

QUESTIONING NORMATIVITY: EXPLORING THE EXPERIENCES OF AUTISTIC
ADULTS WHO HAVE UNDERGONE APPLIED BEHAVIOURAL ANALYSIS (ABA)

by

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An MRP

presented to Ryerson University

in partial fulfillment of the
requirements for the degree of
Master of Social Work
in the Program of
Social Work

Toronto, Ontario, Canada, 2020

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ABSTRACT

QUESTIONING NORMATIVITY: EXPLORING THE EXPERIENCES OF AUTISTIC ADULTS WHO HAVE UNDERGONE APPLIED BEHAVIOURAL ANALYSIS (ABA)

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In this research project I use a narrative methodology to explore the experiences of four autistic adults who have undergone applied behaviour analysis. By drawing upon the work of the neurodiversity movement and implementing a critical disability theoretical framework, I have sought to present the experiences and perspectives of participants as well as provide an analysis of the role of ableism in the systems in which they participated. Through positioning the lived experiences of this study's participants as a credible and trustworthy source of knowledge, I have called into question the ethicality of applied behaviour analysis techniques and implementation by problematizing the way in which it positions autistic traits as deviant and limits the self-determination and autonomy of its subjects. I have subsequently provided recommendations and points for reflection to the field that may serve to decrease the harms described by the participants of this study.

ACKNOWLEDGEMENTS

To the participants of this study; thank you for so openly sharing your experiences and making this possible. To my supervisor Dr. Preston, thank you for your endless patience and dedicated efforts in nurturing this project to get it to where it is.

DEDICATION

For my mother and father; Mary and Joe, who through their constancy and unwavering support continue to ground me and allow me to pursue work that I love - Thank you.

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INTRODUCTION

This research sought to resist ableism through questioning normality and problematizing the current ways in which alignment with ‘normal’ is encouraged and rewarded by existing structures. More specifically, through the personal narratives of autistic¹ individuals, this study drew upon the work of what is known as the neurodiversity movement, a movement positioned in opposition to the use of applied behavioural analysis (ABA) and behaviour modification. Recent neurodiversity discourse challenges the dominant conceptualizations of cognitive normalcy, asserting that autism is a variation of cognitive functioning rather than a neurological deficit (Kreck, 2013; O’Dell et al., 2016; Shyman, 2016). Proponents of neurodiversity take a humanistic perspective to critique behaviourism. From this perspective, often drawing on critical disability studies and the social model of disability, it is maintained that therapy modalities grounded in behaviourism such as applied behavioural analysis, perpetuate ableism through their efforts in modifying ‘inappropriate’ behaviours to appear more contextually ‘appropriate’² (Shyman, 2016).

Using a narrative research inquiry this study involved an exploration of the experiences of adults who identify as being on the autism spectrum and have undergone applied behavioural analysis. This research sought to answer the following question; What are the experiences of autistic adults who have undergone applied behavioural analysis? Through this research, I hope to have contributed to the conversation surrounding the neurodiversity movement and presented

¹ Throughout this research paper ‘identity-first’ language will be used, i.e., Autistic people/individuals, because it is the preferred terminology of autistic people (Kenny et al., 2016).

² Quotations around the words ‘inappropriate’ and ‘appropriate’ are used to refer to the way in which autistic behaviours are arbitrarily or subjectively defined as being in need of intervention or not based on the dominant conceptualization of normativity (Shyman, 2016)

a possible middle ground within the current polarizing perspectives between the field of behaviourism and the autistic community.

Contributions to Anti-oppressive Practice (AOP)

Epistemologically, the positivist paradigm tends to overwhelmingly inform the bulk of research on autism (Shyman, 2016). Consequently, models informed by this paradigm, most relatedly the medical model of disability, dominate policy and practice in the realm of therapy for individuals on the autism spectrum (Krcek, 2013; Shyman, 2016). Anti-oppressive research seeks to disrupt the narrative that knowledge validity is dependent on objectivity of the researcher and quantitative methods of measuring phenomenon (Potts & Brown, 2015). Potts and Brown explain that within critical transformative anti-oppressive approaches to research, knowledge is created through interactions between individuals with differing biases and privileges, rendering knowledge inherently political rather than neutral (2015). This research will contribute to AOP by challenging the dominant knowledge paradigm that has rendered applied behavioural analysis as the default therapy for people on the autism spectrum. Grounded in an interpretivist paradigm, this research seeks to posit that reality is socially constructed and that disability therefore exists within the sociopolitical and cultural contexts where autistic individuals are located (Absolon, 2011).

AOP involves shifting the way power relations function within research and practice (Potts & Brown, 2015). As a neurotypical (NT) researcher I exist as an outsider to the disability community. I acknowledge that the results of my research will inherently be limited given the power dynamic that exists between myself and the research participants of this study. I seek to position myself as a learner and collaborative partner with the disability community to minimize

this imbalance of power. Further details on the ways in which I have addressed this have been expanded upon in the limitations section of this MRP.

Members of the disability community have identified being in opposition to the modification or replacement of behaviours that help them to self-regulate emotionally and cognitively (Kapp, 2019). AOP seeks to put the voices of community members at the forefront (Potts & Brown, 2015). The methodological approach to this study, explored in detail in the third chapter of this research paper, will uphold this value of AOP by prioritizing the voices of community members. In addition, the very nature of questioning the dominant therapy modality used in practice and exploring lived experience as valid knowledge takes the stance of autistic adults into account, fostering conditions for obtaining social justice conducive to AOP.

CHAPTER 1. LITERATURE REVIEW

This literature review seeks to provide a brief summary of existing literature on the use and efficacy of applied behavioural analysis. A critical examination of existing literature will be provided. Epistemological tensions and subsequent methodological and theoretical framework differences will be explored to unveil some of the existing gaps in literature and scholarship.

A large body of both early and recent research exists regarding therapy, intervention, and support for autistic individuals. Applied behavioural analysis is the dominant therapy modality used in practice across North America (Gruson-Wood, 2016). The basic premise of applied behavioural analysis involves the implementation of individualized behaviour modification plans that use environmental controls and reinforcements to teach skills and behaviours that replace socially 'inappropriate' behaviours with increasingly 'appropriate' behaviours (Gruson-Wood, 2016)¹. Despite continuing to be the dominant form of therapy used in practice, there remains a contentious debate surrounding the ethicality of applied behavioural analysis, as evidenced by claims of the neurodiversity movement. It has been argued by autism advocates that behaviour modification therapies silence community members through coerced conformity to a set of able-bodied rules of normalcy, resulting in trauma (Shyman, 2016).

Recent research suggests that the behaviours traditional forms of behavioural therapy seek to minimize or replace, such as stimming, can be useful to self-regulate emotions and communicate thought (Kapp et al., 2019). This points to a need to further investigate alternative therapy modalities that are perhaps more person-centered, allowing for increased autonomy and self-determination on behalf of service users. This same study noted that neurodivergent participants disengaged with their self-regulatory behaviours as a response to feeling marginalized or disruptive to those around them (Kapp et al., 2019). Perhaps the lack of

acceptance for behaviours that differ between neurotypical and neurodivergent populations contributes to oppression as well as a pressure to conform. Through conversations with community members, this research has resisted the dominant discourse that seeks to facilitate this conformity as opposed to challenging the stigmatization of behaviours associated with autism.

Within neurodiversity discourse, an identified trend is the critique of applied behavioural analysis for its perpetuation of ableism. As previously described, the basis of applied behavioural analysis involves the use of reinforcements and environmental controls to target behaviours that are deemed to be in need of improvement (Gruson-Wood, 2016). It is argued that these forms of intervention inevitably turn “rightful activities and provisions into privileges to be earned based on compliance with a set of rules” (Shyman, 2016, p.370). I would add that these ‘sets of rules’ are based on a neurotypical sense of normalcy, thus perpetuating ableism. Several articles call the ethicality of behaviourism into question, affirming that a push towards normality propagates a dichotomy of normal and abnormal, devaluing certain behaviours as culturally inappropriate and thus consequently devaluing autism (Gruson-Wood, 2016; O’Dell et al., 2016; Shyman, 2016).

A gap identified in the literature is the epistemological and methodological frameworks that overwhelmingly dominate the writing regarding the use and effectiveness of applied behavioural therapies. A preliminary search revealed several studies from the disciplines of psychiatry and pediatrics that appear to be informed by the medical model of disability (Matson et al., 2012; Smith et al., 2009; Soltanifer et al., 2011). The medical model views autism spectrum disorder as a diagnosis that should be treated and cured by society, rather than an alternative form of human functioning that should be accepted by society (Gruson-Wood, 2016;

Krcek, 2013; O'Dell, 2016). To address this gap, this research has employed critical disability as its theoretical framework, with the intention of moving away from the pathologizing of autistic individuals and toward the inclusion of their lived experience.

A search of existing literature did not reveal scholarship that centralizes the firsthand experiences of autistic individuals who have undergone applied behavioural analysis. I would argue that if we are going to have meaningful conversations regarding support for the autistic community it would be beneficial to include the voices of those at the forefront of the neurodiversity movement, if not centralize their voices as the most meaningful stakeholders in the conversation. As previously mentioned, my research has attempted to fill this gap through the use of a narrative research methodology, wherein the stories of autistic individuals have been prioritized and their lived experience positioned as valid, credible knowledge.

Summary of Research Findings

In regards to the results of the research studies analyzed, the most prevalent theme is the framing of applied behavioural analysis as the gold-standard behavioural intervention method particularly in North America. Structured applied behavioural analysis procedures or behaviour therapies grounded in applied behavioural analysis are described in the literature as the most widely used, accepted, and effective method of intervention for autistic people across several disciplines (Ben-Itzhak & Zachor, 2007; Dawson et al., 2017; Lovaas, 1987; Mohammadzaheri et al., 2014; Tiura et al., 2017). Various randomized controlled trials using standardized assessment tools all revealed significant 'improvements' in social communication, adaptive behaviours, language skills, and intellectual functioning in autistic children after engagement with applied behavioural analysis and related therapies informed by applied behavioural analysis including early intensive behavioural intervention (EIBI) and pivotal response treatment (PRT)

(Ben-Itzhak & Zachor, 2007; Dawson et al., 2017; Granpeesheh et al., 2009; Lovaas, 1987; Mohammadzaheri et al., 2014; Tiura et al., 2017).

One study in particular confirmed that cognitive functioning at the start of applied behavioural analysis-based treatments impacts the trajectory of intervention, such that participants' functioning improves at faster rates than participants with lower cognitive functioning at the start of treatment (Tiura et al., 2017). This same study suggested that socioeconomic status did not play a role in the effectiveness of applied behavioural analysis as an intervention model (Tiura et al., 2017). This is one example of the ongoing trend across the literature wherein treatment success is equated to the degree to which a client's behaviours and functioning changes towards an able-bodied standard of performance.

Literature on the efficacy of applied behavioural analysis overwhelmingly points to age as being an important variable for the success of 'intervention and treatment'. It has been established that the greatest amount of mastered behavioural objectives, increase in intellectual functioning and social communication adeptness takes place when behavioural modification therapies are introduced at younger ages (Granpeesheh et al., 2009; Harris & Handleman, 2000). One study determined that intervention at younger ages was a predictor of a child's chance of being in a regular educational classroom with able-bodied students as opposed to being in an isolated classroom (Harris & Handleman, 2000). Perhaps the emphasis on identifying an optimal age for treatment is grounded in a larger goal of achieving the highest amount of efficacy of intervention. Intervention at younger ages encourages development that is consistent with able-bodied norms, rendering treatment efficacy dependant on conformity to said norms.

Limited research appears to exist regarding the exploration of limitations to applied behavioural analysis or critical analyses of its effects on the autism community. Two studies in

this area were found, one of which used semi-structured interviews and focus groups to conduct thematic analyses of autistic adults' understandings of stimming behaviours, an emotional regulation mechanism often sought to be eliminated by structured applied behavioural analysis (Kapp et al., 2019). This study revealed that an individual's disengagement with stimming behaviours was the result of feeling disruptive to other people around them (Kapp et al., 2019). This again suggests a pressure to conform to normativity based on able-bodied functioning.

The second piece of literature wherein the efficacy of applied behavioural analysis is criticized is an ethnographic research study of the culture, practices, and experiences of behavioural therapy providers for autistic individuals. This study concluded that applied behavioural analysis reproduces psychocentrism due to its effectiveness being dependent on inciting specific responses related to normative functioning as well as its framing of autism as an individual deficit (Gruson-Wood, 2016). It argues that behavioural therapies "consider the meaning of the lives of autistic people according to ideals of behavioural functionality, neurological capacity, and socialization." (Gruson-Wood, 2016, p. 54). The commonality between these two studies is their assertion of applied behavioural analysis as a reproduction of ableism and reinforcement of autistic behaviours as divergent. These studies make up a small fraction of the literature on this topic, displaying a skewed representation of the efficacy and implications of applied behavioural analysis in academia.

Critical Analysis of Literature

Epistemology is a theory of knowledge creation that provides a foundation for all facets of research, as it informs the questions researchers seek to answer and the methodologies researchers choose to implement (Carter & Little, 2007). It is argued that values are built within epistemologies, thus informing the type of relationships that researchers ultimately have with

their research participants (Carter & Little, 2007). Positivism for instance, views knowledge as absolute and values the objectivity of the researcher, rendering participants of studies as subjects being researched (Carter & Little, 2007). Other epistemologies and theoretical paradigms recognize that knowledge can come from lived experience. As such, a research study grounded in this epistemology might be more likely to include participants as active, collaborative members of every step within the research process, as a group that is studied *with* rather than studied *on* (Carter & Little, 2007).

This can be seen in the differences in relationships between the researcher and participants in randomized controlled trials (RCT) versus qualitative research studies. In Mohammadzaheri's RCT study for instance, reliability and objectivity were prioritized (Mohammadzaheri et al., 2014). Random assignment to control and experimental groups was used along with an independent observer who was naïve to the research hypothesis to ensure validity of results (Mohammadzaheri et al., 2014). Here we see how isolated all parties involved in the research are from one another when the research is grounded in positivism. This is problematic because it has the potential to produce knowledge that is an incomplete or inaccurate representation of the experiences of participants. Contrastingly, in the study involving autistic adults' experiences with stimming, the opinions and thoughts of participants were considered to be knowledge, and there was more of a relationship present through dialogue between participants and the researcher (Kapp et al., 2019). Through the use of in-depth, semi-structured interviews and room for participants to discuss how ableist stigma lead to their marginalization, participants' experiences were centered, rendering them active participants in the research process (Kapp et al., 2019).

The epistemological paradigm within which the majority of the knowledge on the topic of applied behavioural analysis and autism is situated appears to be rooted in positivism. Although not directly stated within the literature, this can be witnessed through the theoretical frameworks that ground the research process. Firstly, many of the quantitative studies follow the very rigid scientific method wherein ‘neutrality’ of the researcher is emphasized (Dawson et al., 2017; Mohammadzaheri et al., 2014; Rivard et al., 2019). Additionally, several of the reviewed research studies seek to measure the success of treatment and intervention models (Ben-Itzhak & Zachor, 2007; Dawson et al., 2017; Harris & Handelman, 2000; Lovaas, 1987; Mohammadzaheri et al., 2014; Rivard et al., 2019;). This success is based on the degree to which a participant ends an ‘inappropriate behaviour’ and adopts a more ‘appropriate’ way of functioning. Due to the overarching goal of measuring behaviour changes which is consistent with the medical model’s understanding of autism as a diagnosis that should be treated rather than an alternative form of human functioning, one can infer that these studies are grounded in the medical model of disability (Gruson-Wood, 2016; Krcek, 2013; O’Dell, 2016).

Data collection tools are one aspect of research where epistemological paradigms and theoretical frameworks are evidenced. In this case, one can infer from the use of the data collection tools used in the available research that it is largely grounded in the medical model of disability. The literature refers to a wide variety of standardized assessment tests and scales such as Mullen Scales of Early Learning (MSEL), the repetitive behaviour scale (RBS), the childhood autism rating scale, and The Gilliam Autism Rating Scale–Second Edition to name a few (Dawson et al., 2017; Rivard et al., 2019). These tests were used to measure variables involving severity of symptoms, intellectual functioning, or presentation of ‘maladaptive’ behaviours that would be used to determine efficacy of treatment or intervention. It is important to note that

these scales measure conformity to able-bodied functioning in one way or another. The nature of what these tools measure suggests that they seek to measure normal versus abnormal, allowing them to be used to devalue alternative ways of functioning that deviate from able-bodied norms. This is consistent with the medical model's evaluation of autism, suggesting that it may be the theoretical basis to the available research.

It is interesting to note that critical examinations of applied behavioural therapies do not exist within natural science disciplines but rather in social science disciplines such as disability studies and social justice journals (Gruson-Wood, 2016; Kapp et al., 2019; Shyman, 2016). That said, there remains research grounded in the medical model that is focused on the treatment and cure of autism across several disciplines. This speaks to the potential epistemological and ideological differences across disciplines. Additionally, as evidenced by the type of sources I have been able to gather, it is apparent that there is overwhelmingly more literature published within natural science disciplines. When it comes to the intervention and support of autistic individuals, the disproportionate literature available translates into practice through the use of applied behavioural therapies as the dominant or rather default intervention method to support youth in particular. Perhaps through an increased emphasis or prioritization of social work or critical autism studies research, autistic individuals would have more equitable options available to them.

Addressing the Gaps

The construction of knowledge is not exempt from socio-political forces. I would argue that the previously mentioned disparities in knowledge production frameworks are evidence of ableism permeating the research process. Dehegemonization refers to attempting to undo the established hegemony (Gegeo & Watson-Gegeo, 2001). In the case of this topic, my MRP

research has sought to disrupt the largely unquestioned use of applied behavioural analysis as the default form of therapy. This will be done by shifting away from the medical model of disability towards critical disability theory as a framework for my research.

Carter and Little describe that particular methodologies produce specific types of data (2007). They assert that methodology is not neutral but rather informed by a particular epistemology, thus informing methods that produce specific types of data (Carter & Little, 2007). For example, an ethnography is likely to produce a ‘detailed interpretation of culture’ while a narrative study is more likely to produce a ‘detailed analysis of life stories’ (Carter & Little, 2007). The same phenomenon or research topic can then be answered through various methods to produce varying data (Carter & Little, 2007). As alluded to in the above literature review the current literature subjugates the voice of the autism community and consequentially inadvertently devalues the knowledge they can offer in part because it uses methods that are rooted in an interpretivist epistemology that value objectivity as opposed to subjective experiences. My research seeks to address this gap through its methodological framework. I will be using a narrative research methodology as it requires active collaboration with participants and views their lived experiences and identities as sources of knowledge to produce an in-depth analysis of said experiences (Creswell, 2013).

CHAPTER 2. THEORETICAL FRAMEWORK

Introduction

The following chapter will provide an overview of critical disability theory (CDT), the guiding theoretical framework through which this research project was conducted. I will provide a brief summary of its emergence as well as an in-depth exploration of its importance in both addressing ableism and contributing to disability research. I will also then examine the core tenets of CDT as they relate to the overarching purposes of this research study; including resisting ableism, contributing to AOP, and highlighting the voices of those with lived experience.

Resisting the Medical Model of Disability

As mentioned in the literature review chapter of this research paper, a gap identified in the existing discourse on the topic is the epistemological and methodological frameworks that overwhelmingly dominate the academic work regarding the use and effectiveness of applied behavioural therapies. It is suggested that the social construction of all topics including disability is in part grounded in the epistemological underpinnings of research which as explored earlier, is historically overwhelmingly dominated by the medical model (Meekosha & Shuttleworth, 2017). The medical model, which continues to inform the bulk of policy and practice surrounding autism, views autism spectrum disorder as a diagnosis that should be treated and cured rather than an alternative form of human functioning that should be accepted by society (Krcek, 2013; Gruson-Wood, 2016; O'Dell, 2016). When applied to practice, consequences of academics' and the general public's over-reliance and seemingly unwavering acceptance of this model include patronizing and patriarchal engagement with the disability community, and a harmful pathologization of human behaviour (Meekosha & Shuttleworth, 2017).

The Emergence of Critical Disability Theory (CDT)

This research seeks to resist this model through the use of critical disability theory (CDT) as its theoretical framework. CDT, which has emerged in the last decade, argues that it is ableism, rather than the physical or cognitive manifestations of a disability, that is the root of the ongoing oppression faced by the disability community. Through its structural critiques and frameworks for emancipatory social change, this theoretical framework allows us to move away from the dichotomy of normal versus abnormal which denies inclusion through its emphasis on deviance and deficiency (Meekosha & Shuttleworth, 2017).

It has been suggested that critical disability studies as a discipline has emerged out of other interdisciplinary theories such as feminisms and social theories (Meekosha & Shuttleworth, 2017). The social model of disability suggests that inclusive environments and recognition of the unique needs of the disabled inform their capacity to participate in society (Meekosha & Dowse, 2007). This opposes the ideologies of the medical model which suggest that success in behavioural interventions or increased conformity create better participation in society (Meekosha & Dowse, 2007). Described as a cross-fertilization between disability theory and critical race theory, critical disability theory (CDT) allows us to resist the ‘medical model versus social model’ binary that has prevented theorists from considering the ways in which biology and culture intersect to produce disability (Rocco, 2015; Waltz, 2014).

Approaching my research through this theoretical lens is the most appropriate because critical disability theorists seek to resist ableism through exploring power relations as well as the social and political contexts within which disability exists (Meekosha & Shuttleworth, 2017). This is ideologically consistent with this research study’s goal of sharing the experiences of autistic adults who have undergone, applied behavioural analysis, a therapeutic modality

critiqued for its abusive history, use of power over the autistic community and dismissal of neurodiversity activism.

Core Concepts of Critical Disability Theory

In reference to Tanya Titchkowsky's work on accessibility, the purpose of critical disability theory as a framework is described as; "to explore the complex interplay of power dynamics, normalization, inclusion/exclusion, accessibility, mobility, identity politics, intersectionality and privilege." (Tihic, 2019, p. 50). This purpose will be the guiding framework for the analysis of the shared narratives from autistic adults.

A core concept of critical disability theory is to resist the medical model and question the notion of cure (Waltz, 2014). This framework then, allows us to problematize the role of service interventions as a control mechanism for the regulation of disabled bodies (Meekosha & Shuttleworth, 2009). This particular tenet of the theoretical lens will guide the data analysis portion of this study. More specifically, a critical disability lens has the potential to, based on the shared narratives provided by participants, permit me to problematize behavioural therapies as an imposed intervention for many autistics and a mechanism for control over neurodivergent behaviours.

A central theme of CDT is the examination of epistemic violence and oppression faced by the disability community; which is rooted in the unjust and unattainable standards of normalcy set by society (Vehmas & Watso, 2014). Drawing on social constructivism, CDT asserts that disability is a social construct, one that is dictated, reproduced, and sustained through language (Shildrick, 2012). As such, critical disability studies theorize that the inclusion of the disabled voice, which is traditionally subjugated to that of the able-bodied voice, is necessary to understanding and shifting our perceptions of disabled embodiment (Shildrick, 2012). In the

context of this research, a narrative methodology and AOP principles have been employed to achieve this.

Critical Disability Theory and AOP

A contribution to critical AOP is a desired goal of this research project. A critical disability theoretical framework will support achieving the goal of contributing to AOP because CDT's acknowledgement of epistemic violence rooted ableism gives us an awareness of power relations and ultimately allows us to achieve the AOP principle of centering the marginalized insider voice (Baines & Edwards, 2015; Rocco, 2005). This informs the overall aim of this research project because centering participant narratives allows us to disrupt the current imbalance of power that exists epistemologically in research as well as on a systemic level across society by placing value on a different type of knowledge, knowledge that comes out of the lived experiences of participants which is currently deemed as less valid than the researcher's voice. This informs my research project specifically because its purpose is to centre the silenced narratives that are currently absent in the conversation.

CDT intersects with AOP in terms of their similar broader goal for social justice. As mentioned above, CDT contributes to social justice because it allows us to value the autistic identity by calling into question the role that service interventions play as a control mechanism (Meekosha & Shuttleworth, 2009). This intersects with the AOP principle of contributing to social justice by considering the sociopolitical and structural issues that exist beyond individuals and groups (Baines & Edwards, 2015). Incorporating a framework that allows me to be critical of dominant discourses is directly in line with AOP's purpose of challenging power and privilege. Again, this relates back to my research due to its goal of disrupting the dominant narrative of the autistic experience and applied behavioural analysis.

Application of Critical Disability Theory

Critical disability theory has been the guiding theoretical framework for all aspects of this research ranging from the development of the central research question to the recruitment strategy and data analysis. The literature on critical disability theory asserts that the rights to autonomy, self determination, and accessibility for the disabled are necessary to challenge the epistemic violence and ableism faced by the community (Rocco, 2005). CDT informed the development of this research question because it challenges the norms that serve to construct disabled embodiment. More specifically, the premise of this study's research question; "What are the experiences of autistic adults who have undergone behavioural therapies grounded in applied behavioural analysis?" calls the ethicality of applied behavioural analysis into question. In doing so, the unique insights and experiences of community members are deemed valuable expertise and the therapeutic norm is challenged.

Critical disability theory has informed the study design as well as the methodological approach of this study because accessibility and autonomy have been prioritized in an active effort to resist ableism. For instance, interviews are taking place through an online platform that can account for variations in mobility, communication, and geographical contexts. In addition, the specific methodology used in this study, narrative research, allows for participants to autonomously decide how much or how little information to share with me. Narrative research allows for accessibility in terms of communication styles because the way in which a personal narrative is shared is based entirely on the choice of the participant. This is particularly relevant as a neurotypical researcher conducting research with a community I am not a part of because there exists a history of autistic people being researched *on* by neurotypical researchers as

opposed to being researched *with*. That said, as will be explained in greater detail later, the results of this study will inevitably be impacted by my positionality as a neurotypical researcher.

CHAPTER 3. METHODOLOGY

The following chapter seeks to provide an overview of the modes of inquiry and analysis used in this study. I will begin by providing an overview of narrative research as a methodology and its related importance to the purpose of this study. A detailed explanation of the role that thematic narrative analysis has played in the data analysis portion of this research will be provided. I will then specify the details of this study's design including the sampling and recruitment methods employed for data collection purposes.

A Narrative Approach to Inquiry

Storytelling is a fundamental part of human culture and an arguably universally understood method of conveying experience; it is one that becomes a vessel for meaning making of past or imagined events by individuals from all social realities (Riessman, 2009). The narrative approach to inquiry, which has gained an increasingly large platform in the academy and subsequently established a more substantial role in the creation of social thought as of late, often involves inviting individuals with lived experience into dialogue to narrate said experiences (Creswell, et al., 2007; Fraser, 2004).

The sharing of narratives allows us to be critical and reflective of our past, to make meaning of our experiences, to process our emotions, and to ultimately create our subjective identities (Riessman, 2009). In the context of this research, a narrative methodology was employed to understand, deconstruct, and re-story the lived experiences of adults who identify as autistic and who have undergone applied behavioural analysis. In accounting for their shared stories, a narrative approach to research has allowed us to be critical and disruptive of assumed truths, by presenting the multiplicity of realities that exist (Fraser, 2004).

As alluded to in previous chapters, a principle guiding purpose of this research is to address the substantive scholarly gaps regarding the inclusion of the neurodiversity perspective and the lived experiences of the autism community. This approach to inquiry is best suited for fulfillment of this purpose as it allows for the lived experiences of community members to be placed at the forefront, permitting the complexity and context in which their experiences are shaped to be accounted for.

Further, through its capacity to hold space for curiosity and reflexivity as well as position participant as expert (Fraser, 2004), this research methodology has the potential to contribute to social justice and thus advances this study's intended engagement with critical AOP. A narrative approach of inquiry involved the sharing of personal truths that in turn allowed for an analysis with greater depth than the statistical analyses presented in the dominating research on the implications of applied behavioural analysis, again, allowing for an increasingly personalized understanding of the implications and efficacy of applied behavioural analysis.

Riessman asserts that the validity of this approach lies in its capacity to both inform future research and work towards social change (2009). It is argued that telling one's story through research can be a cathartic experience for participants, one that contributes to both the perception and formation of identity, and subsequently serves as a potential impetus for social action (Riessman, 2009). This research has held space for the narratives of those excluded by the epistemological gaps in scholarship in hopes of advancing the activism of the neurodiversity movement and contributing to the resistance of ableism experienced by autists.

Study Design

A critical disability framework affirms that disabled people undergo epistemic violence as a result of ableism which must be resisted through the prioritization of self-determination and

autonomy in all areas of life (Rocco, 2005). As such, a key component of this study was to be cognizant of the power dynamics at play between myself as an able-bodied researcher and my participants as members of the disability community as I explored the interplay of inclusion, exclusion, normativity, and power relations evident in their engagement with applied behavioural analysis as a modality. Narrative research emphasizes human agency through its capacity to allow participants to tell their own story in their own unique way, rendering it a well-suited analytic method for exploring and understanding the subjective realities of this study's participants (Grinell et al., 2016).

Narrative inquiry assumes that the way in which a storyteller recounts their experience is purposeful and reflects meaning (Ayres et al., 2016). As such, this approach to inquiry demands and in depth reading of each individual narrative to understand meaning (Ayres et al., 2016). To achieve this, I have used a within-case analytic strategy to hone in on themes that were central to individual narratives. In doing so, I was able to also see patterns or commonalities across interview transcripts that reflected similar experiences or perceptions of their experiences. These commonalities represented across-case themes that I have examined as well. Using within-case and across-case analysis allowed me to simultaneously explore the individuals' narratives in depth whilst identifying the commonalities across those narratives, creating a substantive exploration of participant narrative (Ayres et al., 2016).

In accordance with critical disability theory's understanding that accessibility plays an important role in the inclusion of the disability community, ensuring accessibility was also of grave importance in the design of this study. The literature on conducting accessible research towards the inclusion of the disability community has suggested strategies such as allowing responses via internet sites and provision of consent form prior to the interview process (Rios et

al., 2016). Internet access has also demonstrated promising advancements of social inclusion and e-learning for the disability community (Williamson et al., 2001). As such, the data collection process of this study is taking place via online interviews, which is described in more detail below.

Sampling and Recruitment Strategies

For the purpose of this study, rather than seeking to obtain generalizable results through the use of a larger sample size, data was collected through engaging in dialogue with four adults who identify as autistic. Riessman describes language as a “direct and unambiguous route to meaning” (2006, p. 187). A thematic narrative analysis of a smaller sample size has allowed us to hone in on the specificities of the participant experience and derive meaning from conceptual groupings that are extrapolated from their detailed narratives (Riessman, 2009).

Non-probability sampling was used to recruit research participants for practicality reasons because it is both a cost and time efficient method (Grinnell et al., 2016). In addition, this sampling method is suitable for a qualitative study wherein generalizations to the wider population are not necessarily desired (Grinnell et al., 2016). Purposive sampling was also beneficial in valuing subjectivity and multiplicity of truth within research because it allowed me to intentionally hear from otherwise subjugated voices (Grinnell et al., 2016). Purposive sampling allowed me to hear from subjugated voices because the deliberate choice of participants with specific qualities and characteristics, in this case being an autistic adult and having undergone applied behaviour analysis, enabled the sharing of narratives from the specific group whose voice is absent in the available literature. Given the fact that my research question is centered around exploring the experiences with particular similar characteristics of interest

(age, disability, behavioural therapy service user) purposive, homogenous sampling was the most suitable sampling technique for this project.

The recruitment strategy for this project involved the use of a recruitment poster outlining the inclusion and exclusion criteria as well as the participation requirements. This material was posted online in community Facebook groups, where the desired sample engages in a variety of dialogues and activities surrounding their autistic identities. This allowed for purposive sampling to take place as well as timely recruitment through an accessible resource for community members.

Data Collection

Dialogue was facilitated through the use of semi-structured, online interviews. Semi-structured interviews allowed narratives to be shared in depth, to whatever degree felt appropriate to participants. This preserved their autonomy and served as an accessible data collection method to serve the needs of diverse communication styles. The interview questions ranged from exploring the level of involvement participants had in the elements of the services they received to an unearthing of the skills they were encouraged to learn or unlearn in applied behavioural analysis. Perceptions on the impacts of therapy on their everyday lives were also explored. Conversational interviewing, a tool commonly used in narrative inquiry, is an alternative to standardized interviewing wherein the interviewer can re-phrase or clarify questions in a conversational manner to ensure that the participants interpret questions as intended and are able to respond genuinely (Conrad, 2011). Conversational interviewing allowed me to disrupt dominant ideologies surrounding the efficacy and purpose of applied behavioural analysis by unearthing subordinated ideas about normativity, because participants are able to

provide rich detail based on their own experiences and interpretations (Conrad, 2011; Creswell et al., 2007).

It is critical to note that the results of this study will be impacted by the fact that I am an outsider to the disability community. As an able-bodied woman I recognize that participants' willingness to engage in deeper dialogue may rightfully not be present because of my able-bodied identity. I intended to challenge the inherent power balance between myself and the participants of this study by encouraging participants to share their story in however much detail they saw fit, to whatever degree they were comfortable doing so. Participants were informed that they have the option to withdraw their responses and comments from the interview process at any time during the interview and for up to two weeks following their interview. It was the hope that providing this openness and flexibility from the beginning would give control to the participants over what they shared and how. Additionally, I hoped to create an open and welcoming environment through conversational questioning, the use of open-ended questions as well as a loosely structured interview schedule. These characteristic elements of narrative interviewing promote an environment where participants can tell their story naturally and spontaneously, allowing for rich data made up of stories told in their own unique way (Grinnell et al., 2016). It is the hope that by encouraging the narrators to guide the information shared, their voices have been at the forefront of this study.

CHAPTER 4: RESEARCH FINDINGS

The data interpreted in the following chapter came from the online interviews of four autistic individuals who detailed their experiences with and perceptions of applied behavioural analysis. As noted in the previous chapter, participant recruitment took place using a mixed method sampling approach that involved purposive sampling from autistic community Facebook groups and Reddit communities as well as snowball sampling. All four participants were recruited from Reddit community groups.

In this chapter, I engage with the narratives shared during the four interviews conducted in this study to identify underlying themes within and across their experiences. Based on participant responses, four core themes have been identified, three of which are across-case themes: lack of self determination, autism as deviance, and finding community. One remaining within-case theme drawn from the interview of participant B alone, which I have referred to here as a lack of autonomy, will also be explored in this chapter.³

A Lack of Self-determination

Participant responses determined that their experiences included a stark lack of self-determination through three main avenues: not being involved in the type of services they received, having limited or no access to their personal files, and being unaware that they were subjected to applied behavioural analysis until later in life. When asked about their personal involvement in the services they received or were subjected to, all four participants shared a similar experience of limited to no involvement in the way in which they underwent services.

For instance; when describing the style or format of the schooling program they underwent which was taught by practitioners of applied behavioural analysis, participant B stated

³ Throughout this chapter and subsequent chapters, lacking self-determination refers to a lack of involvement or choice in matters that directly impact participants while lacking autonomy refers to the limited personal agency that surfaces due to the conditioning of behaviours.

the following; “It was very authoritarian [...] Ah, they [the goals the participant was expected to strive for] were set by the teachers, as a prescribed report card with different things they wanted to see.”. Here we see the participant occupying the role of a subject in the process as opposed to an active participant in the services that they were subjected to. This similar narrative was also expressed by participant C as noted in the following statement;

“I don't think i set goals, their ultimate goal was to at least have me talk and and [sic] act as normally as I can. Sure there were report cards but I never saw them, possibly only my parents got them.”

Participants expressed that at the time of receiving services, there was a level of confusion surrounding why or how they were subjected to applied behavioural analysis. Perhaps the role of applied behaviour analysis was not entirely understood by the participants of this study at the time they received services. The following three quotes echo a similar narrative of unawareness, suggesting a lack of self-determination regarding their participation in applied behaviour analysis.

“I only figured out that it fell under the label of ABA a few weeks ago.” “I wasn't sure why I was put there [...] It seemed weird that I was there” (Participant B).

“I only found out through eavesdropping on my father when he was on a phone call.” (Participant A).

“I think i was dragged into a special class in the middle of the day every day from first to third grade”. “I felt like I belonged with the other students, deserved to have friends, and learned the same things they did. [...] I had no idea how damaging ABA was for me until a friend pointed it out and how I knew there was something wrong with this class that I was kicking and screaming every time”. (Participant C)

The fact that most participants discovered in their adulthood that they underwent applied behavioural analysis as a child may suggest that the decision to engage in this therapy was made on their behalf or without an informed understanding of the nature of the services they received. Finally, a lack of self-determination was emphasized through the lack of access participants had to their file. The following statement was made by participant A: “My mother usually took care of the paperwork, I haven't seen it. [...] My mother has copies of the paperwork and files I received. My role was just a patient.”

Participants also discussed the implications of their lack of self-determination such as being disinterested in their learning which in turn proved to be ineffective in the ultimate goal of engaging prosocial behaviours. For instance, participant B recalled the following scenario that contributed towards his perception of applied behaviour analysis;

I remember one time a student threw a pencil and hit another student because they gave us really easy repetitive worksheets to do. There was a discussion of whether the pencil broke the other student's sin [sic] and that determined how many points were given. It seemed like a weird thing also the point scale was something like 1 to 5 points per period per day. Well, I thought they [the behaviour modification techniques] were silly then, and that made me confirm that view. People are intelligent goal-driven machines. It doesn't make much sense for other people to set goals for me. I suppose the assumption was then it was malicious. I remember kids going around the rules instead. Like doing things when no one was watching.

In this scenario participant B explains that the throwing of the pencil was the outcome of being provided with work that was not stimulating or challenging enough. Perhaps the implications of the lack of self-determination in service delivery and goal setting acted as the

catalyst for this adverse event. If there was an increased sense of self-determination regarding the goals or expected outcomes of applied behaviour analysis, there would potentially be different or increasingly mentally stimulating worksheets assigned to students, thus preventing the throwing of the pencil. Participant B notably mentions that they had both the capacity and drive to set goals but were instead told what goals they were meant to achieve. As described above, this lack of self-determination resulted in students conforming their behaviour within the presence of teachers and then acting out of their own volition when these practitioners were not watching. This is a clear example of how individuality is suppressed in a system that utilizes a power-over approach. This sentiment of being under challenged in applied behavioural analysis was echoed by participant C in the following description of the services they recall receiving:

basically if I was neurotypical, I would be allowed to stay with the class and learn Spanish. Instead of learning Spanish, I was dragged to a class where it was rudimentary stuff like speaking, number charts, counting charts, behaviours, facial expressions, and speech. the better parts involved bingo games with teachers. [...] and yes I felt incredibly under challenged where I was but was unable to express it properly due to my autism.

Here we see how this participant did not feel heard in her assessment of how under-challenging the work was. An increasingly accessible environment that accounted for her inability to use speech to communicate may have facilitated a better opportunity for self-advocacy and ultimately a more fruitful learning environment. Additionally, when asked to describe any specific skills that were focused on unlearning or learning in applied behaviour analysis participant C stated: “Mostly language as I talked late. the numbers work was more habit forming if anything, and maybe being told not to cry so much.” Perhaps an increase in self-

determination would have allowed for learning to extend beyond memorization of number charts and created an optimal challenge for this participants' learning.

Participant B recalled a scenario wherein teachers were informed of how their techniques may be problematic. As demonstrated in the quote below, the unwillingness of staff to be receptive to Participant B's feedback further demonstrates the lack of self-determination that was afforded to them as a service user because their input received a consequence as opposed to change.

I actually found that book 'How to talk so kids will listen' on their bookshelf and tried to show them why their techniques may not be as effective as they had hoped. [...] One time a teacher shouted at me when I asked about something and she responded "that's none of your beeswax". I told the principal that was inappropriate to say to me. He didn't do much, I think my points may have been marked down.

For participant B, the provision of feedback resulted in a punishment via the point system discussed earlier. Despite demonstrating the self-awareness required to self-advocate against the use of the techniques, the participants' assessment of the situation was not only dismissed but perceived as a revolt against authority and subsequently punished.

Lack of Autonomy

A lack of autonomy surfaced as a theme across multiple participant narratives in this study. As described in various ways, autonomy was restricted through what appears to be a power-over approach implemented by practitioners of applied behaviour analysis. As explored in greater depth below, when discussing the nature and purpose of applied behaviour analysis interventions, participants highlighted that for them, it was rooted in devaluing or even shaming their behaviours to ultimately influence a favorable standard of behaviour. Participant B shared

the following powerful statement when describing the practitioners that he encountered during his adolescence; “I also think the nature of the intervention comes from a place of imposing one’s will on someone else. [...] If they sought to understand rather than to correct perhaps things would have gone better.” This statement alludes to the idea that the imposition of expectations and correction of autistic behaviours lead to a negative experience overall.

Autonomous decision making was most observably limited through the behaviour modification or conditioning techniques used in applied behaviour analysis to achieve compliance with ‘good’ behaviour. This was implemented through the use of protocol, systems, or support plans that were followed by practitioners. In one particular narrative, the arbitrary allocation of ‘privileges’ by practitioners was central to the modification of behaviours and thus a large part of the services this participant received. Participant B described the following system that was implemented for them at school;

We would have a report card in front of us with different categories of behaviour, and a daily report card that was sent home daily. Every period the teacher would mark down how well we did in each category. [...] We could accumulate points and “spend” them on trinkets at the end of the week. Privileges could be earned by points. If you got enough points you could earn outings and other special trips. [...] But points could be earned for non-behaviour things also. Like there was an Easter egg hunt where you could earn points placed on paper in various eggs. Once you earned enough points you could advance to a different ‘level’ of privileges. One of the privileges that we could get was playing dodgeball at a local community college’s gym. [...] I think cooking was another privilege we could get. I remember making eggs for the class with that.

Within this system, the average outing is deemed something to be earned. Everyday activities are rendered and ranked as privileges and life skills such as cooking are reserved for those with ‘good’ behaviour. As demonstrated by the inclusion of the point system into the Easter egg hunt, this system appears to conflate good behaviour with good intellectual performance. It is apparent that the structure of this support plan is intended to teach participants that bad behaviour has negative outcomes while good behaviour has positive outcomes. However, the arbitrary allocation of points for good behaviour and performance resulting in rewards upholds a rigid standard that does not account for the variations in decision making processes, nor the many factors that influence one’s behaviours. Here, autistic self-governance was replaced with rigid sets of rules requiring compliance and memorization, effectively preventing autonomous decision making because their actions were dependent on a reward system. As a result, the subject’s rationale for their behaviour becomes irrelevant, the behaviour itself is the only thing that is assessed.

Additionally, a false sense of dependency on neurotypical adults is propagated in this model, as desirable rewards are dependent on altering one's behaviours to meet their standards.

Yeah, kids would get marked down if the teacher thought something bad happened, even when it didn't. Negative. Also it trained kids to devalue the points as they just wouldn't care as they gave up hope. I remember one time a classmate told me the lyrics of “Baby got Back” and she got marked down for telling me the lyrics quietly during lunch period. [...] I remember kids going around the rules instead. Like doing things when no one is watching.” I remember that the teachers would give conflicting instructions to kids occasionally, and it was the kids job not to ask different teachers for the same thing.

Here we can see how the allocation of privileges on the basis of good behaviour becomes relative to the subjective opinion of the practitioner. This again leaves little to no room for subjects to justify a rationale for their behaviour, silencing their decision-making process and thus stripping their personal agency. This paternalistic system encourages conformity whilst limiting agency.

Autism as Deviance

All four participants were asked if they would describe their experiences with applied behavioural analysis as negative or positive. While participants spoke to positive implications of their time in applied behaviour analysis such as well-meaning, warm practitioners, and a space to release emotions, all four participants deemed their overall experience a negative one. In response to this question participant A stated; “It [the experience undergoing applied behaviour analysis] was more negative. It was ‘What can you do to make people less uncomfortable.’ That makes it sound like I’m doing something wrong.”. This response revealed a theme of autistic traits as deviant. An overview of the data revealed that the autistic behaviours expressed by this study’s participants were often deemed to be intentionally troublesome or problematic in some way. Across all four interviews, participants spoke to some degree of disinclination towards applied behaviour analysis for its tendency to make them feel as though their autistic behaviours were in need of consequence or correction. For instance, Participant D stated “I felt like I shouldn’t be myself that that was wrong.” When asked about any specific behaviours they were taught to mask, participant D shared “simming [sic] visibly, how to talk and think, not being blunt, how to lie about how im felling [sic] and blend in. belittleing to me.” Additionally, Participant C shared the following, “the ultimate goal was to at least have me talk and act as normally as I can.” These quotes as well as the excerpts from participant narratives shared below

demonstrate how participants were made to feel that their autistic identities were in need of fixing.

Below participant B explains how the point system grounded in applied behaviour analysis that was implemented for him at school served to silence him whilst simultaneously deeming his behaviour deviant.

I remember a different time where we were playing dogeball [sic], and I have poor coordination, and I accidentally touched a girl's chest. I got points deducted for it, it was assumed that I had bad intent. That was really hard on me. Also there's no way to fix that Nothing I could say to convince them otherwise. [...] yeah. I mean, I'm clumsy, I think it comes with autism and having sleep issues

In the point system described here it appears as though both intent and mobility, in this case the participant's poor coordination, was not accounted for. It is important to note that as outlined above that for this participant, the docking of points resulted in limited capacity to participate in activities deemed 'privileges' such as playing in the gym or cooking. Participant B continued to described the system in further detail as well as the implications of a behaviour support plan that does not listen to the perspectives of those being subjected to it;

The categories on the chart were things something like "did you pay attention in class, did you speak out of turn" those types of things. [...] I hated it. When I went in I scored 100% every day. By the end of my school career I was maybe 60%-80% as I felt it was manipulative and teachers were not sensitive to my needs. [...] If they weren't understanding then their advice isn't applicable. So telling me or anyone else what to do while on school grounds might be true, because I conform for that teacher, but when I go elsewhere the rules could be vastly different. So it wasn't something that I could

generalize from. In most of the world, no one follows you around marking up your actions, giving them point values. So why should I modify my behaviour for one that does? Also I couldn't. I wasn't misbehaving because I wanted evil in the world I was misbehaving because I had a sleeping disorder, and autism and sensory problems how could those things be fixed with a behaviour change? Making me feel bad won't make things go away it will make me suffer. and perhaps I'll try to conform, perhaps not.

The rigid set of rules implemented to correct behaviours during his time in applied behaviour analysis required a level of conformity that for this participant was simply inapplicable to what is required in the real world, rendering it irrelevant or ineffective for him. Deeming his lack of coordination that resulted in hitting another student's chest as intentionally deviant proved to be grossly ineffective for participant B as demonstrated by his percentage scores because it fostered a sense of animosity towards practitioners of applied behavioural analysis as well as the system they enforced. In this portion of participant B's narrative, it is apparent that things like attention span, interrupting others, and coordination are deemed controllable and therefore subject to correction.

Implications of Neurodivergence as Deviance

Deeming neurodivergence as deviant presumes that neurotypical behaviours are inherently more productive or desirable. When asked about the ways in which their experience has influenced them today, participant C spoke to some of the focuses of their therapy; "Independent Actions, avoiding being redundant, not stimming, understanding jokes the ABA practitioners had tried to teach it like a normal class". Learning to avoid being redundant implies that their method of communication is abnormal or ineffective and requires correction. Learning

to understand jokes may imply that one processes information too literally. These are not areas of education that place value on neurodivergent ways of knowing.

The labelling of these behaviours as being ‘in need of correction’ lead to feelings of isolation for a participant of this study. When asked if there was anything they would change about their experience with applied behavioural analysis, participant C explained that they wish they would have been mainstreamed because being removed from class increased the social challenges they were already faced with.

I felt like I’d learn much more, connected with my classmates better, actually had friends and give me that real time social experience I wasn’t able to have. [...] I found ABA isolating and wouldn’t like anyone else to go through the same.

This participants' experience was one of isolation from their peers in a manner that felt consequential as opposed to helpful. They communicated feeling under-challenged by the content of the methods they were subjected to and felt as though they would have ultimately been better off around their neurotypical peers.

Since their innate reactions are deemed abnormal, participants described engaging in ‘masking’ as a coping mechanism during their time in applied behaviour analysis as well as in their everyday lives in order to conform to ‘normal’ behaviours. Participant A discussed how their experience with applied behaviour analysis encouraged this masking below;

So I’ve experienced masking in the form of pills and todays without any because you will get looks if I was to act myself. [...] It (aba) can be dangerous. Disregarding prescriptions, if telling a child what they do bothers people, it could make them self-conscious where it’s a hit or miss. It could result in better development of a child or it could result in a little anxiety. [...] Oh don’t get me wrong. Learning to make the people around you

comfortable is just as important as making yourself (a person in the neuro diverse community) comfortable. Its about forcing behaviour that doesn't make a balance (as in you are uncomfortable for the sake of another).

This quote refers to the idea that many of the behaviours that are labelled as requiring correction to achieve ideal functioning are indeed a “hit or miss” as noted by participant A, in the sense that they serve no purpose aside from increasing the comfort level of people around them. Deeming autistic expression as deviant lead to this individual sacrificing their comfort for the sake of others.

As per the narrative shared by participant D in this study, applied behaviour analysis' tendency to equate neurodivergence with deviance was harmful to their sense of self. Participant D spoke to some of their challenging experiences in speech therapy, elementary and middle school, short term one-hour per week applied behavioural analysis therapy as well as a summer camp devoted to curing autism. In the quote below, participant D was conditioned to internalize shame associated with certain behaviours, which subsequently lead to the masking of said behaviours and a distorted sense of self.

Taught to associate negative feelings with behaviours that they did not like: stimming not making eye contact, sensory sensitivities. [...] It has made it harder to be myself [sic] at times. And to cope with sensory sensitivities because I forgot how to stim. I was taught how to pretend things are okay, was taught to dissociate to deal with sensory pain so I could be present and not need to hide away.

Here we see that stimming behaviours were deemed in need of correction, which resulted in their suppression and ultimately lead to this participant forgetting an important emotional regulation mechanism. When asked if willing to elaborate on the implications of learning to

associate feelings such as shame with stimming behaviours participant D stated; “it taught me how to mask but never taught me how to acutely deal with over stimulation.” This calls into question the efficacy of applied behavioural analysis, because for this participant the behaviour change was a conscious suppression of emotions that shifted the behaviour, one rooted in shame as opposed to autonomous decision making or natural behaviour change. Participant D went on to describe some of the consequences for failing to suppress their responses to undesirable stimuli;

As for punishments at school it was only being talked down to and told that I had to change, in the weekly therapy sessions it would look like having bright lights shined on me, playing loud sounds I didn’t like.

The rendering of emotional regulation strategies, coping mechanisms, and innate responses to undesirable stimuli as deviant serves to devalue one’s autistic identity. Introducing consequences for behaviours presumes said behaviours should be stopped or replaced. The above quote shows that in the process of trying to change these behaviours, the participant felt discomfort.

Finding Community

As discussed above, some of this project’s participants spoke to the idea of finding it difficult to be themselves after applied behaviour analysis. Due to the fact that participant’s innate responses to situations were corrected and replaced with other more “appropriate” behaviours, participants discussed feeling the need to mask their natural reactions or behaviours. This masking inevitably limited their authenticity as communicated in the following comment made by participant A when discussing his masking behaviours: “because you will get looks if I was to act myself.” The caveat to this unfortunate reality for participants is that most of them had a common narrative of reconciling with their autistic identity through finding community.

While the therapy they were subjected to made them feel isolated or deviant, three of the participants were able to come to terms with who they are through community. For instance, in the following expert from our interview, participant A explains that he was able to come to terms with his stimming behaviours through the support of a member of his faith community:

I will just walk around in circles in a specific pattern, I would move my arms and hands a certain way, I would say words very rapidly to myself, I would try to move my hand to behind my back and I would try to touch my face. Later did i realize from a church member that there's pressure points in your face to help someone calm down so its not just me. [...] But I at least found communities on Reddit and Tumblr to help educate myself on Neurodiverse culture (something ABA didn't).

Here, the insight on calming pressure points in the face from a church member normalized the behaviours that he thought were 'just him'. Further, he found a sense of community in discovering neurodiverse culture, something that was previously missing from the support he received regarding his autistic identity. Additionally, as demonstrated in the following quote, Participant B discussed similar engagement with social media platforms including a Youtube channel and Tiktok account that explore the use and ethicality of applied behavioural analysis;

And here I see ABA techniques being used for organizational development Like I found this youtube channel called behavior babe from the r/ABA subreddit [...] They're using these techniques in large organizations. Like there's evidence that conditioning works. But no one questions whether it's okay to condition people. The Milgram experiments are evidence based and effective. But highly unethical. [...] You should check out this person: <https://www.tiktok.com/@auteach>.

The online communities mentioned explored the ethicality of applied behaviour analysis and the neurodiversity movement, potentially allowing participant B to better understand his own experience within a broader context.

Finally, in participant C's interview there was an emphasis on social isolation from peers as a result of participating in applied behavioural analysis during school hours. Participant C communicated that while being autistic made it hard for her to have friends, applied behavioural analysis made it harder. When discussing how she came to terms with her experiences; participant C stated: "I had no idea how damaging was for me until a friend pointed it out and how I knew there was something wrong with that class that I was kicking and screaming every time." Here we can see how support from a friend later in life allowed her to make sense of why attending therapy was so emotionally challenging for her.

Conclusion

While all four participants share common aspects of their identities as autistic adults who have undergone applied behavioural analysis, all four narratives were distinct. This is potentially in part due to the varying ways and settings that applied behavioural analysis is practiced, but also to the differences in the human experience. That said, regardless of the variations in their experiences, all four participants shared that their time in applied behavioural analysis was overall negative and involved a lack of self-determination. All four participants described how their autistic identity was labelled deviant to the normative or ideal way of functioning that the applied behavioural analysis was encouraging conformity to. Most participants discussed the role that finding community has played for them in terms of better understanding their experiences and discovering neurodiverse culture.

CHAPTER 5: DISCUSSION AND LIMITATIONS

The following chapter seeks to provide an examination of this study's finding through the lens of critical disability theory. I begin with a discussion of the role of ableism in the production of the core themes identified in participant narratives. I discuss the potential need for a reimagining of the field of applied behaviour analysis as well as some potential ways forward to limit the reproduction of some of the harms described above. I then look at the ethical issues that were presented throughout the research process and discuss the strengths and limitations of this study's design.

The Role of Ableism

The lack of autonomy afforded to participants is potentially rooted in ableist ideas of normativity, capacity, and decision-making processes. In order to act autonomously, one must have a sense of self-awareness to engage in actions that are in line with their own values and self interests (McCarthy & Wilkenfeld, 2020). As outlined in the narratives of this study's participants, Autistic people may be presumed by practitioners to be lacking the self-awareness and decision-making capacity to be afforded the right to self-determination, resulting in their desires and assessments of situations being overlooked or silenced.

For example, as demonstrated by the negative response participant B received from staff upon informing them that their techniques were potentially ineffective, it appears as though self-advocacy, which requires this sense of self-determination, was perceived as deviance. Here, Participant B's self-advocacy, which can be seen as an act of resistance against a harmful system, was silenced through the point system discussed in the findings chapter. This silencing can be attributed to ableism because the perception of practitioners took precedence over the lived experiences and perceptions of service users. Further, the power that is occupied by those

in positions of authority, that being the principal in this situation, is wielded to punish the subject's self advocacy through the point system that established the privileges students were allotted. This system is too a reproduction of ableism because it provides consequences in response to acts of resistance, effectively subjugating autistic perspectives.

The lack of involvement in the development of service or behaviour plans, establishment of goals, or access to personal files that limited the self-determination of participants may be rooted in two axes of oppression; ableism and ageism. It is possible that since all participants underwent applied behavioural analysis during their childhood or adolescence, they were not granted access to or control over their own files because of their age. Participants A, C, and D shared a similar narrative of their parents having this control and playing an active role in the decision-making process. McCarthy and Wilkenfeld assert that parents have 'decisional authority' when it comes to the participation of their autistic child in applied behaviour analysis (2020). It is also relevant to note that parents are often pushed into the use of this modality as it is presented as the only option to support their child (McCarthy & Wilkenfeld, 2020). Similarly, it is possible that ableism played a role in the decisions of caregivers and practitioners to not involve any participants in the services they received. To draw from critical disability theory, ableism functions to devalue disability, consequently subjugating disabled voices (Meekosha & Dowse, 2007; Rocco, 2005). A similar analysis can be applied to the devaluing of autistic voices. Despite participants stating that they "hated" the services they received or that they were "kicking and screaming every time", it is possible that the ableist systems within which they were interacting further limited their self-determination by dismissing their assessments and perceptions of services. Here, agency may have been limited because the individuals may have been wrongfully presumed to not be independent or self-sufficient enough to understand what is

best for them or what a particular therapy modality entails, so the information was withheld or not offered.

In McCarthy and Wilkenfeld's examination of the moral permissibility of applied behavioural analysis, they posit that this modality is unethical, even for young children, precisely because it does not recognize the role that autonomy interest plays in identity development (2020). Their analysis applies well here in terms of highlighting the role of ableism in the experiences of this study's participants. They suggest that preventing autonomy interests of children negatively impacts goal setting, goal acquisition, and long-term planning capacity later in life (McCarthy & Wilkenfeld, 2020). In the context of this study, their autonomous decision making may have been stripped on the basis of young age. It is argued however, that even young children have the capacity, though sometimes limited, to make decisions in line with their preferences (McCarthy & Wilkenfeld, 2020). It is morally significant then to allow children to exercise this autonomy on the basis that it promotes identity development (McCarthy & Wilkenfeld, 2020). As identified in the narratives of this study's participants, their experiences with applied behaviour analysis did not grant them decisional authority over the services they endured because their autonomy interests, that being their values, assessments, and desires, were overlooked or silenced, a consequence of the ableism perpetuated through the justification of services.

As noted in the findings section above, the implications of the lack of autonomy or self determination in the therapy process ranged from feeling isolated and disinterested to deeply skeptical and angry towards the field of applied behaviour analysis. For social workers supporting survivors of applied behaviour analysis it is therefore necessary to take a critical anti-oppressive and trauma-informed approach to our practice. This entails challenging the ableist

notion that autistic individuals are incapable of engaging in decision making processes on their own behalf, or are less knowledgeable than neurotypicals about what will benefit their overall well-being. Professionals should be incorporating AOP by actively disrupting these power hierarchies through taking on the role of a listener to autistic perspectives as well as ensuring the right to self-determination is a priority in their work. Active choice and informed consent to participate in therapy is critical because when changes are made based on someone's individual volition to make said changes, the ethicality of one's practice remains intact (Carter & Wheeler, 2019).

As demonstrated in the findings chapter, all four participants in this study did not speak to their experiences in absolute terms, that being all negative or all positive. While most participants described their experiences as negative overall, all four participants described positive aspects of their time in applied behaviour analysis ranging from the warm practitioners who meant well and did what they could with the knowledge they had, to the tools they learned to avoid the scrutiny that comes along with defying neurotypical norms of the societies within which they live. This duality is well demonstrated by Participant A's perception of behaviour modification that suggests it can have both positive effects in terms of development and negative effects in terms of the creation of anxiety. This speaks to the idea that the techniques of conditioning behaviours are undoubtedly effective in creating changes suitable for an able-bodied world. However, these same techniques simultaneously create anxiety for subjects as it requires them to rid themselves of the very behaviours that feel natural for them. I would argue that understanding social cues is important for many aspects of life; however, if it is at the expense of one's 'balance' as one participant referred to it, perhaps the outcome lacks merit. While applied behaviour analysis techniques create a push towards normativity through masking

for instance, which may increase the comfort of neurotypical individuals and the respect they offer to autistics respectively, it seems to sacrifice the comfort associated with autistic traits or stimming behaviours. Drawing from the social model of disability, it may be more equitable then to disrupt ableism by redefining normal, than to continue inflicting harm and causing discomfort for Autistics.

Implications for Social Workers and Human Services Professions

Social Validity

As discussed in the previous chapter, the applied behaviour analysis techniques proved to be ineffective for some participants and harmful to their sense of self because they deemed sensory responses or other behaviours associated with the autistic identity of the participants as deviant or unacceptable. Perhaps a more effective approach would have been to foster an accessible and comfortable environment wherein sensory triggers are minimized or absent. Identifying natural responses as problem behaviours can condition subjects to view their innate responses to sensory triggers as inappropriate, potentially fostering a lack of trust in one's assessment of an event and producing feelings of shame. This has implications for one's sense of self because as demonstrated by the experiences of participant D, one can forget their stimming behaviours after years of intensely masking them. This is problematic because as noted in the literature, stimming has been proven to serve as a useful emotional regulation mechanism (Kapp et al., 2019). Additionally, as expressed by participant B, the rigidity of the behaviour modification systems incited further deviance, fostered distrust in the system, and propagated an imbalance of power that led to an overall negative experience for them.

While participant C overtly condemned the applied behaviour analysis and took a firm stance that no one should be subjected to it, Participant D stated that there were positive and

negative aspects of the intervention and participant A explained that applied behaviour analysis could result in better development for its subjects. Given this lack of unanimity, future research and critical thought should be given to this topic to discern if applied behaviour analysis should be reimagined entirely or changed from within. However, given the current reality of applied behaviour analysis continuing to be the most popular form of intervention for Autistics, it may be worth making changes to the field to address the negative implications of autistic behaviours being deemed as deviant. One of these changes, that will not necessarily abolish the use of applied behavioural analysis but rather improve the ethical effectiveness of the dominant practice is social validity. Implementing social validity may create change because as described in further detail below, it may improve ethical practice standards as well as professional competence. This may in turn effectively limit the harms caused to autistic individuals, through increased client-centeredness and a transfer of power from practitioner to client.

In conjunction with the prioritization of autonomy and self determination of clients, a recommendation for behaviour analysts that moves away from the idea of ‘problem behaviours’ and towards a broader conceptualization of normativity is the use of social validity. Social validity is a concept used to assess the relevance and usefulness of interventions (Carter & Wheeler, 2019). It considers the subjective perceptions of caregivers, other professionals, and service users, increasing competency of intervention (Carter & Wheeler, 2019). It has been suggested that there is a ‘competency deficit’ amongst behaviour analysts due to the lack of social validity measurements currently used in the research on behavioural interventions (Carter & Wheeler, 2019). This competency deficit is attributed to the lack of popularity in the use of social validity measures which is a result of the stark difference between the subjective nature of

social validity and the traditionally objective nature of applied behaviour analysis (Carter & Wheeler, 2019).

Apart from social validity improving the professional competence of behaviour analysts, it also has the capacity to enhance ethical practice standards (Carter & Wheeler, 2019; Turner et al., 2016). Valuing the perspectives, needs, and goals of service users contributes to shifting the current power imbalance that exists because it values their autonomy, respects their dignity, and promotes their right to self determination (Carter & Wheeler, 2019). Through incorporating social validity into practice, interventions and support for service users that may otherwise be labelled ineffective may be viewed as socially valid by the autistic community, allowing practitioners to shift their approaches to meet the needs of the population as opposed to continuing to perpetuate harm. It is also suggested that social validity offers us an effective way to hold practitioners accountable, because it allows for ongoing self-assessment and reflection of practice during training processes (Turner et al., 2016). While the field of applied behaviour analysis may require a total reimagination of effective supports for Autistics, this may be a helpful way to enhance professional ethics for the time being, potentially minimizing the current harms caused by the field.

Unlearning 'Normal'

The findings of this study suggest a need for practitioners to engage in critical reflection in a number of areas surrounding the fundamental purpose and goal of their practice. Applied behaviour analysis practitioners should continue to actively engage in critical reflection of their interventions with a focus on how we can prioritize the self-determination and autonomy of Autistic service users. For instance, further consideration should be given to the notion of informed consent when it comes to providing interventions for young children. I would argue

that a reimagination of the field of behaviour modification should take place to question our understandings of who needs fixing and why.

As demonstrated in the findings section, Participant B described his suffering in ABA as the result of his behaviours being attributed to mere ‘misbehaving’ as opposed to a product of his sleep disorder and sensory sensitivities. Unlearning ableism requires us to question the structures that intersect to sustain the ideological underpinnings of our current norms. As described by Shyman, behavioural interventions are presented as intended to support autistics in achieving improved social and intellectual functioning (2016). However as conveyed by Participant B, behaviour change was an active choice to conform, one that causes suffering and fails to sufficiently support or get to the root of the catalysts of the ‘misbehaving’. Further consideration should be given then to the fundamental purpose of achieving this optimal functioning. In Dougherty's critical examination of neoliberalism as a mechanism of control, he describes how productivity and independence serve to benefit the neoliberal regime (2019). This, as he describes, is why interventions end once patients can sufficiently self regulate and maintain independence to compete in the market (Dougherty, 2019). I would argue a similar analysis can be applied here. The emphasis on achieving improved social and intellectual functioning propagated by applied behaviour analysis may be rooted in notions of productivity and independence, standards that reinforce inequitable definitions of normal. If the goal of applied behaviour analysis is to achieve optimal or increasingly ‘normal’ functioning, perhaps a restructuring of the world around us to include neurodivergence as normal would eliminate the need to impose changes to ‘deviant’ behaviours. The push towards normality seen here confirms the claim noted in this study’s literature review that applied behaviour analysis propagates a notion of abnormal vs. normal, serving to devalue autism.

Ethical Considerations and Limitations

In this section I discuss ethical considerations and possible limitations of this study. I discuss my positionality in relation to this study's credibility and dependability and provide recommendations for future research. I also discuss the practical and ethical implications of conducting research during the COVID-19 pandemic and detail the ways in which I have maintained credibility and confirmability throughout the research process.

As discussed in earlier chapters, my identity as an able-bodied, neurotypical interviewer in this research cannot be separated from the results of this study. My positionality as an outsider to the autistic community combined with the ongoing ableism enacted by neurotypical people to autistics has inevitably played a role in the results and analysis of this study. Social desirability bias is a type of response bias wherein participants share what they deem to be favourable or agreeable responses based on internalized desirable ways of being (Grinnell et al., 2016). This has the potential to sacrifice credibility or depth of narrative because increasingly open and detailed answers could be available if the participant felt as though their truth would be viewed as appropriate or valid by the researcher (Padgett, 2012). This is particularly relevant for this research study because participants spoke to conforming and masking their natural responses to appease neurotypical people in positions of power during their time in applied behavioural analysis. Further, it is suggested that respondent bias is reduced when an in-depth relationship exists between the researcher and participants (Padgett, 2012). This relationship building aspect was made challenging due to the limited time span in which I was allotted to conduct the study as well as other factors relating to online research and conducting research during the COVID-19 pandemic. Efforts to control for social desirability response bias in this research included a limited structure to interview questions, conversational interviewing, and narrative methodology.

The results of this study are therefore limited on the basis that participants may have had increased openness and willingness to share with more depth or comfort, had this study been conducted by an autistic scholar. Future research should continue to prioritize autistic narratives and may also benefit from being conducted by community insiders.

As mentioned in previous chapters, this study's participation requirements consisted of identifying as Autistic, being over the age of 18, and having undergone applied behavioural analysis. An age range within adulthood was not specified, meaning that the experiences shared in this study could have potentially taken place many years ago. As such, a potential limitation of this study is that it includes both current and past practices within the field and is not necessarily a representation of the way in which applied behavioural analysis is currently practiced.

Similarly, since an age range within adulthood was not a requirement for participation in this study, there may have been a large time lapse between the time that participants underwent ABA to the time they recounted their experiences for this study. The implication of this time lapse may be fragmented or inaccurate memories of their experiences, particularly for participants who discussed taking part in multiple therapy modalities during childhood and adolescence.

It is worth noting that this study was conducted through the COVID-19 pandemic. Throughout this time there has been a drastic increase in employment precarity, financial hardships, increases in caregiving responsibilities, and a general increase in isolation. This has uniquely impacted all parties involved in this study. It is relevant to note that the implications of the pandemic inevitably have disproportionately grave impacts for marginalized populations, including the sample population of this study. Conducting research with humans during this time was therefore both a practical and ethical consideration for continuation of this study. It is possible that the difficulties I faced as the researcher in the recruitment process which required

multiple revisions for approval by the Ryerson Research Ethics Board are in part a result of the COVID-19 pandemic. For example, difficulties in recruiting participants may potentially be a result of community members having limited emotional capacity or time to volunteer in a research study during a time where caregiving responsibilities and social isolation have increased.

Establishing Credibility

It is suggested that credibility of qualitative research is established when participants are able to verify the research findings (Cope, 2014). The limited time frame under which data collection and data analysis took place did not allow space for participants to review the findings prior to my analytical engagement with the data. This absence of member checking has potential negative implications for the overall credibility of this study because my own interpretations of the data which are informed by my theoretical lens are based on unverified data. However, I have attempted to mitigate this limitation in various ways. For instance, I have engaged in numerous in-depth reviews of the interview transcripts and provided substantial quotes in the findings to highlight each theme that surfaced, maintaining the thoroughness of my analysis. Cope suggests that providing rich, detailed quotes allows for interpretations to be substantiated by the reader, further enhancing credibility and confirmability of results (2014). Additionally, during the interview stage I actively engaged in reframing of participant responses to ensure that I understood their narratives the way they were intended to be conveyed to the best of my ability. This process involved reflecting on my positionality as well as my personal beliefs in order to maintain the awareness that my experiences and beliefs can not be objectively separated from the data when seeking to understand participant narratives. Finally, qualitative research credibility can be established through the use of an audit trail (Cope, 2014). Throughout this process I have

kept records of interview transcripts, data analysis notes, as well as versions and drafts of research chapters.

Conclusion

As discussed, several of the identified themes within and across participant narratives are potentially rooted in the structure within which participants received applied behaviour analysis services. The ableist notions that suggest autistic individuals lack decision-making capacity and self-awareness may have contributed to the lack of autonomy, self-determination, and feelings of being deviant or abnormal, that participants expressed in their narratives. Social validity is one potential way to mediate the current power imbalance leading to the lack of autonomy and unethical experiences participants described. Limitations and risks to this study's credibility include social desirability bias, age requirements for participation, and the lack of member checking. These limitations were addressed through reframing of participant narratives, creation of a detailed audit trail throughout the research process, and the use of detailed quotes. Implications of this study's findings suggest a need for further exploration of the ethicality of applied behaviour analysis and reform the oppressive processes that lend to practices that are not client-centered. It may also be useful to reconceptualise our understanding of normal to include neurodivergence.

CHAPTER 6: CONCLUSION

This study has attempted to highlight the experiences of autistic adults who have undergone applied behaviour analysis. While each participant's experience differed, all four narratives shared similar themes of lacking self-determination, autism as deviance and coming to terms with their autistic identity through community. Lacking autonomy also surfaced as a central theme to the narrative of one participant. Lacking self-determination and autonomy seem to have been rooted in the ableist subjugation of autistic decision-making processes and assessments that assumes autistic individuals are better off having decisions made on their behalf. Autistic behaviours were viewed as deviating from normative behaviours and thus subjected to rigid systems of behaviour modification that did not account for social validity or variations in human behaviour. The narratives discussed how this created distrust in the system meant to support them, and a skewed sense of self riddled with shame for behaviours that felt natural for them. Participants also shared similar narratives of reconciling with their identities through discovery of various communities such as members of their faith community or social media channels and groups that discussed neurodiversity. These themes are consistent with the ethical considerations for applied behavioural analysis techniques that have surfaced in the literature on the topic of neurodiversity (Kapp et al., 2019; McCarthy & Wilkenfeld, 2020; Shyman, 2016).

As previously mentioned, unlearning ableism requires us to question and rethink our conceptualizations of normality. Practitioners supporting autistic people should therefore continue to engage in critical reflection of their practice and considerations or definitions of who is deemed in need of help and why. Incorporating social validity into practice is potentially one way to enhance ethicality of one's practice as it prioritizes the goals and assessments of

community members and service users. That said, a fundamental rethink of the underlying assumptions and constructions of the way in which we currently 'support' the Autistic community may be required to sufficiently address the concerns of community members who have shared their stories here. Future research highlighting the experiences of autistic survivors of applied behaviour analysis would be needed to discern the most appropriate way to move forward. It is important that these changes be both informed and led by community members with lived experience and insight into the ways in which our helping systems reproduce harm through power imbalances and ultimately perpetuate ableism.

APPENDIX A: Recruitment Notices

Social Media Recruitment Notice

*The following will be accompanied by the attached recruitment poster



Hello, my name is Brittany Freitas. I am a student at Ryerson University in the School of Social Work. I am posting here to see if you might be interested in participating in a research study. The title of the study is *Questioning Normativity: Exploring the Experiences of Autistic Adults who have Undergone Applied Behavioral Analysis*. This research is being done as part of my Masters Research Project and has been reviewed and approved by the Ryerson University Research Ethics Board (REB Reference ID: REB 2020-036). My supervisor's name is Susan Preston, MSW, PhD. The focus of the research is to explore the experiences of individuals in the autism community who have undergone applied behavioral analysis (ABA) in their lifetime. I am seeking four participants for this study. To participate you need to be an adult (18+) who identifies as autistic. Those who agree to volunteer will be asked to participate in a one hour online interview via Google Hangouts. If you are interested in more information about the study or would like to volunteer, please email bgarciafreitas@ryerson.ca.

Snowball Sampling Recruitment Notice

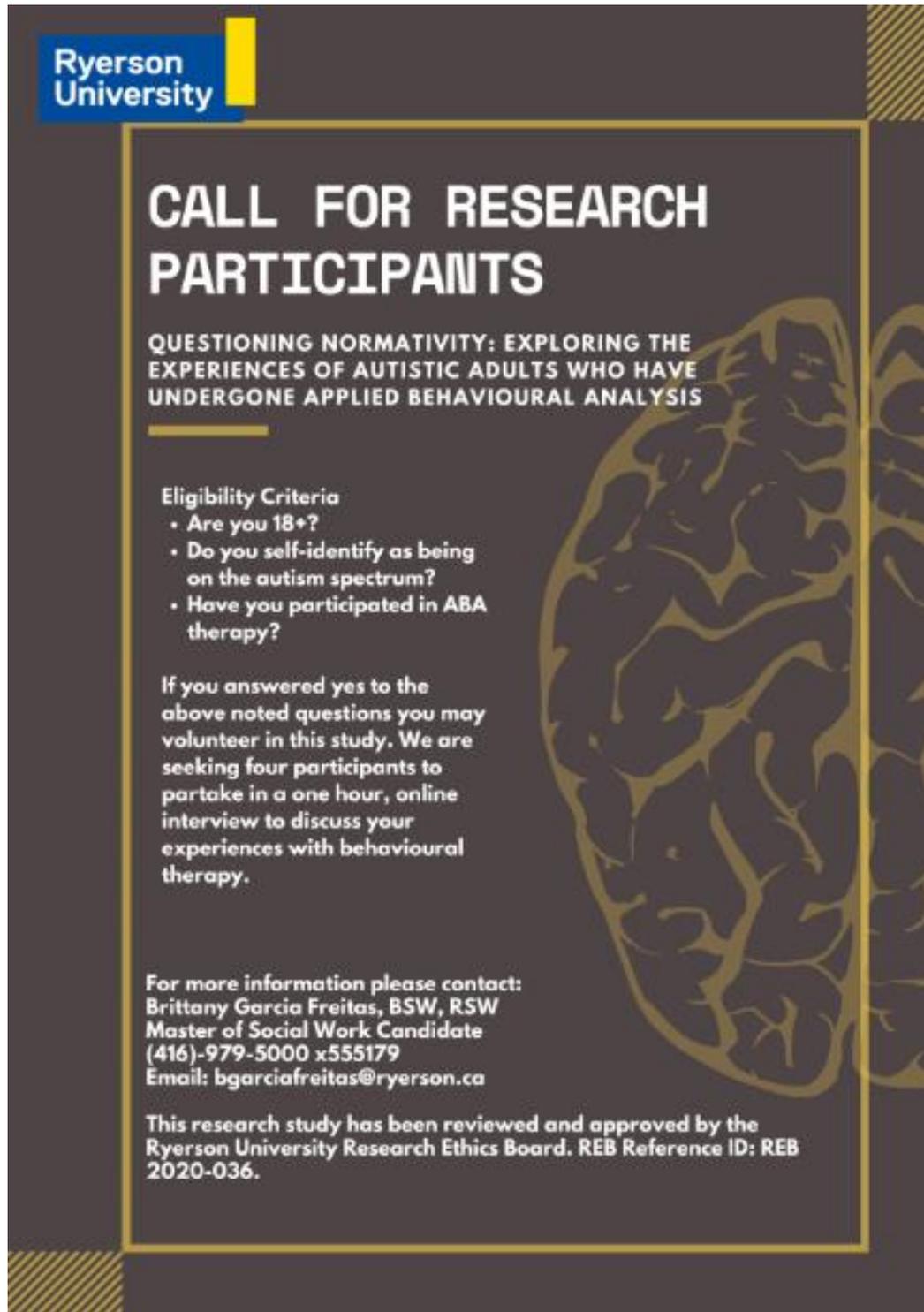
*The following will be accompanied by the above social media recruitment notice and attached recruitment poster



Hi there,

Thank you for your interest in supporting the recruitment for this study. Attached below you will find the recruitment material for this study to be shared with your networks. To ensure participant confidentiality, please note that participants are to contact my Ryerson email listed below should they wish to participate. This is also noted in the statement below. Please let me know if you have any questions.

APPENDIX B: Recruitment Poster



Ryerson University

CALL FOR RESEARCH PARTICIPANTS

QUESTIONING NORMALITY: EXPLORING THE EXPERIENCES OF AUTISTIC ADULTS WHO HAVE UNDERGONE APPLIED BEHAVIOURAL ANALYSIS

Eligibility Criteria

- Are you 18+?
- Do you self-identify as being on the autism spectrum?
- Have you participated in ABA therapy?

If you answered yes to the above noted questions you may volunteer in this study. We are seeking four participants to partake in a one hour, online interview to discuss your experiences with behavioural therapy.

For more information please contact:
Brittany Garcia Freitas, BSW, RSW
Master of Social Work Candidate
(416)-979-5000 x555179
Email: bgarciafreitas@ryerson.ca

This research study has been reviewed and approved by the Ryerson University Research Ethics Board. REB Reference ID: REB 2020-036.

APPENDIX C: Consent Agreement



Ryerson University Consent Agreement

You are being invited to participate in a research study. Please read this consent form so that you understand what your participation will involve. Before you consent to participate, please ask any questions to be sure you understand what your participation will involve.

TITLE OF THE STUDY

Questioning Normativity: Exploring the Experiences of Autistic Adults who have Undergone Applied Behavioral Analysis.

INVESTIGATORS

This research study is being conducted by Brittany Garcia Freitas under the supervision of Susan Preston from the School of Social Work at Ryerson University.

If you have any questions or concerns about the research, please feel free to contact Brittany Garcia Freitas at bgarciafreitas@ryerson.ca

PURPOSE OF THE STUDY

This study is designed to highlight the experiences autistic adults who have experienced behavioral therapy grounded in Applied Behavioral Analysis. Eligible participants will be 18 years of age or over who self-identify as being on the autism spectrum. Up to four participants will be recruited to share their personal stories in hopes of highlighting community voice. The results of this study will contribute to the major research paper (MRP) degree requirement of the Master of Social Work Program.

Participation in this study requires you to;

- Participate in a one-hour interview online via Google Hangouts with the principal researcher of this study.
- Share your personal experiences with Applied Behavioral Analysis.
- Share your views on behavioral therapy, neurodiversity, and normativity.
- Interview questions may include; Would you describe your experience with ABA as positive or negative to your well-being overall? How much of a role did you play in the services you received?

All identifiable demographic data will remain confidential. Results of this study will be made publicly available to all research participants through Ryerson University's online Major Research Paper repository by September 1st, 2020 at <https://digital.library.ryerson.ca/>

CONDUCTING RESEARCH DURING THE COVID-19 PANDEMIC

I acknowledge that COVID-19 has significantly increased caregiving responsibilities, financial burdens and social isolation for many of us. I have made the decision to go ahead with this research amongst the time of a pandemic because it will take place entirely online and hopefully be a time to engage in dialogue and personal narrative sharing during this time of increased isolation.

WHAT ARE THE POTENTIAL BENEFITS TO YOU AS A PARTICIPANT

Potential benefits of this study may include cathartic narrative sharing between the yourself and the researcher. Results of this study may be used for advocacy purposes regarding service delivery. I cannot guarantee, however, that you will receive any benefits from participating in this study.

WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT?

Potential risks of participation in this study are very low. Due to the personal nature of the questions asked, you may reflect on unpleasant memories while responding to interview questions. Should any discomfort occur, you should feel free to withdraw your participation in the study temporarily or permanently, at your discretion.

CONFIDENTIALITY

The interview process for this study will take place via Google Hangouts; an online platform that provides encryption in transit to maintain confidentiality of participant responses. Real names of participants will not be used in published material. All data collected will be stored securely on the Ryerson Google Drive of the principal researcher. All data will be destroyed at the end of this research study no later than September 1st, 2020. Information collected may be made available to my MRP supervisor, Susan Preston for review and guidance throughout the research process. This research will be made available on the Ryerson Library digital repository as well as to the School of Social Work faculty members who read the final draft of the major research paper which this research is being conducted for.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

Participation in this research study is entirely voluntary. You are under no obligation to answer every question or complete the entire duration of the interview process. Should you wish to withdraw complete participation from the study during the interview process, you may also choose to have the data entered up until the point of withdrawal not included in the research study. Data provided during this study can be removed up to two weeks after the interview takes place. Your choice of whether or not to participate will not influence your future relations with Ryerson University or the investigator, Brittany Garcia Freitas involved in the research.

QUESTIONS ABOUT THE STUDY

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact:

Brittany Garcia Freitas, BSW, RSW
(She/Her)
Master of Social Work Candidate, Ryerson University
350 Victoria St,
Toronto, ON M5B 2K3
(416) 979-5000
bgarciafreitas@ryerson.ca

This study has been reviewed by the Ryerson University Research Ethics Board. If you have questions regarding your rights as a participant in this study, please contact:

Research Ethics Board
c/o Office of the Vice President, Research and Innovation Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

Towards Normativity: Exploring the Experiences of Autistic Adults who have Undergone Therapy Grounded in Applied Behavioral Analysis.

CONFIRMATION OF AGREEMENT

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature indicates that you agree to participate in the study and have been told that you can change your mind and withdraw your consent to participate at any time. Your signature also indicates you are 18 years of age or older. You have been given a copy of this agreement. You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print) _____

Signature of Participant _____

Date _____

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