects misses a critical opportunity to apprehend the culture and cultural logics of behaviour therapists, and the multipart forces of power that autistic people encounter when they receive behaviour therapies in their everyday lives.

Further, when interviewing behaviour therapists, I began to understand that it is not just the autistic body that is regulated and subjected to what Foucault (1995, p. 139, 26) refers to as a “micro-physics” and “machinery” of power. In viewing behaviour as a perceptible and knowable object to be tracked, replicated, calculated and modified through highly controlled environmental manipulations, completing behaviour therapy interventions not only requires a “breaking down” and “rearranging” of the autistic body for optimization, it requires this of the behaviour therapist too. Once the focus moves to providers, it is clear that governance, as enacted through behaviour therapies, is created through the disciplining of therapists to come into a new behaviour consciousness that clinically and ethically guides how they relate to, and express care for, their autistic subjects. Discipline is key to the therapists’ self-formation and self-formation fundamentally involves the formation of a behaviour worldview.

### *Discipline and Standardization*

Before moving on, it is important to note how I am orienting to the concept of discipline and how this relates to exercises of standardization. Regarding discipline, I am drawing on Foucault’s description of anatomo-political discipline: a form of “power for training individual bodies through continuous observation and force in order to optimize their utility” (Weir, 2006, p. 9). Foucault (1995) explains how record-keeping, the normalizing gaze, examination, and observation are key techniques used for breaking up time, bodies, and space to produce maximum efficiency. These disciplinary exercises and practices constitute everyday behaviour therapy work, as therapists occupy the unique role of being recorded, surveilled and examined, and using their bodies as reliable instruments for

recording, surveilling and examining their subjects to ensure that they are producing maximum efficiency.

I tie interdisciplinary STS literature on standardization (Star, 1990; Mykhalovskiy, 2001; Rankin & Campbell, 2006, Timmermans and Berg, 2010) into my analysis of discipline to address how standardized documents are used to govern therapists to complete practices of self-discipline. Timmermans and Berg's work dovetails nicely with Good's (1993) analysis of discipline and worldview, as these authors explicitly examine how the "world of medicine is 'remade and moulded' through standardization" (2006, p.10). I show how standardization works to regulate the bodily actions of behaviour therapists to "encourage self-other comparisons as a technology of rationalization" (Mykhalovskiy, 2001, p. 290). Standardizing practices not only work to proscribe therapists' behaviour, but how they *think* of their behaviour and the behaviour of their therapeutic recipients.

### *Worldview as Behaviour Functionality*

Therapists, I argue, adopt a behavioural worldview when they come to think of the human condition through the lens of radical behaviourism, which focuses on behaviour functionality.<sup>18</sup> The disciplinary exercises behaviour therapist's complete are guided by a view of the body that is rooted in the Skinnerian theory that all behaviours have a function—the root of which is either escape, attention or self-stimulation<sup>19</sup>—that can be calibrated

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<sup>18</sup> Radical behaviourism is based on the notion that our thoughts, feelings, and actions are empirically observable and scientifically measurable through our behaviour, which is functional or dysfunctional, and that behaviour operates through the environment in the form of antecedents (stimulus) and consequences (control).

<sup>19</sup> Only one informant, a highly educated behavioural analyst trained in the United States, called Brittney, rejected this theory of behaviour deriving from one of three functions as "reallllly broad" and insufficient for capturing "all of human responding." Otherwise, informants supported this theory but had different interpretations of it. For instance, Ronnie and Georgia explained that finding the function of behaviour becomes more complicated the "higher functioning" or older an autistic or developmentally disabled person becomes. Even with increased complexity, they both believed in behaviour as deriving from one of these functions. Georgia said she believes in this theory because she is a "behaviourist at heart." Hence, to be a behaviourist, one must believe in the function of behaviour, even when it is more difficult to find the function. Margot, explained how prominent the theory of behaviour is to everyday ABA work: "there's always a function that can be traced to one of those three things. Nothing is ever untraceable. And that's why there's this endless search for 'what is the function of behaviour.'" Hence, a few therapists I interviewed described situations where they were not able to target the function of behaviour as very upsetting. These therapists considered these situations as their failure rather than a failure of the theory of functionality.

To understand more about how the theory of the function of behaviour informs behaviour therapists work and affects the relationship between therapist and subject, it is instructive to turn back to the excerpt

with technical efficiency (through empirical observation, data measurement, environmental control and reinforcement schedules), for elimination or functional optimization.<sup>20</sup>

Skinner, with his radical behaviourism proposed that our inner lives—what in psychology is referred to as ‘consciousness’ or ‘psyche’—does not exist. There is no murky or complicated private world of the mind to uncover: this is a mystical quasi-religious hypothetical construct. Radical behaviourism situates thoughts and feelings as existing on the same functional plane as our experiences of the external environment. While harder to empirically observe, our thoughts, feelings and actions are measurable and can be engineered through manipulating the environment. Our behaviours then, can be empirically scientifically analyzed and technically shaped to increase functioning.

My behaviour therapist informants accessed the science of behaviour analysis in different ways. Some are PhDs in behaviour science, whereas others are unfamiliar with ABA research and scientific terminology. Yet the radical behaviourist theory of behaviour function was *the* key governing theory that organized behaviour therapists’ thoughts, feelings, actions and ethical framework in their everyday work.

My concept of a behavioural worldview emerged through analyzing my empirical research. The following describes the key features of this concept. The remainder of the chapter will use ethnographic data to demonstrate how this behavioural worldview is created and maintained as well as its ethical implications. This is what I mean when I say *behavioural worldview*:

1. Behaviours are fundamental to who we are and our life possibilities and can be empirically observed, measured and calibrated through modifying the environment.

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from Becky featured at the beginning of this chapter. As Becky explained to me at a latter part of our interview, she made Sandy finish the race despite her resistance because she viewed Sandy’s resistance as an “escape” behaviour. Crying and urinating was Sandy’s way of trying to avoid completing the race. If Becky let Sandy stop running, she would be validating Sandy’s dysfunctional escape behaviours and thus contribute to further behavioural dysfunction. Hence Becky’s conviction that if she let Sandy stop running, she would pee and cry again, “the next time she doesn’t want to run.” Then Sandy would never finish a race.

<sup>20</sup> What I am describing here is Skinner’s “technology of behaviour.” Rutherford succinctly synthesizes this theory of behaviour as: “treating behaviour change like any other technological problem...”; the belief that “behaviours can be calibrated with precision”; that “new forms of behaviour” can “be engineered where none existed before, and that troublesome behaviours can be effectively reduced or... eliminated” (2009, p.156).

2. Behaviours are functional or dysfunctional, adaptive or maladaptive.
3. The therapist must learn to use her body as a flexible instrument for compliantly carrying out behaviour intervention instructions.
4. To truly care about a therapeutic recipient, the therapist may need to embody a distanced, authoritative figure—or a fun, energetic figure (such as the juggling robot)—whatever reinforcement procedure is necessary for producing the targeted behavioural response.
5. A therapist’s competence is defined by her ability to provide reliable therapeutic results that can be replicated by other therapists.
6. Increasing functional behaviour and decreasing dysfunctional behaviour is the key to quality of life and so behaviour therapy is an ethical project of enabling an autistic person to attain “the good life.”

This worldview has to be produced, so I will share some of the main processes involved in its formation.

### *Overview of Empirical Analysis*

The disciplinary practices that I analyze in this chapter include: the co-behaviour modification of the provider and recipient, surveillance (audible, textual, visual) and automation. Through intensively modifying the therapist’s own pulsing, moving, body, exercises of self-discipline *bring into embodied consciousness* the scientific theory of behaviour functionality in an intimate, felt way. In completing these exercises, therapists learn that their value as a therapist and their autistic recipients’ wellbeing are both tied to optimizing targeted functionality. Self-discipline is fundamental to adopting a behavioural way of apprehending the self and therapeutic recipient.

I begin my analysis with the behaviour modification of the therapist to demonstrate how being the subject of modification teaches therapists to view their own bodies through the lens of functionality, yet their own functionality is assessed by how well they can optimize the functionality of their therapeutic subjects. In this way, autistic subjects become the central reinforcement system for their own professional behaviour performances. To analyze surveillance, I examine how the use of the partition in the ABA centre, video recordings of one-on-one work, and a governing text called the Behaviour

Intervention Plan, constitute powerful regulatory spatial, textual, and social arrangements for teaching therapists to understand, enact, and adopt a new behavioural consciousness. I examine how testing mechanisms aimed at producing replicable therapeutic performances, and professional standards of inter-therapist reliability, teach therapists that their professional abilities derive from their ability to act mechanically, as an instrument for producing reliable functional performances. To complicate things, I analyze how therapists often need to build a rapport at the same time as embodying the automaton.

The second section of my analysis demonstrates how these disciplinary exercises and practices, which help to form a behavioural worldview, result in morally regulating how therapists express care for their recipients. To explain how this happens, I conduct a close analysis of two excerpts: one from Maya, a behaviour therapy assistant in the middle of her training process and the other from Anita, a mother para-practitioner struggling with applying intense behaviour interventions to her autistic children. While these informants (and the rest of the informants for this study) unanimously voiced caring deeply for their autistic recipients, they both aligned care with intensiveness, authority, rigidity and automation. Accordingly, therapists described *regulating* affection as fundamental to optimizing themselves as therapist-citizens, and their recipients as functioning citizens.

### **Co-Behaviour modification of provider and recipient**

In this section, I analyze interview excerpts from my therapist informants Brittney, Lydia, and Natalie. I analyze my conversations with these informants as a window into understanding how the relationship between the therapist and recipient is one of co-production (*see* Jasanoff, 2004), via completing disciplinary practices aimed at changing both of their behaviours. These disciplinary exercises compel therapists to think, not only of their recipients, but of themselves, in a particular behavioural way.

#### *Brittney: exhaustion and reinforcement*

I met Brittney in a fancy coffee shop near her condo in a newly developed part of town. Brittney wore a fitted black blazer and had straight hair matching her perfect posture. She came across as sincere and inscrutable: the epitome of matter-of-fact. She gave short deliberate answers, as if language was an economy and she didn't want to spend more

words than needed. Brittney conversed just like the characters living in *Walden Two* (Skinner, 1948).<sup>21</sup> I was unnerved and clumsy around her and felt that she formed a distinct opinion about me, yet was completely unaffected by whoever she thought I was. She made no move to alter her comportment or affect to match mine: she seemed wholeheartedly sovereign. Brittney had no reservations conveying when she disliked a question I was asking or when I misunderstood a behaviour analysis method we were discussing. Brittney also had no qualms about appraising, this, that, or the other misapplication or misunderstanding of applied behaviour therapies as “asinine” (which she did in regards to simplistic formulations of functional behaviour, the use of aversives in Canada, and continuous data collection during behaviour therapy work). Brittney was a formidable expert in the science of behaviour analysis, which seemed to be more than a topic she researched, but a *form of life* that she animated.

Brittney, now a behavioural science researcher who completed her doctorate in Behaviour Analysis in the United States, spoke of her experiences when she started working in the field. While Brittney does not refer to her training in this excerpt, she demonstrates how learning to work as a one-on-one therapist requires completing exhausting procedures centered on modifying her own body to produce the targeted responses in her therapeutic recipient:

Julia: ...How did you find your experience as an instructor therapist when you began working?

Brittney: It was just very draining. Excessively draining.

Julia: Why was it draining?

Brittney: Well, I think if you do a good job, you put your all into it. And I always set the reinforcement period, so when you were, you know, providing a break, those were exhausting...And like a reinforcer for appropriate [referring to appropriate or inappropriate behaviour]... whatever. So they [the recipient] worked for ten minutes say, then they get X whatever break, it depends... But you're like running around the house, lifting them up, lifting them down, like doing it all to keep the child engaged. So it's exhausting. I'd have like paint all over my face at the end of the day. You know, you just do whatever you can to get the child engaged so if they want to paint on your face, I mean you let 'em paint on your face...

Julia: And did it ever stop getting exhausting?

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<sup>21</sup> *Walden Two* is Skinner's controversial utopian novel about an experimental science-based self-sufficient community that is socially, economically, and politically governed by the principles of behaviour modification and engineering. A number of communities in real life have been created to emulate *Walden Two*.



Brittney: [pause] No. No it didn't.

Julia: Did you have strategies for dealing with the exhaustion? Were you taught... was it part of your curriculum?

Brittney: Oh yeah. I think you're taught to... You have to want to see the child succeed because when they do succeed then that becomes a reinforcement for you, for *your* behaviour, to continue to keep working...um, hard.

Here Brittney describes how she *became* her child's reinforcement during breaks in therapy work, which involved highly energetic and exhausting practices aimed at keeping the child engaged. More than therapy work, the breaks, which were not actually breaks for either therapist or child (as Brittney had to ensure the child performed functional behaviour in the form of social engagement), were the most draining aspect of Brittney's work. Like Margot's colleague who embodied the juggling robot, Brittney used her body as an instrument for producing the correct silly "break time" social engagement response in her child. The reason why Brittney shaped her conduct to such an excessively draining degree was so that the child's therapy sessions could be more effective (enjoyable breaks constitute a positive reinforcement procedure for motivating the subject to complete more therapy sessions, so they are not external but internal to therapy work).

What is most important about this excerpt is Brittney's reason for *why* she continued to discipline her body to such a draining degree to achieve the targeted response in her subject: because her child's success became *her own* reinforcement. While Brittney was her child's reinforcement, her child became *her* reinforcement. Maximizing her own body to achieve the targeted response in her recipient is Brittney's reinforcement to "keep working hard."<sup>22</sup> In short, Brittney understands her professional accomplishments through effectively modifying her bodily conduct to facilitate the effective behaviour modification of her subject.

*Lydia: the "wrap around approach"*

I interviewed Lydia, who is a special education consultant working for the Ontario school board, over the phone. Lydia's voice came through the line like an olive branch that I

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<sup>22</sup> It is likely not unique to behaviour therapists' that they define their professional worth through the success of their recipients, but what is distinctive about Brittney's response is how she defines her recipient's success (providing targeted behavioural responses) and the behavioural language (receiving reinforcements) she uses to refer to what motivates *her* to continue to complete tiring work.

gratefully accepted, and our conversation poured out. What struck me most about Lydia was how comprehensive her notion of the environment was in terms of understanding the function of behaviour. Lydia referred to herself as a “bleeding heart” because she is “almost immune to thinking people are bad,” a characteristic she attributes to adopting a behaviour therapy framework for understanding the human condition. If someone lashes out, commits a crime, even kills someone, Lydia explained, they are not evil, these acts are manifestations of antecedents in the environment (like neglect, for example) that were never understood: “where were the signs beforehand and we never... stepped in and intervened?” Lydia is always thinking about the reasons why behaviours occur, and observes the environment to understand their function.

What is so interesting about Lydia’s formulation of the relationship between behaviour and the environment is that she views *other people’s behaviour* as an integral part of an autistic person’s environment, and so views the modification of others as essential for modifying her recipient. This plays out in a very complicated fashion in the classrooms that Lydia enters, as her role is to train teachers to apply ABA as well as to work with them to modify the behaviour of specific autistic students.

In the following excerpt, Lydia demonstrates how her own work in the classroom is aimed at enrolling non-autistic actors (teachers and students) to relate to themselves and the autistic person in their classroom, through a behavioural lens. To examine this, consider the following excerpt from our conversation about how she trains teachers to apply ABA:

Lydia: As much as people hated it: track some data... or a lot of the time it’s modeling the behaviour for them... The school dynamic can be a tough model... So it’s really just trying to get everybody on board and doing a lot of support. Like ‘Oh that was so awesome when you didn’t respond.’<sup>23</sup> You know? It almost changes into modifying the behaviour of the adult or whoever his [the autistic recipient] responders are. You know, when I have classes, I’ll give reinforcers to students who are ignoring the behaviour of the... individual that’s doing the unwanted behaviour. So often times I’ll put in a reinforcement program, not for the actual student that has a problem behaviour, but for the other kids for their support in having that person [in their class]. And to me that’s been the most effective... I get a lot of ‘buy in’ and I practice also with other students, you know, on how to respond to those behaviours [of the student with the ‘problem behaviour’]. When they do respond well, they might get,

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<sup>23</sup> Not responding, or planned ignoring is a reinforcement protocol completed when the function of behaviour is attention. So the tacit function of behaviour being discussed in this excerpt is attention.

you know, McDonald's for lunch [laughs]...Whatever will make them happy... So I do like a 'wrap around approach' pretty much, like we're all on board...

Julia: So it almost seems like you have to modify the entire---

Lydia: The entire, *the entire* environment.

Here Lydia outlines her “wrap around approach” for modifying the “entire environment,” explaining how, to change the behaviour of the autistic person, she focuses her attention on modifying the behaviour of *every other person* in the autistic person's environment. Lydia shares the strategies she uses—data tracking and providing positive encouragement to the teachers and students when responding correctly—to get these actors to “buy in” to a behavioural way of understanding and modifying their own conduct towards the therapeutic recipient. The most interesting and important part of this excerpt might be that Lydia's work centers, not around modifying the behaviour of the intended therapeutic subject, but around “modifying the behaviour of the adult or whoever his responders are.” Lydia's approach demonstrates how the behaviour of the autistic recipient is modified through the disciplining of others, even beyond the para-practitioner role, to consider their own actions through a behavioural lens.

#### *Natalie: enmeshed behaviour performances*

Natalie and I met at a boutique sandwich shop on her lunch break. She was so excited to talk about her work that she did not eat a bite during our interview, and stayed after her lunch hour was complete to continue talking. Natalie attended a behavioural science college program after completing a psychology degree. She has worked as a behaviour therapist and is currently a behaviour supervisor, with extensive experience working with children and adult populations. Natalie considers applied behaviour analysis work to be her “calling.” Natalie had a sophisticated understanding of the science of behaviour analysis as well as a comprehensive understanding of the structural barriers and social determinants that negatively affect the lives of her autistic therapeutic recipients (I will return to Natalie and explain more about her therapeutic orientation in Chapter Two).

During our conversation, Natalie explained how her training to become a behaviour therapist involved the same disciplinary practices she applies to her autistic recipients. Natalie described how she was trained in the intensive “gold standard” model of “errorless teaching,” involving instruction, modeling, rehearsal, and feedback exercises.

In training, Natalie was shadowed and shaped by senior therapists, had monthly “maintenance checks” testing her performance abilities, and had to pass “mastery criteria” assessments. Strikingly, throughout our interview, Natalie described using *these same techniques* to shape the conduct of her autistic recipients. Natalie succinctly articulated how the intensive behaviour modification of the therapist parallels that of the recipient, with the statement: “when it’s intensive it’s not just intensive for the kids, it’s intensive for the staff. You would do 300 something... teaching trials, and that’s in addition to behavioural intervention.” The phantom figure in this account of the intensiveness of training is the autistic person, who is the subject Natalie is being evaluated *with and through*.

To further highlight the inter-relationality between therapist and subject, a few times when Natalie was describing her training, I was unclear whether she was referring to herself or her therapeutic recipient. I viewed the lack of linguistic differentiation as a meaningful slippage indicating the enmeshment that occurs between therapist and recipient through both being recipients of behaviour modification. Yet it is the therapist who is tasked with the role of optimization, which places the responsibility on her to successfully modify her subject through disciplining her own bodily practices. Recall Becky’s sense that it was her duty to comply with the running intervention, but her compliance could only be achieved through Sandy finishing the race. Becky “just kept going,” so that Sandy kept going, their successes and failures, as therapist and recipient, indelibly bound together.

### *Synthesis*

In this section I argued that when doing behaviour therapy it is not just the kids who are disciplined. The therapist’s body is also regimented and disciplined as a by-product. Behaviour modification of the therapist is a disciplinary exercise of behavioural consciousness raising where the therapist learns to view her own “errorless” functional optimization as the goal—but a goal that can only be achieved through the correct behaviour modification of her recipient. Through this dynamic, the therapist learns to perceive her recipients’ body as an extension of her own, making self-other boundaries potentially copasetic, potentially messy. The twining of self/other is key to the formation

of the behaviour worldview: disciplinary practices that co-produce the behaviour function of therapist and recipient teach the therapist to view, not only their subject, but their own self, through the lens of behaviour functionality.

### **Surveillance: Audible, Visual, and Textual**

In this section I examine surveillance as a key technique of self-discipline (aimed at disciplining the autistic recipient) that leads to the formation of a behavioural worldview. First, I return to Margot's story of the juggling robot to discuss how the spatial arrangement of the partition at Margot's clinic imposes self-disciplinary conduct through a particular audible surveillance dynamic. I further consider how this form of audible surveillance is central to how Margot and her therapist-friends came to adopt a behavioural worldview. In addition to audible surveillance, I analyze the importance of visual surveillance as a technique for disciplining the therapist's conduct and shaping her worldview. More specifically, I address video recordings as a ubiquitous form of documentation within behaviour therapy work that leads therapists to gaze at themselves and others through a behaviour lens. Lastly, I examine textual surveillance as a form of self-discipline that leads to the formation of a behavioural worldview. Here, I specifically examine a governing text in everyday behaviour therapy work called the Behaviour Intervention Plan and show how this document shapes therapists' conduct in such a way that changes their self-understanding to one that is based on functional behaviour.

#### *Audible surveillance: Partitions*

In Margot's account of the juggling robot, she described the clinic as divided by partitions, where one-on-one work was audible but not visible to other behaviour therapy providers and recipients. As anyone in the room could hear a therapy session, including supervisors who write Behaviour Intervention Plans (which I will discuss in the following section), the partitions prevented participants from knowing who, or whether anyone, was listening. This surveillance arrangement first recalls Foucault's notion of "the partition" as an effective technique for supervising the quality and merit of conduct through distributing and mapping bodies to establish "presences and absences," interruptions, and efficient communication at "each moment" (1995, p. 143).

Margot's description of the partition also calls to mind Foucault's architectural metaphor of the panopticon, which he used to describe social relations of surveillance and regulation (Foucault, 1995). The panopticon was designed so that a single overseer could watch all the inmates of an institution, but where inmates could not see each other or the overseer, thus knowing there was always the possibility of being surveilled (Foucault, 1995). Foucault writes:

He who is subjected to a field of visibility, and who knows it, assumes responsibility for the constraints of power; he makes them play spontaneously upon himself; he inscribes in himself the power relation in which he simultaneously plays both roles; he becomes the principle of his own subjection (Foucault, 1995, pp. 202-203).

Margot, her colleagues, and the "kids," were subjected to a similar form of regulatory power. Surveillance created a collectivizing bond amongst therapist-colleagues about the "crazy" extent of their attempts to discipline their own conduct to produce responses in their autistic subjects. Added to this is the strong desire of the therapist to succeed in modifying her kid's performance, which is rooted in a desire to be judged a competent behaviour therapist. As I will argue throughout the rest of this chapter, the criterion to be a competent therapist is the ability to elicit the correct responses in an individual by shaping one's own conduct to optimize the conduct of others (Foucault, 1991; Foucault, et al., 2007). With becoming a juggling robot, the intended correct response was social engagement (hence, laughter), which the therapist achieved by transforming herself into this wacky comical subject. Thus, the sound of laughter of the therapists' kid communicated to the other therapists, and perhaps to the clinical supervisor who *might be* listening, that she was doing a good job.

I interpret the partition arrangement in the EIBI clinic Margot describes as a key technique for building up a behavioural worldview through a spatial surveillance arrangement aimed at appraising the quality of work of the therapist. I understand the shared sense of astonishment, maybe even distress, between Margot and her colleagues, about who they were becoming and the selves they were losing, as indelibly tied to knowing they were likely being surveilled by colleagues and superiors. That Margot thought of the juggling robot story when asked about her early days working in the field, demonstrates how the partition arrangement and its implicit expectation of self-discipline, was key to her process of embodying a behavioural worldview (the expectation to elicit

the correct functional responses in her subject) in learning to become a behaviour therapist.

### *Visual Surveillance: Video Recordings*

Video recorded behaviour therapy sessions produce a lasting moving image of therapy sessions that can be consulted by different people after the fact. Recorded sessions can be understood as a representational and pedagogical technique for teaching therapists-in-training and para-practitioners to correctly shape their own conduct while learning to literally *view* behaviour function (their own and their recipients) as the objective of their work. Videos operate as immutable evidentiary documents that are used to serve different purposes, but are linked to the anatomo-political disciplining of the therapist and para-practitioner, and the formation of a behavioural worldview.

In my research, parent para-practitioners, behaviour therapists and clinical supervisors talked about videos all the time. Often informants would mention the recordings in passing, thus indicating the significance of this documentation method as a naturalized part of behaviour therapy work. Some clinicians interviewed described recorded sessions as an important tool for assessing the performance and skills of both practitioner and recipient. Contrastingly, parents would watch their child's recorded therapy sessions as part of their parent-training program, for the purpose of learning to model the techniques used by the behaviour therapist with their child. Parents would also watch videos of their own behaviour therapy work with their child to receive clinician feedback on their conduct.

I have watched many recorded behaviour therapy sessions at conferences, in documentaries, and online (where behaviour therapy services advertise their work and use videos as a tool for knowledge translation aimed at enrolling new clients). I have also watched many of Margot's recorded home-based ABA sessions, as she wanted to show me her work so that I could understand what everyday ABA work is like. Margot recorded her sessions on her cell phone, while the videos shown at conferences and posted online are recorded from a camera fixed to the wall of the therapy room, indicating this form of monitoring as a "fixture" in center-based behaviour therapy practice.

In my view, video recordings are pervasive in ABA because behaviour therapies are highly embodied and temporally-based therapeutic practices that are often more physical than verbal. I have tried to explain the activities that comprise behaviour therapy work without the aid of a video and it is an incredibly difficult task. The videos thus work as a stand in for what goes on in ABA practice. At conferences and the market halls frequently attached to them (which sell a variety of autism-related products and services) the short (two-to five-minute) ABA videos that play, sometimes on a loop, show ideal-type ABA sessions. When shown for training and evaluation purposes, video recordings are used to analyse both mistakes and success stories in order to guide practitioners' conduct (these videos might be longer, though I have only seen one instance of a therapist's (Margot's) personal ABA videos, which ran from five minutes to about twenty). The videos used online to sell behaviour therapy services and teach techniques are generally between two to 30 minutes long.

In contrast to talk therapists who do not generally show their therapy sessions to colleagues and outsiders, what I hope I have communicated is that the presence of video recordings in behaviour therapy work is ubiquitous. This ubiquity is suggested by the imaginary scenario cooked up by Lydia. Lydia told me how she "always pictures... a video camera watching above," especially when kids "chase" her around the classroom and she's "running around and trying not to make eye contact" with the child (the standard response for when the function of behaviour is considered to be "attention"). Lydia concluded that the agent watching the video would interpret this scenario as being "freaking hilarious" and "absurd." While this humorous appraisal is framed as benign, it is notable that Lydia copes with emotionally stressful scenarios by imagining a surveillance system that appraises her trained therapeutic responses *from above*, implicitly keeping her on task. The figure of the raised camera and of an observer watching the recordings indicates the extent to which behaviour therapists are recorded, view the recordings as powerful tools for assessing their work, and impose a literal behavioural gaze on themselves as a strategy for compliantly completing their work.



### *Video recordings as a testing mechanism*

Video recordings also serve as a testing mechanism for the process of qualifying to become a behaviour therapist. A participant called Tajman informed me that the grading scheme relating to recorded performances can work to co-produce the success of the autistic recipient with that of the therapist. Tajman is now a clinical supervisor, but when describing her own training process in qualifying to become a behaviour therapist, she stated that she had to receive a passing mark on her multiple recorded performances, a standardized 80 percent “mastery” score. I was confused when Tajman told me this because autistic subjects are often required to receive this same eighty percent score to master their discrete trial training sessions and move on to a new session. I asked Tajman to clarify and she let out an uncomfortable laugh. Tajman explained that the therapists in her program needed their autistic recipient to master the session in order to be assessed as mastering the session themselves. This technique teaches student behaviour therapists that they *need* their autistic recipients to provide the correct responses in order to be a competent therapist. This enmeshment can compel an almost desperate desire for the autistic individual to master the correct performance, as evidenced with the juggling robot, and with Becky forcing Sandy to finish the race. The video acts not only as a technique for assessing performance, but as a visually-mediated way of ABA knowing and acting. The camera *is* the figure of the behavioural worldview embodied in living colour for therapists and others to gaze at and appraise how well therapists are functioning in relation to it.

### *Textual Surveillance: Behaviour Intervention Plan*

Texts mediate moment-to-moment applied behaviour therapy work and are another instrument of panoptic surveillance. Many of the behaviour therapists interviewed indicated that in order to understand the function of behaviour to intervene for betterment, data collection is often completed before, during, and after each behaviour therapy session.<sup>24</sup> Behaviour therapists collect data to record and track their empirical observations as well as their own actions. The Behaviour Intervention Plan (BIP) is the governing text for one-on-one ABA and EIBI work. The BIP is a detailed document that includes all the

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<sup>24</sup> Britney again was the outlier here, calling “continuous” data collection “crazy” because you’re “not looking at the kid” or “engaging with the kid.” She thus preferred “discontinuous” data collection.

interventions to be carried out by the therapist. Behaviour Intervention Plans differ based on the individual being assessed, but all plans outline systematic intervention procedures for reducing targeted inappropriate behaviours and increasing positive replacement behaviours. A baseline measurement of the targeted behaviour is conducted before the development of the BIP. The theory of radical behaviourism undergirds the BIP. It is written into the language, form, structure, and goals of the plan.

The BIP is created by the clinical or behaviour supervisor after a therapeutic subject has completed an array of assessment procedures, sometimes culminating in the Functional Assessment/Analysis. The BIP tests the hypothesis of the function of the targeted behavior by creating specific settings, stimuli, and reinforcement procedures aimed at creating positive behaviour change. Safety plans, procedures for outbursts, environmental manipulations, and conditions for consequences are outlined in the BIP.<sup>25</sup>

The importance of the BIP in governing all actors involved in applying behavioural therapies cannot be overestimated. The BIP is an example of a “procedural standard,” which according to Timmermans & Berg, is a textual guideline that proscriptively outlines the appropriate actions to be taken by a professional (2010). I argue that the BIP managerially disciplines the everyday work of behaviour therapists and, so, shapes their consciousness to define their work and professional obligations through the guidelines laid out therein. By breaking up therapists’ time, bodies and movements into proscribed steps and tasks, the BIP compels therapeutic compliance. Leon (a former assistant behaviour therapist at a public EIBI clinic) referred to the BIP as “the Bible” for behaviour therapists as it is treated like “the word of God” and “dictates everything you do.” As Leon explained, there are routine check-ups conducted by clinical supervisors who regularly monitor the data collection documents completed by the therapist. Supervisors reprimand

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<sup>25</sup> The examples of the BIPs I have studied follow a similar organizational narrative. First, the therapeutic subject is introduced and her behavioural background and assessment findings are summarized. Then, a list of problem behaviours are stated under the heading “function of behaviour”; this is followed by a “recommendation” section outlining how to relate to the subject when specific behaviours occur, as well as when and how the supervisor will monitor the instructor’s progress. Subsequently, “targeted behaviours” are listed, which describe behavioural goals as based on the needs of the subject (for example: more group participation, reduced outbursts, reduced obsessive behaviour, or age appropriate vocalizations). Then, there is a “prevention” section detailing how to prevent maladaptive behaviours, followed by the “reward plan” and “reinforcement delivery” sections, which outline the rewards and reinforcements the therapeutic subject will receive during interventions. In situations where caregivers are enrolled to complete ABA work, there is an additional section that is highly proscriptive, detailing the step-by-step responses a caregiver should give when the therapeutic subject elicits problem behaviours.

or praise the therapist according to their degree of compliance with the procedures outlined in the plan and co-workers also regulate each other in accordance with the guidelines of the BIP. For instance, I have met support workers whose supervisors have verbally scolded them for deviating from an intervention outlined in the plan. In another instance, a support worker wrote an “incident report” (which must be sent to management for review) when a co-worker was not following the correct intervention procedure laid out in the BIP.

When speaking to Brittney, who has worked as a clinical supervisor, I understood that textual production and adherence is essential for delegating behaviour therapy work to providers who may not be behaviour analysis experts. When speaking of data collection in one-on-one work, Brittney stated:

Brittney: There’s no point in taking data if you’re not going to look at it and use it on a ongoing basis.

Julia: Right. So constant document verification of what you’re doing in a one-on-one—

Brittney: Yeah. Otherwise, how are you supposed to know what you’re doing is working? Certainly not based on subjective ‘yeah I think it’s going well.’ You wouldn’t want to trust somebody also whose not trained all that well to make those calls. It’s not the clinician that’s in those sessions; it’s somebody that’s out of high school or an undergraduate degree that’s working one-on-one. So you can’t... they don’t always know what they’re looking for.

Brittney’s excerpt shows how texts enable supervisors to surveil and regulate the work of assistant therapists or behaviour therapists (including those who may not be highly educated in the science of behaviour analysis). In turn, therapists learn to conduct themselves in compliance with the managerial authority of the BIP, which enables supervisors to govern when absent. The BIP is also a practice of getting the therapist to think like the clinical supervisor who scripts the performances of the therapist through the BIP. Through completing the proscribed moment-to-moment and day-to-day session work laid out in the plan, the therapist both learns and models a behavioural way of being and doing.

Paul Brodwin (2010) examines how the assemblage of compliance in psychiatric case management convenes through the distribution of the medication cassette. The pre-scripted uses of the medication cassette tacitly impose patient and case worker compliance with pill consumption and “biopsychiatric thinking,” and further enables the psychiatrist—who does not distribute medication himself—to use the case worker as his authoritative

“prosthetic extension” (Brodwin, 2010, p.129). The BIP works in a similar fashion, as it enlists behaviour therapists to not only be compliant with the supervisor’s intervention plans via self-discipline, but to learn to adopt a behavioural way of thinking about their work and their therapeutic subject’s progress.

Becky told me a story about the BIP that highlights how it operates as a way to ensure therapists act in compliance to a supervisor’s instructions when absent. She describes what happened when she accidentally failed to follow one of the procedures written in her individual’s plan when working at a private EIBI centre. This incident, and Becky’s response to it, illustrate how behaviour therapists internalize the expert authority of the clinical supervisor (via the BIP) through exercising self-discipline, and how they invoke and impose such authority on other therapists to insure compliance with this governing document. Becky’s description of her noncompliance is expressed in the following quote:

Each kid has a different reinforcer, and... you gotta be on them. You have to know who’s getting what reinforcement. Some are food, some high-fives, some a tickle... It’s all written in their program [the BIP]. It’s very specific... There were times I remember still to this day, one of the boys I was supporting... was actually not on task. And I didn’t read it [the BIP]. Silly me, I didn’t respond properly...the other instructor she came up and she said ‘He’s... stimming!’ and the stimming looked very normal.<sup>26</sup> His hands were in his pockets... everybody puts their hands in their pockets. But I didn’t know, I didn’t. I just came in and I “shewwww!” I looked over the book very fast...But I should have known because his hand was playing with the string in his pants and that makes him off task. And then there was a correctionary procedure that has to be done.

By voicing regret about missing a very subtle bodily cue—but importantly, one that reinforced a perceived dysfunctional behaviour—that was written into her individual’s plan and “not responding properly,” Becky demonstrates the important panoptic function of this document. Notice too how Becky’s self-reprimands sound similar to those a boss might make when witnessing her employee make an error, thus showing how she’s internalized the authority *and* the behavioural perspective of her boss through (mis)reading and (mis)enacting this document. That the plan is available for any therapist to read, as Becky’s instructor-colleague did, means the behaviour therapist does not know who has

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<sup>26</sup> “A Stimm” or “Stimming” are short forms for self- stimulation most often typified in repetitive actions such as rocking or touching. Stimming is a common topic in behaviour therapy programs and in autistic/autism communities.

the information to monitor her and so regulates her own actions to ensure they comply with the steps laid out in the plan.

Another aspect of the function of the BIP and of Becky's shame about missing the boy's stim, relates to the micro-disciplining of both kid and therapist, and how "dangerous it is to neglect the little things" (Foucault, 1995, p. 140). The BIP works as a method for clinical supervisors to regulate and standardize the *meticulous* movements and exercises carried out by the behaviour therapist "without the slightest detail escaping [their] attention" (Foucault, 1995, p. 141). Micro-disciplining is further achieved by disciplining therapists to align their professional judgment with the dictates of the BIP, which happens through disciplinary procedures, such as the one Becky received from her instructor colleague when she noticed that both *Becky and the boy* were "off task" and required a "correctionary procedure." This is why Becky is still distressed by the times she "didn't read it properly," "didn't respond properly."

Becky's description of her own sense that applied behaviour therapies are empowering for autistic people, coupled with her eagerness to contribute to this study, compel me to think that she thinks of her work as a behaviour therapist as an ethical calling, rather than a practical or economic one. Becky stated that for her, being a behaviour therapist "has nothing to do with money," and that the pay is modest (something other behaviour therapist informants confirmed). Thus, Becky's hyperbolized feelings of humiliation about missing an imperceptible stim by skimming through "the book," reveals the training she has received to align being a competent therapist with compliance with the BIP. The humiliation Becky feels about the situation described in this excerpt is also revealing of what Susan Leigh Star (1990) describes as the ordinary everyday pain of failing to embody standardized practices.

Rankin and Campell (2006) examine the powerful effects of text-mediated nursing work in our current managerial and evidence-based Canadian healthcare system. The authors argue that text-mediated processes constitute a "sophisticated form of power" that is "exercised over nurses and their work" which is different than power that is "exercised by external authority over a passive or unwilling subject" (2006, p. 19). While the clinical supervisor is the prosthetic extension of authority in terms of adhering to the BIP, the BIP itself reorganizes a behaviour therapist's consciousness so that "they become the text's

proponents, active in instituting the new order” (Rankin & Campbell, 2006, p. 19). The relationship between text, managerial authority, and clinical consciousness enacted through the BIP demonstrates Mykhalovskiy’s claim that “managerial and clinical work come to be transformed” and brought into relation with one another through text-mediated practices (2001, p. 274). Through the BIP as a standardized document, the behaviour therapist *becomes* the manager, applied and clinical work *become* institutional work, and the therapist learns the importance of self-discipline in tandem with coming into a behavioural consciousness. The BIP embodies a behavioural worldview and compels therapists to adopt it.

### **Instrumentalization of the self: automation and the calibration of affect**

In this section I examine how behaviour therapists learn to view themselves as de-subjectivized instruments for engineering targeted functional outcomes in both themselves and others. Acting “mechanically” does not only mean acting with precise rigidity or embodying an authoritative affectless mechanism. It can also mean strategically acting happy or silly (like the juggling robot) or working to form *relationships* with recipients or para-practitioners. In essence, acting mechanically means drawing on the self as a blank instrument capable of embodying whatever affect or behaviour is required to yield the best functional behaviour performances in the recipient. In being trained to act mechanically, behaviour therapists come to view their professional success as based on their ability to control their conduct with technical proficiency so as to elicit the correct behavioural responses in others. In the case of cross-therapist replicability, the therapists’ effectiveness derives from self-discipline to the point that their subjectivity does not imprint on the therapeutic work. In the case of relationship building, the therapists’ effectiveness derives from forming collaborative bonds with the para-practitioners they are training. In the process of learning to relate to themselves as flexible instruments, therapists’ come to think of themselves in a new behavioural way.

#### *Cross-Therapist Replicability*

The conduct of behaviour therapists is shaped by exercises of cross-therapist replicability. As mentioned earlier in this chapter, an autistic therapeutic recipient is often required to

respond correctly to eighty percent of the session instructions in order to master and move on to a different session. Many therapist informants explained that the mastered session has to be repeated at least three times with the same results, but by *different* therapists. Becky referred to this standard of inter-therapist replicability as “mechanical.” I orient to the machine in Becky’s formulation *as the behaviour therapist*, as it is she who must carry out the “direct instructions” of the programmer (that is, in an identical fashion to other behaviour therapists) as if *being* a technical device.

Becky emphasizes the importance of the therapist responding with mechanical reliability, stating:

Of course we all [behaviour therapists] have to be responding on the same page. Like if she’s [the kid] getting a high five every three times that she does the response, I need to be reading the program and everybody needs to be responding at the same time so she doesn’t... [Becky trailed off and didn’t complete this sentence].

Becky describes the importance of standardized responses that are consistent and replicable as a fundamental requirement for being a behaviour therapist. Trailing off when stating that therapists need to respond compliantly and identically “so she doesn’t...” indicates how Becky has been trained to consider the programmer’s directions as correct. Becky is not quite sure what would happen if the therapist were not to respond reliably, but she knows that it would lead to an unknown and unfavourable outcome. This excerpt indicates how therapists are trained to consider replicable “mechanical” responses as the yardstick with which to judge their professional merit.

This excerpt from my interview with Margot further indicates the role of the therapist as a technical instrument:

I: When you think about yourself as a therapist... what’s the role of the self?

M: Nothing.

I: Okay. So you don’t exist?

M: You’re the vehicle.

When Margot answers that the role of the therapist-self is to embody “nothing,” to become a de-subjectivized implement, she highlights the instrumentalization *of* the therapist. As I will analyze when discussing my interview with Maya, learning to view oneself as an instrument, a tool for producing consistent outcomes, is a transformational process that is key to adopting a behavioural worldview.

I suggest that the disembodied instrumentation of the self typical of behaviour therapy is linked to its status as an evidence-based method. Timmermans and Berg (2010) explain the loop between evidence-based methods and standardization: evidence-based methods are standardized forms of knowledge that are used to standardize healthcare institutions. They further explain that the turn towards evidence-based practice is “foremost about delineating what sequence of activities constitutes a professional response to a given situation” (Timmermans and Berg, 2010, p. 13). In the examples of reliability I have just provided, the therapist’s actions are delineated to the point where they de-subjectivize themselves as instrumental tools. Becky’s sense that her actions must comply with direct managerial instructions that render her therapeutic practice mechanical, shows the “weight” of standardized instructions in establishing how to “act properly” as a professional (Rankin & Campbell, 2006, p. 9).

Therapists are not only tasked with working as reliable instruments with their autistic subjects, they are also tasked with training parents to work as reliable instruments with their children. As discussed in the Introduction, applied behaviour therapies require intensive and consistent temporal engagement beyond what most centres and practitioners can provide. Accordingly, parent para-practitioners play a huge role in completing ABA work in the home, where they are trained by behaviour therapists to harmonize their parental styles with ABA methods, carry out intervention plans, and collect data on their children. Training parents is a highly complex and delicate endeavour since parents have a pre-formed and strong emotional relationship with their children and they are being trained by an expert-outsider to relate to their children in a whole new way.

To provide effective extra-clinical ABA work, the same standard of reliability and replicability is required of parent para-practitioners. Bobby, a former behaviour therapist, spoke of his experience working in a home-based private setting and standardizing parent’s behaviour by teaching them to become reliable para-practitioners:

Once a week or twice a week I would have a parent training session... It was very rigid in the sense that we had like prompting hierarchies, where we would have to start teaching a skill with full physical prompt either hand over hand where we’re actually doing the skill for the child... Then one of the generalization techniques we would use is that the skill had to be demonstrated with... the family members.... I would have to ask the parents to come down, I would be like ‘Hey, you know,



your child's mastered this skill, I want to make sure they have the ability to do it with you as well, so we are going to need you to come down.' And then basically run this program with them.

Here Bobby describes having to train parents to work with their children in a manner that effectively complies with the ABA intervention program. Bobby describes these parent-training sessions as rigid in the sense that he provided full physical prompts to the autistic child to ensure she mastered the skills *in a way that could be replicated and generalized by the parents*. I understand the purpose of these rigid sessions, where parents are taught by experts to learn the importance of moving their bodies in highly proscribed ways in order to produce specific embodied results in their child, as training parents to adopt a new way of thinking about their bodies. I read the proscriptive rigidity of Bobby's sessions as aimed at the parent, not the child, as the process of precisely calibrating their children's bodies, is a practice of training parents to precisely calibrate their own. These training sessions are tacitly an exercise of teaching parents to learn to relate to their bodies in a new way: as powerful and effective instruments capable of eliciting specific responses from their children through proscribing and controlling their own bodily movements and actions.

### *Rapport*

Many therapists discussed the importance of building rapport, described as friendliness and familiarity, with their therapeutic subject to create the trust and comfort necessary for conducting productive therapy sessions. Yet rapport has to be carefully managed so as to not slide into a "relationship" or to contaminate a therapist's ability to relate mechanically. Hence, rapport is used to advance behaviour therapists' abilities to generate replicable effective behavioural performances, while the relationship contaminates this ability. I asked Leon to expand on the role of objectivity and emotional connection in ABA practice, and whether these topics were included in his behavioural therapy training. Leon responded:

There was no specific training around it but... this is how it was explained: 'if you develop a relationship with a child it will excuse your ability to make further progress because your purview of their abilities is skewed, therefore you shouldn't do it.' It was almost like... a scare tactic. 'So by doing this, you're hurting more kids in the long run.' So... it was brought up, reinforced again, by the senior therapist.

The issue of relationships was mentioned during training and reinforced by Leon's supervisor as both a technical and ethical problem: a bond that would impede a child's progress, skew the therapist's understanding of the child's abilities, and thus hurt the child in the future. Leon describes this intervention from the senior therapist as a "scare tactic." In my interpretation, the purpose of this scare tactic is to train Leon to align disinterestedness with therapeutic progress. Keeping a professional social distance is essential to reliably carrying out ABA interventions that can be replicated by other therapists. Building and regulating the therapeutic connection in the form of a rapport is a practice that requires both self-discipline and adopting the role of the impartial objective mechanical actor.

Leon spoke of the few, but important, methods he used to form a connection with his subjects. Discrete trial training was the prime method practiced at his EIBI clinic, which meant that positive reinforcements had to be enjoyed within the timeframe of a few seconds. When providing these reinforcements, Leon would often add a fist bump and "explosion" to his high fives, a tiny gesture of authenticity that seemed to "go along way." When recounting this insertion of a personal touch, Leon's face lit up, his voice was giggly and his grin was wide. Leon's experience of an action as slight as this as a form of intimacy suggests how his training encourages him to relate instrumentally to his therapeutic recipients.

#### *Relationship: Parent-training*

To complicate things, therapists have to build a *relationship* with parents in order to enrol them to complete behaviour therapy work in their home. The therapist is thus not only taught to view managing rapport with autistic subjects as key to becoming an instrument for advancing therapeutic outcomes. Therapists must create a different affective bond with parents as "partners" to enrol them to apply ABA to their children. Gil Eyal, et al. (2010) analyzes the democratization of clinical ABA expert with autism parent as linked to the wider context of community care. As I will describe in detail in Chapter Three, the deinstitutionalization movement acted as the "great leveller" of expertise, as it put "the psychiatrist on equal footing with occupational therapists and special educators, since all must appeal to and strike an alliance with parents" (Eyal et al., 2010, p. 4). This history is

very relevant to contemporary behaviour therapy practice since parents are still key providers of behaviour therapies. To demonstrate the importance of the relationship between parents and providers, Orli, an undergraduate ABA researcher I interviewed, considered the ability to “be able to negotiate with parents” as a defining characteristic of what it means to be a “good clinician.”

When interviewing Lydia, she discussed the difficulty of teaching parents to collect data and relate to their child through an ABA lens and considered building a relationship with parents as key to enrolling them to complete behaviour therapy work in their home. Lydia described the different strategies she has used to get parents “on board” with applying ABA. When Lydia first began working in the field she used to “bring in all of this research” to prove her methods were right when parents resisted adopting her ABA approach. She now reflects on this strategy as “almost” being in an “attack mode,” as it communicated to parents: “I know more than you.” Parents would respond to this method by “digging their heels in” and resisting her expert knowledge, so Lydia learnt to adopt a different approach, which she described as “making a deal:” “Okay I’ll do what you promised me if you give mine a try.” Compromising, and bringing “a little bit of light-heartedness to the situation,” Lydia explained, is a much more successful method for working with parents. To ensure para-practitioner led ABA will be correct and effective, Lydia has to relate to parents on a level playing field. In contrast to Leon’s description of being trained to create a distance between himself and his therapeutic subject, Lydia felt compelled to strategically drop her authoritative approach and close the gap between expert-therapist and lay-parent to create better therapeutic outcomes.

## **Care**

Now that I have described three of the standardized self-disciplinary practices and exercises therapists complete, I want to show how they set the groundwork for adopting a particular ethical framework towards caring for autistic people. This ethical framework is an important component of the behavioural worldview, and I will spend the final section of this paper, by analyzing excerpts from two informants, demonstrating how.

## *Maya*

I met with Maya between her university classes at a campus coffee shop. Maya, a nineteen-year-old assistant therapist, began working with an autistic teenager who she met when she was a camp counsellor. To Maya, becoming a behaviour therapist was both a calling and a vocation. As a psychology major, behaviour analysis was her most practical career prospect, but she also considered behaviour therapy methods as vital for helping autistic people.

Maya described her struggle with providing behaviour therapies. When asked to explain the source of her discomfort, Maya described having to actively temper her compulsion to “be nice” to provide “effective” behaviour therapy interventions. If nice gets in the way of progress, being nice can actually be unkind, Maya explained. Thus, in training to become a therapist, Maya re-signifies niceness as harmful to her individuals’ progress.

Throughout the interview, Maya laughed nervously, spoke quietly, and smiled often. She appeared shy and warm, and spoke of her affection for her autistic therapeutic recipients. It was evident that acting in a way that did not feel nice would be challenging for Maya. The following interview excerpt provides context for Maya’s rationale, and elucidates how her process of becoming a behaviour therapist involves breaking down and reconstructing, not only her identity, but her ethical orientation towards caring for autistic people.

Maya: I still have a lot more to learn because there will be situations where I feel like I’m not being effective. Someone else who’s been working with her [the recipient] will be doing the exact same thing as me but *will* be effective... It’s just about how you portray yourself... It’s a lot about implicit authority... the way you stand, the voice you use, the tone... It’s funny because I was... a very... diplomatic type of person to begin with. When I started this I felt like: ‘Am I becoming rude? Am I being authoritative?’

Julia: Do you remember the growing pains when you first started implementing [intensive behaviour interventions]?

Maya: Still sometimes making her do things that she doesn’t want to do. I think it’s actually still the same thing: following through. I tend to... adapt to her, which I guess people would do in general... The thing you have to remember about ABA is that you’re trying to help them be functional, so if you adapt to when they’re being dysfunctional... you’re not really helping them, right? If they’re going to keep... throwing a tantrum and you’re trying to adapt to that, that won’t be right.

An important part of this excerpt is Maya's sense that her ability to become a good therapist is premised on her ability to produce the same level of effectiveness as other behaviour therapists. This indicates that Maya has been disciplined to view the merit of her work in terms of its cross-therapist replicability. Maya also discusses having to change how she portrays herself. She "began" as a diplomatic person, but in applying ABA, she questions whether she has become a different *kind* of person: a rude and authoritative one. Maya embodied these two kinds of people while she was explaining this to me. When referring to her diplomatic self, Maya was bubbly and animated, her back slouched, body leaning towards mine, and her hands expressive. When describing her therapist self, she shifted her posture dramatically; her back was rigidly straight, face blank, tone commanding and terse, and arms tucked under the table. These two identities were very different. When Maya explained behaviour therapy work as requiring her to refrain from doing what "people generally do" (i.e., adapt to the autistic person) she articulated how the process of becoming a therapist is constitutive of a new ethical worldview, which involves unfamiliar perceptions, knowledge-practices, and ways of interacting. Maya still struggles to "follow through" with the practices required in this new behavioural view, and actively works to obey and make sense of them.

Maya's struggle with obeying and making sense of this behavioural worldview is linked to the difficult process of learning to act in accordance with clinical behaviour analysis standards. Star examines standardization as an affective and pedagogical process of translating uncertainties into certainties, where "old identities" are "discarded, and the focus of the world" is "narrowed into a set of facts (Star, 1990, p.47). Star continues: "the uncertainties of our selves and our biographies fall to the monovocal exercise of power, or making the world" (Star, 1990, p.48). Consider how often Maya's sentences featured in the above excerpt are posed as questions, which I read as at once rhetorical and pleading. These hybrid sentences and sentiments archive the process of translation (from Maya's biographical description of her non-ABA diplomatic self as opposed to her new authoritative ABA self) where ambivalence is discarded and transformed into a monovocal truth, but one that Maya has clearly not yet comfortably digested. Maya works to "remind herself" about the logic and goals of applied behaviour science; this act of reminding is the tool Maya uses to settle uncertainty. Reminding is how Maya's question about whether it

is “right” not to adapt to her subjects dysfunctional behaviour (“if you adapt to when they’re being dysfunctional... you’re not really helping them, right?”) is transformed into an assertion in the following sentence (“If they’re going to keep... throwing a tantrum and you’re trying to adapt to that, that won’t be right.”).

Maya’s motivation for following through with standard behaviour analysis methods is linked to her newly-adopted behavioural orientation towards kindness, as well as to her practical hope for employment after graduation. As explained in the Introduction, assistant therapists make a modest salary and often have little job security; senior therapists, behavioural consultants, and clinical supervisors usually have greater job security and higher salaries. Leon described a “chain of command” in ABA work, descending from supervisors to senior therapists to behaviour therapists with assistant therapists at the bottom. When I asked him how he felt about this chain, Leon responded:

I never had... any issues with them [his senior therapists] taking authority... I did what I was told to do... But that was my goal eventually, to keep moving up. So kind of the classic Foucauldian idea of being a good citizen, does good work, does what they want them to do, will have more success than the one that resists, right?

Maya’s incentive to conduct herself to be as “effective” as other therapists working with her autistic recipients resonates with Leon’s analysis of compliance as related to moving up the chain, where being a good citizen corresponds with conforming to organizational rules and norms of professional conduct.

When Maya works to settle the uncomfortable discord between how she likes to act versus how she is being trained to act, she cites “effective” forms of conduct as central to reducing her clients “dysfunctionality.” Maya thus draws on behavioural language to organize her perception of autism as an innate individual deficit requiring behavioural intervention. Maya further uses behavioural science terminology to legitimize her new authoritative role. In transitioning from nice to authoritative, Maya’s perception of how to express empathy shifted in sync with her new ethical framework. Maya still wants to be “good,” but she now sees “good” through the lens of behaviour analysis. In rejecting niceness, Maya understands her new authoritative conduct as a form of kindness, but kindness (“helping”) has been reduced to behavioural effectiveness.

I understand gender as an important aspect of the formation of Maya’s ethical behavioural world, particularly in relation to how she understands “niceness,” “kindness,”

and being “authoritative.” First, it is important to explain that behavioural therapy is a feminized profession. For example, all but four providers interviewed for this study identified as female, two of the men interviewed moved “up” the “chain” to be clinicians, and the other two had since left the field.<sup>27</sup> While I did interview many female clinicians, supervisors, and consultants, only my female informants were directly applying ABA as behaviour therapists, assistants and para-practitioners.

Despite applied behaviour therapy being a feminized field, behavioural analysis is based on masculinist ideals of disinterested objectivity, measurement, automation and rationalization. It is also important to note that men primarily established and developed applied behaviour analysis (Rutherford, 2009). The use of the therapist as a technical instrument for applying a highly rigid and controlled scientific technology of behaviour change, further demonstrates this. Many female therapist informants (including Becky, Maya, and as will be evident, Anita) harmonize discordant gendered expectations by considering their efforts to embody a mechanical therapist (distanced, functional, rigid, affectless) as the best way to respond *empathetically* to their autistic subjects. To this end, notice how Maya rationalizes embodying the masculine ideals of behaviour science (authoritative, mechanic, distanced) as the correct expression of empathy. Being authoritative and mechanical is very hard for Maya, but is done in the service of helping the other. Maya sacrifices her self-image of *appearing* nice in order to provide care she knows is best, which is a higher form of empathy. I consider that Maya only embodies the removed objective, commanding therapist, because she sees this role as fitting socialized feminine ideals of empathetic self-sacrifice. As such, gender management is part of the process for Maya becoming a behaviour therapist and adopting the particular ethical framework inherent to the behavioural worldview.

Maya’s journey of adopting a behavioural worldview also chronicles a struggle about how to care about autistic people while being a competent therapist. Byron Good and Mary-Jo DelVecchio (1993) analyze how care and competence become binary opposites during the training process of becoming a medical doctor. Once working in the field, medical students who were initially drawn to the profession because of caring aspirations, learnt to reconsider care as being an innate human quality rather than a

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<sup>27</sup> Informants also spoke of ABA as a female dominated field.

medical skill. Care was further recast as something that belongs to the providence of the humanities. Competence was perceived as a “science.” Good and DeVicchio (1993) argue that the higher the stakes of not being competent, the more students feel they need to re-train their orientation towards medicine as mastering a science rather than providing care. Thus, medical students often finish medical school having abandoned the major reason they applied: to care for people.<sup>28</sup>

Maya’s story provides a more complicated dynamic between care and competence in training to become a behaviour therapist. Maya did not view care and competence as oppositional but instead viewed competence as *the most responsible and beneficial way* to care for autistic people. Maya still frames care, wanting to help, as central to her desire to be a competent therapist. She actually “reminds” herself in this excerpt that if she wants to help autistic people she needs to learn to be competent, which to her means following through with increasing their functionality and decreasing their dysfunctionality. Hence, while care is central to Maya’s work, she needs to manage and repress *expressing care* in order to *care properly*.

I orient to Maya’s experiences of becoming a behaviour therapist as expanding Susan DiGiacomo’s (1987) insights about care and medical doctors. Different from Good and DeVecchio, DiGiacomo claims that a key part of being a medical doctor is learning to actively manage compassion in order to provide the best patient outcomes. In considering her work as principally concerned with optimized functional outcomes, Maya reconfigures competence as the best way to channel compassion. Expressions of compassion must be tempered to “follow through” with “authoritative” therapeutic interventions.<sup>29</sup> Empathy can be felt, but not expressed. This controlled performative suppression, and sometimes expression, of empathy is, I would argue, foundational to becoming a competent behaviour therapy provider.

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<sup>28</sup> Good and DeVecchio (1993) consider this dichotomy between caring and competency as indicative of the western tendency to dichotomize and compartmentalize disciplines and phenomenological experiences (for example, science versus art). This analysis provides important context for the highly regimented and technical field of behavioural science.

<sup>29</sup> I hope the process articulated here sheds more light on Becky’s actions described at the beginning of this paper.



### *Anita*

I end this Chapter by sharing an excerpt from my interview with Anita. The topics addressed when analyzing Maya's excerpt (such as, the management of care and competence, gender management, and the relationship between disciplinary behaviour therapy training and the formation of an ethical behavioural worldview) are further evident in my interview with Anita. Because I provided a detailed analysis of these topics when discussing my interview with Maya, I do not recapitulate them with Anita, but it is important to notice that they are reflected in Anita's statements and experiences too.

Anita's interview is important to include as it provides a window into how motherhood and the space of the home are reshaped through disciplinary behaviour therapy practices that lead to the formation of an ethical behavioural worldview as governing the parent-child relationship. I further use Anita's interview to show how, for some parents, autism is constituted *through* learning to apply behavioural therapy to their children.

Anita lives with her parents, husband, and three children, two of whom are diagnosed autistic. She works as a full-time unpaid ABA para-practitioner to her autistic children. Anita explained that she came to know about ABA through the government funded parent-training programs she was encouraged to take after her children were diagnosed. She described applying severe interventions to her autistic children. Most parents use disciplinary strategies to compel children to express themselves in relation to social norms of capacity and optimization, so it is important to note the particular ways that Anita was trained to parent as an authoritative, mechanical, compliant behaviour therapist. It was clear that Anita loved her autistic children and thought ABA was the best thing she could do to help them. To understand the logic behind this understanding, I asked Anita about her knowledge of autism and ABA. I also invited her to describe how her kids reacted to ABA, and how those reactions made her feel. This is an excerpt from her response:

Lots of tantrums... That was challenging, being a mother. The challenging part is to withhold your emotions and... keep that child crying until he realizes that, 'okay she's not going to give me milk, she's not going to give me my favourite toy unless... I use my words.' That was a *very* challenging issue I faced. And it's still challenging sometimes... Where sometimes they don't want to speak or if

they're in a bad mood... 'Ma, you should know what I want'... If they're not telling me what they want, they're not getting it... For a normal child this is our cultural thing that we do, that... we have to change the diapers before the [child asks for it] – when we know the diaper is wet... And the milk should come right before the child builds up time for milk... We just learned about this whole spectrum thing, that, okay, we have to wait until the child demands for it... but... being a mother, it's hard to see all of that crying and like you are not giving milk to your own child... Being a mother – it's painful to see. But, we know that it's the only thing that we can do to conquer that spectrum stuff. So that's why we did that.

In this excerpt, Anita portrays a home that has been reorganized to operate as a behavioural therapy clinic, where her parental conduct complies with the goals of ABA work, and where she ensures that other family members also comply. Anita expresses a behavioural worldview when she interprets not giving her kid milk or toys, not as a kind of deprivation or neglect, but as the most effective tool or technique to break through “the spectrum thing” to enhance her children’s quality of life in the long-term. Anita actively rethinks and reimagines her own actions from a behavioural point of view. Her ethical framework is remade so that she comes to view eliciting behaviour functionality as the highest form of expressing maternal love and caring, and she recasts “normal cultural” parental forms of nurturing as a form of neglect.

Like Maya, Anita separates her ethical framework from mainstream culture’s, by adopting a behavioural paradigm of personhood and care. Like Maya, Anita does not like taking on an authoritative role, which she experiences as painful, hard, and damaging to her identity as a mother. In stating that she just “learned about the whole spectrum thing” and was told that it is the “best thing she can do” for her children, Anita indicates how she has been trained by clinical experts to align being a good mother with being a good ABA practitioner. The jobs of good mother and good practitioner converge into the obligation to actively help conquer autism through completing ABA work. Although Anita and her family speak English as a second language, for a while they spoke only English around her autistic boys, on the advice of a behavioural therapy expert. Anita only learned about the spectrum through her children’s diagnosis, so this ethnocentric orientation towards understanding and intervening on autism was taught to her by experts, and was formative in shaping her perception about how to care for her autistic children. In this way, I orient to Anita’s experience as a form of psychopower: a concept invented by Jackie Orr (2006)

to describe when treatments define or create, the very disorders they are said to cure. While ABA did not “invent” autism on systemic level (though Gil Eyal (2010; 2013) has argued that the current autism “epidemic” has been created through a matrix of ABA and deinstitutionalization) it was a common experience of the parents I spoke with to learn about ABA at the same meeting that they learnt about their child’s autism diagnosis. Thus, Anita found it ethically necessary to responsabilize herself and her family to apply these “effective” yet painful interventions, because she *is* a good mother, because she *does* love her autistic children.

### **Conclusion**

My fieldwork indicates that the behavioural worldview is created by: intertwining the behavioural modification of the provider with the recipient; intensive exercises consisting of panoptic forms of audible, textual and video surveillance; and automation via becoming a technical instrument for producing optimized functional outcomes. Exercises of compliance and reliability, aimed at creating the disciplined therapist, work to objectify therapists’ body and behaviour (i.e., use them as technical objects), so that they come to identify their professional and personal worth through the ability to incite specific responses in their therapeutic subjects. From a behavioural worldview, the good therapist is compliant to standardized behaviour therapy methods, and being a good person means being a good therapist.

As a field of discourse and practice, behavioural therapy draws all actors involved into understanding autism through an individual deficit model. To be optimized, the autistic subject is subjected to normalizing disciplinary techniques and practices. While I will complicate this in the following three chapters, behaviour therapy providers are often taught to view and accept clinical interventions as necessarily intense, and to consider the meaning of the lives of autistic people according to ideals of behavioural functionality—and frequently, neurological capacity, and normative socialization. Self-discipline is the prime subjectification technique used in applied behaviour therapies, where each subject involved must self-govern in order to govern others.

Moving the discussion from the disciplining of the autistic person to the disciplining and world-making of the therapist allows an important analysis of expert

knowledge and power: it is not just autistic people who are disciplined and monitored through governmental and pastoral forces (Foucault et al., 2007) aimed at compelling conduct towards collective norms. The complex network of power draws upon numerous subjects and technologies, such as clinical supervisors, training curricula, government policy, textual protocol, and video documentation. These technologies merge to shepherd the conduct of the behaviour therapist for the purpose of shaping the conduct of both autistic people and the experts themselves.

Another feature of working in the field of applied behaviour therapies is the complex gendered expectations that impact the work many therapists do, and how they make sense of their work. As particularly evident with Maya, Becky and Anita, masculine ideals of objectivity, the self-disciplined body as technology, and the use of intensive methods, were considered essential to being compassionate towards autistic people. Behaviour therapists are required to regulate compassion in order to be competent, which many do through managing gender ideals.

Lastly, subjection to disciplinary exercises to train linking optimized effective functionality with empathy, is a distinctive collective identity building experience that marks the process of becoming a behaviour therapist. Intensive disciplining is both conceptual and material: autism is considered a problem of behavioural dysfunction, and care is understood as increasing functionality. However, through their entanglement and co-production with autistic people, behaviour therapists can reproduce or resist these key aspects of their training. This is a topic I will address throughout the remaining chapters of this thesis.

## CHAPTER TWO

### **Managerial, Institutional, and Professional Governance**

In the last chapter I emphasized the ideal mechanical and standardized nature of behaviour therapies and how this leads to the development of a behavioural worldview, where therapists come to consider the ability to create functional behavioural outcomes (by engaging in intensive and reliable therapeutic work) as the correct ethical response to supporting autistic people. In this chapter I complicate this argument by analyzing how practitioners, in their everyday work, encounter various institutional practices that challenge their ability to do the work they want and are trained to do. Here, the ethnographic analysis focuses on examining how managerial governance and self-regulation fundamentally shape everyday behaviour therapy activities and methods. To examine this, I focus on three topics: 1) time and numbers; 2) certification; 3) institutional behaviour management. An analysis of how behaviour therapies are actually being practiced on the ground reveals how larger regulatory, political and institutional forms of management and governance shape therapist's everyday applied therapeutic work.

This chapter is particularly influenced by scholarship in the area of institutional ethnography (Diamond, 1995; Mykhalovskiy, 2001, 2003; Smith, 1995, 2005), a sociological method of inquiry concerned with analyzing how everyday interactions are organized and coordinated extra-locally by institutional structures. One of the important ways that this area of scholarship analyzes governance is by mapping how local everyday social relations and work practices are ruled translocally by imposing standardized rules, procedures and tasks (such as organizing an employee's work day through the completion of a daily checklist) to coordinate and synchronise workers' actions to ensure the proper bureaucratic functioning of the institution. Governing people's everyday work through rationalized textual documents such as checklists is a managerial-institutional technique aimed at reshaping what workers do. At the same time it redefines what counts as work in ways that obscure the complex actualities of people's everyday activities. In this chapter, I examine the broader social and institutional organization of what behaviour therapists do, and how the organization of behaviour therapists' workplaces challenges what they want to do. I further address the role of textual documentation practices in behaviour therapists'

everyday work. I focus on how behaviour therapy practices are put to work to produce managerial forms of knowledge and how such practices fit within the larger managerial model of healthcare governance in Canada.

The first section of this chapter addresses how behaviour therapy practitioners working in publicly-funded centres are compelled to torque their everyday practice so that it fits with the quantitative numerical forms of assessment the provincial government uses to evaluate behaviour therapy services. The expectation to convert everyday work into quantitative, numerical data, governs and reshapes everyday therapeutic practices. I draw on Theodore Porter (2012) and Dorothy Smith's (1995) scholarship on the power and political work of quantitative numerical forms of assessment, to both understand the deep historical roots and local effects of this manner of therapeutic governance. I further explore how the managerial-political issue of waitlist management does not just shape the everyday work behaviour therapists complete, but that of other autism experts and stakeholders, such as medical clinicians, diagnosticians, and parents.

The second section examines how the recent provincial move towards certification, which is a step towards professionalization, is something important happening within the field, and something providers have to take on and deal with in various ways. Certification has created new forms of *academic* workplace governance for behaviour therapists. It is a social process that has created a split in the workplace between those who want to be certified and those who do not. I lay out how therapists who advocate for certification think this form of regulation would create clear professional standards and enhance accountability. Providers who resist certification do so because they view it as the death of the *form* of behaviour analysis that they practice, which prioritizes effective and creative one-on-one work over a clinical evidence-based academic approach. I extend my analysis of the effects of certification to consider how therapists internalize the disciplinary power of their newly internally regulated system of practice by regulating not just their actions, but also their *thoughts* about their actions. Behaviour analysis certification reconstitutes who gets to be, and what activities comprise, the everyday work of behaviour therapists.

The final section of this chapter examines how behaviour therapy is applied to aid institutions that serve autistic adults (and often, those concurrently labelled with developmental disabilities), to run more smoothly. In this section I incorporate Alexandra

Rutherford's (2009) important work on the history of the token economy system in the asylum, to suggest a connection between the use of behaviour analysis in the asylum and the present day group home.<sup>30</sup> For adults in institutional spaces, the scope of behaviour interventions can be focused on improving problem behaviours so that the individual does not disrupt the functioning of the institution. To demonstrate this, I focus on my interviews with two social workers, Sam and Louisa, as well as Wyatt, a family member of an autistic group home resident, as they each provide important accounts relating to how behaviour therapies, and the Behaviour Support Plan, can be used to redirect institutional problems into a problem of individual behaviour, thus perpetuating systemic oppression against disabled residents. I contrast these accounts with that of a behaviour therapist named Natalie who works with autistic adults in custodial care settings, to show how much of Natalie's work is advocating against the use of behaviour therapies as a form of managerial control aimed at protecting the institution rather than the people in it.

### **Time and Numbers**

In this section I examine how time and numbers are used as valuable managerial tools for translocally governing behaviour therapists' work in such a way as to both quantitatively assess the quality of behaviour therapy services and to efficiently manage lengthy waitlists. What I demonstrate through analyzing my interviews is that the expectation to transform everyday therapeutic activities into numbers negatively governs and shapes therapists work, so that providing "good numbers" often means providing therapeutic care that does not feel beneficial to the therapists providing ABA programs.

#### *The Numbers Game*

Bobby was the first person I interviewed for this study and I am still thankful he was my entry into fieldwork. Bobby lived in a one-bedroom apartment unit. He welcomed me into his place wearing a casual T-shirt and a huge smile, offering me a glass of water in a bright orange plastic cup. His place was colourful, casual, and seemed like a happy breathing entity. Bobby's living room was filled with art, consisting of signs and stencils

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<sup>30</sup> Token economy is a systematic program where tokens are given to therapeutic recipients for correct behaviour performances, and once they are accumulated, can be exchanged for material goods or privileges such as treats, or outings

with queer slogans, retro movie posters, needlepoint, and DIY T-shirts hanging up on the wall. By the time we sat down on his couch to begin the interview, I felt like I knew Bobby well. Maybe it was our shared queer culture that felt so familiar, but I think it's more likely that Bobby has that magical mixture of charisma and kindness that refracts onto the spaces around him, like a prism does with a bright sun.

Bobby spoke so quickly and with such precision, all while stroking his bushy beard, that even when I started to transcribe his interview and turned my recorder as slow as it could go, he still spoke faster than most of my informants did at real time. I thought Bobby's tempo embodied the urgency with which he wanted to get his stories out of his body so that they could jump onto a printed page to be heard by others.<sup>31</sup> I got the distinct sense that Bobby had been rehearsing these stories for years, so that whenever he has the opportunity to tell them, he tells them right. I consider that Bobby wanted his personal experiences to be documented so as to “merge from the margins” and take its place “in the public domain of knowledge” (MacDonald, 2007, p. 18) about behaviour therapies.

Bobby expressed his disillusionment with working at various ABA and EIBI centres, both public and private, as well as in home-based programs, over the past decade or so. Bobby conveyed enthusiasm about behaviour therapies in-and-of themselves, considering creativity and excitement two of the most important qualities for a behaviour therapist to have, yet he described how various philosophical and institutional constraints hampered the therapy work he actually wants to do. Paramount among them is how his everyday work is ruled by efforts to acquire the right kind of numbers for the government. Getting these numbers shapes how Bobby provides behaviour therapies and requires him to work at a very fast pace.

The following quote details how, to survive as a publicly-funded ABA program, Bobby must torque his therapy practice to be accountable to government stakeholders. To provide context for this excerpt, Bobby was telling me about how “exhausting” it is to work within the “regulation framework” of public behaviour therapy services in Ontario. I asked him to elaborate on what this framework is and to describe how it exhausts him:

Bobby: Well it's more... the one-on-one work, I mean on a day-to-day basis I'm dealing with, and my day starts, it's... often pre-school kids. They, number one, might not be toilet trained. So I'm going to

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<sup>31</sup> While I do not describe this here, Bobby shared how disturbed he was by the multiple aversive and punishment protocols he witnessed at one of the public-private EIBI clinics he worked at about 9 years ago.



have to be dealing with diapers, toilet training schedules, daily living skills... And then there's the behaviour aspects. So you have a child...that has no verbal language, but communicates with behaviours... That's very challenging... when you have two hours to work with a child.

Julia: Two hours!

Bobby: That's the length of our groups. Two hours twice a week, or sometimes two hours once a week. So you have this limited amount of time where often times you're trying to rush, rush, rush, rush! You're like: 'Oh my god!' But if a child has a behaviour you can spend an hour-and-a-half... dealing with the challenging behaviour and you get a little fifteen-minute break and you go right back into group. And [then you] might be having to deal with another child's tantrums but this time it might be a sixteen year old who might throw a desk across the room. So, you know, it's a very challenging experience, and right now specifically within my program we are in the infancy stage where we have been guaranteed five years of funding. We're in year three now... And it's a number's game. It's not about what service we're providing. It's about how do we get as many children through our service and our numbers up so that when we present that info to the government, it looks good. It says that we are given enough funding for 110 kids, 'but look, at this quarter we served 135 kids.' So that tells the government: 'Wow, you're doing a really good job servicing these kids, this is an important service, so we need to continue funding.'

But the reality is that service that the child is getting, is probably not the best. It's being [*Bobby quickly snaps his fingers together three times*], because I want to get that child in and out of our service and I want to maintain that we have these numbers, and we'll worry about what specifics this child is going to be taught later. But right now, we just need to be sure that we're teaching this child *something*. So, it gets incredibly frustrating... That's again a very trying thing, is when you're trying to... teach somebody a skill that they have no desire to learn, and they don't need, but I need to make it look like we taught this child something on paper so that when we submit our final numbers to the government they give us a hand clap and say: 'Here you go, here's some more funding.'

Bobby's work is exhausting because he has to deal with many competing needs and factors that delimit the possibility to provide the best ABA care. First, Bobby describes the short time frame for each session: two-hour group sessions once or twice a week, where providers switch from delivering one-on-one to group therapy work. During these sessions, Bobby might spend the majority of the time dealing with daily living skills, like changing diapers. Or a "challenging behaviour" like a participant throwing a desk, might take up the majority of the session. Yet Bobby feels pressured to cycle people through his program quickly and to ensure he completes work activities that enable him to record that he taught participants "something on paper."

In addition to trying to work within the short time-frame of each session, Bobby describes the additional fast paced tempo of the program itself: he and his colleagues feel compelled to “rush rush rush” to get their kids in and out of the program in order to keep their enrolment numbers high (as if to embody this, Bobby told me about the pace of his program while speaking so fast that I wondered how long he could go without taking a breath). Later, when Bobby’s program becomes an established service, he can worry about the “specifics” of what he is teaching participants, but right now he must ensure that in his everyday work he masters “the numbers game.” Bobby describes the numbers game as manifesting in a Faustian-type tradeoff between providing good care and receiving government funding, which he laments is “very trying” and “very frustrating.” Ironically, the more successful Bobby is as playing the numbers game, the worse he thinks his program is. In other words, in his experience of everyday work, the achievement of a “hand clap from the government” for providing good care actually reflects the opposite.

Dorothy Smith’s (1995) institutional ethnographic work is useful for considering the power, processes and effects inherent in the disconnect Bobby describes between his everyday activities and his requirement to represent these activities through recording them via standardized data sheets. Smith views extra-local administrative and managerial texts, such as Bobby’s data sheets as organizational techniques aimed not at representing, but at objectifying, the work experiences of employees. Smith argues that an important function of these texts is to preclude the “admission” of the workers’ everyday practices into “the textual realities operative for the organization” (1995, p.97-98). In essence then, the power of institutional systems of ruling is precisely that of “subdu[ing] and displac[ing] the perspectives of particular subjects” (1995, p.97). Hence, the “organization of ruling” is “insulated” from the “effects of disjunctures between the lived actualities as people know them in their everyday/ everynight lives” (1995, p.97).

To add to Smith’s important contributions, the powerful and intended disconnect between numerical representation and everyday phenomena encapsulates what Theodore M. Porter describes as “funny numbers:” numbers that are misleading, deceitful, and humorous (2012, p.593). Since modernity, (quantitative and statistical) mathematical numbers have been the dominant way to reveal and represent the ‘Truth’ of reality (Porter, 2012). Because numbers have the power to represent reality, misleading numbers have the

power to misrepresent it, to act as a foil for what's actually going on, and to insulate the goings-on of actual everyday life from further consideration. Funny numbers can exist uncontested because of our trust in numbers. Similar to Smith, Porter explains how “funny numbers” are often the result of decentralized efforts to reduce data in order for numbers to speak a truth that aligns with particular social, political, institutional or economic motives (Porter, 2012, p. 595). Bobby’s description of his everyday work-practices illustrates Porter’s claim that a trust in numbers is not indicative of “some cultural disposition to put implicit faith in measures and calculations, but about the containment of subjectivity” (2012, p. 595). In Bobby’s work, the numbers he gives to the government do not just contain the subjectivity of all the actors involved in his program, these numbers are funny because they represent a picture of everyday activities that does not connect with Bobby’s understanding of the quality of his work. Paradoxically the pressure to get his “numbers up,” is what makes the numbers Bobby submits to the government so funny.<sup>32</sup>

Porter’s claim that numerical forms of governance not only represent reality, but reshape it, brings into focus key features of Bobby’s account of his daily work. Porter contextualizes the institutionalization of standardized tests in North American high schools as a paradigmatic pedagogical intrusion that remodels the education system so that educational curriculum is reconstructed to “match the content of the tests” (2012, p.597). Following Porter, I am drawn to consider how Bobby’s everyday ABA work is reconstructed through being accountable to the government’s numbers-based framework for determining the quality of ABA services. In essence, Bobby’s description of his work

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<sup>32</sup> To grasp all the important implications of Bobby’s description of his work, it is crucial to explain a bit more of Porter’s scholarship on the topic of funny numbers within the realm of mental healthcare and the education system. Porter provides a historical account of the role statistical data played in containing and presenting the truth of life within the asylum, primarily in the late 1700 throughout the 1800s, in Europe and North America. He considers the history of the asylum as the best example of the rise of a form of truth-governance through numbers, which has extended and flourished into current day forms of governance. To demonstrate this, Porter provides a range of examples from various asylums where quantitative numerical renderings of asylum life were strategically tweaked to present favorable data regarding the value of the asylum model and its curative potential. In other words, for a long while the asylum could be presented as a successful and harmonious place while chaos and disharmony only grew behind the smoke screen of funny numbers. Most interestingly, Porter explains how data about high cure rates could only be achieved by deliberately *not accounting for* patient relapses. For example, in the Bloomingdale Asylum in New York, many of the patients recorded by the data as “Cured” were often readmitted multiple times, with one “admitted a total of 59 times over a period of 29 years and discharged as recovered 46 of those times” (Porter, 2012, p.590).

experiences brings to life what happens when healthcare is ruled by “thin description” (Porter, 2012, p. 595). Thin description defines the achievement of “impersonal regulation” through trusting numbers over local and textured knowledge-based accounts. Thin description is the primary methodological way the Ontario government assesses the quality of Bobby’s ABA program, yet as Bobby’s account illuminates: thin description leads to thin programs.<sup>33</sup>

Another important aspect of Bobby’s description of his work is his sense of how the accumulation of autistic bodies (via cycling people through the program quickly) secures funds. Porter describes the neoliberal agenda as “not simply about the superiority of private enterprise” or the “shrinking of the state” but about “making private enterprise a model for public agencies” through “decentralized action and decisions directed by well-designed incentives” (Porter, 2012, p. 596). The pressure Bobby feels to torque his everyday practice to respond to the decentralized expectation to have high enrolment and to document quick improvement, is indicative of how public behaviour therapy programs are shaped by a wider neoliberal healthcare agenda, in which services are assessed translocally through numerical-statistical forms of quality assessment.

### *The Time Game*

Similar to Bobby’s account, another informant named Hailey (who I discussed in the Introduction) emphasized how speed is an expectation that governs all levels of publicly funded autism care in Ontario. In a different way than Bobby, Hailey’s interview compelled me to consider how the “numbers game” is also a ‘time game.’ While Bobby provided an everyday account of how time and numbers map onto each other, Hailey offered a structural description of how these two forces connect to govern autism services more broadly. Hailey is a prominent clinician who, as I discussed in the Introduction, is

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<sup>33</sup> In addition to government funding, Bobby arranges his therapy program so that he not only conducts interventions that look good on paper but that will please parents (the relationship between therapists and parents is a topic I will expand on in Chapter’s Three and Four). Bobby expresses further frustration about this aspect of his work when he recounts the situation of the fourteen-year-old that I will call Norman, who he taught to use a voice output device in order to answer the question: “What is it?” Bobby describes how this intervention was not beneficial to Norman (as Bobby states: he “doesn’t need” and has “no desire to learn” these skills), yet he completed it because he knew that Norman’s parents want him to learn skills that reflect cognitive and communication norms. Bobby explains how answering “What is it?” will not result in Norman authentically understanding and learning to identify what an object is. Instead, what he is teaching Norman to do is to perform and *mimic* skills that others feel are valuable because they appear normal.

secretly a critic of behaviour therapies, as she works in a behaviour therapy-centric autism organization. Hailey's interview helped me to understand how behaviour therapy services are just one node in the apparatus of a healthcare system that ensures clinical activities adhere to translocal managerial objectives. Hailey condemned autism services as governed by "management 101:" "people come out of university and they just manage you." Hailey further argued that healthcare is organized by the "human remains department" and described her everyday work as "management-based practice" as opposed to "clinical or evidence-based practice:" "All they do is tell you how to march... they tell you how high to jump and you have to do it." Hailey referred to autism care in Canada as a "bad situation: everything about it is bad."

Dividing, cutting, maximizing and speeding up time are key techniques of managerial governance. Hailey passionately lamented the speed of clinical and therapeutic encounters for impeding the possibility of supporting her autistic patients the way she is trained to do. For instance, she viewed her organization's Ontario Health Insurance Plan-governed policy, of only allowing autistic people to come into her office (because it would take too much time for Hailey to do home visits), as centring around time concerns. Hailey explained that coming into the office is sometimes traumatizing for her autistic patients who have sensory sensitivities and who struggle with a change in routine. If coming into her office traumatizes her patients, the possible benefits of Hailey's care work are negated. Hailey also stated that autistic people are overmedicated because medication is the quickest solution for dealing with emotional and behavioural issues. Further, she described the training process for autism providers as too fast paced as well, focused more on cycling people through programs than on taking the time needed to develop comprehensive expertise relating to autism and developmental disabilities. Hence, Hailey defines her clinical activities as managerial in nature and situates speed as a central strategy of managerial governance. Hailey and Bobby's experiences paint a picture of a situation in which both provider and recipient are together caught in a system ruled by numerical calculation, accumulation, and acceleration.

*Data sheets, waitlists and diagnostic categories*

In this subsection I tie Bobby and Hailey's accounts of how their work is managerially governed by organizing their activities through time and numbers, to the issue of managing long behaviour therapy waitlists. To demonstrate how the issue of eligibility and waitlists inform and structure everyday behaviour therapy work, I turn back to my interview with Leon (who I introduced in Chapter One). When discussing his work at a publicly-funded EIBI clinic, Leon explains how numbers, time, and therapy data are hooked into the production of managerial knowledge for reducing long EIBI and ABA waitlists. Leon also describes how long waitlists influenced the daily behaviour therapy methods he completed. To explain this further, consider this excerpt where I asked Leon to describe where his daily checklist data goes:

Leon: Generally...it stayed within the centre, but what we did have to do was report, definitely on a weekly basis and then on a monthly basis, on kids' progress. So, you know... we had to report: are they making progress? And if they aren't making progress, at least for us it was six weeks, if they sort of plateaued... they're taken off [the EIBI program]... 'Cause from the government standpoint there's a three-year waiting list, or something like that... From the government's perspective, if kids are not making progress it's not worth their while to continue, therefore let's get the next kid in... data based on the checkmarks is what determines kind of the next steps... If they had a lot of 'no's,' in let's say five different areas, so it could be: communication...behaviour, eating, hygiene, the motor stuff - if they had no progress...based on those checkmarks, that then would be given to the senior therapist who's then expected to make a decision about whether or not the kid receives the therapy - and if they don't, then they get the next kid.

Julia: How important are texts actually to you? Like if you could have it your way...How much would you be collecting data...?

Leon: I think it depends on the structure right? When the entire structure is built on getting kids in and out, and getting kids funded publicly, then it's hard to evade. Because those numbers and facts and quantitative data is what speaks to what you're doing, and which kids get access and which don't. So I may have told you the example of... the kid that maybe doesn't have enough problems to get therapy but they're too autistic to receive therapy, so to speak. So in that sense there's very little wiggle room cause you need kind of a hard fact to show and demonstrate why they get therapy...

This excerpt illuminates how clinical data is put to work in an everyday setting to solve the political-managerial problem of long waitlists. Like Bobby, Leon describes how “the entire structure” of publicly funded centre-based EIBI work is built on “getting kids in and out.” Checklists are an integral component of the science of behaviour analysis: empirical

data tracking documents like checklists are part of how antecedents and consequences can be charted and converted into graphs for calculating behavioural trends. Yet what Leon describes here is how the checklist data are being used primarily as a decision-making tool: there are long waitlists and the checklist is a technique for clinically justifying cycling kids in and out. Leon primarily orients to “checkmarks,” not as useful clinical indicators, but as managerial technologies to determine “next steps” related to program access. Like Bobby, “numbers and facts and quantitative data speaks [sic] to what” Leon is doing and “which kids get access and which don’t.” To echo Hailey’s sentiments, Leon describes how the everyday clinical work of the senior therapists at his centre are shaped to generate managerial knowledge useful for managing time vis-a-vis dealing with the infrastructural problem of long waitlists.

The six-week standardized timeframe is another part of the assemblage of behaviour therapy inclusion/exclusion decision-making criteria, shaping and constraining the overarching structure of the therapy programs autistic children receive. The six-week effectiveness window is based on waitlists, where results must be quick and sustained to legitimize a child’s funding: therapeutic improvement must be measurable and it must be measurable quickly. Leon’s also paints a picture of how his checkmarks are tacitly used biopolitically, inscribing which autistic people will continue to be chosen as capable of optimization via behaviour therapies, and which will not.

At the end of this excerpt, Leon discusses what another informant and I termed the “goldilocks paradigm” for receiving EIBI services<sup>34</sup>: kids are denied EIBI if they are considered “too autistic” or “not autistic enough,” their autism has to be *just right*. My fieldwork suggests that this goldilocks paradigm for receiving EIBI has created a ricochet effect, in that it modifies other forms of clinical knowledge and work practices. For example, Lorelai explained how ABA and EIBI centres have themselves reshaped the diagnostic criteria of autism by separating autism into a measurable continuum of “mild” to “severe.” While those diagnosed as not being “severely affected” will be eligible for ABA, those with ‘severe’ autism will be eligible for EIBI. This scale of “severity” is not part of the official autism diagnostic criteria found in the DSM-5, and as Lorelai explains,

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<sup>34</sup> I am referring to EIBI specifically here because many parents want their kids to receive EIBI because it is more intensive.

because these categories are highly interpretive and murky, they grant flexibility to each ABA and EIBI program to decide who is eligible to receive which service. Lorelai told me that she has no idea what “severe” autism means or how to objectively diagnose severity in the children that she sees, yet she will write “severe” on their diagnostic reports so that they have a higher chance of being considered eligible to receive EIBI. While I have read clinical articles that indicate that the EIBI centres in Ontario have specific formalized ways of calculating what constitutes “severe” autism (Flanagan, Perry, Freeman, 2012) it is telling that Lorelai is both cut off from the process of organizationally-based diagnostic assessment and compelled to reformulate her own medical practice to conform to these unofficial managerial renderings of autism diagnoses. In essence, behaviour therapy centers are socially redefining the medical diagnosis of autism: organizational diagnostic renderings “loop back” (*see* Hacking, 1995) to reconstitute formal medical diagnoses. Lorelai’s account brings to the surface how “new forms of description,” such as the mild to severe scale created by autism programs, make “new kinds of intentional action possible” (Martin, 2007, p. 230).

To add to this cycle of diagnostic modification and everyday actions, Rosa, a parent of two autistic children, explained to me how, through her network of other parents, she has figured out what criteria behaviour therapy programs (as well as other important autism services) look for when considering eligibility, and so she (and her parent friends) strategically describes her children’s autism characteristics to experts in a way that conforms to their criteria. In sum: behaviour therapy waitlists reshape eligibility criteria, which reshapes diagnostic categories, which reshapes diagnosticians’ practices, which reshapes how lay actors articulate their kids’ autism to clinical experts, which reshapes waitlists. Around and around we go. The coordinating capacity of the waitlist governs expert knowledge and therapy practices, but extends beyond this, affecting the activities of autism parents and other autism healthcare professionals.

### **Certification: Behaviour Analyst Certification Board**

In this section I demonstrate how the move toward certification, which is a step toward professionalization, is something happening within the field that providers have to take on and deal with. I examine how certification is a social process that creates particular



relational dynamics between behaviour therapists in the workplace; how the growing pressure to complete the Behaviour Analysis Certification Board (BACB) process is affecting the professionals I talked to; and how the presence of certification has already created a narrowed set of everyday behaviour therapy practices. Participants described BACB practices as fitting within an academic, evidence, and research-based framework, and as leading to increased standards within the field. What I demonstrate through interview data is that certification has created a split between providers about the importance of evidence, research and academics in applying behaviour therapies. It has also led to a wave of professionals who are being pushed out of the field for refusing to certify, and thus, refusing to conform their practice to one that is academically based.

### *Context and Background*

Applied Behaviour Analysis has already become a certified profession in the United States through the BACB, but despite the announcement on June 8<sup>th</sup> 2017 that ABA will be regulated in Canada, this has yet to come into fruition here. A degree in the applied behaviour sciences as well as the BACB qualifying exam are required to practice as a Board Certified Behaviour Analyst in the U.S. With the BACB, there are four different levels of certification, each with increasing levels of autonomy and responsibility. A “Registered Behaviour Therapist” is the lowest level of qualification, and these providers have the least amount of responsibility and education: they have a college degree and must be supervised by a board certified Behaviour Analyst. Only providers with a graduate degree in Behaviour Analysis can become board certified analysts, while those with an undergraduate degree can be certified as an Assistant Analyst (<https://bacb.com/bcaba/>). A board certified Behaviour Analyst-Doctorate” is the highest level of qualification, as these providers hold a doctoral degree in the behaviour sciences. BCBA-D’s can work as independent practitioners (<https://bacb.com/bcaba/>) and supervise Behaviour Analysts and Assistant analysts. Certified Analysts first start on a three-year cycle where they must complete research publications and thirty-six hours of certified continuing education activities such as approved university or BACB offered courses. After this three-year cycle, analysts can move to a two-year renewal/recertification cycle, where they must complete 32 hours of certified continuing education activities each cycle. Hence,

continued clinical production and academic learning are key parts of acquiring and maintaining certification.

In Canada, behaviour therapy providers do not need to be certified through the BACB to work as a behaviour therapist, but important changes within the field are currently underway. My informants explained that, in the past ten years, there has been a strong push for certification from both behaviour analysts and autism employers, to the extent that the U.S. BACB system is heavily influencing the workplace activities and hiring practices of public and private centres (and home-based therapy settings) in Canada. To give a sense of the growing influence of the BACB in Ontario: there are currently over 50,000 registrants, and 550 BACB or BACB-D's here (Marchese, Perry, Walton-Allen, Ward, & Zorzos, 2017). A growing number of Canadian post-secondary institutions are now accredited by the BACB so that students can become certified through this U.S. board.

Currently, it is technically voluntary for behaviour therapists to become certified, though as my informants indicated, many employers only hire BACB registered therapists. Many influential autism organizations like *Autism Speaks* also spread the word to parents that they should only hire BACB certified practitioners for private home-based therapy work (Autism Speaks, 2018). Further, some parents whose kids are on waitlists for centre-based EIBI services are given money from the government for direct funding to receive private ABA therapy in the interim, and parents must choose from the government directory list of certified therapists (Abacus, 2018; Ministry of Children and Youth Services, 2016). As more Canadian post-secondary institutions construct their programs to comply with BACB standards, the more prevalent and necessary certification has, and will continue to, become for those who practice behaviour therapy here.

That the BACB is becoming a requirement to work in the field, and that certification requires the continued completion of academic activities, means that the behaviour therapy provider is becoming an academic actor whose everyday practices are governed by clinical evidence-based research: this is distinct from pre-certification ways of practicing behaviour therapy in Canada. Thus, while certification creates specific qualification criteria to practice as a behaviour therapist, it also creates, as Timmermans

and Berg (2010) articulate, “a new world” of practices and people that reconstitute what Applied Behaviour Analysis is.

*Certification, Standards, and Exclusion: “A more clinical space”*

Rutherford (2009) explains how the endeavor for behaviour analysis to become a certified field in the U.S. derived from wanting to separate legitimate providers from the illegitimate ones, after behaviour modification programs in prisons and asylums in the 1960-70s were charged (by the ACLU and other important academic and public stakeholders) as being unethical and inhumane. My fieldwork indicates that current proponents of certification often express a similar desire for certification to weed out imposters, or the so-called “old school” ABAers, from those who carry out “best practice.” A participant I interviewed called Ronnie, a behaviour science researcher who is heavily involved in efforts to regulate, described the importance of certification as deriving from many factors, the first being that anyone with any kind of training can currently call themselves a behaviour therapy expert and can charge hundreds of dollars an hour to work in the private sector.<sup>35</sup> Ronnie thus views regulation as creating a “minimum standard in the field,” and further explains that behaviour analysts have been in conversation with the Ministry of Children and Youth Services for about ten years to regulate the profession. Ronnie thinks that regulating will not only be vital to the advancement of the profession as it would enable behaviour analysts to work with different populations and across different healthcare fields, but it would establish clear ethical standards for ABA practice.<sup>36</sup>

In contrast to professionalization raising the yardstick of ethical and professional accountability, Bobby views the BACB as merging the corporate expansion of behavior

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<sup>35</sup> Bobby acknowledges this occurrence too, telling of horror stories of parents spending their life savings to hire people who claim to be behaviour specialists, but who do not have adequate training.

<sup>36</sup> To echo Ronnie’s arguments about the ethical importance of certification, a few other behaviour therapists, such as Lane and Natalie (who I interviewed separately, but who are co-workers), identified certification as important principally for introducing ethical safeguards and professional accountability for those working with autistic people. With the BACB, the topic of ethics composes a significant portion of a behaviour analysts’ training, and there are ethical review boards in place to discuss the use of particular intervention techniques, especially when punishment or aversives are being considered. Lane and Natalie also think certification would promote “best practice,” which they defined as the use of ABA methods to gently support autistic people to learn to emotionally regulate, build important skills, and to communicate their needs. These two participants further vied for ABA interventions to be created with the input and consent of autistic people and their caregivers whenever possible. Lane and Natalie also thought certification would have the beneficial affect of excluding the “radical” ABA providers who haunt their field.

therapies with a new research-based focus to frontline work. Bobby spoke at length about how the new “clinical space” of professionalization impacts the everyday work his colleagues complete, and explained how important it now is for therapists to contribute to academic research if they want to be successful in the field:

Bobby: ... I am very different in a lot of ways from my...professional colleagues in the sense that I don't have a psychology background, most of the people I work with do.

Julia: Has that changed since you began working?

Bobby: Ummm, yes! I feel like I got into the field when there was more opportunity for people like myself and the, you know, support worker role, and then [ABA] moved into this more clinical space. Now, it's just become so regulated, and it's become soooooo..... rigid, that if I were to apply... if *I, myself* were to apply for a job in this field right now, I wouldn't get it. Like it's drastically changed in the ten years that I've been here...Are you familiar with Board Certified Behavioural Analysts?

Julia: Yeah

Bobby: So that is really in the last five years taken precedence over anything. If you are going through your BACB, you are... set. That's good because you're being board certified. You have proved that you can use evidence-based research in a clinical setting and modify people's behaviours. But what is really interesting that's starting to happen is that there is this notion that BACB is starting to sell out. They are all of a sudden putting a lot of financial importance in staying accredited which wasn't the case before. So now you are starting to pay upwards of \$1,300.00 a year to maintain your BACB certification.<sup>37</sup> You're also having to do more courses constantly, so you're constantly having to spend more money on these courses that keep you legitimized and seen as a position of power within the clinical field. So even supervisors that I knew like five, ten years ago, are now having to spend a lot of money to keep themselves accredited to be a part of the BACB... Board certification has become such an integral part of the system and only supervisors that are accredited... can apply for a supervisory position... I don't want my BACB, I'm not interested in doing that. So that's kind of put me in a bit of a limitation in my career because I can no longer move up...Like I'd love to be able to be a supervisor in a program. I have ten years of experience. But I don't want the BACB that's required now. So unfortunately I don't have a choice. I'm kind of stuck. So, I'm actually currently in the middle of looking for other jobs outside the autism field.

Here Bobby first explains that the population of behaviour therapists have dramatically shifted within the field: when he started ten years ago, there were more people like him, “support worker-types,” and now the field is mostly populated with people with a clinical psychology background. Bobby describes the BACB as a recently established obligatory point of passage for working in the ABA field, so much so that regardless of a therapist's

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<sup>37</sup> The BACB requires its members to pay \$100.00-\$135 for annual certification (BCBA-D's pay the highest price in this range).

training or experience, only certified therapists are eligible to apply for important positions like clinical supervisor. Bobby views the BACB as not just requiring members to have specific academic research credentials, but as constituting a business unto itself requiring monetary contributions in exchange for professional legitimacy. Bobby points to the pressure to certify as a pivotal moment of transformation within his field, where practices and providers are being reshaped and reconstituted as academic actors. He does not like how ABA providers are governed by the evidence-based research focus of the BACB and would rather leave the field than comply. Because he refuses certification, Bobby feels he has “no choice,” but to leave the field. Margot (analyzed in Chapter One) echoes Bobby’s sentiments about the BACB with the following excerpt:

Julia: Are you at all connect to the BACB?

Margot: No.

Julia: Do you see that as influencing your work in any way?

Margot: I could never do it. Like everybody wanted me to be board certified and I just thought: ‘I’m not spending more of my time looking at math equations, looking at... doing something that I don’t believe in. So I never say ‘I’m a behavioural analyst.’ I’ll say ‘I use behavioural methodology in an early intervention sort of style.’

What Bobby and Margot’s sentiments indicate is that certification has fundamentally reconstituted what it means to practice behaviour therapy and has resulted in a turn-over of providers. Bobby and Margot refuse acquiring their BACB because they view it as devaluing “people like” them, and remaking ABA into a quantitative academic enterprise they do not relate to.

### *The old and the new behaviour therapist: Nature/Art versus Academic/Science*

In the following subsection I draw on interviews with Bobby, Georgia and Lydia to demonstrate how certification has edged out a more creative, intuitive and person-centered way of practicing behaviour therapy and replaced it with an evidence and research-based way of practicing. I show how the BACB has shaped providers sense of, not only what can be done (what activities providers should complete), but what can be said, and felt, about the work they do. I emphasize how behaviour therapy has come to be governed by academic ways of practicing that have made expressing intuitive and artistic understandings of behaviour therapy a taboo.

Bobby's story about his first job interview in the behaviour analysis field, back in 2005, provides an important entry point for understanding how everyday behaviour therapy practices have transformed through the growing movement to certify. A senior therapist interviewed Bobby for his first IBI job, asking him to "grab a bucket of crayons" and "make it into a fun toy." Bobby took the crayons and just tried to be "creative" and "silly with it." The therapist told Bobby he got the job, saying: "I know that you don't have a lot of experience and I know that you don't know what IBI or ABA is, but I liked how you were creative in the sense that you took a bunch of crayons and you turned it into five different teaching situations." Bobby understands now that the senior therapist considered the test as a way to see whether Bobby *innately* had a "lot of ideas about how to modify the environment" and that he was competent in using the "environment to teach a skill." The ability to take something a child likes and find multiple different ways to teach her to engage with it to learn new skills is the core of how Bobby orients to ABA. Even though after he was hired he received clinical training by senior therapists, Bobby still thinks the root of his "effective teaching" stems from having the type of skills he naturally had in his first interview with the crayons.

A key moment in Bobby's interview occurred when the senior therapist referred to how he was aware that Bobby did not have ABA experience or know what ABA is, but wanted to hire him anyway. This statement is crucial because it illustrates how much has changed in just over a decade. It would be ludicrous for someone applying to work as a therapist now not to know what ABA is. But in 2005, ABA was not a well-known therapy for autistic people in Ontario, and to find people to practice ABA, clinicians had to *make* behaviour analysts out of those working in the disability service sector.<sup>38</sup> Another important aspect of Bobby's interview is how both Bobby and the senior therapist tacitly defined the behaviour therapist as having *an innate* behaviour analytic approach to working with autistic people. Rather than constituting the foundation for becoming a behaviour therapist, clinical training was used to *build upon* the creative skills that Bobby already had. Bobby was not appraised as needing an academic degree in behaviour analysis to apply it. What he needed was the raw skills to modify the environment.

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<sup>38</sup> This is another example of the generosity of behaviour therapies.

My interview with Lydia demonstrates how certification has led to different forms of standardization, not only in terms of the practices therapists can currently engage in, but of therapists' thoughts and feelings about their work.<sup>39</sup> Similar to Bobby, Lydia views creative and intuitive skills as central to her work, yet when speaking to me it was clear that she felt she needed to conceal this perspective. There were a few times over the course of the interview where Lydia referenced her "gut" or "instincts" when on the job, but she always referred to these felt experiences as something to be ashamed of and to hide. To analyze further, consider this excerpt from the end of our interview when I asked Lydia why she thought it was shameful to use her instincts in her practice:

Lydia: Well, because it gets [sigh]... I debate this with my friends a lot. For me, teaching and working with kids with special needs or whatever, has always been much more of an art form... I get the point that you need to have the technical training aspect, but... you either have it or not. I can go to, say, a hairstyling school, and I can get the exact same training as the person beside me but I am not that person that can envision hair... Like for me, it's actually very much an art form. Why is it shameful? Because people are fighting in society to have this proven: 'This is a science, this is scientific best practice.' So it's takes away from the validity of it being a science and best practice, when I say 'I just get it,' or 'I just know...' A lot of people still fight over wanting to maintain the integrity of the ABA piece, or the practice around it... I can provide the training to people and some people will be amazing at it and some will just be good. Just like teachers will be good because you know they've learned 'This is how we do assessments'... whereas great teachers are the ones that have a different level of understanding - and to me that's more of an artistic aspect to working. So shameful in that I'm probably upsetting a lot of people when I say: 'Oh I just know'... I can take all the data and say: 'Yeah, I was right'... For other people it doesn't come nearly as *naturally*... Like I'm very, very observant so I can pick up on these things quickly, whereas other people don't notice... So sometimes it takes a little bit longer to get data for those people where it's not very, very instinctual, but data is that grounding piece.

Julia: That's interesting...It's not the first time I've talked to somebody providing behavioural therapy who's framed their personal, or sort of 'felt' convictions around their work, in a way that they... describe as shameful... And I'm wondering whether...one of the pitfalls of the emphasis on science is creating a sort of underground where people don't feel comfortable—

Lydia: It's sad that you're not allowed to—like I do it with my friends... What do I use data for? I use it to prove my point. 'Cause when I say to people: 'I just know,' I'm not taken seriously even though

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<sup>39</sup> My analysis of regulation and certification here can be linked back to Chapter One, where I included Rankin and Campbell's (2006) important analysis of the effect of standard protocols on shaping the consciousness of healthcare providers.

I *do* just know... to convince people of an argument, that's how I use data. But for people who are just getting started or for people where it's not just a natural thing... I've seen it be very good for changing people's perceptions about how they feel about a child... If I want people to hire me... I have to be able to show: 'Look what I did here and look what I did there...'

In this excerpt Lydia describes how she *actually* makes clinical judgements: through being closely attuned to her surroundings and being “very, very observant.” She does not need data to learn to “pick up on things correctly.” She describes having an innate aptitude for behaviour therapy work, similar to how the best teachers or hairstylists have a natural ability for their art form. Lydia further explains how data is important first for legitimizing *to others* that her innate knowledge is correct; and second, for teaching those who do not have a knack for applying behaviour therapy to become competent providers. Importantly, Lydia deems the best providers as those with a natural instinct for ABA work: those who do not have a natural instinct can become “good” providers, but not “amazing.” Also, in this excerpt, Lydia describes how the push to establish ABA as a “science,” has resulted in the standpoint, within the field, that disinterested data-based activities lead to “scientific best practice.”<sup>40</sup> This is why Lydia views her perception of ABA as an “art form” as a betrayal to her profession. If Lydia were to openly acknowledge the role of instinct in doing her work she would be invalidating “the fight” for scientific legitimization.

Notice how Lydia brings up speaking with her colleague “friends” about the art versus science “debate” about ABA. The role of friendship is significant: Lydia is careful not to circulate these ideas around public professional spaces. Like Bobby with his job interview that was focused on the crayons, versus his description of his current work, Lydia describes the transition of behaviour therapy from an art to a science but views herself as belonging to the wrong side, and so she needs to bury her views.

The last example I will use to discuss how certification is a powerful discourse that shapes providers sense of what can be done, said, and felt, is my interview with Georgia. Georgia is a behaviour therapist trained through a college program. She currently works at an EIBI centre. On three separate occasions in our interview, Georgia qualified what she was about to say as not being “scientific” but as coming from her “gut feeling.” I had a

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<sup>40</sup> STS scholarship on science and scientific practice examines the role of art, creativity, intuition, affect and embodiment in the production of scientific evidence (Landecker, 2011; Myers, 2015; Myers & Dumit, 2011). What is interesting about my interviews is that participants described a culture in which it is not permissible for practitioners to hold science, fact, art, and intuition as occurring together.



palpable sense that she was fearful of speaking candidly about her professional experiences in a way that might deviate from how she thought ABA was *supposed to be* discussed, as if there was some master narrative she felt obliged to rehearse and felt guilty about straying from. Like Lydia, I followed up with Georgia at the end of our interview to tell me more about her “gut feelings” and why she felt it important to articulate certain statements as coming from a personal place:

Julia: ...You’ve mentioned a couple times... ‘this isn’t scientific, this is a feeling, this is my own [opinion]’... What’s your relationship to the scientific aspect of ABA and IBI? Because there seems to be—correct me if I’m wrong—but there seems to be an increasing focus on ‘evidence’ and ‘the research.’ the scientific and the clinical aspect of these therapies, with the creation of the BACB and all of these sort of regulating certification boards. And it seems to me that—

Georgia: I know, I have been indoctrinated.

Julia: No, no, no. I was going to say that maybe you’ve sort of... you were almost... separating yourself from that a little bit? In saying, this isn’t scientific, this isn’t---

Georgia: Yesssss. Yeah, yeah. And maybe I feel like I’m not... providing like, I’m not speaking on behalf of behaviourists. Or I wonder if people... would argue with me ... This is why I think your study is so interesting, is because ABA is very... we’re a convincing body of people, right? Because... we can be like: ‘Here you go.’ But you run into a lot of controversy because people feel it’s weird... But because there’s no evidence, there’s no graph, being like: ‘Look see, look here you go, this is weird!’ you don’t have an argument. And... that’s really challenging. That’s a really difficult thing... And I’m thinking of a client right now in particular ... where they were doing like a behavioural reduction program with him... He engages in stereotypy, and you’re like: ‘Do this, do this, do this’ [hand gesturing]. Then that usually interrupts it [the stereotypy] and reduces it and that has diminished that behaviour. But it’s in a very structured setting. And now... anecdotally... the stereotypy [is happening] in other environments where it wasn’t really happening before... And that won’t get published... *I don’t know, its just, you know, you wonder if...* you’ll probably see a nice graph where, you know, this gets reduced but you’ve also had a child sitting at a desk for the majority of the day... You’re just left with this sort of like: ‘Is this okay?’... And again you’re going to have the ABAers be like: ‘Well just check this out, this is great’ and you’re like: ‘Are you really capturing the quality of this person’s life?’

“Gut feeling” is a phrase that Georgia used to ensure that I would not consider her views as representative of “behaviourists.” A very meaningful part of this interview excerpt is towards the end, when Georgia says: “I don’t know, it’s just, you know, you wonder if...” I view this cluster of fragmented almost-statements—this pacing back-and-forth between disavowal, critique and depersonalization—as Georgia dipping her toe in and out of what

she feels can and cannot be said. Georgia wonders if what she sees in her work is both ethically and clinically “okay,” but importantly, she does not, perhaps cannot, wonder this in the first person (“You wonder if”; “You’re just left with this sort of feeling”; “Are you really capturing the quality of a person’s life?”). That Georgia clumps “behaviourists” together as a univocal group that collectively endorses and denounces certain ABA accounts, is telling of the professional milieu in which she works. Further telling, Georgia went directly from answering a question about her gut feelings to “wondering” if other people in her field would disagree with the views and experiences she was sharing with me. Through fieldwork I have observed how important it is to many of my informants that they manage their representations of ABA, to the extent that expresses a culture of fear, *even between dedicated providers*, around critiquing certain aspects of their discipline. I consider this culture as linked to the quest for certification, which is the quest for pedagogical and philosophical unity, where, to use Lydia’s words, those that deviate from representing ABA as “scientific best practice” are hurting what so many people “in society” are “fighting for.”

Interestingly, after using “gut feeling” as a way to share her thoughts and everyday experiences, Georgia went on to show how the data, evidence and graphs produced from her everyday work misrepresent what she “anecdotally” witnesses, but that they nevertheless exist as powerful representational tools for silencing those who think ABA is “weird.” Georgia describes how data creates a frame for reducing reality, where anecdotal observation is “sentenced to nonexistence” (Foucault, 1978, p. 4) and where quantitative data is used not only to represent reality but to construct an environment of “Truth” that tells others that there is “nothing else to see, nothing else to know” (Foucault, 1978, p. 4). The story Georgia tells about the Stereotypy intervention is a story about the representational power of funny numbers, funny graphs, funny publications. Georgia is concerned with what the graphs miss, and how the graphs are intentionally framed to capture specific results, but not the “quality of a person’s life.” I read this segment of the interview as Georgia existentially questioning some of the ABA activities that occur at her workplace while considering her own incapacity to speak truth to graphs. Georgia grapples with whether the graphs and her day-to-day front-line academic activities are ethically

“okay,” but she only feels safe grappling with this quietly, and compartmentalizing her concerns as personal feelings, rather than professional assessments.

### *Research and Practice*

In this section I include excerpts from Bobby and Georgia, where they describe how certification had led to a split in their workplaces between those who prioritize “floor-time” (one-on-one work) and those who prioritize academic research. These excerpts also show how certification has resulted in a variety of activities, such as career development and research production, that reshape one-on-one behaviour therapy work and create a chasm between the new wave of academic certified providers and the older wave of non-academic uncertified providers. To explain a bit more about this topic I turn again to Bobby:

One of the things... I've seen more and more now, is you have more and more people who are textbook knowledgeable about IBI and ABA and autism. So they can list off to you the seven different criteria it takes to get an autism diagnosis. And they can list off to you all these different therapy sessions. Or they can list off to you all these definitions of terms. But when you actually put them in front of a child and say: 'teach them how to pick up that pencil appropriately,' they're kind of like: 'Errrrrrrrrr...so I know that I have to use a reinforcement system and I have to prompt, but I...' There's this complete lack of creativity that allows them to understand and think about different ways that they can get that child to pick up that pencil.

There is a difference for me between teaching and effective teaching. And a lot of times what I saw is people teaching for the sake of getting their data. They need to run ten trials for a program. Or they need to be able to get data that says: 'I ran this program ten different times... so I'm just going to run it without any thought about what this child is doing. The important thing is that I did something, the child responded in some way and I get to mark whether it's right or wrong.'

I tend to come from: 'I don't care if there are ten trials done, I need to let this child know that there's an important skill I'm trying to teach them, and it might take a bit of time...' And so I'm going to use a variety of different ways... I want to get the child interested in doing an activity that requires them to pick up the pencil - that's a better way to teach, then me just saying: 'Pick up the pencil,' and then fully prompting their hand-over-their-hand to pick up the pencil...

A lot of times...the teaching would be this rapid succession of instructions but it had no context to what the child was actually going to use this skill for. So pick up a pencil ten times in a row said to the child in a two-minute period, and you get three-out-of-ten and it's like: 'Wow, that's great three-out-of-ten, they were able to pick up the pencil on their own.' But... it's not because the child wants to pick up the pencil, but because they fall into a routine... They're just doing the teaching of: 'I've

gotta get this done, I've gotta run ten trials, my supervisor says I run the program,' but the child's skill acquisition is really the most important thing, and that gets forgotten.'

Here Bobby provides a picture of what happens when providers with clinical “textbook knowledge” conduct everyday one-on-one work. These textbook providers come from a clinical background, where “getting the data” and “running programs” organize their activities. Bobby’s example of the difference between his way of teaching how to pick up a pencil versus how the textbook provider would do so, is a description of two completely different renderings of behaviour therapy practice. To pick up a pencil, Bobby works to teach the importance of using a pencil, which requires “a bit of time” to try a number of different strategies to get his kid “engaged.” Bobby doesn’t even worry about finishing ten trials so long as his kid learns the importance of the task. In contrast, Bobby considers the textbook strain of therapists as not having the frontline skills or the motivation to teach “effectively.” They have little experience working with recipients and orient to one-on-one work as a way to get data for clinical research. As a result, they speed up their work, delivering a “rapid succession of instructions” while using hands-on prompting techniques to ensure the child picks up a pencil “ten times in a row... in a two-minute period.” Bobby explains that they work with a child to get a program “done,” and are principally concerned with “marking” their activities down. Bobby views the expectation to turn one-on-one work into research as another layer that impedes the therapist’s ability to prioritize effectively teaching the autistic person they are working with. In sum, Bobby describes a recent flip in one-on-one work caused by certification, where the therapeutic recipient is a means of getting the data, rather than data being a way to understand the person.

As a stark example of how being data-focused has influenced everyday behaviour therapy work, at another point of the interview, Bobby described how some of his textbook colleagues would actively create intervention programs because they made good research projects. These colleagues would create programs by pushing a child to the point of a behaviour outburst in order to justify creating a program that would involve using specific clinical methods that the therapist wanted to try out to present or publish. For Bobby these experimental programs were linked to the proliferation of large ABA conferences, in which behaviour therapists are compelled to share data from their “floor”

work to advance within the field, or to reach their certified education curriculum hours for their BACB accreditation.

The split between the data-focused and teaching-focused behaviour therapist does not only influence frontline work, but work culture. Georgia described that there are power struggles between the new wave of university-level academically trained behaviour therapists, and the older wave of college or community trained therapists. Georgia further described the fraught relationship between these two groups as having to share a workplace while being trained in “very different ways,” with both sides thinking the other “doesn’t know anything.” Yet Georgia considers the fragmentation between those with practical versus academic experience as hierarchical: the academic group imposes their “way” onto those with, often extensive, practical experience—despite lacking experience with one-on-one work.

Georgia further describes the academic group as “controlling,” not just to people like her, but to their autistic “primaries” (their one-on-one subjects) they work with. Georgia gets the sense that these providers demonstrate a sense of ownership over “their kid,” as their clinical test subject. She further shared her concern that “textbook” Board Certified therapists who know a lot about research but do not have the experience or comfort level to “help” her with her day-to-day work, are now supervising her.

Like Bobby, Georgia explained that more people are coming into the field who are academically trained and consider floor-time as a stepping stone to move “up and away” to a supervisory or clinical research role. Both Bobby and Georgia’s accounts point to the reality that the process of certification has already led to less people like them being qualified to work in the field. It has created a new workforce of academic providers, many of whom have research-based goals and operate from a place of research and evidence. It has meant the beginning of the end of therapy providers who refuse to certify, like Margot who already stopped providing, and like Bobby and Georgia, who both, after our interview, decided to leave the field.

### **Institutional Behaviour Management**

In mainstream autism discourse, the importance of applied behaviour therapies is described primarily in relation to children, through a politic of hope and futurity. The

discourse of “early intervention” stresses the increased efficacy of behaviour therapies when applied intensively to very young children. As a prominent clinical psychologist, stated in her presentation at the Canadian Autism Spectrum Disorder Alliance (CASDA) Summit in 2015, when applied very young, EIBI has the potential to “catch” autistic children “up to their peers.” The science of neuroplasticity informs the discourse of early intervention, as proponents tend to view young children’s brains as most susceptible to rewiring and, thus, consider this time as the most effective period to receive behaviour therapy (Gordon, 2012, 2012; Lovaas, 1987; Mulligan, 2017). The metaphor of an “early intervention window” is often used in mainstream autism discourse, to refer to the optimal age period (often between 18 months and 6 years) to receive intensive behaviour therapies.

Behaviour therapy is often described as the best chance an autistic child has to learn to speak and communicate, to be educated in mainstream classrooms, and even to play sports, have friends, and one day fall in love. To encapsulate this orientation to behaviour therapy, when giving the commencing speech at CASDA (2015), Senator Jim Munson pronounced intensive behaviour therapy as “a stepping stone” for an autistic person to “take his place in our society.” He went on to describe the individual case of a boy named Tahir, and the difference in Tahir’s capacity levels before and after therapy: “this was not the same little boy that came in a few years ago. We owe it to Tahir to build that bridge so that Tahir can be loved, not just as an autistic person, but as a person” (CASDA, 2015). At both CASDA (2015) and another conference called *Autism In Motion* (2015), I heard early intervention behaviour therapy being compared to chemotherapy, a comparison that tacitly equates autism with cancer. In this context, intensive behaviour therapy is literally contextualized as life giving, and principally, soteriological in nature, for autistic children.

But what happens when autistic people have grown up into adults, have missed their so-called early intervention “window,” and have not reached the normative milestones that are often articulated as the purpose of behaviour therapy work? What is the reason for applying behaviour therapies when these adults live ‘in the system,’ in segregated institutions, such as psychiatric units and group homes, while they spend their days in institutional day-programs? I contend that when applied to adults, behaviour therapies cannot ride on the economy of hope, but rather on the goals of the asylum:

vocational training, life skills, and behaviour management. In short, when the hope for a normative bright future has supposedly come and gone, the application of behaviour therapy is quite different. The purpose of this last section is to demonstrate how, when behaviour therapy is applied to adults living in institutional spaces, a distinct set of behaviour therapy activities emerge. These practices are often not person-centered but centered on maintaining the flows and functioning of the institutions in which these autistic adults reside.

In this section I examine how behaviour therapy is used with adult populations in institutional settings to show how providers can be compelled to shape their therapeutic activities to conform to the managerial aims and priorities of the institutions that these adults live within. I further demonstrate how, when applied in institutional settings like group homes, behaviour therapies can be used as a managerial technique for concealing or rectifying individual suffering caused by managerial decisions which prioritize the financial and organizational functioning of the agency over the wellbeing of autistic residents and front-line staff. The use of applied behaviour analysis, as a form of institutional management, reflects the historical uses of this form of therapy as vital for *both* improving the human condition, and the functioning of the institution.

*Context: Applied Behaviour Therapy and the Asylum*

Applied behaviour analysis has been applied in a variety of different settings—in the classroom, prison, home, asylum, group home, hospital, and workplace—where it serves different purposes including improving the functioning of prisons, asylums and other institutions as well as rehabilitating or improving the functioning of individuals in order that they might leave institutional environments. ABA has been used to both modify the individual in order to help the institution to function better, and to modify the institutional environment to help the individual function better. Lovaas considered behaviour analysis as valuable principally because it could enable autistic people to leave the institution and integrate into mainstream society (Smith & Eikeseth, 2011). My empirical work indicates that, while governmental bodies, mainstream autism organizations, and clinicians view applied behaviour therapies as important for optimizing the lives of young autistic people,

these therapies are also still commonly applied as managerial techniques for managing and disciplining adult institutionalized disabled bodies.

In her historical critical work on B.F. Skinner, Alexandra Rutherford (2009) explains how applied behaviour analysis has been used within a variety of institutional spaces in order for the behaviour of the individual to be modified in such a way as to help the institution run more smoothly. To this end, Rutherford (2009) discusses the work of Theodoro Allyon who, as a doctoral student in rehabilitative psychology at the University of Houston in the late 1950s, traveled to Wayburn, Saskatchewan for a three-month stint at an asylum called the Saskatchewan Hospital. Allyon's work at the asylum was to create behavioural change in the patients by developing a token economy system for the staff to apply to them. What Allyon did first was enlist the help of those most involved with the patients: the psychiatric nurses. He asked the nurses, to tell him which patient behaviours were "most disruptive in the day-to-day running of the ward" and which behaviours compromised the "safety of the patients and the workers" (2009, p.67). These behaviours were the targets for the token economy system and Allyon taught the nurses, who he enrolled to be behaviour engineers, how to apply a "variety of operant procedures to rearrange...contingencies, reduce the frequency of undesirable behaviours and, in some cases, increase desirable behaviours" (Rutherford, 2009, p.67).

In his later work, Allyon applied a token economy to enroll patients to actively help the asylum function better by completing various duties such as laundry, cooking, serving meals, providing secretarial assistance, clerical work, running errands, and more (Rutherford, 2009, p. 70). Tokens brought patients privacy, outings, the opportunity to attend religious services, "recreational opportunities," and the ability to buy "commissary items." The premise of this token economy program was to take away the basic amenities that patients formerly had access to and to make them earn them by performing the correct behaviour modification activities, which often involved completing unpaid work for the institution.

In 1971, doctoral student Douglas Bilken observed a token economy program at a state hospital psychiatric ward. He stated: "the token economy appeared to reinforce 'institutional' patient behaviours, that is, those that made the functioning of the ward and the institution easier" (Rutherford, 2009, p.76). Bilken further observed that these



programs often resulted in infantilizing patients, treating them like children and thus “reinforcing an old institutional theme” (Rutherford, 2009, p.76). In the U.S. in 1972 it was ruled in the *Wyatt vs Stickney* case that institutionalized psychiatric patients have the right to “basic amenities,” “personal property,” and that “involuntary patient labour” was not allowed, even if considered part of a therapeutic program (Rutherford, 2009, p.75). This ruling put a lid on most token economy programs in institutional spaces in the U.S., though some programs continue on (Rutherford, 2009), adhering—at least on the surface—to this ruling.

The history of the application of behaviour therapies within the asylum that Rutherford recounts is important to consider when thinking about the way applied behavior therapies are used within the current group home and day-program system in Ontario. What I have observed in my fieldwork is that behavior therapies can still be used to strip residents of their basic rights and amenities, but not primarily through enforcing a token economy system, but through enforcing behaviour therapy more generally, and the Behaviour Intervention/Support Plan, specifically.<sup>41</sup> My fieldwork experiences align with Bilken’s observations. They indicate that the BIP can be used in a group home setting to reinforce institutional patient behaviours that make the functioning of the group home easier, thus reviving old institutional themes of control and infantilization. Instead of nurses being the behaviour engineers, it is most often front-line individual support workers who are tasked with carrying out ABA practices. These frontline workers are compelled to act as “prosthetic extensions” (Brodwin, 2010) of managerial power in their everyday work with autistic and developmentally disabled residents. To continue to analyze this topic, I turn to a discussion of my ethnographic findings, beginning with Sam and Louisa.

#### *Sam and Louisa: Behaviour Intervention Plans and System-Based Therapy*

The following interview analysis is used to demonstrate how providers working with adult populations in institutional settings are pressured to provide certain kinds of behaviour therapy practices that comply with managerial procedures and institutional objectives. My

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<sup>41</sup> My research indicates that a Behaviour Support Plan is interchangeable with a Behaviour Intervention Plan except for Intervention Plans are supposed to include a formal Functional Behaviour Assessment whereas this is not required with Support Plan’s, which can be created far more informally, with far less clinical observation and calculation procedures.

interview with Sam and Louisa, two social workers who spend a considerable portion of their everyday work pushing back against Behaviour Support Plans provided to autistic people living in group home settings, described how behaviour therapies are used in these spaces as a form of institutional behaviour management. Like Hailey's sense that autism care is "management-based," Sam and Louisa frame ABA as "systems-based:" a term that articulates their sense that autism services are geared to making autistic people's lives fit within a bureaucratic and technocratic healthcare system.

The agency Sam and Louisa work for, which I will call *Connections*, is a community-oriented social justice-based service that focuses on creating sustained, mutual relationships between disabled and nondisabled community members to create a more socially inclusive society and to decrease isolation and loneliness. There are no intake procedures or clinical documents required to join this service, and no quantified outcome data is generated regarding the effectiveness of these relationships. *Connections* was spawned during the deinstitutionalization movement and Sam explained that there were many branches when it was first established. But fast forward thirty years, and now there are only two.

Sam has worked at *Connections* for thirty years and spoke to me about how transformative relationships between disabled and nondisabled community members can be. Some aspects of this transformation are tangible, such as decreased visits to the emergency room or increased employment and social engagement, whereas others, such as happiness, kinship, and self-esteem, exist within the realm of meaning. Sam refuses to engage with quantifying the benefits of his service, a choice he pays for with a lack of government funding. *Connections* is a small organization that only has a few paid employees. It is situated in a cramped office space in a strip-mall-like fifties-style bungalow building shared with other businesses. The space itself communicated how underfunded this relationship-based approach to autism care currently is. Still, I thought it important to ask Sam and Louisa whether they think cultivating supportive relationships for autistic people is viewed by the government as an valuable thing to invest in: Louise briskly replied: "No!" while Sam just laughed at the absurdity of my question.

Louisa explicitly articulated the application of behaviour therapy as "nonsense" when describing how it is used to manage autistic people so that they contribute to the

functioning of the organization: “it was all about the needs of the organization offering the therapy, which is again bureaucratic nonsense... Like so IBI and ABA don’t become person-directed... it becomes about the program.” To expand on what she meant by this, both she and Sam told me multiple stories relating to ABA practices in the group home setting. In these stories they described the Behaviour Support Plan (BSP) as a powerful strategy to ensure an autistic person’s behaviour conforms to specific managerial institutional outcomes: as a way to enforce “institutional patient behaviours” (Bilken in Rutherford, 2009, p. 76). In one case, a participant at a day program who is Deaf lost her staff member who communicated through ASL. The staff member was not replaced by anyone who could sign and so the participant started engaging in “challenging behaviours” like head banging. Louisa recounted that the staff at the day program created a BSP to reduce the participant’s head banging behaviour, without addressing client’s loss of a communication system. After eight months, the staff at the organization reviewed the behaviour of the participant and decided that she did not “meet the expectations of the Behavioural Plan” and so was discharged from the program. Sam and Louisa viewed the BSP in this instance as a textual technology for redirecting an institutional problem by making it into an individual behaviour problem. While the BSP is a clinical document, it is used to legitimize managerial decisions aimed at ensuring the institution runs smoothly.

Sam and Louisa also told a few stories where group home residents were angry about certain aspects of their living situation and wanted more autonomy and freedom, but instead of staff opening up a dialogue with them, a BSP was created to reduce their “problem behaviours.” In three instances, Sam and Louisa described how relationships were used as part of the reinforcement systems in the BSP, meaning that if the resident had a “challenging behaviour” they would be denied upcoming visits with their friends or family, so as not to positively reinforce problem behaviours. This scenario is actually something I am quite familiar with. I have been the family member who has been told to cancel my visit with my autistic kin living in a group home because she had a “behaviour outburst.” Withholding social events was the protocol written in her BSP. I even remember one Easter where my kin was not allowed to attend our family celebration because of her “problem behaviour.”<sup>42</sup>

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<sup>42</sup> These situations happened about six years ago.

It is important to further analyze how behaviour therapies are used with adult populations in institutional settings as a managerial tool for resolving institutional mistakes. Sam and Louisa explained that a large part of their job is helping their participants transition from one environment to another, such as a group home to a supportive living environment. What they found is that when a “transition was not well thought out” or when their recommendations “were not implemented, there would be behaviours and then it was all of a sudden ‘we need a behaviour therapist.’” Instead of examining “how we could have avoided all of that,” Sam and Louisa describe how harmful management decisions are rectified through “labelling things as behaviour” in order to ensure the resident does not disrupt the flow of the institution.

*Wyatt: Resident Transfers at Oak Ridges*

To demonstrate how behaviour therapy and the BSP can be used to remedy managerial missteps and the maltreatment of adult populations in institutional spaces, I offer this extended account from my informant “Wyatt.” Wyatt is the family member of a group home resident living in a small rural community, but he asked that I do not connect him to any of the residents he describes in his story (for fear of management finding out he has spoken up and firing his kin’s support worker, or transferring his kin to another group home location). The story Wyatt told me began with a resident called Debbie. Debbie was living in a group home called “Oak Ridges,” which is run by an agency I will call *Unison*. She was transferred to a different *Unison* group home, in order for a new resident named “Charlie” to move in to Oak Ridges. Debbie had been in the group home system since she was a young child, and the front-line staff at Oak Ridges cared for her deeply; they were upset when they heard news of her transfer, as they were her closest thing to family. While Debbie was nonverbal, she was not assessed as requiring one-on-one support. As another support worker informed Wyatt, government funding is often the reason her agency transfers residents in and out of different group home locations, as more money comes from residents who need higher levels of support. As the support staff worker explained to Wyatt: residents who need one-on-one or two-on-one support pay for broken appliances and home renovations. Charlie had been assessed as requiring one-on-one support, which

is why Wyatt thinks he was transferred into Oak Ridges, and why Debbie was transferred out.

As Lane and Natalie, two behaviour therapists working in an in-patient/outpatient unit informed me, transitions into group homes are supposed to take months to complete, as it takes time and multiple visits for people to get acquainted with their new living environment. With Charlie, this was not the case. He was taken to Oak Ridges one afternoon to live there permanently. Because the move was so abrupt, he did not adjust well. He screamed continuously, shattered mirrors, punched holes into walls, chased staff who had to run out of the house, and he broke one staff member's foot by slamming a door on it when she went to block him from charging at a female resident. Wyatt told me about how this female resident was re-traumatized by Charlie's move, as an overnight support worker at Oak Ridges had recently sexually assaulted her and Charlie seemed like another scary man living in her home. This woman's family members fought *Unison* management to move Charlie to a different home. In addition to this, another resident had lived with Charlie in a previous group home when they were both teenagers and had been repetitively physically hurt by him there, and so was terrified at the prospect of living with him again. This person's family members also fought management to place Charlie in a different home. In fact, Wyatt described how both families took their kin out of the home for a period of time because of how scary the environment was.

Wyatt portrayed how frightened the staff and other residents seemed at the time of Charlie's move. As many of the Oak Ridges residents are non-verbal and do not have access to other forms of linguistic communication, Wyatt witnessed them hiding in corners, and making themselves scarce, when he visited the home. Support workers began complaining to management too, saying that they felt unsafe in their work environment and that they felt the other residents were also unsafe. Still, management refused to reassess whether Charlie's fit at Oak Ridges was appropriate. Instead the approach they took was to increase Charlie's time with a one-on-one behaviour therapist and to move his room down to the basement. Charlie then had a behaviour therapist with him from eight a.m. until eleven p.m. everyday. For the first few weeks of receiving intensified behaviour therapy, Wyatt described the therapist as seeming more like a guard, trying to contain Charlie from hurting himself and others, than anything else. While Wyatt described how

working with the behaviour therapist did over time decrease Charlie's "challenging behaviour," it is important to consider how intensifying behaviour therapy was used to cover up management's inadequate transition process and their inappropriate placement of Charlie into Oak Ridges in the first place.

After a month or so, the other resident who had been sexually assaulted began to talk about self-harming and also began to be described, by some support staff and management, as "behavioural." Once described as "behavioural," she was provided with more behaviour therapy and an updated Behaviour Support Plan to try to reduce her challenging behaviour. As the family witnessed their kin receive harmful behaviour therapy interventions in her last group home, they pushed back when management first communicated that it might be helpful to construct a new BSP for her. Management replied to the family's concerns with an email that Wyatt shared with me. The manager stated that she understood the family's resistance to "a lot of behaviour therapy" but that the "effectiveness" of a "well written" Support Plan depends on "consistency and follow through" by family and staff. Management then reiterated the importance of a behaviour therapist coming in to work with their family member as a means to help her "through the challenges she may be experiencing."

After receiving this message, the family realized that management was not asking, but rather informing them of the plan to increase their kin's behaviour therapy. A support staff privately told Wyatt that it is Oak Ridges' policy to provide behaviour therapy in these circumstances, regardless of the reason for the escalation of the client's behaviour. Wyatt explained that the family were fearful that their kin would be transferred to a new home or lose her personal support worker, if they continued to push management, and if their kin's behaviour did not improve, so they backed off. The Support Plan that was created targeted four problem behaviours including "aggression," "lying to staff about being hurt" (keep in mind, this was targeted after this resident came forward with being abused by a staff member) and "public nudity." It was stated in the Support Plan that if the resident did not immediately respond to staff interventions on any of her targeted behaviours, she was to be administered a "P.R.N." for an extremely powerful

antipsychotic, followed by another dose thirty minutes later if her behaviour still didn't change.<sup>43</sup>

What this story, along with Sam and Louisa's account indicates, is that when applied in a group home setting, behaviour therapy can be used as an effective strategy for ensuring the institution is managed effectively. In the group home setting with the adult populations described in these accounts, ABA was not primarily applied as a clinical therapeutic service but as an important managerial technique for concealing and resolving complex social and infrastructural issues, constraints and mistakes. Hence, as Jonathan Metzl articulates (but in reference to the human sciences) "far from being value-neutral" or objective" behaviour therapy "disciplines particular subjects in order to reify particular power structures at particular moments in time" (2006, p. 157). In the account shared by Wyatt, ABA was used to enforce social stability after executing a transfer that was contrary to the needs of all the actors living and working in the Oak Ridges home. It was used to ensure the institution would continue to function properly after making a decision that would knowingly harm workers and residents. It was called upon as a method for enforcing, not only institutional patient behaviours, but institutional staff behaviours, so that the trail of hurting bodies could not injure the institution that injured them.

As Wyatt further explained, the support worker staff at Oak Ridges, as with many other agencies, is composed primarily of racialized employees who often have precarious work contracts, juggle multiple jobs, and fear losing their job if they speak against management. Management knowingly put these racialized bodies on the line with Charlie's transfer. It was primarily these bodies getting bruised, broken, and chased, when trying to care for the new resident, and trying to protect themselves and the other residents, from the fall out of the transfer. Meanwhile, the disabled residents, including Charlie, who were powerless to control any aspect of their living situation, had no choice as to whether or not they wanted to be transferred or wanted to receive behaviour therapy. Accordingly, the use of ABA in this situation is an enactment of "structural violence," which occurs when "seemingly benevolent social institutions can dominate, oppress, or exploit minority populations" (Metzl, 2009, p. 203). With behaviour therapy and the Behaviour Support

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<sup>43</sup> P.R.N. is the abbreviation for "pro re nata," which is a latin word often used within the medical field to indicate that a medication or procedure be administered as needed or as the situation arises.

Plan, this lifeworld of anger, pain, oppression, displacement, care, and loss was textually made to disappear and re-emerge as an individual problem behaviour. Metzl describes a remnant as a “fragment, a shard, a vestige, a left over piece” (2009, p. 186). This is how I consider the discursive use of ABA in some current institutional settings—a remnant of approaches to care based on containing and disciplining abnormal selves so that systemic power structures are enacted and camouflaged by locating the problem as the oppressed person’s bad behaviour.

*Natalie: ABA therapists working against Institutional Behaviour Management*

Natalie’s perspective adds to the complexity of the use of ABA as a technique for institutional behaviour management in group home and day program settings. Not everyone who does ABA with adults is doing institutional behaviour management. Natalie for example tries to use it in a different way.

Natalie works as a behaviour therapist in an adult in-patient/out-patient unit. Her role is not only to provide individuals with therapy, but to advocate for them and train providers in the institutions that her clients come into contact with. For example, when a client is transitioning from an inpatient unit to a group home setting, Natalie is not only involved with helping this client transition, but is also involved with training the group home staff to apply behaviour therapy to her. Natalie formerly worked with children and described the application of behaviour therapy with this population as quite different from that of adults. While Natalie described how children getting ABA often receive a form of therapy based around a “yes” model (described as creating fun interventions that use only positive reinforcements and that involve multiple break times) she did not find this to be the case with adults.

Like Bilken, Natalie suggests that, at times, behaviour therapies can be applied in such a way as to infantilize adults by taking away their basic rights to choice and self-expression. For example, Natalie described a situation in which a client living in a group home setting was told that he could not wear his favourite Mickey Mouse shirt because it was childish. As long as it is clean, no adult should be told how to dress, Natalie asserted. In another example, Natalie discussed how nurses on her in-patient unit would view a client as “challenging” “bad” and “noncompliant” every time they did not listen to them,



tacitly treating adults diagnosed with intellectual disabilities as children who must obey their practitioner-authorities or be reprimanded—punished even, in locked seclusion.

Throughout our interview, Natalie described how she uses ABA to increase her adult clients' ability to communicate their needs and express themselves.<sup>44</sup> Like other behaviour therapists I spoke with (such as Brittney), Natalie was consistent with describing her ABA practice in such a way as to understand behaviour as communication and to increase communication skills in a non-invasive agency enhancing way. Natalie specifically tied an “increase of challenging behaviour” for instance, to the stress of transitioning from one environment to another. Natalie viewed her role as that of understanding and supporting her clients' as they express their feelings, rather than to punitively try to eliminate their “behaviour.” When contrasted with the story of how behaviour therapy was applied at Oak Ridges, Natalie's description of challenging behaviour and the purpose of the BSP, demonstrates how divergently ABA can be interpreted and enacted in an everyday setting. Further, when considering Natalie's understanding and application of behaviour therapies to that of Oak Ridges, the major difference is that while Natalie's ABA work prioritizes the person, the ABA activities completed at Oak Ridges were institution-centered.

It is important to recognize that a substantial part of Natalie's ABA work activities are working against the management-based application of behaviour therapy that governs many group home settings. Here Natalie describes a bit more about the problematic ways she has witnessed ABA be applied in institutional spaces for adults and how she wants to see change:

...I would like consistency. It's something we preach a lot - there's inconsistency... I'd like supervision and accountability... I hear about things... So people are coming to us when things on a secondary level, or primary level even, aren't working. And then I read their Support Plans and I'm like: 'What is this?' 'On the first instance of this, give them a PRN' and kind of tell 'em: 'No' and

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<sup>44</sup> She also explained that she refuses to use ABA techniques to modify behaviour to seem more “normal.” For example, Natalie was asked to create an intervention program to stop an individual from picking his nose. Natalie was appalled by this, stating:

So Johnny picks his nose. 'Yeah okay he picks his nose!' I don't know what you want me to do about that. Does he pick his nose so much that he's bleeding and he's, you know, unable to engage with others because his hands are continuing...? Does he wash his hands after? If you offer him an alternative like a tissue, will he use it? Has someone ever showed him how to blow his nose with a tissue? Is he suffering some type of medical issue and sinus congestion or does he need a nasal spray? Like I really want to know like specifically how significant it is and who's it a problem for.

Hence, Natalie will not engage with modifying behaviour if the behaviour is not actually an individual problem but a societal one based on adhering to social norms.

‘No hitting’ and all these things. I wish I could call up a disciplinary board... and we don’t have that right now. And it’s disappointing. So I think consistency, evaluation, supervision ... and more of a focus on the ‘cans’ than the ‘cannots’ would be a good thing to see. Or, or maybe in addition... the people who work with kids, bringing that same enthusiasm and playfulness and imagination and cooperation with adults would be really, really great...

In this excerpt, Natalie again describes the variability between how ABA can be applied to children versus adults and wishes there was more consistency, supervision and accountability in the application of behaviour therapy. She further explains how she reads the ABA Support Plans created by actors in other institutional spaces like group homes, as a misuse of ABA. A substantial part of Natalie’s work as an ABA provider is to work against the application of ABA as a form of managerial power for enforcing institutional patient behaviour on residents. Residents, support workers, and even behaviour therapists themselves, are all caught in the managerial matrix of institutional behaviour management.

## **Conclusion**

I wrote this chapter because I wanted to analyze how managerial forms of rule and self-regulatory forms of governance, fundamentally shape everyday behaviour therapy activities and methods. I examined how politics, regulatory frameworks, and systems of governance affect the everyday production of behaviour therapy data and work. I further argued that governing bodies use ABA data as a valuable resource for generating translocal forms of bureaucratic knowledge, which are used to advance the current managerial healthcare system. Additionally, because behaviour therapy is flexibly applied to respond to a variety of different social, economic and systemic needs, it has become an important institutional technique for managing institutionalized adult disabled bodies.

In the first section I showed how daily behaviour therapy work is governed by the “numbers game:” a game that reflects a management-based approach to healthcare governance that results in time austerity. I demonstrated how “getting the numbers” reduces the quality of ABA services while increasing the probability of acquiring funding. I further considered how ABA data sheets are *put to work* to solve the managerial problem of long waitlists. Waitlists have also resulted in the managerial tweaking of ABA/EIBI eligibility criteria, which affects the local activities of diagnosticians and parents alike.

In the second section I focused on how the process of behaviour therapy certification has led to different sets of therapeutic practices and knowledge relations within the profession. The academic emphasis of the BACB has already transformed the behaviour therapy workforce, edging out those who are more interested in frontline work and effective teaching than clinical research pursuits. Floor-work has become the primary platform for academic research production. The process of certification has also re-solidified ABA as a scientific discipline that casts creativity and intuition as taboo and requires disinterested technical empiricism. Therapists are no longer comfortable *speaking* of their therapy work as “art.” Certification has not only restructured ABA practices but what can be said and felt about these practices.

In the final section I focused on the topic of managerialism and behaviour therapy in the context of residential and institutional spaces that serve adult autistic populations. I included my interviews with Wyatt, as well as Sam and Louisa, to show how behaviour therapy can be used to solve mismanaged group home or day-program care by ensuring residents comply with “institutional patient behaviour.” These informants shed light on how the Behaviour Support Plan can be used as a strategy to deflect complex social and systemic problems into an individual behaviour problem. Even behavior therapists are caught up in these managerial appropriations of ABA and some actively challenge managerial ABA governance.

To complicate the argument I made in Chapter One, behaviour therapy is not just about repetitive standardized clinical activities. It is not just about an idealized behavioural worldview where the autistic subject is understood through the science of functional behaviour and caring becomes about enhancing adaptive functioning. Behaviour therapy is integrated in systems of power and resistance, and is put to work to produce different forms of knowledge and sustain certain forms of governance. When ABA gets done in real time and place, it is often subordinated to managerial imperatives and larger governmental approaches to healthcare reform whereby everyday healthcare work is made accountable to rationalized, quantitative and translocal forms of reporting and representation. In sum, behaviour therapy practice is governed by larger institutional structures that require practitioners to apply behaviour therapy to achieve desired systemic ends. Like most everything else, behaviour therapy work is caught inside the gummy mouth of culture.

## CHAPTER THREE

### **Para-practitioners and the generosity of applied behaviour therapies: Relationships, Power and Variability**

Para-practitioners are key providers of applied behavior therapies. A prominent clinician speaking at a large annual autism summit I attended spoke of a behavior therapy pilot program he developed, and explained how the program relied exclusively on parents to carry out therapeutic work. The clinician called this model of parental enrollment the “train the trainer model”: “rather than training experts, experts train family.” This statement was delivered simply and without elaboration, as if once family are trained, they do the work of the expert, end of story. But this kind of training is only the beginning of the complex relationship between experts and para-practitioners. Rather than being passive recipients of expert training, in this chapter I analyze how para-practitioners actively interpret and creatively carry out behavior therapy work, shaping much of how behavior therapy is practiced in the everyday.

In Ontario, unpaid parent, teacher, and support worker para-practitioners are woven into the infrastructure of autism public policy (Ministry of Children and Youth Services, 2017; Ministry of Children and Youth Services, 2007). Para-practitioners are key actors in the clinical apparatus of behaviour therapies, so much so that it is rare that any autistic person would receive them without direct para-practitioner involvement. Yet little social and academic attention has been paid to the lively and varied work that constitutes para-practitioner participation in applying behavior therapies. Also missing from current academic literature is a rich account of the *relationship* between therapist-expert and para-practitioner that analyzes how power, emotions and knowledge practices shape everyday behaviour therapy interventions. The ubiquity and importance of para-practitioners also presents an important paradox: behaviour therapies are defined as an applied science—one that is evidence-based and objective—yet lay actors, often with very little clinical training, are instrumental to implementing these therapies.

Applied behaviour therapies are conducted by a variety of non-expert actors in a range of institutional and public settings, such as the classroom, the family or group home, the grocery store, the park, the dental office, and the bathroom. Behaviour therapies

become the framework for many autistic actors' everyday lives, where teachers, front-line group home staff, parents, siblings, grandparents, and sometimes, friends, are taught to apply behaviour therapy methods whenever they interact with autistic people. Building on the last chapter that examined how managerial knowledge challenges clinical standardization, this chapter draws on ethnographic data to examine how para-practitioner involvement is another contextual factor that deeply influences everyday behaviour therapy activities. I consider how the integration of para-practitioners into everyday behaviour therapy work means that behaviour therapy methods become quite open-ended and variable. As discussed in the Introduction, the involvement of para-practitioners is an example of what Nikolas Rose calls (1994; 1998), the “generosity of expertise”, in this case the expertise of behaviour therapies. These therapies exist *in and through* the multiple permutations of the many lay actors that apply them.

Para-practitioner accounts are important to analyze as their experiences shed light on the actualities of the therapy work autistic people receive. Here I analyze the complexity of the para-practitioner role and the involved relationships they form with experts. I consider how local everyday behavior therapy practices do not consist of a top down model of experts training lay actors, but of lay actors negotiating, translating and creatively interpreting the methods they learn. Lay people make meaning and construe behaviour therapies to fit within their own social fabric, and their moral and political frameworks, and in turn make up the activities that constitute applied behaviour analysis. By focusing my analysis on the accounts of only a few para-practitioners, I am able to provide an intimate and extended portrait of how each para-practitioner creates their own version of behaviour therapy methods. When applied in everyday life, applied behaviour therapies exist as a decoupage of the beliefs, feelings, and contexts of those who apply them.

In this Chapter, I provide a close analysis of my interviews with four para-practitioners: Rosa, Donna & Joey, and Sunnivah, whose stories demonstrate the diverse, interesting, and deeply complex ways that they orient to and apply behaviour therapies (they all refer to their therapy work as “ABA” so this is the terminology I use throughout this chapter). I also weave a few important accounts from Lydia (the special education resource consultant who I discussed in Chapters One and Two), the only informant whose

entire job consists of training para-practitioners, to consider the additional complexity of para-practitioner involvement from the expert's point of view.

By including accounts of the dense interactions that occur between expert-therapists and para-practitioners, I show how the struggle to enroll para-practitioners to carry out standard behavior therapy methods often paradoxically results in further transformations of these methods. A heterogeneous group of actors with a wide array of interests and commitments are enrolled to apply (*see* Callon, 1984) ABA and they each interpret ABA differently. Further, since behavior therapies are standards of care, many para-practitioners are obliged to apply it, yet I demonstrate how these actors can work within constraints to manage and resist expert knowledge in such a way as to significantly expand and diversify behavior therapy methods.

Chloe Silverman (2011) examines the role love plays as a powerful affective tool for vying for access to biomedical and clinical autism interventions. However, social science literature on behaviour therapies has not examined how emotions, interpersonal relationships, political orientations, and larger systemic infrastructure, constitute *the everyday* behaviour therapy work that gets done. Thus, I demonstrate how para-practitioners and experts negotiate behaviour therapy methods and interventions, and how these negotiations, of what Eyal calls "jurisdictional struggles" (2013, p. 887), often centre around the completion of data tracking forms. I aim to show the thick and messy world of relationality, personal commitments, beliefs, thought-processes, and concessions that occur outside of the intervention plans, columns and checklists that para-practitioners complete. As I will demonstrate, para-practitioners are tasked with carrying out the goals and aims of the clinic, but this does not mean all these actors come to view themselves as clinical conduits, clinical actors, or ruled by clinical forms of governance.

I begin by providing background and context to the rise and prominence of behaviour therapy para-practitioners. I use Nikolas Rose's work (1994; 1998) to understand the dispersal and modification of ABA techniques among para-practitioners as an instance of the generosity of expertise. To provide further context relating to the integration and implications of involving lay-practitioners in everyday practice, I include Eyal's (2013; Eyal et al., 2010) important work on the history of the rise of behaviour therapies, expertise, and autism. I use Eyal and Rose's work to argue that behaviour

therapies are best understood as various different therapeutic objects constituted by the range of subjects who apply them.

The rest of this chapter is divided into three sections, each of which offers an extended ethnographic analysis of one or more para-practitioner's behaviour therapy activities as fitting within their social fabric. In the first section I focus on the meaningful factors that shape how para-practitioners approach and complete ABA text-based activities by analyzing my interview with an autistic parent named Rosa. The second section focuses on how parents actively take up behaviour therapy methods in such a way as to manifest as an extension of their natural parenting style. I examine one couple (Joey and Donna) to demonstrate how parental enrolment was achieved by *naturalizing* clinical techniques, activities and interventions to maintain their pre-formed familial structure. The last section focuses on a teacher para-practitioner named Sunnivah to show how a complex of forces, institutional arrangements, and responsibilities, shape her ABA activities. Sunnivah learns to tinker with the official ABA activities she is provincially required to complete in order to deal with the realities of her work duties.

### **Background and Context: Generosity, expertise and the rise of ABA**

Before Ivar Lovaas pioneered autism-specific applied behaviour analysis in the 1960s, autism was an uncommonly diagnosed condition, and autistic people often lived within an institutional or asylum setting where parents were shut out of their child's therapy interventions, and sometimes blamed for causing their child's autism (Douglas, 2013, 2014, 2016; Eyal et al., 2010; Eyal, 2013; Silverman, 2012). When Lovaas began his work in the applied behavioural sciences, his primary goal was to free people whose minds were "enslaved" by autism (The Lovaas Center, 2016) to enable them to function as close to "normal" as possible, so that they could live outside of an institutional setting and join mainstream society.<sup>45</sup> As explained in the Introduction, to see improvement, Lovaas asserted that the autistic person must engage with behavioural therapy work "during almost every waking hour" for "365 days a year" (Lovaas, 1987, p.5), thus effectively

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<sup>45</sup> Contrary to Lovaas' aims, other ABA experts were using ABA to both help the mental institution function more efficiently and effectively (Rutherford, 2009), and to provide better care within it. Other providers, such as Lovaas, oriented to ABA as a means to transfer care to the family home or to other community spaces. It is important to recognize that ABA was applied in a myriad of different settings and for a myriad of different reasons and not, purposively or exclusively, designed to enable deinstitutionalization.

clinicalizing their everyday life (Zucker & Donovan, 2016). Lovaas did not have the clinical resources to pervasively apply ABA to autistic people, and so he needed to invite para-practitioners to complete ABA work too (Eyal et al., 2010; Eyal, 2013; Lovaas, 1987; Silverman, 2012). Lovaas thus responsabilized parents to conduct ABA in the home.

Far from being passive conduits tasked with performing therapeutic work, Eyal et al. (2010) describe how many parents were eager to take on an active role as clinical partners, becoming co-therapists and colleagues. Parents' embrace of their newfound clinical responsibility has to be considered in the context of being previously excluded from their children's clinical and residential institutional care. In contrast to the hopelessness of the "psy" asylum model where, in the 1950s-60s, the goal was more custodial than rehabilitative (Eyal, et al., 2010; Goffman, 1961; Grobb, 2011; Rutherford, 2009), parents were told that with intensive ABA work, their child could improve and perhaps overcome their perceived deficits related to autism. In other words, rather than constituting an innate and global state of being, with ABA, autism was considered a "bad habit that could be unlearned, or a lack of skills that could be corrected" (Eyal, et al., 2010, p.142). As Lovaas succinctly stated: "The success of behavioral treatments seems to make the constructs of intelligence and autism superfluous" (1993, p.625).<sup>46</sup> Parent para-practitioners considered ABA as key to their child's emancipation from institutional segregation and wanted to do their part to reshape their family and parental style to conform to the goals and exercises of the ABA clinic (Zucker & Donovan, 2016). Accordingly, Lovaas' ABA work created a two-way network of expertise, where clinical labour and inscriptions (data tracking and collection) flowed and relayed between parents and clinicians instead of being produced solely within the citadel of the clinical laboratory (Eyal et al., 2010; Eyal, 2013).

Before moving on to contextualize parents' role in providing ABA as related to the democratization of expertise, it is important to dwell here on how Lovaas' work presented a different proposal for understanding the so-called abnormal or pathological autistic subject as this created new possibilities for optimization. I suggest that the power of Lovaas' clinical enterprise originates from his reconceptualization of the self as a

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<sup>46</sup> Rutherford's work provides the contextual framework for considering how Lovaas' "can-do" approach to modifying autistic people as that which can be traced back to Skinner and his work with "psychotic" and "schizophrenic" patients in asylums in the early 1960s (2009, p.64).



functional mechanical organism composed of individual technical components, where each component can be examined as its own autonomous subject. By viewing the self through a functional behaviourist lens, that is, as an entity defined through individual behavioural outputs (rather than through a psychological lens of the self as that which is constituted through deep and imperceptible forces of the mind, psyche or soul), autism was brought to the surface, externalized, and rendered visible through specific actions or behaviours without worry about an underlying ‘pathological’ self.<sup>47</sup> Autism became nothing other than a diagnosis defining an assemblage of unlearned skills, and dysfunctional or maladaptive behaviours, to be localized and compartmentalized for individual tracking, measuring, and modification (Eyal et al., 2010).<sup>48</sup> Moreover, functionality required the ability to mimic and perform a set of behaviours or skills, rather than the ability to embody a core cohesive functional self (Eyal et al., 2010). As Canguilhem (1989, p.39) once said in reference to medical conceptions of the pathological: “To act, it is necessary at least to localize.” When paired with the erasure of the ontology of the self, the hyper-localization of ABA, not only rendered action possible, but augmented the possibility of achieving little but perceptible positive localized results that in the end would ideally lead to broader change. ABA’s ability to improve the functioning of individual *parts* provides parents and autism experts with a dawning topography of hope for optimizing at least some aspects of an autistic subject’s constitution.

To return to the subject of parents’ involvement: Lovaas “generously” democratized (Rose, 1994; 1998) clinical work by *empowering* parents to apply ABA, “putting them on equal footing with the expert,” so that there was nothing they could not do themselves without a little guidance (Eyal et al., 2010, p. 125). When using the term “generous” I am referring to Nikolas Rose’s formulation (1994, 1998) of the psy sciences as governing the modern liberal democratic ‘soul’ through governing difference spaces (the school, home, court, hospital, factory) and through democratising psy expertise (via advice columns, pop psychology, and self help books) so that everyone could act as her

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<sup>47</sup> Carlos Novas and Nikolas Rose (2010) examine modern genetics as indicative of an understanding of the self that has moved from depth to surface.

<sup>48</sup> To provide further context: Michael Pettit explains, behaviourism as a “movement, sought to replace nineteenth-century introspective psychology, which studied the mind, with a more exacting science grounded in the observation of controlled and measurable behaviours” (2009, p.395).

own psychologist. Rose argues that the power of expertise is not exercised by exclusion, as in experts exclude the public from participating in their specialized knowledge. It is generous and democratized in the sense that the concepts, vocabulary and ways of thinking that mark an expert form of knowledge are made available to the public. It is only through people taking up expert forms of knowledge that expertise productively exerts power effects. In other words, with generosity, “a network of expertise...becomes more powerful and influential” than experts in and of themselves, because of their power to “craft and package its concepts, its discourse, its modes of seeing, doing, and judging, so that they can be grafted onto what others are doing, thus linking them to the network and eliciting their cooperation” (Eyal, 2013, p. 876).

To summarize the generosity of Lovaas’ ABA enterprise is this proclamation made by Lovaas himself: “there are no ‘experts’ in this field” (1993, p.626). What Lovaas was essentially communicating with this statement is that there need not be a distinction between being an expert and having expertise.<sup>49</sup> Para-practitioners are central to, not only applying, but creating, applied behaviour therapy methods. Though defined as an applied science and an evidence-based practice, ABA straddles the interstitial space between public and clinical application and lay and expert genres of proof and practice.

It is important to emphasize how generosity and the active role of parents and other para-practitioners were key to the rise of ABA since the era of deinstitutionalization, and how the case of ABA is critical for understanding the new assemblage of care in North America for those diagnosed with cognitive, developmental and behavioural disabilities. Eyal (2013) explains how deinstitutionalization and the move to community care reorganized clinical practice and expertise, as this ideological and spatial shift provided the ecology for an “alternative network of expertise” to be assembled. In this new network the authority and identity of parent, professional and advocate were levelled and blurred. Instead of a psychiatric superintendent working autonomously to treat the disabled using

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<sup>49</sup> Eyal’s (2013) sociology of expertise, which requires separating “the expert” from “expertise” and analyzing forms of expertise as “gradually assembled” networks of “objects, actors, techniques, devices and institutional and special arrangements” (Eyal, 2013, p. 864). While an “expert” is an actor who makes jurisdictional claims based on disinterested credibility, “expertise” is the ability to “accomplish a task better and faster” typically through being socialized into a particular group of experts (Eyal, 2013, p. 869). The analytic distinction between expert and expertise maps onto the relation between ABA expert-therapists (formally trained professionals), and ABA para-practitioners (lay people tasked with applying frontline ABA therapy through their natural engagement with autistic persons).

psychoanalysis within the closed and protected walls of the asylum, care-work was redistributed to a wide array of actors (Eyal et al., 2010; Eyal, 2013; Grob, 2011). Because the intensiveness of ABA far surpassed what clinicians could provide, lay people as well as managerial and helping professionals became responsible for distributing behavioural modification therapies (Eyal et al., 2010). As stated in the Introduction, psychologists, behaviour science researchers, teachers, education assistants, residential support workers, personal support workers, parents, siblings, psychologists, occupational therapists, special education teachers and, as my interviews have demonstrated, even other school age students and autistic people receiving therapy themselves have been invited into the assemblage of behaviour therapy work as they have been tasked with applying these therapies to autistic people. The “rewired network” of collaboration between parent and clinician spread and further dispersed “onto multiple local authorities” and various “decision points” (Eyal, 2013, 888). Clinical practice thus became “an active surveillance system reaching out into the population” in which there were new answers to the questions “who is the therapist” and “who is the subject with the authority to administer treatment?” (Eyal et al., 2010, p. 116). I suggest that the dispersed network of collaboration that constitutes the assemblage of behaviour therapy providers is responsible for spreading the popularity of ABA and increasing its methodological flexibility.

The generosity of behaviour therapies has been extended with the rise of autism diagnoses and the establishment of these therapies as the “obligatory passage point” (Callon, 1984) for autism support and intervention through being designated a “gold standard” of care (ONTABA, 2017, p.3). In fact, in my fieldwork I discovered that behaviour therapies are now beginning to be marketed and applied to children without an autism diagnosis, but who may have autistic *symptoms*. One clinician who spoke at a recent autism conference practices a form of therapy that incorporates ABA; she showed a video of her work and claimed afterward: “I am not sure if this child has autism, I haven’t done the legwork yet.” She stressed the importance of intervening “at the earliest *sign* of autism, even without a diagnosis.” The generosity of ABA, the compartmentalization of the self as a mechanical organism composed of autonomous parts, and the generosity of the DSM diagnosis of autism as a “spectrum,” have converged to raise discursive consciousness of both autism and “autistic traits,” so that autistic traits *as well as* being

autistic, constitute a “spoiled identity” (*see* Goffman, 1963), and thus a reason for ABA intervention.

The rise and generosity of ABA *and* autism is linked to a larger social discourse: the increasing medicalization of everyday life. Peter Conrad defines medicalization as the mounting “emergence of medical definitions for previously non-medical problems” (1992, p.223). Conrad explains that the secularization and rationalization of modernity has brought the realm of human maladies into the purview of medicine. The variegated states of the human condition have been scientized and categorized into distinct medical problems to be observed, assessed and worked on through specific proscribed courses of treatment. As Conrad further explains, medicalization breaks up so-called deviance and life processes into more and more classificatory boxes and is thus a potent form of surveillance and social control. It is important to consider how both autism and ABA are part of the larger assemblage of governance through medicalization.

ABA is further indicative of the turn to an insurable, managerial, neoliberal evidence-based healthcare system, in which services for disabled people are clinicalized, rationalized, and privatized, and where day-to-day activities are measured, calculated and quantified so as to assess their legible effectiveness, qua their worth. The particular importance of parents to the clinical enterprise of ABA derives from being highly “interested” actors: they are supposed to love their children more than anyone and be moved to provide helpful interventions. Yet they are also enrolled to participate in practicing ABA because they provide free clinical labour that can be geared into expanding the ABA enterprise. To illustrate this, consider the statements made by two speakers at the 2016 Canadian Autism Spectrum Disorder Alliance (CASDA) summit. The first speaker, who while detailing a recent project called the “National Surveillance Strategy” (aimed at surveilling epidemiological autism rates and intervention data), stated the importance of conducting “forensic data-mining” of parents’ ABA archives, since “every session the child had was surveilled, was data tracked.” This clinician was particularly interested in reaching out to parents with eighteen-year-old autistic children who have “recovered” from autism, to yield over their home-kept “secret data sets,” to contribute to clinical ABA-effectiveness data. To overtly link parents and the private space of the home to the public and clinical economy of ABA, this clinician concluded: “we all

know when we have good data, we have good funding.” Here, parents, and the private space of the home, are considered a natural resource for the production of clinical data, and as central to the production of behaviour therapy work.

The comments from another CASDA speaker further demonstrate how extending the practice of ABA to parents is tied to the fact that parents are motivated to complete unpaid behaviour therapy work with their autistic children because of their affective closeness to them. This speaker, “Dr. Guan,” presented a new off-shoot of a behaviour therapy program based on play and development that is parent, not expert-implemented. Dr. Guan merged love with good science and fiscal austerity in articulating his rationale for centralizing the parent as therapist, stating: “parent-based practice is best practice” because “no one cares more than parents” and because they are “less costly.” He continued: “we really don’t want to waste our most valuable resources” and “assets... let’s harness the power of parents.” Parents’ affect draws them into completing unpaid therapeutic work, and in so doing, they become invaluable therapeutic resources.

Eyal’s analysis of the rise of ABA and its generosity in extending clinical governance to those with ABA expertise is important for understanding the centrality of para-practitioners in ABA work, and the politics of knowledge in current ABA-centric autism services. Yet by depicting collaboration, democratization and a levelling of power between clinician and para-practitioner as characteristic of ABA practice, Eyal’s analysis (2013; Eyal et al., 2010), and my synthesis of it until this point, misses the complex and fraught power struggles and extra-clinical factors that often arise in the everyday practices that occur between these actors. While I focus specifically on the topic of power relations and advocacy struggles as centered on the relationship between parents, autistic actors, and therapist-experts in the following chapter, I start to analyze the “microphysics” of power (Foucault, 1975) present with the involvement of ABA para-practitioners here.

Epstein (1996) describes a microphysics analysis as characterized by accounting for the “cracks and crevices of the social system; the omnipresence of resistance at every site; and the propagation of knowledge, practices, meanings, and identities out of the deployment of power” (p. 4). I use the animate character of ethnographic work to complicate the notion of ABA as a collaboration between experts and para-practitioners to show how power is a rousing productive force and a moving target in these encounters.

The ethnographic work presented in this chapter further demonstrates how power struggles often occur through people's engagement with behaviour therapy texts, particularly the Antecedent-Behaviour-Consequent (ABC) Chart. This chart has three columns: the first lists the event of behaviour that directly precedes the un/desirable behaviour (Antecedent), the second lists the un/desirable behaviour (Behaviour), and the third lists the event that immediately proceeds the behaviour (Consequence).

Now that I have provided context and background for para-practitioner involvement in ABA, I can move on to the fieldwork section of this chapter, beginning with Rosa.

### **Rosa: Inscribing the expert-therapist—para-practitioner relationship**

I interviewed Rosa over the phone. Her voice was soft and tentative yet animated. Rosa was trained as a scientist and I got a sense of her as intelligent, introspective, candid, and generous. I instantly liked her and felt an overwhelming feeling of accountability to her about how I would represent and analyze the experiences she was sharing with me.

Rosa, and her two children have been diagnosed as autistic. Rosa thinks her husband is autistic too, he just does not know it. As an autistic adult used to being underrepresented by autism research, Rosa was eager to participate in my study, but she needed to clarify her confidentiality before signing the consent form. Rosa explained that she once signed a consent form for one of her kids to participate in video-recorded therapy sessions and did not realize that in doing so she consented to have the video shown publicly. Rosa learnt that one of her daughter's videos was viewed during a conference presentation in front of hundreds of people. She clarified, using the most diplomatic tone possible, that she wanted to make sure this would not happen again. I wanted to be Rosa's ally and felt an added responsibility of living up to the role while balancing an academic account. In a substantial portion of my interviews, feelings like this played out in my thoughts like an annoying racket.

Throughout our interview, Rosa referred to her two children affectionately as her "little ones" and called me during their nap. She nervously laughed as often as she apologized, which was frequently, and I mirrored these actions back to her while too

emphatically reassuring her that she was on point.<sup>50</sup> My interview with Rosa focused on her experiences with getting her children autism services. Throughout this interview I learnt how Rosa negotiates, works within, and resists, systemic constraints to insert her own values to ensure her children receive the specific forms of supports she thinks they need. Her experiences shed light on how parents and therapists deviate from official behaviour therapy programs when working in the home to create interventions they identify as important. As I learnt through Rosa's story, parents can orient to filling out data tracking sheets as a way to strategically leave out their deviations from scripted therapy methods. My analysis here complicates my argument in Chapter One about how behaviour therapists are subjectified through carrying out the rigid protocols proscribed in the Behavior Intervention Plan (BIP). The BIP, I argued, governs behaviour therapists' work and disciplines their conduct. By contrast, my analysis of Rosa's story demonstrates the agential actions para-practitioners and experts complete together, to work outside of the proscriptive scope of this document. Finally, Rosa's account offers a window into understanding how some parent para-practitioners relate to texts, not primarily as scientific documents but as expressive inter-relational affective objects. I orient to Rosa's experiences as an opening for revealing the richness of parent para-practitioners' daily practices, and how these practices are inscribed, or not inscribed, into their writing practices in the form of data tracking sheets.

### *Negotiation, Cooperation and Writing Practices*

As an autistic person, Rosa understands the importance of nurturing autistic people's special interests: topics of intense and sustained focus. In Rosa's experience, many behaviour therapists and parents try to dissuade autistic people from forming special interests because they perceive them as obsessive and distracting. Contrastingly, Rosa views these interests as central to an autistic person's way of being and as beneficial to

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<sup>50</sup> Often, Rosa would apologize for getting off topic or talking too much, a gesture of self-consciousness that I considered as deriving from a fear that I might perceive her through a clinical lens: assessing how she matched up with stereotypical autistic traits. Does she internalize this clinical lens in coming to make sense of herself (what Ian Hacking describes, as constituting the phenomenon of an "interactive kind"(1995)? I also questioned how gender influenced Rosa's self-consciousness: was she afraid I would perceive her "autistic traits" as a breach of feminine gender norms? Did she orient to apologies as a safeguard for showing both her concern with taking up too much space as an autistic person *and* as a woman?

building self-confidence and the ability to cope with different environmental stimulus. For example, Rosa finds it difficult to speak when in stressful situations, yet language comfortably pours out of her when conversing about her interests. She noticed this with one of her daughters, whose interest is animals. She was so passionate about animals that she would wake up in the middle of the night talking about them. Rosa worked with an ABA therapist, who provided Pivotal Response Therapy (PRT) (an ABA method that does not focus on specific behaviours but on working on developing skills within the natural environment) to her daughter and built interventions around this interest to teach language and to work on sensory desensitization. Rosa's daughter only received PRT as an interim service while on the waitlist for government funded ABA services, but she wishes her kid could continue to receive PRT instead of the government program. Rosa stated that she's only ever heard parents speak of their experiences with ABA as "negative" and "bad" because they have experienced it as "ineffective." However, Rosa was able to have a "very positive" experience with PRT because "we tied it into special interests." I orient to the "we" in this sentence as referring to Rosa and the therapist working together as colleagues to co-create interventions.

After waiting for eighteen months, Rosa received the government funded ABA services for her first child. A therapist now comes to her house once every three weeks to coach her to apply the intervention program they created. Rosa describes her initial experience with this service as a "big disappointment" because it was "very, very specific." Rosa gave the clinical supervisor who came for the initial visit, a "big list of things to work on" and the supervisor told her "no, no you have to pick something more specific." The 10-week ABA program that Rosa received ended up being exclusively created to teach tooth brushing. The other ABA program she has more recently received for her younger kid focused exclusively on *sitting* on the toilet, as a *preparation* for toilet training. Rosa recalls her initial disappointment: "it seems like at that rate, it will take ten years just to know how to do your morning routine. Doesn't seem so effective." Rosa recounts how she kept hearing from her dissatisfied parent-friends that even when focusing on such a specific, small skill, their children "didn't take to it;" that "it [ABA] didn't work."



Rosa was worried her ABA experience would be the same as her friends but she luckily ended up getting a “really good person” (therapist) who provided “so many tips [for toilet training prep] that were useful for other things.” Rosa explained that for the toilet training preparation intervention, their therapist deviated from the official BIP to provide techniques and methods for helping out with a lot of other skills. In fact, Rosa described how her daughter’s therapist thought it was “silly” to focus on such a diminutive, specific skill, and so “guided” them towards completing other tasks, “even though on paper she’s supposed to work on the one skill.” Rosa added, “But I think the way she *had* [my italics] to write it up for the official paperwork was just that it was focusing on her [the daughter’s] amount of time on the toilet: five seconds, six seconds.”

Rosa’s experience with these ABA programs demonstrates how therapist and parent para-practitioner can work together to manipulate official behaviour therapy practices and to complete work that exists outside of what is proscribed in the BIP. Rosa further describes how the second therapist she works with actively works against the narrow scope of the BIP, considering such an approach “silly.” Through strategically teaching toilet training by providing a variety of strategies and activities that are useful for other tasks, the therapist craftily enacts both compliance and noncompliance: she provides the program she *has* to, but goes outside the frame by providing more than she is supposed to. I orient to Rosa’s home, a space outside and away from other behaviour therapists or clinical supervisors, as affording both para-practitioners and behaviour therapists more opportunities to flexibly relate to ABA methods and to creatively relate to the BIP. It is also important to recognize that though the therapist strayed outside of the scope of the BIP, her actions of omitting her modifications from text signify that she wanted these actions to go undetected by parties outside of the client-parent-therapist triad. Her strategy for concealing actions that exist outside of the BIP was to actively *not* textualize them. That this therapist felt comfortable telling Rosa that she fills out the forms to represent only one aspect of the activities they complete is a testament to their relational bond, and to their status, not just as co-therapists, but as “co-conspirators” (Todd, 2017). Compliance with filling out texts can accomplish ad hoc alternations, rearrangements and translations to transpire imperceptibly. Their agreement to leave out activities that fall outside the

scope of the BIP indicates their social ties as formed through enacting and resisting the structural relations assigned to them.

Both Rosa and the behaviour therapist she was working with in her home recognize the regulatory intent of the BIP and craftily find a way to act in a non-compliant manner by paradoxically *inscribing compliance*. Said differently, they performed compliance through their writing practices, which they strategically used as a way to resist compliance in their actual work: compliantly filling out the text *was their alibi* for enacting a different set of activities and relations. Rosa's account suggests how they were regulated by the BIP even as they surreptitiously resisted it.

Medical anthropologist Joao Biehl identifies the job of the anthropologist as that of bringing back “the everyday stories and writings of characters that might otherwise remain forgotten, with attention to the ways their own struggles and visions of themselves create holes in dominant theories and policies” (2010, p.216). Biehl continues to claim how, through the experience-near narrative-based form of ethnographic work, the ethnographer can excavate the stories that would otherwise be “doomed not to be analyzed” (2010, p.216). Despite her compliant textual traces, I understand Rosa's act of speaking to me about the actions she took with her therapist as an act of wanting to further inscribe her own resistance. If not for my conversation with Rosa, her actions with the therapist might have remained untraceable on a systemic level. This fieldwork encounter is valuable for how it brings to the surface the holes in the data sheets Rosa and her therapist inscribed as well as the complex actions, relations, and moments that persist in and through proscriptive ABA documents aimed at governing the bodies, behaviours and actions of both providers and recipients. Rosa and her therapist use writing practices to carefully *negotiate* power, compliance and noncompliance, and behaviour therapy methods.

#### *Inscription as an affective tool: care and dishonesty*

As our interview went on, Rosa expanded on her complex relationship with completing ABA texts, and provided an account of how her friends with kids receiving ABA oriented to them too. Rosa explained how she is tasked with completing consistent data tracking throughout her children's ten-week ABA program. She describes her data tracking responsibilities as “time consuming” and “tedious” (especially with two kids receiving

ABA) and as an activity she despises “with [her] entire soul.” With her one daughter, she currently has to “track her every time she defies us [her parents], which is sixty or more points a day,” and has to “write out what happened before, after, and during for each event” on her Antecedent-Behaviour-Consequence (ABC) Chart. Rosa states that she would “rather rely on visually noticing: ‘Yeah it’s working, it seems better,’” but understands that the therapists need this tracking to “validate that it’s a working method,” which is why she complies. Yet she nervously confessed: “I know for a fact that many parents fake that data.” I asked Rosa why some parents fake the data and she stated that though they tend to “feel bad” about doing it, parents “don’t want to tell the person [their therapist] that it’s not really working and so they pretend it’s working, they tick it off, and next time they don’t sign back up for the next round of ABA.” Rosa continued, “I guess people have a really hard time after somebody’s worked with you, to say ‘Hey! This didn’t really work at all!’ [laughs]. So I’m kind of worried that maybe ABA is not so effective and they keep funding it because people just don’t want to tell the truth about it.” I asked Rosa more about this phenomenon to try to get a clearer picture of the dynamics occurring in the home between (mostly mother) para-practitioners, behaviour therapists, and data tracking:

Julia: What it seems like you are suggesting to me is that parent’s feel sort of... empathetic or obligated to the practitioners so much so that they feel so bad about saying... ‘This isn’t working.’

Rosa: Yeah and I can see that, I’ve had to say ‘something isn’t working out’ and it’s super uncomfortable, cause you feel terrible [laughs]. So I can see where they are coming from. And that’s not for everybody. That would be the over-polite parent type and then there’s the opposite, which, ya, have no problem [laugh].

Julia: Is this because there tends to be a bit of a close relationship there?

Rosa: Yeah for sure. You tend to build a relationship with them in that time because you are seeing them, it could be up to... one to two times a week for ten weeks. You do tend to get to know them really well at that time.<sup>51</sup>

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<sup>51</sup> Conversely, in the following excerpt Lydia discusses how commonly both parents and para-practitioners dishonestly complete data sheets, but how she uses strategies of review, cooperation and pragmatism to acquire textual compliance:

...When I was working on a behaviour team, [para-practitioners] would fill the data, you know, just because they knew we were coming to look at it. It’s like: ‘we don’t have to do this for us, we’re here to help you.’ And you know, ‘basically this is all a lie,’ you know, like, so when we looked at the function of behaviour, same things, functions of data: ‘What is the purpose of this? Why are we filling out these checkmarks?’ and sometimes can get people on board... I’ve gone to cases where it’s very clear that the staff are done and they think the student should be referred to a treatment centre or whatever: ‘Well look, we can’t put forth any sort of package to request that a child be considered for a treatment centre, until we have evidence of, of data being taken. And showing, not only what you’re saying is a problem, but... we have to have proof of all of this.’ I think, and again, you’re still like, about filling it out properly or not, I think that it’s always reviewing that together: ‘I know it’s this,

This account from Rosa gestures to the important role parents play in completing ABA data tracking as well as the variable actions, feelings and motivations that influence how they orient to, and complete, their data obligations. Interestingly, Rosa describes how some parents who fake the data do so because they are motivated by affective protectionist feelings of care towards the therapist, who they fear hurting if they were to be honest about the therapy not working. The parents Rosa describes orient to data as affectively loaded, as an object that confers, not just the child's progress, but the therapist's value, which is complicatedly articulated through their child's progress. The decision to manufacture positive therapeutic results illustrates how different actors understand the positivist clinical ABA form. While Rosa, a scientist, prioritizes the virtue of honesty in completing the ABC Chart to accurately validate progress, regardless of how much she despises it and how "uncomfortable" stating a lack of progress may be, the other parents Rosa describes primarily come to read the ABC chart as a *relational object* capable of injuring a therapist's sense of professional competence, and thus her feelings. Dishonest ABA data tracking is motivated by relational attachment and prioritizing the virtue of kindness above therapeutic effectiveness, yet, as Rosa points out, these doctored forms may be instrumental in affirming the clinical effectiveness of ABA. While ABA is based on Skinner's technology of behaviour and radical behaviourism, which espouse the importance of mechanical automation, reliability and replicability, there is a whole other messy realm of subjective interpersonal feelings and emotional attachments that occurs in the everyday application of behaviour therapy and these are worked out and performed through the completion of data tracking documents.

To add another complex layer, many of the behavior therapists I interviewed commonly described being wary of para-practitioner ABA work, and worked to ensure para-practitioners were completing the correct activities and filling out data sheets accurately. One of the ways behaviour therapists determined whether para-practitioners were completing therapy programs compliantly was by juxtaposing their data sheets with the behavior of the autistic person. This was the case with Lydia who stated that ABA "data doesn't lie." I asked her whether it is possible that data could lie if para-practitioners do not fill the data out properly. Lydia agreed that data *can* lie and that para-practitioners

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what do you think about it? I'm filling it out like this.' So just a lot of dialogue. And there are some people that will never get it and you just have to [laughs] keep chugging along...

*do* commonly lie about completing interventions. The following excerpt provides context for how Lydia deals with dishonesty and how she orients to the autistic body as an evidentiary object for evaluating the truthfulness of work completed by para-practitioners:

Julia: Do people...lie about implementing—

Lydia: Oh yeah for sure.

Julia: How do you figure that out?

Lydia: There are... a ton of situations where, you know, you didn't write it on paper and it does not get executed for whatever the reason. You know, teachers are scared for their jobs. Or you know... people lie to cover up for a bazillion and one different reasons. I feel like we could all go a lot further in the accountability piece... When parents say: '...I've definitely been doing what you say at home,' like, 'I know you're not because this thing happened.' Like I had a case where, you know, the father was just obsessed with having his son watch wrestling with him. Well, his son unfortunately had a ton of mental health issues, autism issues, you know, aggression issues. He literally morphed into a real wrestler and tried to kill his classmate. And it's like 'okay I know you're still doing it, because every Thursday that follows the Wednesday night wrestling or whatever, the behaviours are like...' you know. It doesn't take a genius. We've been tracking the data: good, good, good, Tuesday's great, or Wednesday's great, next day: this is what happens...

Here Lydia identifies dishonesty as a common phenomenon in her work with para-practitioners, which she discovers in a variety of ways. First Lydia identifies the problem of para-practitioners choosing not to write down behavioural occurrences on paper, therefore demonstrating that they did not execute the intervention program. The second way Lydia identifies dishonesty is through comparing data tracking documents to an autistic person's behaviour. With the example of the father watching wrestling with his son, Lydia described pulling up the data-tracking sheet as an archive to be compared to the current embodied actions of the autistic person. This text-person comparison was used as proof that the father did not do what Lydia instructed, and watched wrestling with his son. In this way, the behaviour of the autistic person, combined with data sheets, becomes a key technique for experts to assess the dis/honesty and non/compliance of para-practitioner work.

The fieldwork examples in this section indicate that data sheets are not simply regulatory safeguards for ensuring para-practitioners enact behaviour therapies in a compliant manner. For example, Lydia describes interpreting and analyzing the truth of para-practitioners ABA practices as a common practice in her work, and Rosa describes

parents' attempts to hide their dishonesty as a common practice in their work. While para-practitioners work to hide dishonesty, Lydia tries to excavate it, though as Rosa's story articulates, therapists can also work with para-practitioners to conceal the actual practices they engage with from clinical supervisors. The truth of what actually goes on in ABA work is a game of cat and mouse, and both para-practitioner and expert relate to data as a way to "catch" or evade it, in order to achieve their own ends. Whether or not the truth is ever revealed, obscuring and searching for it can constitute a substantial portion of the work that both expert and para-practitioner complete. Para-practitioners find ways to make behaviour therapy methods their own, and there are lively stories hidden within their data sheets.

### **Joey and Donna**

I met with a married couple, Joey and Donna, who have an autistic adult son, Sam, in their beautiful home in an upscale neighbourhood. I interviewed Donna over the phone a year prior to coming to her town to interview her and Joey. I initially connected with Joey and Donna through my friend, Rayna, who is Donna's relative. I stayed with Rayna when I came to town to interview Joey and Donna and I spent quite a bit of time with all of them before the interview. I remember how welcomed and uncomfortable I felt as ethnographer and houseguest at Donna and Joey's weekly family Sunday night dinner: there I was, eating their food, drinking their wine, and laughing with them, all while knowing my professional role was to turn their lives and stories into analysis and argument. This was the first interview I conducted with people who opened up their homes for a social occasion and I remember how troubling this felt.

Joey and Donna have been married for about thirty years and they seemed very happy. They finished almost all of each other's sentences, which was heart-warming to witness, but very irritating to transcribe. Joey is bubbly, talkative and open, while Donna is quiet and soft-spoken, but she has a dry, sardonic sense of humour with a thundering laugh. As Donna put it: "Joey comes from an emotive Italian-Catholic background. I come from a Protestant... WASP" background, which stands for: "we all suffer privately."

*“The Buffet approach”: Pragmatism, Nature, and Ethical Frameworks*

The interview excerpts that I share from Joey and Donna are intended to show how some parents choose ABA practices based on their pre-formed ethical parenting philosophy and are more likely to engage with ABA methods if the therapist is able to translate them to match parents’ ethical frame. Joey and Donna’s personal and interpretive application of ABA methods complicates conceptions of behaviour therapies as standardized, measurable, evidence-based methods, elucidating how some parents incorporate therapeutic practices in the form of a bricolage: or what Joey and Donna refer to as their “buffet approach.” My analysis here extends Brian Wynne’s (1992) characterization of public science to behaviour analysis: people incorporate ABA in a way that makes sense with our social fabric and moral lives. Yet, because these para-practitioner actors are so central to the enactment of ABA, they are key *creators* of this applied scientific method. Specifically, Joey and Donna, relate to ABA practically: they view selective ABA methods, which they apply creatively and interpretively, as useful without ‘buying into’ the science itself.

In her book about the changing landscape of modern midwifery practice in Ontario, Margaret McDonald (2007) analyzes Margaret Lock and Patricia Kaufert’s notion of “pragmatism” as a concept for describing how women who choose to birth with a midwife, relate to available birthing medical technologies. MacDonald explains how women’s decisions about which medical technologies to engage with are grounded in pragmatism rather than “compliance or resistance” to biomedicine (2007, p. 110); hence, “women use technology to achieve their own goals, but doing so does not necessarily mean that women accept the ideology behind it” (2007, p.110). As I will demonstrate with Joey and Donna, parent para-practitioners can use ABA to achieve their own goals for their child and can do so without accepting the ideology of behavioural science. They can even ideologically oppose ABA and reject a behavioural worldview (as defined in Chapter One). Parent para-practitioners play an active role in modifying expert ABA methods and intervention plans to fit with their own ethical, political and philosophical parenting styles and family culture.

Pragmatism is another concept that complicates my analysis in Chapter One, which primarily focused on subjectification, as it highlights the active way that lay people take

up technology rather than how they are subjected to it. It also highlights the diffuse, and shifting power relations that comprise the everyday practice of behaviour therapies. Behaviour therapy experts can also relate to ABA pragmatically, to modify “official” practices to connect with the social lives of para-practitioners in order to enrol them to complete ABA work (I discuss this in the next section where I return to Lydia and use the concept of “tinkering” to describe her work with teacher para-practitioners.).

Without being asked, Joey and Donna launched right into their story of their son Sam’s, diagnosis (something almost all the parents I spoke with tended to do, often in near rote form). Sam is now in his twenties and so ABA services were starting to be introduced in Ontario when he was diagnosed around the age of two. Joey and Donna’s first encounter with an autism service was when an ABA provider came to their house and told them that they had to go through mandatory parent training in order for Sam to receive support. Donna recounted how this therapist, on her first visit, corrected Donna’s parenting on two occasions, telling her she was “positively reinforcing” Sam’s dysfunctional behaviour. After the therapist witnessed Donna give Sam an apple after he asked her for one, she told Donna that what she “*should* have done” was cut the apple into tiny pieces so that Sam would have to ask for each piece. Donna recalls the therapist communicating to her: “If you’re interested in helping him, you’re going to have to learn...to modify your approach to him and create an environment that forces him to communicate and constantly... sets up rewards for communication.” Donna and Joey were both appalled by this therapist and her intrusion into their home and parental relationship with Sam. In fact, this was the second time Donna told me this story, thus indicating the extent to which it upset, and has stayed with her. They refused services from this therapist despite being told she was the only one available to them. They had to fight the hospital where Sam was diagnosed, to find different supports and eventually advocated to receive services from a psychologist they knew who used ABA techniques, but in a manner that worked for them and meshed with their parenting philosophy. While wanting to avoid overgeneralizations, I consider Joey and Donna’s racial and class positioning—middle class, university educated, white, and Canadian citizens—as important contextual factors for their sense of entitlement to advocate for particular autism services.



While Joey and Donna did not like the first therapist because of her focus on modifying behaviour to fit into a pre-existing neurotypical environment, this second therapist focused on modifying the environment for safety and comfort, which they viewed as more respectful to Sam and enabled them to fulfil their parental role in a way that resonated with their pre-formed parenting styles. For example, when Sam was unscrewing all the bolts on the power outlets, this therapist suggested that Donna and Joey intervene by super gluing the bolts, rather than trying to change Sam's interest in completing this task. When Sam was throwing everything he could find down the stairs, inevitably breaking things, the therapist gave Sam a bag of potatoes to throw down the stairs instead. When Joey and Donna asked the therapist for help with trying to get Sam to sit down for a meal, the therapist questioned whether this was a practical goal and asked if instead they could work on getting Sam to *be* with the family over dinner. In this instance, Joey and Donna were impressed that this therapist pushed them to realize and modify *their own* normative expectations of Sam, in order to reflect what they referred to as their “bi-cultural” orientation to parenting. To explain what they meant by this term, they situated autism as constituting a cultural identity, and so having an autistic family member, like having a family from a different racial or ethical background, requires including the cultural practices of their kin into family traditions, rather than forcing assimilation to the dominant cultural identity of the family. Joey and Donna characterized their relationship with this therapist as collegial and dialogical, where their desires and orientation to parenting were listened to and embodied in how she designed Sam's interventions.

Interestingly, with this new therapist, Joey and Donna were more than happy to fill out standard ABA data collection sheets, such as the ABC Chart. They described the ABC Chart as “probably the most valuable thing [intervention] we got,” even though it constitutes what they would call, a “classic Lovaas” ABA technique, which they were in ideological opposition to. Yet the pair described using the information gleaned from the chart in a way that diverged from, what they referred to as, “old school” ABA. I was fascinated by how Joey and Donna described engaging with clinical activities but did not consider these activities clinical, so long as they could consider them *an extension* of their natural parenting style.

MacDonald (2007) analyzes how the concept of “nature” in reference to a “natural birth” was used by her informants as a flexible concept, often evoked when referring to their decision or requirement to incorporate unnatural biomedical interventions to assist with labour. MacDonald’s informants rationalized incorporating activities that might challenge their pre-formed birthing philosophies by *naturalizing* their use of biomedical technologies. Similarly, I consider how Joey and Donna also rationalized their engagement with classic ABA clinical methods by naturalizing clinical work, which they did by contextualizing this work as a way to actualize their established parenting philosophies. The attempts by the first therapist to enrol Joey and Donna to apply ABA by relating to them as an authoritative clinical ABA expert failed because her efforts could not be naturalized. The second therapist succeeded in enrolment because she related to the parents as co-conspirators and worked to translate their ethical orientation to parenting into a particular formulation of ABA centered on environmental modification, which fit with Joey and Donna’s bi-cultural understanding of their family structure. Through focusing on the environment, Joey and Donna were happy to complete “classic” clinical inscription work that centered on behaviour modification—and were likely compelled to compliantly complete it because it felt self-directed—as long as they were able to frame efforts to change behaviour as fitting within their parenting style. Completing these actions still involved shaping the actions and activities of all members of the house, but the therapeutic emphasis on environmental modification complimented Donna and Joey’s philosophical orientation towards autism as a “cultural difference” requiring accommodation and understanding, not normalization or assimilation.

The thematic thread that stitched our interview together was how Joey and Donna actively selected ABA methods to fit with their parenting philosophy. But I also focus on how they interpreted and selected certain aspects of specific ABA methods. For instance, while Joey and Donna hated the regimented Discrete Trial Training method, they decided to implement the hand-over-hand prompting method to teach Joey to help bring in groceries from the car. As mentioned, Joey and Donna were critical of the “classic” ABA focus on optimizing desirable behaviours and reducing autism-specific inappropriate behaviours, but they were willing to use this frame when Sam exhibited behaviours that

they viewed as unsafe or *universally* inappropriate for autistic and non-autistic people alike. To explore this further, here is an excerpt from our interview:

Donna: One of the times we used a daily classic Lovaas with him [Sam] was when... [in] high school... he came home with some really off colour language... and we were quickly wanting to shut that down. Like it started with, as he was leaving in the morning, turning around smiling and saying: ‘Goodbye Fuckheads!’

Joey: Loud. Like really loud.

Donna: Plus we also had, there was some behaviours along those lines that were serious, non-negotiable behaviours... He was burning stuff on the gas stove so we started giving him money and I think we had to start with a really short time period. I think it started like every five minutes he got money all evening long... So like, we have used those types of techniques when we’ve needed to and they’ve been, in those instances, very effective... Again it kinda comes back to the buffet approach ... like he was trying to understand why words existed if you weren’t allowed to say them and so we said: ‘Okay, you can say them, but it costs you a quarter ever time you say them, but it costs a quarter for everyone in the house’... And the thing that was hilarious was that it quickly turned that Sam was getting rich from this scheme. Because the person who caught the swear word got money so [laughs]... Sam relished when I had book club here because he would be like—

Joey: Hovering, listening. And then you’d hear from upstairs ‘That’s a quarter!’

Donna: Like my one friend would walk in the door and hand Sam a toonie ... paying him in advance [laughs]. But like I certainly think those types of approaches of managing things... obviously in a parental relationship it’s... you do have a power dynamic, and you do need to foster appropriate behaviors and, you know, motivate and reward. It’s the *artificial environment* of those therapeutic interventions where *it’s not part of the natural occurrence of the day* that it’s happening... You’re isolating them, making it a full time job, and it’s not, there’s no teachable moments...

Donna and Joey describe creating a system of continuous positive reinforcements, in the form of giving money, to stop Sam from burning things in the stove and also describe taking money away as a negative reinforcement for swearing. Donna describes the basis for instituting these reinforcement procedures to be Sam’s “non-negotiable, serious” behaviours. While Donna and Joey do not like the power dynamic of “artificial” therapeutic ABA sessions that involve “isolation” and temporal intensiveness, they used classic ABA behaviour modification techniques to resolve a situation that they perceived as warranting the *inherent* authoritative power dynamic of the parental role. Donna here contextualizes motivation and reward as a “natural” part of parenting, and so she considers her use of ABA as an extension, rather than an artificial intervention on, innate parenting methods. Motivation and reward only become a problem, Donna articulates, when applied

in a synthetic setting where the therapy and reward systems become life itself for the autistic person. Donna and Joey further refer to their use of classic ABA in these two examples as representing their “buffet approach” to therapies, and to ABA methods themselves. While they were highly critical of ABA, they resourced methods in certain circumstances that aligned with their political and philosophical orientation towards parenting and family life, and found them effective when they did.

Another important part of this excerpt is how Sam engaged with the swearing-money ABA intervention. Sam quickly turned what was meant to be a negative reinforcement for him (having to give away his own money for swearing) into a positive reinforcement by instead acting to monitor and ‘catch’ others swearing. In this sense, Sam’s interests had to be translated into the ABA methods that were used in the home. Thus, it is not only parents and para-practitioners that creatively interpret and negotiate ABA methods, so too do autistic recipients. Donna and Joey’s experiences speak to the variability of ABA providers and practices and the active character of parents in choosing which version of ABA they are willing to enrol themselves to apply, and their children to receive. Joey and Donna’s account of their application of behaviour analysis is instructive for showing how parents flexibly choose to adopt the ABA methods that experts teach them to apply as based on their preformed ideas of their “natural” parenting styles.

### **Sunnivah: Teaching ABA at school**

I met Sunnivah in the evening at her school, where the student body is composed of people diagnosed with developmental delays. The school is located at the edge of an urban centre, in a diverse working class area with lots of newcomer resources, low-income and social housing, affordable mom and pop restaurants, box stores, high-rise apartment buildings, and giant parks. I love this area, but it did not feel surprising that one of the few segregated schools for people with developmental disabilities was located in a geographically marginalized neighbourhood where many of those who are socially marginalized are placed. I entered the school after hours and was greeted by a receptionist behind a glass barrier who I spoke with through an intercom. She called up to Sunnivah and buzzed me in. Sunnivah came downstairs to meet me and we walked up the stairs to her classroom, which was extremely colourful and filled with photos, art, puzzles, and

toys. My initial thought was that this room might be a nightmare for someone with autism, as I felt so visually overwhelmed. In the middle of the room, there was an octagon table with eight chairs. In front of each seat was a picture of the student who sat there during the day with their name typed underneath. Some seats also had a sticker with four square pictures inside that illustrated the steps involved for eating and cleaning up breakfast. These pictures are used to prompt students to complete routinized activities and they are also used as communication devices: the pictures work as a substitute for verbal language for students who can point to objects but not articulate them through words.

Sunnivah invited me to sit down at the table and so I sat in Kelly's seat, with a picture of her bright shining face right beside my notebook and recorder. Throughout the interview, I kept glancing at Kelly's picture; I remember it still. Her face enlivened the stories about the constraints Sunnivah experienced within her classrooms' walls. I remember how, after the interview was over, Sunnivah confessed that she felt that the school administration viewed her students as "bodies taking up space," and that "most of the teachers at this school aren't good." These statements only put into words my felt experience of being in this space. Kelly's sweet face was one of these bodies discarded by the education system, and I felt a palpable kind of sadness about the lifeworld that existed within these walls.

*"The Visitors": Tinkering in the Classroom*

My interview with Sunnivah sheds light on how "special education" teachers, though required to work as ABA para-practitioners, negotiate and modify the instructions of ABA consultants who come into their classrooms to implement provincial ABA curriculum. Sunnivah describes the consultants as outsiders who enforce standard activities and teaching goals that do not work in her classroom and that erase the complexity of her actual everyday work. I consider the consultant visits and the standard ABA texts as governing techniques for ensuring Sunnivah applies the provincial curriculum. As Sunnivah's experiences indicate, the ABA curriculum does not just require practicing ABA methods but transforming teaching work into a technocratic skill.

Timothy Diamond's (1995) work is useful for understanding how the rationalization of healthcare work affects, transforms, and erases the actual activities

healthcare workers complete. I orient to his analysis as highly applicable to Sunnivah's teaching work. In his seminal ethnography on nursing homes, Diamond (1995) examines the role of standardized bureaucratic texts in transforming nursing homes into an efficient technocratic business of care. Diamond argues that the role of the nursing assistant is transformed through nursing charts. The work of nurses' aides is written out of the chart because it is only the physical life of residents that is monitored and recorded. Care work, which involves the unquantifiable labour of attending to changing emotions, bodily needs, human aches, are not only made invisible but meaningless. Constituting nursing work through the completion of distinct checklist-ed tasks erases the complex care work nurses complete, which makes it much harder for them to care for their patients.<sup>52</sup> Through charts, people are turned into nodes in the apparatus of this business of care. As I will demonstrate throughout this section, Sunnivah's work is rationalized through ABA document obligations, which renders it more difficult to organize, teach, and care for her students.

I consider the special education teacher as a hybrid occupation that involves carrying out educational, support, and healthcare activities, each of which is rationalized through the implementation of ABA (which itself is a hybrid lay-expert therapy-science field with the hybrid aims of improving intellectual, behavioural and communication abilities). I demonstrate how Sunnivah works against the rationalization of her work by "deliberately tinkering" (Boonen, Vosman & Niemeijer, 2017, p. 31) with expert instructions. Deliberate tinkering is a concept that describes how, within the management and evidence-based rationalization and standardization of healthcare work, healthcare workers learn to tamper with official protocol because standard procedures do not account for the complexities of their everyday work. As Bonnen et al. state: "this tinkering should not be seen as a thoughtless or automatic acting, but rather as something which is nurtured through a constant deliberation," even though tinkering is performed "under (institutional) circumstances which hardly allow for any divergence (2017, 34)." An important part of tinkering is that it is stealth enough for healthcare workers to complete non-standardized

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<sup>52</sup> For example, the skill and time involved in getting a resident into the bath or to the lunch-room are textually removed, so a nurse's job responsibilities are reduced to timetabled check-marked items such as "bath" "lunch" "toileting." Nursing work and patient schedules are created to ensure the proper economic and organizational functioning of the nursing home.

actions without the standardized system being interrupted. In this final section, I demonstrate how ABA para-practitioners can learn to tinker with official ABA intervention instructions to pragmatically meet their professional needs and how ABA experts also learn to tinker with ideal type ABA methods in order to enrol teacher para-practitioners to complete ABA work.

Sunnivah is almost impossibly soft spoken. She reminded me of a character in a Carol Shields novel and I imagined her gardening in a big home in the prairies. Before we began the interview, Sunnivah apologized for having to delay meeting with me and told me it was because there were so many “visitors” in her classroom that she had to prepare for. These visitors created a lot of extra work for her. They required Sunnivah to show them things and make them things, which took a lot of time to produce. These visitors, who I later learnt were ABA-informed education consultants from a large local autism agency, came up quite a bit in our interview. I understood Sunnivah as orienting to them as oblivious to the environment and the systemic challenges she faced in her classroom. They required her to comply with standardized requests that were impractical for her to implement. As Sunnivah stated: “sometimes consultants... don’t have as much of a grasp on what’s working and what’s not working. So that’s a part of the problem, where maybe I’m not getting very good at advice on what I could be doing.” The connotation of an alien invasion implicit in calling the consultants “the visitors,” articulated how Sunnivah related to them: as outsiders occupying and governing her classroom; outsiders she had to learn to appease while quietly working to resist.

Throughout our interview, Sunnivah described the various ways that these consultants intervened on her teaching to reorganize her classroom, and how she responded to these interventions. As I will demonstrate, Sunnivah took the parts of the ABA consultant instructions that worked within the actualities of her classroom and completed what she had to, to *seem* accountable to them. The first way that Sunnivah did this is through texts. When I asked Sunnivah about the role of documents in her work, for instance, she explained how consultants came in to teach her the importance of completing data sheets—such as the ABC Chart—properly, but how, in the actuality of her everyday work, these texts “recede a little into the past, except for the salient points” because “the job itself is just so hectic and the kids are just so unpredictable that you’re constantly on

your toes.” Because of this, Sunnivah described completing the ABC Chart as “stressful” yet “required,” and so, she only uses the data when it is most important to do so. One of the situations Sunnivah identified as important is when she needs to get one-on-one support for a student, as the ABC Chart is the only way for a teacher to apply for a student to receive this support. The ABC Chart, as Sunnivah understands it, is the only form of “proof” that legitimizes a teacher’s assessment of the support needs of her student.

I asked Sunnivah if she knows where her ABC data goes, beyond getting her students support, to which she responded that she knows “it’s used” but does not know how: “I have no idea. It’s really... You’re really cut off. It’s really like being blindfolded.” She further stated that she “never gets feedback” on her data, except for when the vice principal says she needs to add something to a column before officially submitting it. These comments indicate how Sunnivah’s work is governed by the consultant’s interventions aimed at textualizing her work through the collection of ABC data. The ABC Chart is a “coordinating text” (*see* Smith 2005) that affects the everyday activities in Sunnivah’s classroom but is used for purposes beyond it. Sunnivah knows this as she feels like she has been “blindfolded” and “cut off” from how her own textualizations are used. She actively creates her own relationship to the ABC Chart based not on its usefulness to her as a teacher or to her students, but based on pragmatism (getting her student’s the supports they need and appearing compliant): she only completes the chart when she discerns that it is required to do so.

Sunnivah also described how the consultants observed and made recommendations about which activities should be completed in her classroom: “they spend really brief moments in your classroom...they do a quick scan...usually they’re accompanied by the principal and vice principal... They usually do the talking and they don’t really ask questions of me.” Sunnivah then added: but they make “specific requests.” Sunnivah explained that she is visited by three managerial bodies—consultant, principal and vice principal—who assess and request her to reorganize the classroom without engaging in a conversation about her teaching, her work with Education Assistants, or her students. These managerial bodies, according to Sunnivah, come to her class to regulate it, from the top down. The lack of dialogue with Sunnivah further indicates the role of management in



implementing standardized activities that must be completed, regardless of local teaching practices and environments.

Sunnivah further explained how these consultants also instructed her to adopt a particular pedagogical approach, advising her to limit teaching to life skills, rather than trying to build academic ones. Sunnivah said she “kind of” listened to these instructions by focusing on life skills, though does still insist on teaching some academics, which she thinks the consultants view as “odd.” When I asked why, Sunnivah said it is because the consultants stated that there is “no evidence” that teaching academics to this population will be beneficial or effective. Some of the consultants have asked Sunnivah: “to what end do you want to do that?” Whether effective or not, Sunnivah’s response is that she believes that education has to be about providing the “opportunity to be opened up to something that might be bigger” than who we are. In other words, Sunnivah views teaching as a moral enterprise and academic learning as an education right, and one that persists even if it exists outside of quantification. Conversely, the consultants want both Sunnivah and the students to complete activities that have been proven statistically effective for this specific population, to ensure education can lead to beneficial outcomes that are *measurably* effective. Evidence is the frame for the activities that Sunnivah should complete in her classroom, and as will be clear, she knows this and tinkers with how to comply and resist this standardized pedagogical infrastructure.

The consultants make other curriculum recommendations that Sunnivah does not see as optional because “they come from the top,” such as completing the “success criteria” curriculum that involves creating pictorial representations of each student completing activities targeted in their Individual Education Plan (IEP). Sunnivah admitted: “I don’t know how much this is benefiting the kids, but it’s something that we were asked to do.” Turning teaching curriculum into step-by-step pictures indicates the technocratic rationalization of teaching work: teaching becomes the quantified task of completing standardized, calculable, and visible learning outcomes. The obligation to turn teaching work into pictorial representations also works as an evidentiary tool for ensuring teachers’ compliance with consultant instructions. Sunnivah showed me a book which consisted of a series of images all involving a teacher and a little boy holding a ball. It had typed words at the bottom of the pictures that narrated the student asking for, and holding, the ball. The

goal of the activities represented was to increase a student's communication skills by using the ball as a positive reinforcement to be enjoyed if the student learns to ask the teacher to hold it. Sunnivah agreed with this communication exercise but told me that collecting these pictures in a book format was actually *her* idea. What the consultants required, and "checked that she did," —she said this with a smirk—was put these pictures up as posters all over her classroom walls. Sunnivah thought the posters would over-stimulate her autistic students and so, instead, decided to make the book, which she could pull out and show to her students, and to "the visitors." I understand Sunnivah's book as her attempt to both adhere to and work against the "top down" instructions that standardize her teaching work.

Another area of conflict for Sunnivah was enacting the philosophical ideals that undergirded some of the activities the consultants implemented. For instance, Sunnivah discussed how "independence" was a goal the consultants viewed as principally important for Sunnivah to teach, but one that Sunnivah found impossible to foster given her classroom dynamics. Here is an excerpt from Sunnivah's interview to demonstrate how this played out regarding a consultant trying to modify the student's classroom breakfast routine:

When she [the consultant] came in she saw how I was doing my breakfast routine, which was for the most part verbal prompts, and she said 'try to have pictures instead so that the kids can be more independent and follow a picture routine of what's happening' - which is good, but on the other hand it's hard because this girl who sits here is really obsessed with dumping things.... So she would take a bottle of my paint for art and she'd be in her glory if she could squish it all down the sink, or she loves to flush things down the toilet.... Anything from here [points to her cupboards], if she got the chance... So if I give her more independence you can imagine what's going to happen. It's just going to be havoc in here... I can't be wasting things all the time and her being running [around] 'cause she'll wreck the toilet and then the plumbers have to come in and I get into trouble [laughs] with the caretaker. So, it's a real fine line. And then this kid over here... he's... always ten steps ahead, [with] something he wants. And so he would be all over the place too, doing something that's not with the program. So it's a real interesting balance... So yeah, that was her suggestion.

Here Sunnivah describes the complexities inherent in following this consultant's recommendation to modify her students' breakfast routine to foster their independence. Sunnivah explains how using instructive pictures instead of providing verbal prompts, designed to promote independence, would in actuality create "havoc" in the classroom:

one student would dump classroom materials, and might run from the classroom to clog up the toilet, while the other would be “all over the place” to go after the things he wants. Not only would this recommendation create issues within Sunnivah’s classroom, but the loss of classroom supplies and increased demand for cleaning and unclogging would impact the economic budget for the school, which Sunnivah would also be accountable for. Sunnivah refers to encouraging independence as requiring “an interesting balance” between the consultant’s recommendations, the actual context of her classroom, and the other institutional pressures she faces. She keeps the instructional pictures on her students’ desk, but she does not use those pictures as the consultant requested. If Sunnivah were to be compliant with the consultant’s advice, she would not be able to correctly complete her other duties, and so, she needs to walk this fine line, tinkering with her visitor’s direct instructions, but in a way that still appears like she’s following them.

*Lydia: Enrolling ABA implementation*

To provide a robust picture of the dynamic between teacher and education consultant, I turn now to an examination of ABA standardization in the classroom from the point of view of the expert tinkering with ideal type ABA methods to enrol the teacher para-practitioner to follow ABA procedures. The following excerpt details Lydia’s strategies for teaching teachers, as well as parents to apply ABA, and the kinds of methodological permutations to standardized data sheets that she facilitates in order to enroll their participation. I consider how she has to augment ABA data collection standards as a tradeoff for teacher compliance and reliable para-practitioner results. This excerpt also demonstrates how the consultant governs the conduct and alters the work practices of teachers, parents, and principals in order for them to abide by the provincial legal requirement to provide ABA.

Just before the beginning of this excerpt, Lydia was discussing the problem of teacher and parent non-compliance with ABA. This excerpt is a response to my inquiry about para-practitioner compliance and outlines how she deals with noncompliance:

Lydia: So often, there’s always parent problems, because parents are anxious and stressed, it’s a very stressful thing to have a kid with autism or special needs and be their advocate... And again, I think I’m more of a fan of ‘let’s try to make this data as simplistic as possible.’ Just because ah [sigh]...the more complex like... if you try to do like what you do in a clinical setting, like that’s not possible for

everybody in the school setting. And more often than not you just get skewed results that like, you've wasted everybody's time and the pieces of paper...

I was invited one time...to present to a group of teachers on autism, cause there was a network on data and this other guy had been invited too... He got up first and he like had his spreadsheets and was like: 'Every Wednesday I do this and I compile it and dadadada.' He like blew everyone away. And then my whole presentation was on: 'Hey did you know how to checkmark data?' Two polar opposite views. He would be brilliant for the clinical setting, you know, a real jewel... He's a brilliant teacher... But I find that even just the word 'data' scares people a lot. But sometimes they'll understand: 'have you done your checkmarks?' or whatever. Like data can be a worksheet. I'm trying to get them to understand, it's not a big and scary as it seems and you get people to actually execute a little bit more. And the more they do it the more proficient they can get at it... It's tough. I don't know how familiar you are with PPM140, have you—

Julia: Yeah, I'm familiar. I've read it a couple times...

Lydia: So whether or not a lot of teachers, even though it's a legal requirement now... Part of that is: ABA practices are so tied in with data. Like there's no way around it, now we have to. You're teaching an autism class or you're a support staff in an autism class, guess what: you're legally required, so.... It's not a scare tactic, but at the same time...this is what our province has decided and whether you feel that you can or can't, you now are qualified to do it... So just even getting a start with very simplistic forms...So for example, this year... I had clipboards for everybody with the data sheets on it, and you know my principal was saying 'you know it's not an expectation to have them carrying around clipboards' and I was saying 'It's a legal expectation.' But... for the first month, I don't even care if you're writing on that sheet, I want you to get used to the practice of carrying around a clipboard. It's just - it's a requirement! ...You can't just be anecdotal, you know?

Lydia begins this excerpt discussing her work enrolling parents to apply ABA. She refers to her work to get parents to complete ABA interventions as difficult: in fact she frames her work with parents as consisting of "parent problems." The way she works against parents' and teachers' resistance to ABA is by simplifying the data sheets as much as possible. If she did not simplify the data, she would be wasting time and paper because these actors cannot complete ideal-type clinical ABA work. Lydia thus draws a methodological distinction between "clinical ABA" and "para-practitioner ABA": if you try to implement clinical ABA in a school setting, the methods will fail and the reported outcomes will not be reliable. Lydia juxtaposed her own approach as oppositional to the story of the teacher who presented on his extensive data collection and organization practices to the group of teachers. Lydia classified this work as "brilliant for the clinical setting" but impractical for her own consulting work, where even the word 'data' "scares

people.” Accordingly, Lydia modifies not only her approach to data collection but to language, referring to data-work instead as “checkmarks.” Through simplifying and re-articulating data-work, Lydia has found that people are more likely to be enrolled to complete it.

In the second section of the excerpt Lydia refers to the PPM-140 and repeats multiple times that with the implementation of this policy, collecting data is a “legal requirement.” Here Lydia evokes the hard line of the law while simultaneously describing how she tinkers with clinical ABA methods to enrol teachers to collect data. In fact, for the first month of school they only have to *hold* a clipboard. I consider that Lydia orients to the clipboard as a prop, but one that will lead to data-naturalization. Lydia’s description of her work establishes methodological tinkering as *the foundation* for translating clinical ABA to para-practitioner ABA. She further communicates that para-practitioner ABA is distinct from clinical ABA, but she is tasked with ensuring that para-practitioners provide a form of ABA that conforms to provincial ABA standards. Paradoxically, complying with legal standards means modifying the standards themselves: in the complex actualities of her everyday work, in order to get teachers to apply behaviour analysis, she has to simplify it to make it less standard. When implementing ABA in non-clinical spaces to lay actors, tinkering with clinical standards of data collection is the only way to receive reliable results.

## **Conclusion**

In this chapter I analyzed how para-practitioners engage with behaviour therapy methods and relate to therapist-experts, to bring to life the complex range of activities, emotions, rationales, and relationships that constitute how behaviour therapies are practiced in everyday life. Para-practitioner practices make up the everyday ABA work that gets done, and so examining para-practitioner’s experiences shows how this applied clinical method is actually enacted on the ground. What I have aimed to demonstrate, through providing a close reading of four para-practitioners experiences, is the full world of meaning, practices, and motivations that constitute and shape their ABA activities. In chapter One I focused on the constraining and subjectifying aspects of power involved in learning to become an ABA provider, but I have spent the last two chapters analyzing power as a

“productive relation” (Mykhalovskiy, 2003, p.334) in ABA work. Like Biehl, I orient to ethnography as a technique for bringing intricate tensions to the surface, in which “a sense of the present as embattled and unfinished” is articulated through conversation and through text (2010, p.228). Para-practitioner work, and ABA as a clinical enterprise, is actively being made, contested, reformulated and transformed by the multiple actors who apply and receive it. Despite the ideal-type mechanical clinical practices of what is said to constitute standard ABA practice, the rich lifeworld of everyday work demonstrates the diverse, messy and prismatic actualities that constitute applied behavior analysis in everyday life.

This chapter has been dedicated to demonstrating that behaviour therapies hold a diversity of relationships, social arrangements, and practices within it. Tasking para-practitioners to provide behaviour therapies means that people who do not have formal specialized knowledge or training make up a substantial portion of the actors who apply this therapeutic method. Some of these para-practitioners apply ABA from the affectively interested position of being a parent, while for teachers and education assistants, behavioural therapies might be an overwhelming additional task added to their already hectic workday. The situatedness and personality of the para-practitioner fundamentally shapes how each actor engages with orienting to and completing ABA work.

Another important component of this chapter was analyzing the various ways that para-practitioners relate to texts, primarily the ABC Chart. Studying para-practitioners excavates the textured and complex stories that haunt the columns, checkmarks, and borders of the clinical data sheets they complete. While experts can use texts as a way to govern para-practitioner work, para-practitioners can resist these textual forms of governance in creative and sneaky ways.

The crafty decision of Rosa and her therapist to oppose the narrow direct instructions of the BIP, but to inscribe their compliance to it, demonstrates how regulatory texts do not always regulate action and do not always reflect the work that is actually being done. Rosa’s account further demonstrates how both para-practitioner and therapist-expert can be aware that ABA clinicians orient to data tracking texts as representative of the actions they complete, and so work together to ensure their texts inscribe those actions while choosing to complete different ones. When Rosa discussed the phenomenon of her

parent-friends “lying” when completing ABC Charts, she revealed how some para-practitioners may not orient to ABA texts as clinical documents, but as affectively loaded evaluative interpersonal objects for appraising their therapist. The story of Joey and Donna’s completion of the ABC Chart when working with a therapist who framed ABA as an extension of their natural parenting styles, provides insight into how lay enrolment required naturalizing clinical work to fit within the affective and cultural infrastructure of the household. Sunnivah’s deliberate tinkering with the textual activities required by her ABA “visitors” was her way of trying to both comply to and resist the technocratic rationalization of her classroom and to insert her own teaching philosophy. Further, Sunnivah tinkered with texts in order to work out the incompatibility of her “visitors” requests when dealing with the complex realities of her classroom. I incorporated an analysis of Lydia’s work as a consultant to show how she must learn to tinker with ideal type clinical ABA texts and methods to successfully implement ABA for para-practitioners, but the trade off for doing this is a *bifurcation* of clinical and para-practitioner led ABA.

I further demonstrated how Lydia and other ABA experts, look at what a particular autistic person does in a particular moment of time to make a judgment about whether para-practitioners have been compliant with ABA standards. What all these accounts point to is the use of texts as sites of contestation and negotiation that can be used by para-practitioners to resist authoritative expert instructions or to achieve non-clinical goals. Textual compliance does not always indicate compliance in action.

I have also examined how para-practitioners do not primarily orient to ABA as a clinical method, but as a pragmatic or strategic way to acquire the support they need. As behaviour therapies are practiced in everyday life, they become a range of different activities and methods, multiplying in form, content and meaning. Standardized data sheets are supposed to hold behaviour therapies together as a reliable, objective, and measurable applied scientific practice, but data can be also be oriented to as a catalyst for completing a variety of activities that fall well outside of the scope and intended purpose of applied behaviour analysis work. The generosity of behaviour therapies means that they become many different objects, each one constituting its own story of practices and activities. Generosity manifests in methodological elasticity. Unlike my argument in

Chapter Two, where I showed how behaviour therapists are governed by larger managerial and institutional systems, here I argue that applied behaviour therapies are profuse: para-practitioners shape therapy programs to suit their own needs and to match their moral codes, despite comprehensive oversight and attempts to standardize practice.



## CHAPTER FOUR

### Applied Behaviour Analysis and Political Discourse

The last chapter focused on how para-practitioners' activities both shape and introduce substantial variation into everyday behavioural therapy interventions. I further engaged with how para-practitioners and behaviour therapists build interpersonal relationships with each other and participate in power struggles as they complete specific therapeutic activities, such the Antecedent Behaviour Consequent Chart. In this chapter, I move away from analyzing clinical delivery to look at the broader movement in which applied behaviour therapies are situated. These therapies have not only shaped public policies and autism discourse, they have structured the social and political terrain of everyday autism social relations, particularly in relation to topics of political voice, representation and expert credibility.

Behaviour therapies have become the social nucleus in which contemporary autism-based communities and politics take shape. This chapter is about rethinking the politics of autism advocacy movements and the role of behaviour therapies therein. Current social science literature on the political and social implications of behaviour therapies has examined how autism communities are marked by a severe cleavage between critics and proponents. A number of social science autism scholars (Bagatell, 2010; Eyal et al., 2010; Orsini, 2009; Orsini and Smith, 2010; Solomon, 2008) have provided accounts of the political discourse of applied behaviour therapies as comprised of mostly non-autistic parents (mothers) and clinicians as proponents (these actors comprise what has been called *the autism movement*), and mostly autistic self-advocates as critics (these actors comprise what has been termed *the autistic movement*). Autism researcher and autistic ABA critic Michelle Dawson (2004; 2005) has described the conflict between critics and proponents from the *autism* and *autistic movement* as “the autism wars.” Actors from both the *autism* and *autistic movement* actively vie for the role of autism spokesperson: both sides want to define the meaning of autism and occupy the role of the credible autism advocate (Orsini, 2009, 2012; Orsini & Smith, 2010).

The point of this chapter is to contribute new insights to the autism wars and autism advocacy in relation to ABA. While current literature on the impact of behaviour

therapies in structuring the politics of autism communities is highly instructive, my empirical analysis indicates that autism politics is, in some notable ways, more complex than the metaphor of war suggests. Conceptualizing what is happening in the lives of actors invested in autism as a war brings important discursive struggles to the surface, but may inadvertently obscure the politically diverse and intricate power struggles that happen around behaviour therapies and autism advocacy in the everyday.

In the ethnographic sections of this chapter I demonstrate how my participants interpret and activate the debates about ABA and autism advocacy in such a way as to both *reinforce and complicate* scholarly and discursive accounts of the autism wars. There is a central tension in my argument in that I both support and critique the normative account of the autism wars. An analysis of how autism/autistic actors take up behaviour therapies in their everyday lives is simultaneously a meditation on how autism governance works on a micro interpersonal scale. As I will show, the power relations and political discourse of behaviour therapies and autism advocacy are both concrete and fluid.

Being for or against behaviour therapies has become the language for speaking a particular autism politic and a particular view of expert credibility that is steeped in the history of autism care and advocacy. Eyal et al's. (2010) genealogical account of the clinician-governed autism network of the 1940s and 1950s and the move to a parent-led autism network in the 1960s, is particularly important for this chapter because it describes the power struggles related to autism interventions and advocacy that I argue shape current autism-ABA discourse. Eyal et al. (2010) also demonstrate how these power struggles relate to larger political and epistemological debates about expert credibility. I consider how current advocacy debates that centre on the topic of behaviour therapies revivify *all the different historical moments* of autism governance that Eyal et al. (2010) describe, but in new and complicated ways. My participants, for example, decided on who (clinicians, parents, or autistic self-advocates) should constitute the best autism advocate based on how they evaluated objectivity, partiality and standpoint knowledge. Interestingly, each participant evaluated these topics differently. Their views about behaviour analysis dovetailed with their political formulations of advocacy, which were actively shaped by larger scientific and social conversations as well as by different historical responses to autism care.

The first empirical section of this chapter affirms the reality of the autism wars but aims to expand how these wars have been studied by considering how the fissure between critics and proponents is coordinated by gender, sexuality, and identity politics more broadly. In this section, I primarily draw on my empirical work at conferences organized by those from both the *autism* and *autistic movement* to analyze how differing worldviews towards autism and behaviour therapies are formulated through queerness and sex/gender norms. I demonstrate how advocates from both sides of the war conjure gender in particular ways to critique the other side, and that much of the normative dialogue concerning behaviour therapies that I observed was expressed through aligning with queerness or heteronormativity.

The second empirical section of this chapter complicates the normative characterization of the autism wars by showing how my participants' views of autism advocacy embody complex formulations of identity, scientific credibility, and political voice. I begin by examining my interview with Orli, an autistic person and aspiring behaviour therapist affiliated with the self-advocacy movement. Orli identifies the political value of behaviour therapies as paradoxically defined by the fact that they provide an apolitical and objective account of the autistic subject, yet she considers how her personal knowledge of autism augments her clinical objectivity. Following Orli, I analyze how my behaviour therapist participant Bobby views behaviour therapies as shaped by cultural norms and as innately biased towards the "normal" subject. Conversely, my informants Sam and Louisa consider behaviour therapies as governed by managerial bodies intent on fitting disabled people into their institutional system, and they recognize parents as the best advocates for autistic people because of their affective closeness. I further discuss how my informant Laurie, an autistic self-advocate, considers both parents and behaviour therapists as untrustworthy advocates because of their affective and clinical bias against autistic people. In Laurie's view, autism advocacy is a matter of identity politics: only those with standpoint knowledge can be credible spokespeople.

Before moving on to my ethnographic analyses I will provide a detailed synthesis of Eyal et al. (2010) and Orsini's (2009; 2012; Orsini & Smith, 2010) work to contextualize how the recent shifting history of autism governance shapes the political responses and social collectivities that have come into being through behaviour therapies.

## **Background and Context**

Eyal et al.'s (2010) historical work on the shifting eras of autism governance and advocacy, from the emergence of the “disorder” to present day, is key to understanding the context of the autism wars and how things like political voice and representation shape autism politics and political responses to behaviour therapies. To provide further context for analyzing how my participants view autism, advocacy and ABA, I also synthesize Orsini (2009; 2012) and Orsini & Smith's (2010) work on the burgeoning autistic self-advocacy movement and the autism wars. In the first empirical section of this chapter I aim to contribute to Eyal et al. (2010), Orsini (2009) and Orsini & Smith's (2010) research, as well as to emerging research by Yergeau (2018) and Gibson & Douglas (under review) about ABA and gender norms, by studying how categories of gender/sex/sexuality structure the autism wars and contemporary autism-ABA governance relations. In the second empirical section, I draw closely on Eyal, et al.'s (2010) work to analyze how my participants' formulations of ABA and political voice are shaped by many different moments of autism governance and expert credibility but in ways that challenge the depiction of ABA as primarily taken up by actors in autism/autistic communities in rigid and severely oppositional ways. My participants adopted a range of views towards ABA that were often quite nuanced. These views were influenced by larger cultural factors and discourses as well as different historical eras of autism care and advocacy. Understanding these diverse factors is key to learning the power relations within autism communities and how members of these communities make sense of autism, ABA, advocacy, and political voice in their everyday lives.

Eyal et al. (2010) identify the 1940s as a time when prominent psychologists and psychiatrists began to research autism. As mentioned in Chapter Three, during this period and up until the deinstitutionalization movement, leading clinical autism experts viewed parents as “damaged and damaging” to their autistic children (Eyal et al., 2010). For example, holocaust survivor and Austrian psychologist Bruno Bettelheim directed the Chicago Residential Orthogenic School for autistic children starting in 1944 (then called “severely emotionally disturbed children”), to rehabilitate them from their so-called harsh and traumatizing mothers and home environments (Douglas, 2014; Eyal et al., 2010;

Silverman, 2014). In his notorious text, *The Empty Fortress* (1967), Bettelheim developed his concept of the “refrigerator mother,” where he likened mothers to the cold and punishing Nazi soldiers of concentration camps, essentially blaming them for causing their child’s autism. Bettelheim (1967) thought extracting children from their mothers and home environment, to place them in a warm and loving clinical environment (a substitute family home) was the effective way to treat autism.

In addition to Bettelheim, Leo Kanner, the father of child psychiatry (who, in his seminal paper “Autistic Disturbances of Affective Contact” (1943) coined the term “infantile autism syndrome,” now known as “autism”), blamed parents in a similar manner, while also relying on their meticulous observations of their children for his clinical assessments (Eyal et al., 2010; Silverman 2014). Kanner described autism parents as “cold, detail oriented, gifted observers” (Eyal et al., 2010, p.177), who were thoroughly obsessive in their thinking. Kanner pathologized parents for being autistic-like yet viewed their autistic-like traits as making them valuable data collectors, though he still felt obliged to heavily parse their data to ensure impartiality. Eyal et al., explain how, while vital to Kanner’s clinical findings, parents’ “testimony” was “discredited” and the “clinician was positioned as an obligatory point of passage in this network” of autism care (2010, p. 177). The pathologization of parents by leading autism clinical experts as well as a lack of funding, awareness, or support for autism, is what inspired parents to form a parent-centric “network of expertise” (Eyal et al., 2010, p. 172). In the United States in the mid-1960s, the era of de-institutionalization and the rise of autism diagnoses, parents created the National Society of Autistic Children (NSAC) and mobilized as “parent-activist-therapist-researcher[s]” (Eyal et al., 2010, p.171). Eyal et al. consider (2010, p. 172) how the formation of NSAC was key to solidifying the governance power of the nascent autism parent movement: the “autism parent” became a new and politically powerful, expert vocation. These parents had a “common enemy in dynamic psychiatry and a common goal: to reinstate parents as credible witnesses so as to protect their observations, opinions, and interests in the public and professional discourses about autism” (Eyal et al., 2010, p.177).

NSAC was founded by Bernard Rimland (a prominent autism parent, psychologist, and author of *Infantile Autism*) and supported by influential autism parent-researchers,

such as prominent psychiatrist, Lorna Wing (Eyal et al., 2010). Both Wing and Rimland were unhappy about institutionalization and the little clinical information available about autism at the time, so they (independent of each other) fervently researched autism to search for more treatment options (Eyal et al, 2010). Eyal et al. (2010) explain how during the first NSAC meeting Rimland positively introduced Lovaas' work and explained how valuable parents could be in carrying out ABA sessions with their children. Through their advocacy and research, Rimland and Wing became central parental, clinical, and political figures, and NSAC became the main hub through which ABA, autism research and community flowed (Eyal et al., 2010).

Eyal et al. (2010), argue that the solidification of this new parent network owes to how well parent-advocates were able to draw in leading clinical experts into their activities. In turn, these experts came to rely on parent networks to expand their therapeutic enterprises (as discussed in Chapter Three, this was particularly the case with Lovaas and the rise of ABA). Eyal et al. (2010) explain how German-American developmental psychologist and founder of the TEACCH method in 1971, Eric Schopler, was another key clinician enrolled by NSAC. Schopler opposed the dominant clinical and psychiatric approach to autism research and considered parents to be his principal allies. Schopler pushed for parents to become "experts of their own child," as he considered them to have the highest level of motivation as well as the highest access to information regarding the autistic child (Eyal et al., 2010, p.182). Schopler also discredited the dominant clinical view that parents caused their child's autism. Instead, he proposed that any coldness parents displayed towards their autistic child was a *reaction* to their child's affective (in)difference, not caused by it. As Eyal et al. encapsulate: the autistic child "went from being disturbed to disturbing" and the "arrow of harm bent back" from "child to parent" and thus from mother to clinician (2010, p.180). In essence, parent-experts now cast psychiatrists as unreliable observers and untrustworthy actors that they needed to vet. As Eyal et al. state: "The economy of blame and worth was... completely inverted, with parent testimony becoming credible and clinical insight discredited" (2010, p.180). NSAC reversed the power and expert relationship between clinicians and parents. Parents became powerful political actors through becoming clinical autism experts, and their clinical

knowledge created autism social collectivities that governed the production, transfer and dissemination of clinical autism work on a systemic level.

Schopler, along with other autism experts invited into NSAC's network, like Reichler and Lovaas, reoriented to the contributory role of parents: parent data was "the best... to be had" (Eyal et al., 2010, p.180). These clinical experts viewed parents' data as so valuable *because of* their affective closeness to their children (Eyal et al., 2010). Parents' love for their child fuelled their clinical work and rendered it trustworthy and their access to their child constituted the possibility for ubiquitous clinical observation, which is something no clinician, no matter how invested, could have. Parents were no longer viewed as culpable because of their "proximity and entanglement," but as the only actors through which "relevant information" flowed and could be synthesized (Eyal et al., 2010, p.183).

Like Schopler, Lovaas explicitly framed parents as the obligatory points of passage for therapeutic work, suggesting they be clinical partners and "managers of treatment teams" (Eyal et al., 2010, p.183). In this new network of expertise, parents not only became the best "therapists-experimenters," but the best advocates (Eyal et al., 2010, p.184). Hence, not only could parents provide the most reliable and thorough clinical data but they were viewed as possessing "enough knowledge and discernment to undertake... [the] task of radical translation" (Eyal et al., 2010, p.192). Autism parents responsabilized themselves to be both interpreter and advocate for their autistic child: they became autism researchers, and autisms' representatives.

### *The Second wave of the autism network of expertise*

Eyal et al. (2010) explain how in the 1990s another restructuring of the autism network of expertise emerged with the autism self-advocacy movement. Autistic self-advocates argue that their status as radical translators is superior to that of parents or clinicians. Hence, "When it comes to reporting on the experience of being autistic, what it feels like, and therefore what it might mean when an autistic child says or does something peculiar" self-advocate accounts should be considered "the best currency around" (Eyal et al., 2010, p. 229). Autistic self-advocates often directly challenge parents' positions as autism spokespeople (Bagatell, 2010; Davita-Raeburn and Spectrum News, 2016; Eyal et al.,

2010, Orsini; 2009; Orsini and Smith, 2010; Sinclair, 2002). While a number of autism scholars and self-advocates take up the issue of behaviour therapies and autism advocacy (AnxiousAdvocate, 2015; Bagatell, 2010; Broderick and Ne'eman, 2008; Dawson, 2004, 2005, 2007; Inks and Dagers, 2015; Real Social Skills, 2014, 2016; Unstrange Mind, 2016; Schaber, 2014; Sequenzia, 2015, 2016; Yergeau, 2018; Zurcher, 2012), Michael Orsini, both in his own work (2009; 2012) and through his collaborative research with Miriam Smith (2010), provides the most thorough scholarly account of just how complex and conflictual the advocacy struggles between self-advocates and pro-ABA parents currently are.

As introduced earlier in this Chapter, Orsini's (2009) scholarship demonstrates the bifurcation of autism collectivities into the dominant *autism movement* and the *autistic movement*, forming the autism wars. Orsini (2009; 2012; Orsini and Smith, 2010) explains that the *autism* and the *autistic movement* have different conceptions of the meaning of autism. Those from the *autism movement* often think of autism as a devastating disorder to be fixed through science and medicine via biomedical treatments and behaviour therapies (Autism Speaks, 2014; *Auton vs British Columbia*, 2002-2003; Defeat Autism Now, 2014; Gordon, 2012; McGuire, 2016). In contrast, those from the *autistic movement* generally adopt a civil and disability rights approach by conceiving of autism as a form of cultural difference to be respected and included like other kinds of differences (such as those of race, class, gender, sexual orientation) (Autism Self Advocacy Network, 2012; Autistics.org, 2008; Baggs, 2007; Dawson, 2005; McGuire, 2016; Sinclair, 2002).

Orsini's corpus of work (2009; 2012; Orsini and Smith, 2010) situates autism as a social health movement. His research is grounded in the nexus of policy studies, critical disability studies and STS. Two of his articles (2012; Orsini and Smith, 2010) include empirical data of twenty-three interviews he conducted with autistic self-advocates and their allies. These participants shared their thoughts about autism, ABA and their interactions with those in the *autism movement*.

Orsini's scholarship primarily engages with how the "disagreements that have been prominent within the autism and autistic communities are a product of fundamental disagreements about the proper role of knowledge and experience in society and in policy making" (Orsini & Smith, 2010, p.54). He analyzes this from many angles, which I will



briefly synthesize. First, (2009) he studies the contentious politics inherent in the tendency of parents (mostly mothers) from the *autism movement* to make proxy biocitizenship claims (*see* Petryna, 2005; *see* Rose and Novas, 2005) for ABA to be funded as a medically necessary service for autistic children. These parents have become the political mouthpiece of mainstream autism discourse and policy in the U.S. and Canada even though they directly contradict the views and goals of those in the adult autistic self-advocacy movement (Orsini, 2009) who actively fight against them. Orsini (2012) further examines how the autism wars bring up the limits of liberal concepts of diversity in the welfare state when it comes to including cognitive forms of diversity. The power of non-autistic actors to organize autism services around a biomedical model indicates that autistic people are not considered active citizens capable of articulating their rights, hopes and dreams but passive subjects to be spoken for by others (Orsini, 2012).

When collaborating with Smith, Orsini incorporates STS literature on expertise (Collins and Evans, 2002; Fisher, 2009; Hacking, 2000; Haraway, 1988; Gottweis, 1998) to describe how actors invested in these movements adopt different kinds of expert knowledge when staking claim to funding for autism services. While those from the autism movement who promote ABA often present scientific evidence as neutral and objective confirmation of the legitimacy of their technocratic advocacy platform for shaping policy, self-advocates use their embodied knowledge to advance their biosocial claims. As I will discuss shortly, Orsini and Smith (2010) demonstrate how the embodied knowledge form of expertise adopted by self-advocates is not only often discounted by those in the autism movement, but by autism policy makers in the U.S. and Canada. Lastly, throughout his work Orsini importantly considers how ‘autism moms’ are the most vocal advocates in the *autism movement*. I expand on this important insight in my first empirical section by analyzing how sex, gender and sexual orientation fundamentally structure the normative discourse of the autism wars.

To speak more specifically about the autism wars and ABA, Orsini (2009; 2012), Orsini and Smith (2010), as well as others (Bagetell, 2010; Devita-Raeburn, 2016; Solomon, 2008), illustrate how behaviour therapies are central to the autism wars. As stated above, they explain how actors in the *autism movement* are often active proponents of ABA, legally advocating for free access to it on the basis that it be classified a human

right and medically necessary (*Auton vs British Columbia*, 2002-2003; Dawson, 2005; Orsini, 2009; Orsini and Smith, 2010). Conversely, actors in the *autistic movement* commonly mobilize against these therapies, viewing them as oppressive forms of autism conversion therapy (Dawson, 2007; Birdmadgrrl, 2017; Gibson & Douglas, under review; Molnar, 2017; Sequenzia, 2016). In this movement, it is not uncommon for behaviour therapy recipients to speak out about the abusive experiences of their childhood behaviour therapy programs and urge governments, parents, and clinicians to reform or stop applying behaviour therapies (Bascom, 2011; Fleischmann, 2013; Zurcher, 2012). Former behaviour therapy providers invested in the goals of the *autistic movement* have also spoken out to decry ABA as abusive (AnxiousAdvocate, 2015; Birdmadgrrl, 2017; Inks and Daggers, 2015).

The *autism movement* not only dominates autism discourse but often marginalizes and villainizes anti-ABA autistic self-advocates. Autistic self-advocates sometimes view parents from the autism movement as their central opponents to living a free and just life (Bagatell, 2010; Dawson, 2007; Orsini 2009; Orsini & Smith, 2010). A common refrain from the self-advocate community is that situating parents as the most credible advocate-spokespeople silences the voices of autistic people and the voices of self-advocates in particular. As prominent self-advocate and founder of the Autism Self-Advocacy Network (ASAN), Ari Ne’eman states: “What aggravates me is the idea that it’s so inconceivable that we should have something to say about our own lives... you should involve autistic people instead of trying to make autistic people ‘normal.’” (O’hara, 2011, para 16). To this end, self-advocates have adopted the famous disability rights slogan “Nothing about us, without us” (Eyal et al., 2010; Sinclair, 2002, ASAN, 2016).

Alternatively, many autism organizations led by those in the *autism movement* have banned anti-ABA autistic activists from their organizations (these organizations generally do not have any autistic people serving on their boards either) and deploy a number of strategies to undermine their political positions (Bagatell, 2010; Dawson, 2004): 1) they invoke the power of genetic kinship, hierarchicalizing the affective bond of the parent/child to situate autism as a disorder that effects the whole family (Bagatell, 2010; Doherty, 2009; Eyal, 2013; Ne’eman, 2011); 2) they strategically invoke autistic diagnostic characteristics, such as a lack of empathy or theory of mind, to describe these

activists as uninformed and unempathetic (Bagatell, 2010; Dawson, 2004; Orsini, 2009, 2012; Orsini and Smith, 2010); 3) they argue that the activists who received behavior therapies as children and are against these therapies now paradoxically serve as therapy success stories (Gruson-Wood, 2014) because the therapies enabled them to develop the capacity to articulate their views, and; 4) they strategically fracture the ontology of autism. For example, autism advocates resource the gradient notion of the “spectrum” to argue that those who are “higher functioning” are not really autistic and therefore do not understand or have the right to speak for those with “severe” autism: those who exist on the “lower” end of the spectrum (Bagatell, 2010; Davita-Raeburn and Spectrum News, 2016; Jager, 2010; Orsini, 2009; Orsini and Smith, 2010). Hence, people with autism are either too autistic to have a voice or not autistic enough for their opinions to matter. As I witnessed in my fieldwork, it seems that the very identity of *autistic activist* de facto has come to define an autistic person as too high functioning to speak for people with autism. In sum, in this rewired expertise network, the economy of blame and worth rebounds back and forth between autistic adults, parents and clinicians, as each can deem the other as damaged translators and untrustworthy advocates for reasons related to issues of identity politics, disability politics, ethics and expert credibility.

Critical autism scholarship on the autism wars provides an important contextual map for understanding different arrangements of autism governance and how these arrangements inform current autism advocacy discourse centering on behaviour therapies. In my ethnographic sections I both extend and complicate Eyal et al. (2010), Orsini (2009) and Orsini & Smith’s (2010) work by showing how the power struggles (between parents, clinicians, and autistic self-advocates) that culminate around behaviour therapies clearly exist but can be viewed as unstable in certain respects. Characterizing the impact of behaviour therapies as that of a war may capture certain elements of what’s going on in autism communities while masking the significantly complex and active social character of ABA and autism advocacy in everyday life. I further consider how this fraught history of autistic-parent-clinician relations, relating to the topics of power, trust, reliability, identity, advocacy, objectivity and interestedness animate the views and politics of my participants in a way that indicates an *actively unstable and contested network* of current autism expertise and advocacy.

I will now begin to analyze this by building on Orsini's scholarship about ABA, the *autism/autistic movement* and the autism wars, by showing how these wars are structured by categories of sex/gender/sexuality and larger discourses of identity politics, power and difference.

### **How sexuality and social markers structure autism/autistic communities and shape 'the autism wars'**

While scholars in the social sciences are beginning to produce gendered analyses of autism advocacy discourse and behaviour therapy interventions (Douglas, 2013, 2014, 2016; Yergeau, 2018), more literature on how the autism wars are shaped by gender, sexuality and other social markers is needed. Patty Douglas (2013, 2014, 2016) has contributed greatly to a gendered analysis of the *autism movement*. She has examined the mother-centricity of autism advocacy movements and the hetero-patriarchal imperialism of the highly pervasive autism mother-warrior crusade (Douglas, 2013, 2014, 2016). In her forthcoming collaborative work with Meg Gibson (under review), the authors perform a history of the present to analyze the twin history of Lovaas' ABA work on autistic and queer children respectively. Gibson and Douglas argue that a "queer disability studies lens opens up the richness of autism as a cultural nexus, and deepens understandings of intersecting and contested histories of science, professional scopes of practice, and dominant futurities" (under review, p.1). In addition to this work, Melanie Yergeau (2018) importantly argues that autism *is* neurological queerness and that applied behaviour therapies tacitly work to straighten the autistic subject. Yergeau's work is vital to my analysis, and I contribute to her findings here by showing how my fieldwork encounters indicate that the autism wars are shaped by heteronormativity and queerness. What surfaced through my ethnographic research is that systems of gender and sexuality structure the *autism* and *autistic movement* and the social response to ABA that these two groups advance.

In this section, I share ethnographic data from autism conferences and events to consider how autism, autism discourse and behaviour therapies are created in and through categories of sex/gender/sexuality. But before doing so, it is important to discuss one aspect of the history of Lovaas' ABA work that I have yet to describe, which is his

investment in using behaviour therapy as a form of “gay” and gender conversion therapy. Lovaas’ gender-based ABA work establishes the origin story of ABA as built on intervening on the queer *and the* autistic subject respectively, and this history impacts how actors within autistic communities currently view ABA.

### *ABA as a form of “gay” and gender conversion therapy*

In the early 1970s Lovaas’ embarked on collaborative work with George Rekers (his former graduate student and a well-documented Christian Fundamentalist), on so-called *atypical gendered behaviour* at the UCLA Lovaas ABA clinic. In these studies, ABA was used to prevent, cure, and convert gender “disturbed” children, mostly feminine boys, into “appropriately” masculine subjects. Reker and Lovaas’ (1974) most well-known study was called the “The Feminine Boy Project” (colloquially referred to by critics as “Slap Away the Gay”), which involved a case study of Kraig, a young effeminate five-year old. In this study, Lovaas & Rekers (1974) used positive and negative reinforcements (praise from clinicians and parents when Kraig chose masculine toys and planned ignoring for when he chose feminine toys), and aversives and punishment (spanking and belt beating by the father when exhibiting a certain amount of feminine behaviours in the home) to train him to play with toy guns and trucks over purses and dolls. Kraig was also conditioned not to emulate his mother or to be friends with girls but to fight and watch sports with boys (Rekers & Lovaas, 1974). The study claimed that ABA was successful in conditioning Kraig to be a well-adjusted *typical* boy and follow-up analysis during Kraig’s teenager years confirmed the success of the treatment (Bronstein & Joseph, 2011). Part of the rationale Rekers & Lovaas provided for conducting their gender conversion work was that “gender disturbance” is: a burden to the whole family; leads to criminality, suicide, vagrancy, homosexuality and “transgenderism”; and it is more realistic for an individual to change to fit an unaccepting society than it is for an unaccepting society to accept a diverse individual (Rekers, Bentler, Rosen, Lovaas, 1977).

Rekers built his gay-conversion ABA career on Kraig’s success; however, Kraig committed suicide when he was thirty-eight years old, and the family blames the UCLA treatments for his death (Bronstein & Joseph, 2011). They say Kraig lied during the follow up analysis as he was conditioned to respond correctly and feared abuse for incorrect

responses (Bronstein & Joseph, 2011). As I will discuss shortly, behaviour therapy critics often cite Lovaas' participation in establishing gay conversion therapy as evidence that autism-based ABA is explicitly political, intrinsically harmful, and clinically ineffective. Conversely, proponents of behaviour therapies tend not to speak of Lovaas' gender-conversion work at all or they distance 'old school' 'hard core' ABA from current practice.

### *Gender and sexuality at autism conferences and events*

To provide a detailed picture of the way heteronormativity and queerness organize autism politics and responses to behaviour therapies, I will narrate my day at an autism conference called *Autism In Motion* (2015) in Montreal, Quebec, that was attempting to be inclusive to self-advocates, and contrast this event with other autism events I attended as part of my research. *Autism In Motion* is a particularly interesting conference to analyze because, while primarily representing the needs and perspectives of those in the mainstream autism movement, it did include actors from both movements. In my experience with conducting observation research at autism conferences, it is rare for these two sides to co-mingle in public autism spaces.

As the day began, some of the morning speakers described their view of autism as a deficit to be clinically intervened on and evoked normative gender roles to describe their advocacy and to express their desire for a normal child. For example, towards the beginning of the day an autism father and CEO of a large nonunionized company that hires a high percentage of disabled people presented, stating: "I love that he [my autistic son] gets road rage because that's typical...by the way, I've never played a game of catch with my son. I never have. Not once."<sup>53</sup> Another pro-ABA father-presenter described his feelings about his autistic son: "If I was asked: do you want him to talk, to have a girlfriend, to be a typical teenager, fall in love... I dream about that." Later on in the presentation, the father stated: "one day, he'll [my son] wear a Montreal Canadian's jersey." These presenters described the heartbreak of autism through their sons' 'atypical'

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<sup>53</sup> While enthusiastically lauded by the audience for hiring disabled employees, this speaker also made a number of troublesome comments related to his disabled employees. First, he stated that if companies are anxious about hiring disabled employees they should start with "the Deaf" because they are the hardest workers. He also said disabled employees are great for companies because they are grateful for the work and therefore are unlikely to complain to a union about their workers' rights.

gender expression and sexuality. They both tacitly expressed their vision of the ideal son as a heteronormative one and considered heteronormative milestones as constituting a brighter future for their autistic child.

During the lunch break I visited the large market hall, a giant carpeted room with high ceilings and rows and rows of kiosks where a few autistic artists and dozens and dozens of corporate vendors tried to sell attendees their products and services. There were natural beauty and medicine companies, Costco selling vitamins (“kids with autism take a lot of vitamins and Costco sells the cheapest vitamins!”), BMO giving credit card deals, hyperbaric oxygen chamber rentals, sensory toy companies, summer camp programs, private behaviour therapy programs, and ABA sports programs. When I opened the big double door to the hall, *Massive Attack’s* “Teardrop” was quietly playing in the background, giving the space an ethereal womb-y feel. Almost each vendor I spoke with asked if I was an “autism mom” or just assumed I was.

A woman selling dead-sea beauty products grabbed my right hand and scrubbed the nail of my thumb with a natural rub. When she was done she compared my new glossy nail to the dull thumbnail of my left thumb. “Look,” she said, “It’s amazing! You can have a French manicure without having to use the harmful toxins that may hurt your child... because children with autism are very sensitive to chemicals, I hope you know.” Suddenly I felt embarrassed by my unkempt nails. *I am not the feminine ideal I should be* this vendor seemed to be communicating. *Just because your child has autism doesn’t mean you can’t be pretty and well groomed.* With one scrubbed nail, this vendor reinforced the ‘autism mom’ as a heteronormatively gendered subject while actively capitalizing on the assumed fears/desires of autism moms to both protect their child and maintain their femininity. She did this by actively linking motherhood with femininity and nail polish toxicity to autism.

After I returned from the lunch break, prolific autism researcher Simon Baron-Cohen (who, most notably invented the theory, Theory of Mind) gave a virtual presentation. Through linking high testosterone levels to gender essentialism and collapsing gender into sex, Baron Cohen proposed that autism *is* “the extreme male brain” (2002, 2015). Baron-Cohen claimed that autistic traits are the “extreme of typical male pattern of interests,” which can be attributed to elevated levels of testosterone found in

autistic people of all genders and sexes (in one clinical sampling). In stating: “testosterone masculinizes the brain,” Baron-Cohen reinscribed gender essentialism by viewing biology as predetermining gender expression. Baron-Cohen further stated that though it is “controversial” to think of “typical” male and female brains in essentialist terms there have been “hundreds of studies” of “spontaneous toy choice” showing that little girls and boys *naturally choose* different toys to align with their “sex:” boys choose Lego and construction while girls create social stories. In essence, Baron-Cohen proposed sex/gender as outside of culture and context, viewing typical girls as innately feminine and typical boys as innately masculine. The notion that there is such a thing as a “male brain,” and an “extreme male brain” at that, re-naturalizes pre-feminist, hetero-patriarchal, essentialist scientific accounts of gender and sex. In Baron-Cohen’s account, autism, as the sex/gender atypical ‘other,’ is both created through, and is used to reinscribe, the heteronormative gender/sex binary.

After Baron-Cohen spoke, there was a panel that included an autistic self-advocate, “Emmanuel.” Emmanuel was against normalizing and medicalizing autistic people via behaviour therapies and other interventions and he critiqued the medical model view by pushing back against Baron-Cohen’s clinical formulation of autism and gender: “I am a man but I don’t have a ‘male brain.’ I would love to wear nail polish...for me the medicalization of autism depersonalizes people. It destroys relationships we can have as people by doing that.” He continued: “We have a duty to speak up and say our neurology...it’s extremely important to come out of the closet, and if I compare it to homosexuality, who were really the bane of existence, they got to where they are because they spoke out...we can’t always let others speak for us.” Emmanuel then went on to overtly critique behaviour therapies and said that they can cause harm to autistic people.

The first question Emmanuel was asked was from an audience member who identified him as “high functioning,” and requested to know “the statistics” of how many autistic people “are like him.” The insinuation was that Emmanuel was speaking for a small group of the so-called “high-functioning” self-advocates and should not be speaking for the majority of the so-called “low-functioning” autistics. “I don’t know the stats, they are not important” Emmanuel confirmed. “You have a classically autistic person in front of you. I didn’t speak as a child. If I was a child now, I would have been given this or that



therapy. You should listen to me.” The neurologist on Emmanuel’s panel interjected to confirm that she *did have the stats* and that “high functioning autistics” comprised a “very small group.” With that, Emmanuel’s account was deemed statistically insignificant. Being categorized as a statistical outlier meant that his views and his advocate status could be dismissed.

The other self-advocate presenter at the conference was famous autistic author and pyrotechnic, John Elder Robinson. During his presentation, Robinson spoke directly against both intensive therapy programs and viewing autism as a problem to be fixed. Instead of aligning autistic rights to the coming out movement, he framed emancipation as a civil rights issue and one that should primarily draw on the 1960s civil rights movement. Robinson explained how, if you were Black in the 1960s (when he was a child) and a kid was being racist towards you, and “you came home at the end of the day and told your parents what happened, they would support you and tell you about Dr. King and the long legacy of historical Black heroes and systems of bigotry.” Now, contrast that “with an autistic kid like me, who got a note from my teacher that said ‘I was a bad kid I threw a chair at the wall...’” and then my parents told me I was a bad kid, and then my doctor told me the same.” Robinson affirmed: “we need a community of heroes.”

In the question period someone asked Robinson how to achieve a neurodiverse community and Robinson stated: “Jewish people have been persecuted and marginalized longer than we have, so they come together now...we need to welcome ‘wandering autistics’ like the wandering Jews.” A medical doctor in the audience then raised his hands and asked: “do you want autistics to be so cut off from society like the Jews?” Robinson responded that he did not view Jews as cut off but as creating their own safe spaces.

In this conference, discussions about clinical interventions were shaped by sex and gender norms and discussions of emancipation from social marginalization. While the lines are not always so neatly drawn in the sand, on this day (which was supposed to be about embracing different approaches to autism) voices advocating for medicalization were advocating against sexual, racial and ethnic difference, and voices critiquing medicalization situated autism as an emancipatory issue indelibly intertwined with other racial, sexual and ethnic emancipation projects.

*Conferences and events organized by the autistic movement versus the autism movement*

Similar to Robinson and Emmanuel's comments, which linked a rejection of medicalization and autism acceptance with LGBT rights, civil rights and activism, the autistic advocacy-led workshops and conferences I attended were often overtly queered and adopted an intersectional anti-oppressive approach, and this extended to a critique of broader normative values. As autistic queer scholar and self-advocate Melanie Yurgeau states, "autistic conventions can be more capaciously read as a neuroqueer mode of engaging, resisting, claiming, and contrasting the interstices of sociality" (Yurgeau, 2018, p.23). At a few of the self-advocacy led or allied workshops I participated in, participants were asked to self-identify their preferred gendered pronoun and autistic queer and trans people made up a significant portion of the attendees. These events were never held in hotels, never had market halls, and took place in community centres or post-secondary institutions. Often participants were asked to wear badges with a red, yellow or green sticker on them: green means you are open to conversation, yellow means you might start a conversation but do not want to be approached, and red means you do not want to talk to anyone. Fidget toys were available in bins and sometimes participants went around the room to offer these toys to other participants like food on trays. There was a diversity of bodies doing various things: sleeping, stimming, making sounds. Explicit comments were made about the space being safe for all bodies and all types of movements: there were always quiet sensory rooms and the lighting in the main room was dimmed. Some events provided mini-presentations on the kinds of views towards autism (autism as a burden, a disorder, a kind of evil) that would not be accepted within the space. The events often started with Indigenous land acknowledgements and speakers often described their intersectional approach to politics and autism social justice issues.<sup>54</sup>

There was an almost unilateral rejection of behaviour analysis at these events, where autistic participants (some of them mothers themselves or mother-allies) would talk about the ABA fights they would get into, mostly with "pro-ABA moms," on chat groups. Lovaas and his Feminine Boy Project was often evoked and critiqued as part of ABA's

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<sup>54</sup> Discussions and talks commonly centered on issues relating to emancipatory arts-based autism projects, medical, cultural and economic oppression, and autism representation. Money and employment were often discussed: most attendees were broke, and the privileged positionality of the (primarily non-autistic) academic allies was often openly problematized.

oppressive legacy: participants often viewed behaviour therapy as intent on taking *both* the gay and the autistic out of them.<sup>55</sup> To sum up the general sentiment expressed at these conferences, is Yurgeau's statement: "Autism treatment enterprises, many of which share origin stories with gay conversion therapies, enact a rehabilitative response as a means of de-queering the autistic" (2018, p.27)

Alternatively, at many of the mainstream autism conferences I attended the heterosexuality of the room was often assumed. This was conveyed through speakers' comments about mothers, fathers and their heteronormative gender roles, and through casual conversation I had with a few fellow participants who asked if I had a "husband" or "boyfriend." I felt out of place as a queer, politically-left person in these conference spaces, surrounded by large room/s of mostly "normal" corporate-looking people in gendered business attire: skirt-suits with pantyhose and chunky-heeled mary-jane shoes were the common uniform for women, button down shirts with trousers and a blazer, were most common for men. Of course, there were parents, students, clinicians, service providers, therapists and, it seemed (both from how participants and presenters self-identified and how presenters often identified the audience), a *very small* number of autistic people in attendance, but there were also people working in the military, entrepreneurs and corporate CEOs presenting at these conferences. I have never seen so many BlackBerries. I remember how happy I felt at one of these conferences when I spotted someone with dyed blue hair until I saw her matching blue autism-puzzle piece pin and realized she was just "lighting it up blue" because it was autism acceptance day: the popular annual corporate-charity inspired awareness campaign.

Mainstream autism events are often not catered to autistic attendees. Many of these events have bright lighting and one conference even used flashing lights to signal to presenters that their time was almost up. There were often no 'calm' or 'sensory rooms,' no fidget toys out, or announcements about body movement or being in a safe space. Participants mostly sat quietly while presenters spoke. Once I witnessed a non-autistic presenter tell his autistic teenage son who was sitting on the floor leaning up against the

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<sup>55</sup> In addition to the links between queerness and the self-advocacy movement that I have described, there is even an online platform called *Twainbow* for autistic queer people. This website considers how autistic queer people have suffered the collective historical trauma of ABA as being applied to both convert their sexuality/gender expression and their neurology (Coloma, Molnar, & Rowe, Date Accessed: Mar 5, 2018).

wall, to “get up and sit with everyone else at the table” because he “looked like he was being antisocial.” If autistic people presented at these conferences they often did not challenge the biomedical model (as Emmanuel did) and instead would present their creative works or speak of their employment success.<sup>56</sup> These autistic presenters were often met by paternal audience responses about how inspirational they were, or they were asked pathologizing questions (as the members of an all-autistic film program were asked, at a conference I attended in 2016) like: “how do you work with other autistic people? I am not autistic and I find it hard to work with others so it must be much harder for you. Is social skill building part of this program?”

The content of these conferences often focused on and tacitly advocated for behaviour therapies, biomedical interventions, private clinical autism ventures, physical activity programs, and getting autistic people into the workforce. Autism was viewed as an individual medical condition, not a social topic: instead *access* to “effective” clinical or medical treatment was viewed as a political topic. ABA was viewed as a value-neutral and universally applicable intervention model. As a speaker at a conference I attended in 2015 stated: “ABA and IBI are scientific and effective for *every* community.” Politics entered into the conversation when considering the issue of recruitment. For example, at two conferences that I attended (2015-2016), a number of speakers articulated the dire need to spread ABA to “underserved communities,” particularly to Northern Indigenous territories: “we need to do better.” These talks focused on expanding federal resources and

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<sup>56</sup> Employability was a big topic at many autism conferences. I observed a few corporate CEO presenters make the argument that autistic employees are far superior to neurotypical ones because they are so focused, detail-oriented, enjoy repetitive tasks, are not distracted by socializing, and are often happy staying in the same position for a long period of time because they do not like change. A CEO for one company explained: since the economic hardship of the “oil sands” out west, employers have had to cut back on their labour force but have still been able to produce at the same level because they’ve started hiring one autistic person to fill the jobs of two fired non-autistic employees. *They are that productive*, the CEO argued. This CEO further told of how autistic people, because of their keen attention to detail and ability to focus on meticulous, repetitive tasks, have been recruited by the Israeli Defense Forces to the Visual Intelligence Division, conducting arterial analysis. Another key point a corporate presenter made is that since it is so hard to find jobs that do not stigmatize against autistic people, they are often so grateful for the opportunity to have a job that they are very loyal and satisfied employees. These CEOs framed their efforts to hire autistic people as guided by both philanthropic and economic ends, all the while diagnostically profiling autistic people for economic extraction (and in some cases, exploitation) to an extreme degree: the invisible hand posing as the helping hand. For anyone interested studying autism from a political economy angle, examining how the autistic subject is being capitalized on as offering a superior kind of psy-value (like bio-value but instead of the body, the psyche) for expanding the corporate-industry and the war-industry, would be fascinating.

engaging in “knowledge translation” activities with so-called reluctant elder gatekeepers who did not buy into a medical understanding of autism or a medical approach to intervening on it. The events themselves often had an array of corporate sponsors and sometimes there were corporate market halls. At many of these conferences, the clinical collapsed into the corporate: clinical autism is big business now.

To sum up, sexuality, identity politics and larger systems of power and oppression organize the *autism/autistic movement* and shape discursive debates about advocacy and behaviour therapies. Many in the autistic community, if not queer identified, understand autism and their advocacy movement, as innately queer and interpret medicalization as both an ableist and heteronormative system of oppression. Melanie Yergeau summarizes the link between autism and queerness, and medicalization and heteronormativity this way:

The autistic subject, queer in motion and action and being, has been clinically crafted as a subject in need of disciplining and normalization... What autism provides is a backdoor pathologization of queerness, one in which clinicians and lay publics alike seek out deviant behaviors and affectations and attempt to straighten them, to recover whatever neurotypical residuals might lie within the brain, to surface the logics and rhetoric’s of normalcy by means of early intensive behavioural intervention...ours are neuroqueer brains (2018, p. 26, 23).

Thus, undergirding the autism wars and advocacy debates are sex/gender/sexuality categories that shape the worldview of each community. When shaped through gender and sexuality, a lot of the dialogue between proponents and critics did focus on people’s moral normative discourse around the therapies. In this way there is an intersection between queerness, difference, and the moral normative distinction in current autism communities.

### **Advocacy and the politicization of scientific virtues**

In this empirical section I shift gears and complicate the normative characterization of the autism wars that I just described. Here I analyze how my participants’ views of autism advocacy and ABA express complex interpretations of political voice and identity that are wrapped up in larger political and epistemological debates about expert credibility. My participants appraised ABA and made decisions about who (clinicians, parents, or autistic self-advocates) might best serve as an autism advocate based on how they evaluated objectivity, partiality and standpoint knowledge. Each participant evaluated these topics

very differently. I further study how my participants' views resurrect *all the different historical moments* of autism governance that Eyal et al. (2010) describe but in new and complicated ways. What this means is that each network of expertise that Eyal et al. (2010) synthesize is not so definitive or distinct, they bleed into each other and seep into contemporary everyday autism social relations in important ways that require recognition. Autism governance is not a baton pass from clinician to parent to self-advocate. My informants paint a picture of contemporary autism governance as comprised of a million different arm wrestles where each winner is always contested, and so the struggle always begins again.

In the first part of this section, I examine how the scientific ideal of disinterested objectivity principally shapes how my participant Orli views behaviour therapies and the advocacy potential of behaviour therapists. Orli's response demonstrates how the political views of actors invested in autism communities are not only shaped by contemporary autism discourse, historical debates about disability advocacy and clinical credibility, but by larger discussions about scientific ideals and methodologies.

*The clinician as modest witness, the modest witness as political advocate*

Orli is autistic, part of the self-advocacy community and hopes to become a behaviour analyst. Orli has worked in behaviour therapy centers and studies behaviour therapy in University. I met Orli outside her building on a bright and sunny day. Before we met, Orli set important boundaries for our meeting: that I refrain from small talk and commenting on her home or appearance. Prior to meeting, Orli yelled at me on the phone when she discovered I took a taxi to meet her while she was, unbeknownst to me, stuck on a delayed bus (I was also stuck on another delayed bus, which is why I took the taxi). When we met and I spontaneously asked how she was, she responded curtly with: "*Why?*" which was stated as a reprimand rather than as a question. One of the most uncomfortable moments in my fieldwork was managing my compulsive concern with making conversation on the long, seemingly infinite elevator ride to Orli's unit. My anxiety seemed to creep up with each floor that we passed in silence. I felt constricted and exposed without being able to connect by doing the things I usually do. Those stretched out uneasy moments revealed how ingrained my structures of interacting with others are. It was one of those moments

where I could observe myself from the outside in. While all my interviews were conducted in the professional context this one felt like it was purely instrumental, highlighting how deeply social conventions structured my other conversations.

Once we entered her unit Orli grabbed a box of crunchy crackers, which she ate throughout much of our interview. Chomp, chomp, chomp. When I turned on the recorder and began asking questions, conversation poured out. Throughout our discussion, Orli openly assessed me informing me that, “I am too nice,” “too worried,” and she laughed condescendingly whenever I asked a question she considered self-evident. I was captivated by her frankness, a quality that I (the apparently too nice, too worried person) do not often possess. But I disliked that she snapped at me for asking how she was but felt entitled to overtly assess me as a parent or psychologist might. While I occupied the privileged position of non-autistic researcher, I felt stupid and little during the interview process. Power coursed through this encounter like a heavy wind that I could not hold, could not see but that pushed and pulled and did not rest.

My interview with Orli provides a complex formulation of autism advocacy that embodies different historical discourses relating to issues of political voice, credibility, and who can be trusted to be an autism spokesperson. Advocacy, and the matter of how involved parents should be in governing behaviour therapy programs, first came up when Orli explained how behaviour therapy programs are created:

Orli: They [behaviour analysts]... perform like functional behaviour assessments. They perform interviews with parents and...bias comes in here because the parents might say like: ‘I want a normal child and make my child do this and this and this.’ And sometimes the therapist just has to say: ‘No I can’t do that.’ [laughs]. ‘You have very unrealistic expectations’...

Julia: That sounds like it could be a hard thing to do sometimes...Do parent’s sometimes get upset when therapists say that to them?

Orli: Well you have to be really resilient to be in this profession. [Laughing]. Like, it’s not realistic... it’s not possible... No matter how much therapy a child gets, they will still be autistic in their thinking... You could seek skills but... those skills might not even be very compatible with the way the child see’s the world - and what are the implications of that?

Julia: That’s interesting... there seems to be this emphasis on family-first [in mainstream autism discourse]: ‘family is the most important thing in an autistic persons life, we have to listen to the family.’ What do you think of that?

Orli: I don’t agree with that. I think from... a neurotypical perspective you can’t... say for sure what a person on the spectrum needs. And you’re only talking from your own perspective, so like if you’re

saying, 'I'm really worried that my child doesn't have friends' and the child doesn't actually want friends... with parents, they look at other children and they always compare their child... They never chose to have a child on the spectrum so they probably have this... ideal child in their mind... They grieve and they're disappointed... It's a huge shift for them...

Julia: And how do you think that that influences the work of the clinician or the practitioner?

Orli: I think it influences it negatively [laughs]... Even though the parental observations are important... I think a good clinician... would see all the biases and try to extract [them] as much as possible... A behaviourist only looks at behaviours so you only have to take what the parent reports, that is actual observed behaviour, that's not seen through any kind of lens, and use that to help structure their program but also assess the child...

Later in the interview I asked Orli:

Julia: ...Could you expand on your definition of a good clinician?...

Orli: I think a good clinician would be...first of all a really good communicator and be able to negotiate with parents even if the parents have certain views, it's almost like you have to be an advocate and you have to say to the parents in a really respectful way, that even though they want this kind of child, it's not going to be a good idea for the child, it's not going to be a good idea for the plan [the behaviour intervention plan], and it's not a very good goal to make a general.

Orli explains that neurotypical parents can lack a fundamental understanding of what someone "on the spectrum" needs: they are stuck in the mud of culture and cultural norms; they compare their autistic child to the 'ideal child;' they feel grief and disappointment; and they want interventions that reflect their own way of being in the world rather than their child's. Orli thinks neurotypical parents troublingly transmit their myopic views of autism onto their children. By contrast, the "good clinician" is able to extract parental, affective, and cultural biases. She empirically observes behaviour in an unfiltered manner in a realm free from interpretation or disability politics and works to manage and reduce parents' normative expectations. Only the actor who does not view autism through "any kind of lens," can see it clearly.

Orli's assessment of parents as un-credible translators is informed by the autism wars, and the issues that have arisen from parents speaking for their autistic children and against self-advocates. By positioning clinicians as advocates for autistic people *because* they are capable of impartial objectivity, Orli pulls apart both the first and second wave of autism networks of expertise (Eyal et al., 2010; Orsini 2009, Orsini & Smith, 2010). She returns to older discourses of clinical governance but for entirely different reasons. When Orli explains that while "parent observations are important," they can be biased and



require parsing by an objective clinical actor, she revives Kanner's perception of parents limited contribution to producing clinical knowledge. In Orli's view, clinicians should return to being the obligatory points of passage for knowledge production and syntheses and they should position parents as necessary but pathological and partial data collectors. Unlike Kanner and Bettelheim though, it is not parents' (biological, affective, or familial) proximity to autism that renders them untrustworthy translators but their distance from it: they are steeped in normality and want their autistic child to be normal too. Parents are once again cast as un-empathetic figures, this time not because they are autistic-like, but because they are both so far from autism yet so *interested* in shaping their autistic children.

Orli's account of autism advocacy signals how contemporary autism governance exists as a multiplicity of 'governances,' comprising both older forms of rule and a new discursive era of *post-de-institutionalization*. Because parents, through their affective bias, failed (according to some) as reliable translators during and after the deinstitutionalization movement, clinicians (because of their impartiality) are once again considered credible advocates and their political importance specifically derives from their clinical disinterestedness.

In describing a good clinician as an actor who is capable of viewing behaviour free from interpretation, Orli tacitly reinscribes culturally specific notions of clinical objectivity and the scientific self. Orli defines science through the Weberian lens (1918) of being divorced from politics: science is separate from beliefs, facts, and is oppositional to values. Orli further positions the good clinician as the modest witness (Haraway, 1997): a figure that occupies a transcendental "view from nowhere," a figure who plays "god tricks" (Haraway, 1988, p.254, 252). This archetype of the scientist comprises the modern, intrinsically European and masculine, ideal of the scientific self (Haraway, 1997; Shapin & Shafer, 2011). This powerful figure is a gentlemanly virtuous actor capable of evacuating subjectivity to operate as a vessel for recording the absolute truth of the natural world (Shapin & Shafer, 2011). As Haraway writes, the modest witness: "guarantees the clarity and purity of objects. His subjectivity is his objectivity" (1997, p.24). He is the "legitimate and authorized ventriloquist for the objective world, adding nothing from his mere opinions, his biased embodiment" (Haraway, 1997, p.24-23). In Orli's formulation,

the behaviour therapist embodies this virtuous scientific subject: a subject trained to empty his own situated self to observe and uncover the truth of what an autistic person genuinely needs. The ability to exist outside the situated world to operate outside of politics, is what for Orli makes this actor *so politically vital*. The good clinician renounces himself, and in so doing, protects autistic people from the harms of the interested subjective world.<sup>57</sup>

Interestingly, my informant Natalie (a behaviour therapist introduced in Chapter Two) had a similar formulation of the advocacy inherent in the role of the behaviour therapist as deriving from her vocation as a modest witness. She explained how family members, staffing compliments and para-practitioners at her inpatient autism unit assign meaning and intention to behaviours like hitting or yelling by labeling them ‘aggressive’ or ‘violent.’ Natalie explained that these labels are problematic because they are moral interpretations not technical descriptions. Hence, “hitting” is the action of using a hand to strike something and it is only aggressive *if the intention behind the action* is aggressive. Natalie works to teach her colleagues to adopt a behavioural lens, so that they refrain from assigning moral intent to behaviours without conducting the necessary empirical work. In viewing behaviour as actions “without any kind of lens,” Natalie works as an advocate for autistic people, her objective empiricism grants her the ability to be, in her view, a reliable translator and the most credible professional advocate.

### *Standpoint Knowledge, Intuition, and Objectivity*

Orli’s views toward behaviour therapy, advocacy and objectivity became increasingly complex as our interview progressed, and as we conversed more about the conflicts between parents and self-advocates. The following excerpt is Orli’s response to whether

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<sup>57</sup> As Haraway further asserts, writing (via recording) is a “literary technology” (1997, p.23) that confirms the virtue of the modest witness. In their important text, *Leviathan and the Air Pump*, Shapin and Shaffer (2011) analyze the scientific enterprise of Robert Boyle (1627-1691) and how his prolific descriptive written observations were key to confirming the credibility of Boyle’s “self invisibility,” his modesty, his objectivity (Haraway, 1997, p.23). As argued in Chapter Two of this thesis, quantitative data comprises the current epistemological and literary technology for representing the transcendental truths of the natural and social world (Porter, 2012). Data sheets, checklists, and graphs are the literary texts produced in applied behaviour therapy work. These texts operate mostly through markings, not sentences, cutting out the interpretive nature of language and thus the interpretive nature of the clinician: turning both simultaneously into automated objects. In essence, quantitative data erases the pen strokes that trace back to a situated living being. Consider for instance the assertion of “Dr. Voz” at the 2015 CASDA summit: “we need to dig deeper into our data sets to understand each child’s needs.” Here, the behaviour analyst is a medium for data synthesis.

she ever witnesses parents discrediting self-advocates by calling them “too high functioning” to speak for other autistic people:

Orli...I think the reason why some parents might say ‘this person is too high functioning to speak on behalf of their child’ is because there are some [self-]advocates who go out there and they say ‘this is *the autistic experience* and I know everybody experiences this...’ There is a problem with that because you can’t generalize - and you’ve met one person with autism, you’ve met one person with autism, so. But as a professional, like if I’m working with a client [providing behaviour therapy] and I know the client’s patterns, I think having my experience facilitates... my *instinctual* understanding of what they might be experiencing.

A little later on, I asked Orli why she wanted to be a behaviour therapist:

Orli: I kind of wanted to surround myself with people on the spectrum as much as possible because I felt a lot more comfortable around them. I just think I’m in a good place because I can really communicate about *the autistic experience*, because I’m really in touch with all of my sort of patterns and all of my... thoughts and feelings... I’m very self-aware and a lot of times I can use that knowledge, I can use that intuition, to be better than some other professionals in the field...

Julia: ... What does it mean to you, ‘the autistic experience?’

Orli: Just like how I kind of perceive things day to day and what kind of things might set me off and, what kind of things make me comfortable and...why I might get exhausted. And like, how do I balance my life so that I could achieve an optimal level of functioning... I guess I’m kind of focused also on optimizing my performance and just doing as well as possible...

Orli does not think that shared identity automatically makes autistic people trustworthy advocates. Like parents, Orli considers that self-advocates can be clouded by their own personal experiences with autism, which impairs their ability to understand the nuances *among* autistic people: their subject positionality renders them *too interested*. Hence, autistic people can misrepresent the needs and lives of fellow autistics by providing overgeneralized and politically motivated representations of “the autistic experience.”

Yet, when working as a professional, Orli draws on her *instinctual understanding* of autism to *enhance* her clinical lens. Orli’s self-awareness, her ability to be “in touch” with and communicate her own autistic experiences, provides her with a valuable kind of situated knowledge that augments her objective clinical observations. Orli both essentializes “the autistic experience” (it is something she understands) and individualizes it (‘you’ve met one person with autism, you’ve met one person with autism’). Being a professional gives her tools to both assess each autistic person uniquely, while intuiting underlying autistic patterns and ways of being. This double vision of disinterested

interestedness may provide her with the ability to be the most credible translator for autistic people: clinical knowledge when coupled with experiential perception enables Orli to be “better than some other professionals in the field.”

The last part of the excerpt is particularly poignant as Orli turns her clinical lens onto herself: when I asked her to describe the “autistic experience” she quickly shifted to using behaviour analysis language - optimization, functioning, and performance - to organize her self-perception. Orli describes the “autistic experience” as the various affective states that govern her everyday life, but she observes these affective states from the outside in: she does not just *live* her day-to-day self, she clinically observes it. In the subsequent line, Orli switches to describing how she orients to herself: she is focused on achieving an “optimal level of functioning” and on “optimizing” her “performances.” Stating that the autistic experience *is* wanting to optimize functioning and performances is a profound slippage in which the essential experience of autism is defined *through the goals* of behaviour therapy. In other words, behaviour therapies do not just organize Orli’s advocacy politics but, also, her *understanding of* autism. Orli is at once herself (her moods and feelings and patterns) and her own good behaviour therapy clinician (the objective actor that understands her moods, feelings and patterns in order to best optimize them). A hybridized subject who can be simultaneously deeply outside politics and subjectivity and deeply within it embodies Orli’s formulation of the most credible autism advocate. The good clinician both has no lens and speaks objectively from behind the tinted glass.

*The untrustworthiness of objectivity: identity politics, power and advocacy*

Bobby (the behaviour therapist introduced in Chapter Two) shares Orli’s concerns about parents’ ability to be reliable translators and trustworthy advocates, yet he differs from Orli in terms of his epistemological understanding of behaviour analysis. To explain, consider the following excerpt, where Bobby describes his dissatisfaction with working as a behaviour therapist:

I sometimes...don’t agree with the treatments that are being put forward because again, it might be coming from a parent’s desire for their child to be quote unquote normal, rather than understanding the complexities of their child’s needs at that moment. They’re just looking, they’re yearning, for their child to be normal. So a lot of time we might focus on programming for a child that is irrelevant for them, but it made sense for the parents because they want to see their child as normal... And that’s

a big problem for me because you are really erasing what the child needs in that moment...as much as people don't want to think identity politics play a part in clinical services, I actually think they should be playing a bigger part because of—and again this is my own experiences with the emphasis on the biopsychosocial model ...the whole medical model being the standard as to what we are referencing for a person with autism is problematic because the medical model automatically situates a person with a disability as below somebody who is able-bodied, right? So you are automatically framing your teaching as 'you are not normal' and then I am going to teach the skills to be normal...

Similar to Orli, Bobby describes how parents' desire for "the normal child" negatively governs and contaminates his therapeutic work. Contrary to Orli's vision of the behaviour therapist as the resilient advocate standing up for the needs of their clients, Bobby tacitly positions behaviour therapists (akin to the second wave of parental-based autism governance) as subservient to parents' desires. In his clinic there might be direct programming to respond to parents' needs, which Bobby thinks is a "big problem." Also, unlike Orli, Bobby situates behaviour analysis as epistemologically biased because it operates within the medical model framework, which he thinks favours the normal, able-bodied subject. Alternatively, Bobby thinks behaviour analysts would be better able to advocate for autistic people by becoming *more* self-consciously politicized. As Bobby articulates, if behaviour analysts *do not* pay attention to "identity politics" and do not incorporate a "biopsychosocial model," their "automatic frame" will be troublingly yet unconsciously politically biased: it will not understand autistic people but rather teach them: "you are not normal."

Bobby thinks behaviour therapists are stuck in the same mud of culture as everyone else: their view from nowhere is a view from somewhere. Yet behaviour analysts have a greater potential to serve as advocates than parents do, if only their work is guided by a biopsychosocial approach. In Bobby's assessment, to be a good clinician *you have to be situated* in culture and you have to understand the systems of power and identity that undergird the medical model that behaviour analysis tacitly perpetuates. In sum, to accurately understand and represent the needs of autistic people, Bobby thinks the behaviour therapist needs to understand and respond to the cultural contexts in which both they and their clients exist in. With this formulation, the most credible advocate is politically aware and applies behaviour therapy within a social justice framework.

*A non-clinical reimagining of the first wave of autism expertise: managerialism versus the market-based health economy*

Sam and Louisa (introduced in Chapter Two), two social workers who run an advocacy-mentoring program that connects disabled and nondisabled community members, expressed deep dissatisfaction with behaviour therapies and the current “systems-based” managerial approach to autism care. Sam and Louisa described mainstream autism services as based on regulating and normalizing autistic bodies thus denying autistic citizens the right to experience community, friendship and wellbeing. Given their macabre assessment of the behaviour therapy-centricity of autism services, I asked Sam and Louisa if they were hopeful about the future of service supports for autistic people in Ontario.

This was their response:

Sam: ...I think the shift is coming from families who are saying: ‘We don’t want that [systems-based services]. But agencies are still very resistant. Part of its resistance...is, they don’t know what to do differently...

Louisa:... It’s changing and families are pushing for that change... If you looked within the system, they are becoming more managerial because they’re facing more challenging people... As the newer generations of families come through, like they won’t put up with that.

Julia: ...So you see families as holding the key to a more progressive ---

Sam: Oh families are driving change. Absolutely. Absolutely. Absolutely. Especially younger families.

Julia: Okay. A lot of parents are advocating for like Mineral Miracle Solution (bleach enemas), Chelation (intravenous injections to remove heavy metals in the blood). I’m thinking of the *Auton vs British Columbia* case where ABA was being fought to become a medical necessity *by* parents... autistic people were the claimants against these parents saying ‘We don’t want that.’ So I guess I’m trying to--

Sam: ...From my perspective there’s two groups of parents. There are those groups of parents who have mourned what they thought was going to be and they moved on. And then there is the other group of parents who have not stopped mourning... It’s that group that you’re talking about. We’re talking about the other ones, who have basically gone through their grieving process and mourned but are actually moving on.

Louisa: Well historically ... government funding goes to agencies to create spaces for people... There’s a whole group of families that are saying: ‘No, we want you to give us the funding so we can determine...how to best use it, and we can do a better job of using it. And then we’ll decide whether we want to go to this agency, that agency, or whether we want to just hire our own people.’ That is the way it’s going to go in the future... We’ve got this whole system that knows we’re going to move

to a market-driven model... where parents are going to be the consumers with the money - as opposed to assistant-driven model where we [autism agencies] have the resources, we have the power... we make the decisions of who gets it and who doesn't...that shift is going to happen so that families who want the choice will have it.

Here Sam and Louisa reinscribe NSAC's vision of parents as the trustworthiest spokespeople for autistic children *because* they are so affectively interested. According to Sam and Louisa, parents should be the obligatory points of passage in which clinical knowledge and social services must flow and be synthesized. Yet Sam and Louisa view autism services as currently governed, not by clinicians, but by management. At the beginning of this excerpt, Sam and Louisa morally venerate parents and devalue management-based behaviour therapy-centric autism services. When I challenged Sam and Louisa to consider some of the powerful actions parents have taken to *establish* the current management and behaviour therapy-centric "systems-based" approach to autism care, they reformulated their answer to divide parents into two groups: those who have mourned their child's disability and moved on versus those who accept it. Thus, not all parents, but those *with a particular political orientation* (resistance to systems-based approach) *and a particular affect* (acceptance), are the "drivers of change" that Sam and Louisa are referring to. However, Sam and Louisa still think that placing funding decisions in all parents' hands, granting them with the power to choose services, would systemically change autism care to be more equity-based. Further, Sam and Louisa view pairing parental governance with a contemporary market-based consumer health system as politically critical: when provided to the right individuals, they think individual consumption choices will lead to a brighter future for autistic children. Through a market-based economy, Sam and Louisa think parents (like those of NSAC) will again have the power to invite clinicians into their own networks of services rather than services slotting children into their agencies. But unlike the clinically savvy parents of NSAC who were so fundamental to establishing ABA as a standard of care, Sam and Louisa think these parents will reject the behaviour therapy-centric managerial model of autism care and be progressive autism advocates by *consuming* emancipatory services.

*The second wave of autism advocacy*

In contrast to Sam and Louisa, who view families as the drivers of change and as the natural advocates of autistic people, I interviewed an autistic self-advocate, former behaviour therapist, and autism parent named Laurie. Laurie thinks autistic people should govern clinical autism services and autism political discourse. In this excerpt, Laurie is speaking to me about the heated conflicts she has on online autism chat rooms with non-autistic autism parents. Laurie's views fully encapsulate the politics of the second wave of autism expertise and represent the normative discourse of the autism wars. It is important to consider Laurie's views in the context of the range of different positions of autism advocacy that I have just analyzed. Laurie's political position highlights standpoint knowledge as the key quality required to be a credible autism expert and advocate.

Julia: ...Why do you think there is so much conflict there in terms of how to understand autism?

Laurie: Probably because parents think they follow the doctors first of all, and they're not autistic and because we're autistic there is something wrong with us, right? Like...we need all this help, which yeah, we need help, we need lots of support, but we're not dumb. And we know what we need... But they think we need other things... Some of them, I feel sorry for their kids...

Julia: ...What do you think the relationship is between clinicians and parents? Who do you think takes the lead there most often?

Laurie: Usually the clinician, but most of them have no clue either. Some of them are really bad. They have no idea. So.

Julia: ...How does that play out: 'They have no idea?'

Laurie: Well some of them can't even tell if the kid has autism in the first place. And then once they have autism, they don't know anything about it. They need to learn from autistic adults... They just think: 'You send a kid to IBI and there you go, that's all there is for you.'

Julia: Do you think that autistic people are being listened to?

Laurie: No.

Julia: Why do you think that is?

Laurie: Because we are autistic. That would be the main reason...

Julia: Okay. So do you think parent's hold a lot of the power here?

Laurie: Yeah, yeah. They are the ones who tell everybody what they want. Tell autistic people what they think they should have.

Laurie embodies the second wave of the network of expertise (Eyal et al., 2010; Orsini, 2009, Orsini & Smith 2010) where advocacy and identity politics converge. Laurie describes autistic people as the only actors who can truly translate autistic people's needs,



and parents and clinicians need to “learn from” them. Laurie describes how clinicians, themselves “clueless,” often govern parents as to how to understand and care for their child yet it is parents who adopt the role of spokesperson “telling everybody” what autistic people need and speaking out about what autistic people “should have.” In Laurie’s view, clinicians are not only unsupportive, but naïve. Like Orli, Laurie does not think that parents’ affective closeness to their autistic children provides them with enlightened insight into their child’s needs. Yet unlike Orli, Laurie voices how *both* parents and clinicians do not listen to the views of autistic people because they hold prejudicial views towards them. To use the language of Eyal et al. (2010), Laurie indicates how autistic people (much like the parents in Kanner and Bettelheim’s time and much like the clinicians in Rimland, Scholper and NSAC’s time) are currently viewed as “damaged” subjects and therefore untrustworthy translators and advocates incapable of advocating for themselves.

### *Synthesis*

Not only did my participants’ views differently incorporate the many historical moments of autism governance and social movements that Eyal et al. (2010), and Orsini (2009; 2012; Orsini, Smith, 2010) describe, but they also actively took up wider scientific debates about the value of objectivity, bias, intuition, and standpoint politics in their formulation of behaviour therapies and advocacy. Advocacy power struggles are not always neatly hinged around whether one is a proponent or critic of behaviour therapies, more micro nuanced positions take shape around these therapies that are influenced by wider social, scientific, and political discourses. My participants’ interpretation of these wider debates shaped both how they considered the issue of autism advocacy and the politics of behaviour therapies. Further, my participants assigned particular qualities to particular actors: they viewed clinicians, parents and autistic people as holding certain views and being (in)capable of embodying certain ideals. Each participant viewed the advocacy potential of the clinician, parent, and autistic person differently, and they considered advocacy in terms of how objective or interested each subject was. The diversity of my participants’ stances on the issue of advocacy demonstrates how unsettled the topic of

autism advocacy is, and the role of behaviour therapies in relation to it, when examined on the ground.

## **Conclusion**

In this last chapter of my dissertation, I moved beyond an analysis of the clinical activities of behaviour therapists. I demonstrated that behaviour therapies are central to current conversations and struggles about autism representation and political voice as they culminate in the autism wars. These are topics that Eyal et al. (2010), Orsini (2009; 2012) and Orsini & Smith (2010) and others have analyzed, but I expand on this corpus of scholarship in an effort to bring into view the sorts of power struggles that are often overlooked when autism governance, discourse and social relations are conceptualized as a larger, macro advocacy struggle between parents, autistic people and clinicians, or between pro and anti ABA groups. Eyal et al.'s (2010) formulation of autism governance as a linear shift from clinician to parent, and then to a role shared between parent and autistic self-advocate, is too simplistic.

In the first empirical section, I provided a gendered-analysis of the autism wars and argued that behaviour therapies and autism communities are coordinated through categories of hegemony and difference, which are often coded through sex and gender norms. The autistic self-advocacy movement employs a queer politic to communicate their political stances on autism and behaviour therapies. What my research at conferences demonstrates is that queerness and heteronormativity shape the *autism* and *autistic movement*, and therefore the autism wars. When shaped through gender and sexuality, a lot of the dialogue between proponents and critics did focus on people's moral normative discourse around the therapies. In this way, there is an intersection between queerness and the moral normative distinction of the autism wars. In sum, gender relations organize everyday enactments of behaviour therapy work and the social and political discourses surrounding behaviour therapies.

In my final ethnographic section I extended and complicated Eyal et al. (2010), Orsini (2010) and Orsini & Smith's (2010) work by showing how the power relations between parents, clinicians, and autistic self-advocates that culminate around behaviour therapies and autism/autistic advocacy are quite unstable in some key respects. I further

considered how this fraught history of parent-clinician-autistic relations is taken up differently by actors within autism communities, and that the current ABA-centric autism wars hold all of these different historical power relations within it. Lastly, I demonstrated how actors within autism communities make sense of ABA through larger scientific discourses of expertise and social discourses of identity, disability and ethics. As with ABA practice as it is enacted in everyday life, the social relations and advocacy responses that have taken shape in response to ABA, are as certain and concrete as they are varied and deeply complicated.

## CONCLUSION

Applied behaviour therapies organize the lives of both autistic people and autism providers. These clinical methods have created particular and powerful forms of autism social relations that did not exist before and could not exist without them. My goal with this dissertation was to understand and analyze the practices, activities, methodologies, interactions, feelings and philosophies that constitute everyday behaviour therapy work. I wanted to piece together both the cultural logic of behaviour therapy providers and the larger institutional healthcare infrastructure that governs them. I oriented to intimate fieldwork encounters as a way to uncover the systems of governance that shape everyday practice and autism social relations. Being embedded in autism communities and facilitating the unfolding of my participants' stories enabled a complex account of how autism, autism governance and applied behaviour analysis manifest and fold into each other in everyday life. Applied behaviour therapies have coordinated the social and political lives of almost every actor invested in autism and this dissertation is an entry point for analyzing all the ways that this is so. The popularity and controversy of applied behaviour therapies also tells us how actors in autism communities struggle to define, view, and engage with autism. By analyzing behaviour therapies we are analyzing wider cultural notions of health, illness and healing systems.

In this dissertation I used an ethnographic STS approach to studying my topic, and adopted a theoretical framework that combined an anthropological approach to culture and meaning with a Studies in the Social Organization of Knowledge approach to governance and power. By analyzing the culture of behaviour therapy providers and the cultural significance of behaviour analysis, this dissertation principally contributes to STS scholarship critically studying autism, clinical experts, psy diagnosis, and the social implications of new 'psy' interventions (Bagatell, 2010; Biehl, 2010; Dumit, 2004; Eyal, et al., 2010; Good, 2004; Martin, 1995, 2009; Metzl, 2011; Davidson and Orsini, 2013; Rose, 1998, 2007; Rutherford, 2013; Schechter, 2014; Silverman, 2014; Traweek, 1992). This study also responds to the political-ethical debates that surround behaviour therapies but does so by looking beyond the individual relationship between provider and recipient

to consider everyday practice as shaped by a complex “epistemic culture” (Knorr Cetina, 1999).

As an interested ethnographer, applied behaviour therapies have shaped the activities that have occurred within my family since I was a youth, and I have been invested in ethical debates about them for years. As described throughout this dissertation, applied behaviour therapies mark a fault-line in autism/autistic communities and have caused profound tension among actors within them. Yet despite dissenting views, behaviour therapies have become the hegemonic way to intervene on autism. Currently, non-autistic proponents hold much of the political and social power in terms of mainstream autism advocacy, while autistic self-advocates are often silenced and sidelined, particularly at the level of policy, representation and autism governance. Often this silencing is justified (by policy makers and those in the mainstream autism community) by charging self-advocates with having a distorted view of ABA and for speaking in anecdotal terms, while offering no research or “proof” to support their claims. Autistic self-advocates have been disenfranchised from their own movement as mainstream autism culture reinscribes the systems of oppression autistic people face in society more widely. For these reasons, examining the culture of behaviour therapies means engaging in a civil rights health struggle for knowledge, power and political voice. My contribution to this struggle is to study everyday practice and the complex social, political and scientific forces that shape it. As a well-educated non-autistic person, I hold a fair amount of social privilege. I wanted to use my privilege to create a research study that self-advocates may find useful in their struggle to be listened to and to improve autism services. I also intend for this study to be useful for behaviour therapists and autism service providers in thinking about the work they do and the institutional forces that shape it.

Some autistic people and parents have offered important descriptions, mostly presented through the blog format, of the applied behaviour therapy programs they have received, observed or studied (Dawson 2004, 2005; Real Social Skills, Aug 26 2014, Oct 12 2014, June 1 2016; Unstrange Mind, 2016; Schaber, 2014; Sequenzia, 2015, 2016; Zurcher, Oct 10 2012). Former behaviour therapists have also provided descriptions of the programs they have provided (AnxiousAdvocate, May 22 2015; Inks and Daggers, 25 Feb

2015, Mar 2 2015). These contributions by community members and professionals are critical and inspired me to write this dissertation. Yet most critical autism scholarship has focused on studying the political debates about behaviour therapies. While research on the autism wars is highly useful for understanding how autism actors collectivize and clash in response to behaviour therapies, little scholarly attention has been paid to what goes on when people actually provide and receive these therapies. Without understanding everyday practice we do not have much of an understanding of applied behaviour analysis. We cannot grasp the complicated nuances of power and governance that manifest in everyday practice. We cannot understand the beliefs and activities that have caused and continue to animate the autism wars, and so our understanding of these wars is limited. Also lost in this trajectory is the behaviour therapy provider whose role is reduced to whether or not she harms or helps her therapy subject, which is vitally important to consider, but stopping there delimits a wider contextual analysis of the forces of power that shape the therapist/recipient dyad. We cannot fully understand the context in which behaviour therapy work exists unless we engage with providers and study their beliefs, work activities, workplaces and emotions.

In Chapter One I began by analyzing the subject formation of the behaviour therapist as created through disciplinary exercises aimed at splintering and reconstructing the therapists' view towards herself and her therapeutic subject. The subject formation process, I argued, creates a distinctive clinical-ethical behavioural worldview that hinges on the science of behaviour functionality and structures therapists' daily actions, feelings, and beliefs. The second chapter focused on the larger institutional contexts in which behaviour therapists conduct their work (such as waitlists, certification, and custodial care) and demonstrated how everyday practice is organized by translocal managerial forms of governance concerned with solving particular fiscal and social issues. Chapter Three analyzed how, despite the disciplinary and managerial governance of providers, the central role para-practitioners play in applying behaviour therapies complicates any attempt to regulate practice, since para-practitioners apply behaviour therapies in a way that fits with their social fabric, moral code and work duties. The last chapter considered the wider discursive culture in which behaviour analysis exists, studying how actors invested in autism communities engage with behaviour therapies to shape formulations of autism

advocacy, representation and political voice. Here I showed how historical approaches to autism care, larger scientific ideals, sex/gender norms and identity politics structure not only how autism stakeholders politically evaluate behaviour therapies, but the therapies themselves.

Prior to discussing some final points about the major analytic themes of this study and my suggestions for future areas of research on ABA, it is important to list some of what limits my inquiry. First, because of my ethical concern with observing therapy work provided to autistic children incapable (by virtue of their age) of consenting to my presence, I did not conduct sustained ethnographic fieldwork of actual behaviour therapy programs. Ethnographically observing providers' work *in action* would have enabled a richer and more authoritative account of everyday behaviour therapy work. If I did observe autistic children though, I would have been replicating the problematic power dynamics that I was calling attention to here. Because I witnessed so many behaviour therapy sessions in my own family life and through my work experience in the field, I had a robust sense of what happens in behaviour therapy work to draw on. As discussed in the Introduction, my insider/outsider status prevents me from including the extensive personal knowledge I have regarding behaviour therapy work yet this knowledge provided the essential background information necessary for this dissertation.

An additional limitation to my study relates to scale. For this dissertation, I interviewed thirty-two providers and recipients of behaviour therapies yet a much larger study with a team of researchers could ideally engage hundreds of participants in the interview process and observe a variety of autism spaces and events. Further, because my study aimed to provide an overview of behaviour therapy providers, I studied all types of providers: parents, teachers, assistant therapists, behaviour therapists, clinicians, consultants, and support workers. In an effort to include a wide range of providers, I could not provide an in-depth analysis of each *kind* of provider. Those considering future studies of applied behaviour therapies may consider conducting a project that specifically analyzes the work practices of one type of provider.

Before concluding, it is important to draw out some of the key themes that ran through each of the four empirical chapters.

*Applied Behaviour Analysis and managerial healthcare infrastructure*

It is important to contextualize ABA's vision of the human subject as fitting within a larger biomedical cultural system characterized by a functionalist-mechanical approach to the body and a rational, science-based approach to health and illness. Applied Behaviour Analysis is grounded in a distinctly modern and staunchly atheist science that exists in ideological opposition to the elaborate and ethereal human subject envisioned within the psychological sciences. As examined in Chapter One, a mechanical understanding of human life undergirds the science of applied behaviour analysis whereby behaviours are central to who we are and can be calculated and calibrated with technical proficiency to increase functionality. To calculate, one must create a calculable subject. With behaviour analysis, there is no murky subterranean self, no deep unconscious psyche to unravel. The human subject is approached as a perceptible and programmable organism. Everything you need to know can be observed and everything you observe can be measured, tracked and modified. With ABA, there is no human spirit that escapes the grasp of quantification because there is no human spirit.

The science of applied behaviour analysis compliments and bolsters the current evidence and management-based technocratic healthcare system in Ontario. Cataloging and calculating the activities and performances of provider and recipient is at the heart of ABA but is also indicative of the wider context of Canadian healthcare reform aimed at managing through textualizing and thus rendering healthcare work legible and transferable (Rankin & Campbell 2006; Timmermans & Berg 2010; Mykhalovskiy, 2001). Rankin and Campbell (2006) explain how measurement is the key to healthcare management and they include a poignant quote from Michael Dector, who as chair of the board of the Canadian Institute of Health Information, said: "If you can't measure it, you can't manage it (CHSRF 2000:6)" (2006, 17). An important aspect of my dissertation, particularly in Chapter's One and Two, was to demonstrate how the techniques of behaviour analysis knowledge production share important characteristics (such as, transparency, proscribed activities, textualization, and numerical and quantitative forms of representation) with managerial techniques of healthcare governance. The managerial *appropriation* of ABA



texts and practices, organizes, constrains, and effectively conceals local everyday ABA practice. Both providers and recipients are ruled by managerial efforts to organize therapeutic activities. Behaviour therapies circulate in such an impressive capacity and have this degree productive power because the priorities and qualities that characterize this moment of managerial mental health governance are fundamentally compatible with the science of applied behaviour analysis.

It is also important to consider that applied behaviour therapies fit perfectly into the current “quick-fix, medication-centered world of managed behavioural health” (Schechter, 2014, p.1), where complex human maladies are brought to the surface (*see* Novas and Rose, 2000) and governed through an evidence-based logic of accountability and effectiveness. “Effectiveness” is a word that encapsulates the modern rationalization of the mental health field (Foucault, 1988): it indicates a new way of understanding the human subject as visible, observable and measurable. As my clinician participant Hailey poetically encapsulated: “In North America there is such a behavioural way of looking at the world. It’s all about fixing behaviours, not analyzing the inner life...We live in dreams, we live in creations, and we live in hopes. This is our inner life. It’s not just behaviour.” The autistic subject exists within this rationalized field as a subject to be known through her behaviour, to be worked on to increase functioning and to be brought into an ordered scientific world. “Autism” becomes a thing that can be calculated and calibrated and in such a way as to be quantifiable and chartable. Accordingly, behaviour therapies are not just interventions deserving of analytic attention because they are the standards of autism care: they provide a platform for understanding the nature and values of contemporary disability and mental healthcare governance in Ontario.

### *The Ambivalence and Multiplicity of Everyday Practice*

Despite managerial forms of rule and the rationalization of the autistic subject, through this research project I encountered an impressive level of ambivalence and variability between providers in terms of their actions, beliefs and scientific understandings of behaviour analysis. Consider for instance how my informants Becky, Anita, and Maya centred their ABA work on modifying the autistic person to adapt to her normative environments. By contrast, Bobby, Orli, and Natalie centered their work on

modifying the environment to increase communication skills and foster meaningful inclusion for the autistic people they work with. When comparing the work of para-practitioners, it is hard to find any similarities between the practices carried out by Sunnivah, Anita, Rosa, Laurie, and Joey and Donna. Attending to the everyday activities of the range of actors involved in providing behaviour therapies demonstrates the methodological richness, subjective uncertainties, and ideological differences that actually comprise behaviour therapy work.

A number of the behaviour therapists I encountered in this study used behaviour analysis in such a way as to have a complex understanding of their therapeutic recipients. A surface approach does not always indicate a shallow one. For example, think of Lydia who (as discussed in Chapter Three) said it is impossible to blame anyone for their (even criminal) actions since it is society's fault for failing to perceive and intervene on the antecedents and consequences that led to these acts. Or think of Orli and Natalie who considered (as discussed in Chapter Four) behaviour analysis as constituting an important safeguard and advocacy tool for protecting autistic people against experiencing discrimination. These participants considered behaviour analysis as requiring a value-free and objective empirical analysis of behaviours that is unfiltered by any kind of lens and is therefore free from preconceptions and stands outside of politics. Natalie described how referring to an autistic person as "aggressive" for hitting is a problematic assessment that constitutes a discriminatory attitude toward the autistic person. Hitting is an action and aggression is a morally-charged interpretation, Natalie explained. Of course, throughout my dissertation, I challenged this modest witness formulation of the behaviour analyst, but, even still, it is important to note how some providers orient to the empiricism of behaviour analysis in a progressive agency-enhancing way. Further, the scientific notion that all behaviours are shaped by the environment and that *the environment (not the individual) is the "problem" that requires modification*, can also result in providers (like Natalie and Orli) orienting to behaviour therapy as the best way of modifying the discriminatory environments and institutions their autistic clients are situated within.

Fascinatingly, as I detailed in Chapter Two, Natalie shared the same view as Sam and Louisa, two staunch ABA critics. Natalie, Sam and Louisa each described spending their everyday work hours advocating against oppressive Behaviour Support Plans created

for autistic adults in custodial care settings. Sam and Louisa argued that “behaviours” erupt when clients are not being listened to and that often in behaviour therapy work, Behaviour Support Plans are created to silence their clients’ anger and discontent. Natalie argued the same thing but considered *quality* behaviour therapy work as an effective way to counter this kind of maltreatment that is egregiously (in her view) done in the name of behaviour therapy. In essence, proponents and critics can *share the same views* regarding the ethical treatment of autistic people while forming oppositional appraisals of behaviour analysis.

When I read the transcript from my interview with Natalie, I am moved by her dedication to the autistic people she works with and how conscientiously she applies behaviour therapy. Whenever I think about Natalie I get this uncomfortable feeling in my stomach paired with an urge to light my dissertation on fire as I fear I’ve misrepresented applied behaviour analysts. But then I think about Wyatt’s story of Oak Ridges, Sam and Louisa, Anita, Becky, all the autistic self-advocates who have told their ABA stories and all the times I’ve witnessed ABA be applied to my kin, and I continue on with writing these words—even though as I do so I think about counter examples of behaviour therapy providers who I view as doing helpful work. Back and forth and back and forth I go. Since the inception of this project I have struggled with how to represent the ethical teeter tottering of behaviour therapy practices and providers that constitute the local culture of applied behaviour analysis that I have witnessed. My study feels important and real and hurtful all at once. I am not at peace with turning my interviews into narratives constructed as truth claims. But I am confident that this dissertation captures a *partial truth* (see Clifford, 1986) about ABA in the everyday. Natalie’s interview in particular burrows into me like a bad bug bite where I feel with acuity how “staying with the trouble” (Haraway, 2016, p.55) can sting and itch and linger.

Yet I think I’ve arrived at some sense of strained resolution with the following thoughts. Because behaviour analysis is a standard of autism care, a range of activities that occur within the autism service sector are done in the name of ABA even if some of these activities are repugnant to some behaviour therapy providers. ABA can be ethical but also constitute maltreatment because it is called on to answer and adapt to such a wide range of social and institutional problems. Contrary to the proscriptive, programmatic behaviour

science that undergirds it, *ABA has become the standard of autism care because of how adaptable and flexible it is*. One could say the group home, the ABA/EIBI centre, the school, the government, the asylum, or parent para-practitioner advocates (and so on and so forth), have appropriated ABA to suit their own institutional or political agenda, but this would be a misnomer. ABA is constituted by *all of the activities* that are called “ABA” by *all of the actors* who have been tasked with providing it. To understand ABA, we need to meet it as it exists, not as some ideal, but in everyday life.

The animate character of ethnographic work complicates a linear account of power or a cohesive account of ABA practice. Studying behaviour therapy providers brings the *microphysics of power* (see Epstein, 1996; see Foucault, 1975) to the surface. The reason a microphysics approach is important is because it challenges over-determined arguments about the critical views of autistic self-advocates as misguided and ill-informed, as well as critical views of behaviour therapies as solely perpetuating the subjugation, normalization and compliance of autistic people. As examined, sometimes behaviour therapists are managerially ruled by the government requirement to turn their therapeutic work into quantitative numerical forms of assessment. Sometimes behaviour therapists feel subjected by the wants and needs of parents. Sometimes parents feel subjectified by the ABA programs clinicians implement. Sometimes behaviour therapists work to normalize and create compliant autistic subjects. Sometimes behaviour therapy providers create ABA programs that counter attempts to normalize autistic subjects and they work to increase the autistic person’s voice and choices. Sometimes the Behaviour Support Plan is used to manage and silence autistic people *and* behaviour therapy providers to ensure the proper functioning of the institution. Sometimes behaviour therapies are used to defy oppressive institutional practices. Sometimes parents and behaviour therapists work together to secretly construct ABA practices that deviate from the official Behaviour Intervention Plan created by clinical supervisors. Sometimes parents lie to their behaviour therapist about the ABA activities they complete. Some therapists think of behaviour therapies as mechanical, technical, and objective, while others think of them as creative, artful, and intuitive. And while all autism teachers are governed by ABA provincial policy, some teachers covertly tinker with ABA methods in order to manage their classrooms.

An important point of this dissertation is my emphasis on how behaviour therapies, as an applied scientific practice, are constituted by the multiple interpretations, creative applications, and resistances of its providers as well as by managerial and clinical attempts at standardization and regulation. Provincial ABA infrastructure is highly problematic yet the institutional forces that govern and shape local ABA work do not necessarily overrule intimate provider/recipient relations or always succeed in shaping providers' consciousness. In the nuances of everyday life the activities, beliefs and power dynamics in ABA work are both highly proscribed and quite capricious.

### *Gender*

As I argued in Chapter Four, gender dynamics shape discursive debates about behaviour therapies, the autism wars, and autism/autistic communities more generally. Gender dynamics also shape the daily production of ABA work. The majority of ABA providers for this study were women and male providers tended to be higher up on the clinical-academic ABA ladder. As described in Chapter One, ABA can activate complex gender management in female therapists who must learn to juggle the highly masculinist ideals of behaviour science with feminine ideals of nurturing self-sacrifice. Further, mothers are the primary ABA para-practitioners for their children and the ones who often stay at home or cut back/quit their paid work to provide free therapy to their children. Ontario ABA healthcare infrastructure thus tacitly relies on both a feminized (mostly precariously) paid *and* unpaid workforce to deliver everyday ABA programs. Women, primarily mothers, also compose the most active political figures in autism ABA discourse: they are at the centre of social and political campaigns and lobbying efforts (Douglas, 2013, 2014, 2016). For these reasons, the political economy of behaviour analysis and mainstream autism advocacy are entwined with larger systems of gender, family relations and power.

The mother-centricity of ABA para-practitioner work and mainstream autism advocacy discourse makes sense when considering the traditional social role of the mother as that of raising the citizen for the betterment of the nation. Donzelot (1979) writes of how governance happens in and through the family with mother and child at the centre. Ruth Feldstein describes the family as a “civilizing force that mediate[s] between self and society” where the mother is “the emotional force that mediate[s] between child and future

citizen” (2000, p.145). It is in the context of governance and the governance duties of the heteronormative mother role that ABA circulates through the family and rose to clinical prominence (Silverman, 2004). An important topic for future studies would be to specifically examine gender roles in everyday ABA practice and to ethnographically follow a pool of families as they carry out their home-based ABA programs.

### *Generosity, flexibility, and gatekeeping*

Another important finding of this dissertation is that behaviour therapies are not just popular because they fit within our current managerial healthcare system, they are popular because they operate as a generous form of expertise (Rose, 1994, 1998). It is only through the profound generosity of behaviour therapies that they have become the most prevalent autism intervention and the standard of autism care in Ontario. Since their inception with Lovaas’ clinical enterprise, parents, graduate students, and support workers, have been central to the everyday practice of these therapies. The generosity of behaviour therapies has, I’ve argued, encoded (from day one) variability and contradictions in everyday practice.

Flexibility is the key technique for enrolling a large lay-expert workforce and for expanding the generosity of behaviour therapies. Flexibility extends beyond the qualifications for becoming a provider. As a profession, behaviour therapy is symptomatic of a larger flexible workforce. Emily Martin (1995) argues that since the 1990s, flexible specialization has been an important neo-Darwinian trait within the neoliberal capitalist workforce. Flexible workers are those who can adapt to managerial organizational demands and demands that keep changing as the workplace evolves, expands, contracts, and shifts to meet market needs. Martin further claims that to reflect the virtues of the social body, flexibility has become a virtuous personal trait: the ability to “be flexible” mentally and physically is a moral quality.

As I described in the Introduction of this dissertation, prior to becoming behaviour therapists many of my informants were psychology majors who felt lost in the labour economy before they stumbled upon behaviour therapy programs. They described finding behaviour therapy programs as “fate,” considering the availability of new, fast-paced ABA college programs with flexible enrolment options as the main reason they applied. Being

able to enrol part-time or complete night classes, online classes, or complete the program in a condensed period of time, enabled my informants to continue to care for their children or work their full-time jobs while completing their degree. My other participants, who started practicing behaviour therapies through their support worker jobs, described successfully interviewing for ABA positions without even knowing what ABA was. The flexibility of ABA expands beyond formal training to encompass flexible qualifications: some ABA providers are highly trained academic actors, while others are camp counsellors, grandparents, high school students, or even autistic people providing ABA to their peers while receiving their own ABA program.

In addition to being drawn to the profession because ABA programs and positions often embrace flexible qualifications and schedules, many providers are asked to be flexible workers: they are often non-unionized and circulate between a number of private and public behaviour therapy centres. Providers often learn to be adaptable and enterprising in terms of where they work and how they practice. Many participants for this study have moved around from public to private centres, from working with children to adults and from Canada to the U.S. to overseas. Further, many providers flexibly relate to their profession, like Margot who (as discussed in Chapter Two) began as a behaviour therapist but in refusing to complete her BACB began to describe herself as a child psychotherapist who uses “behavioural methodology in an early intervention sort of style.”

As I demonstrated in Chapter Two, when discussing ABA certification, now that behaviour analysis has become such an established method with a large workforce, there has been a push to make ABA a regulated academic profession. To make this happen, there has been a concerted effort (from government stakeholders, parent advocates, and clinicians) within the field to standardize and gatekeep behaviour therapy practices and providers. As a result, the myriad of actors who were invited into the ABA fold in order to quickly create an ABA workforce where none existed before, are now beginning to be excluded from the field. The clinical-academic focus of professionalization has started to create a uniformity of ABA practices and providers on the one hand, and “shadow stories” on the other (MacDonald, 2007, p.23). Support worker types like Bobby who were fundamental to the establishment of ABA are now finding themselves pressed up against the glass of an academic citadel, peering in. An important direction for future social

science research on this topic is to address how professional certification will continue to shape everyday behaviour therapy practices and providers. Might regulation lead to a less generous formulation of this applied science? And if so, how might regulation influence both the practices and the political-clinical capital of behaviour therapies?

### *Future Directions*

Before sharing my final thoughts it is important to discuss my next steps and future directions for research on this topic. Currently, I have begun a two-year Post-Doctoral Research Fellowship which studies gender roles in family-based behaviour health interventions. While not focused on ABA, this new research project will further explore how behaviour-based health interventions govern citizens through working within the family structure, clinicalizing the space of the home, rationalizing care-work and affect, and democratizing scientific knowledge. During this period I also intend to turn this dissertation into a book. Following my Post-Doctoral Fellowship, I plan to pursue a faculty position in an interdisciplinary health studies department where I will conduct an ethnographic research study focusing on the use of ABA in group home settings.

For other scholars interested in studying applied behaviour analysis, there are a number of areas that require further exploration. First, a political economy approach, which focuses on the corporatization of ABA and public-private partnerships, would be critical. As discussed in Chapter Two, there are very long waitlists for publicly funded ABA services. As a result, there has been an outgrowth of private ABA services and centres for parents who are waiting for their autistic kid to get a spot in the public system or for those who think private ABA services offer higher quality programs. ABA has thus become a target for corporate business ventures and is being marketed to new and different autistic subgroups (like adults or children with “autistic-like” traits) thus shaping not only the production of ABA, but autism too.

An ethnography that follows behaviour therapy students through their degree process would be instructive and interesting, as it would enable a detailed analysis of the primary methodological and pedagogical approaches involved in teaching people to become trained behaviour therapists. A local study that exclusively focuses on interviewing autistic adults who have received behaviour therapies in Ontario is also much



needed as this would provide a greater understanding of how healthcare recipients understand, feel, and think about the ABA programs they have received. Likewise, an ethnographic study of the activities, work practices, decision-making processes, and policies of the Behaviour Analysis Certification Board would provide a prescient opportunity to conduct an in-depth analysis of the institutional body that translocally governs behaviour analysts and behaviour therapy services in North America and beyond. A final area in need of study is the increasing use of ABA in Indigenous communities. While conducting my observation work at conferences, I listened to many presentations about ABA clinicians trying to increase services and enrol Indigenous actors to apply behaviour analysis to autistic people in their communities. Conducting an ethnography of these emerging ABA services and their political and ethical implications would be extremely important for those in the fields of medical anthropology/sociology and Indigenous Studies.

### *Final Thoughts*

In this dissertation I worked to create a text where an analysis of behaviour therapy providers and work practices could begin to be addressed, but that invited multiple interpretations and openings for further exploration. Inspired by Eric Mykhalovskiy's autoethnographic scholarship, I worked to create a dissertation that:

In recognizing the possibility of many readings, left spaces for others to speak. I wished for a text that welcomed, rather than concealed, contradiction and tension (Richardson, 1993) and that would allow readers to include feeling and participatory experience as part of knowing and reading (Ellis, 1993). I hoped to write a text that would make possible a reading stance that moved away from incorporation or abstract theoretical rumination; one that in its reading, would encourage the writing of other lives, the telling of new stories (1997, p.139).

I hope that this text continues to be one of many that grapples with the phenomenon of behaviour therapies and the social lives of those who provide and receive it.

As my final comment, it is important to clarify that with this dissertation I intentionally did not analyze autistic people but I hope they haunted these pages. I hope that by speaking, not of you, but of some of the things done to you, you clamour through this text like a party of ghosts stomping in the attic. I hope some of your lives emerged as a second reading silently spun. I wanted you to appear like the force of a strong wind, that

materializes through the shadows of branches on grass, as they fall loose and smash together in mid-air. I hope that by not speaking about you, you could exist everywhere, but never be spoken for. And that others might know more about, how much they might not know about, what, in this moment of time and in this place, your everyday lives might be like.

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