Including Autistic-Neurodivergent Perspectives in Adapted Physical Activity Textbooks

By

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Abstract

Pedagogical textbooks are oftentimes the first introduction undergraduate students and future Adapted Physical Activity (APA) and Adapted Physical Education (APE) professionals have to the discipline. These texts can set the epistemological and axiological framing through which all subsequent knowledge is judged and incorporated for learners. This means that the ways in which APA and APE textbooks introduce experiences of Autism could inform future interactions learners have with Autistic individuals. Further, because textbooks play a key role in the identity narrative of a discipline, it is important to consider whether or not stories told about Autism are representative of APA's purported values as a field.

The purpose of this study was to compare the ways in which experiences of Autism are represented in neurodivergent communities to the ways they are represented in pedagogical APA textbooks. This work was done with a theoretical lens from the neurodiversity paradigm. Through a comparative thematic analysis I sought to answer two questions: 1) *what are the biggest similarities and differences between how etic APA experts and emic Autistic experts talk about and strategize around Autism-related inclusion?* And 2) *What can this thematic comparison teach us about how APA and APE textbooks are constructing and promoting the APA values of self-advocacy, self-determination, and choice for Autistic individuals?* From the analysis, I found that APA textbooks could better support Autistic communities by including neurodivergent understandings of Autism in their texts, teaching and exemplifying trauma-informed practice, differentiating between harmful and different characteristics of Autistics, and rejecting harmful organizations and practices like Autism Speaks or Applied Behavioural Analysis.

Preface

This thesis is an original work by Hue An Nguyen.

Dedications

I dedicate this thesis work to my older brother, Thomas Nguyen.

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To my supervisor, Danielle Peers: I cannot properly put into words how thankful I am to have had you on this journey. You've taught me so much about disability studies, yes, but also about self-care, acceptance, and kindness. Thank you from the deepest depths of my heart for making space for me here, and inadvertently teaching me how to make space for myself in future spaces as well.

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Prologue

I spent most of my life wrapped up in the empirical sciences. I loved the subjects of biology, physics, and chemistry in high school, and enrolled in those courses in my first years of university. For every question (at least in those entry-level courses), there seemed to be a concrete answer. As a kid, I was always interested in *Truths* about my world. I guess studying sciences was part of me wanting to learn and acquire these Truths.

I grew up with an older brother who is visually impaired and Autistic. We are Vietnamese, and in our culture, birth order often determines your role in the family. Although my brother was the oldest, my parents and relatives always reminded me that because he is "different," I should be the one to take on the duties of a first-born child. Truths my family and community taught me about my brother were that he was incapable, a tragedy, and inspirational.

That he was incapable: my parents never let him do the things they let my younger sisters and I do. I once remember when he wanted to help me wash dishes, so he did. When my mom noticed, she took the dishes away from him and said, "you won't be able to wash them cleanly, just sit down." My brother was always asked to just "sit down"—*you're in the way*.

A tragedy: I cannot count how many times as kids (and adults) my brother and I would meet a distant relative or family friend for the first time and they would stare at him with pitiful eyes. They would grab his hand (without consent), then turn to *me* and say something like "poor him" (usually in Vietnamese). Sometimes, they would even start tearing up while rubbing his hands gently. I would usually nod politely with an uncomfortable smile.

Inspirational: after guests at our home get over their initial sadness for my brother's disabilities, they would come in to get to know our family a little more. Like clockwork, once

they find out my brother can navigate around our house without a guide, and brush his own teeth, they would begin fawning over him and express how *amazing* that is.

I was just a kid, learning from my surroundings. Although there was a lot I knew from spending time closely with my brother (like it was normal for him to be able to shower on his own), I am a nondisabled person and the teachings I received from nondisabled people dominated my belief system. The *Truths* I knew about disabled people before entering university were that they were broken and less-than, without a shadow of a doubt, I believed that. Ha! Boy, was I ever wrong.

It was the summer of 2017 when I met a new university friend, who after getting to know me, said: "do you ever think about how for some people like you¹ no matter how hard they try, they will never be able to achieve some things in life?" I, as someone who grew up with parents who preached the values of meritocracy to me like the Bible, was shook. *That could not possibly be true? If you work hard, you can achieve anything, right?* I realized I was wrong. Arrogant to say, but this is the first time I realized I even *could* be wrong about something I felt so sure about. What followed this summer was meeting my now supervisor and an epistemological rupture² in my understanding of disability through studying with them.

When you go to university, you learn a lot. Then, you proceed to realize more and more that you do not know. Learning that I do not know has been the single most valuable take away from my 9-years in university. This is sort of what my thesis is about: no matter our intentions or

¹ For context, my parents are refugees of the American War (also known as the *Vietnam War* in North America), I am a first-generation university student, and my family grew up on welfare in Vancouver before coming to Edmonton to open a Pho restaurant and achieve financial stability. ² An epistemological rupture refers to a shift from a "previously established way of knowing" (Kingsmith, 2017).

certainties about something, it is possible that we do not know, and realizing we do not know is key to opening the gate towards learning and possibly a better world.

This thesis is me humbling myself—*sit down*! This thesis is me learning from disability communities. This thesis is me realizing that truths are not only discovered (like in biology, physics, or chemistry), rather they are contextual, subjective, and experienced, as well.

I want to make it explicit that I am not making a value judgement to say that subjective truths are more or less valid than objective truths. All I am saying is that *truth*, in itself, exists in many forms, and the least we could do is acknowledge the *alternative* truths—especially from the very individuals experiencing these truths. Nothing about disability, without those experiencing disability (Charlton, 1998). Let's go.

Chapter One: Introduction

Adapted physical activity (APA) is a cross-disciplinary field involving research, practice, and theoretical knowledge focused developing and implementing activity and environmental "adaptations that could facilitate physical activity across a wide range of individual differences" (Reid, 2003, p. 22). Adapted physical education (APE) can be thought of as a subdiscipline of APA that focuses on supporting physical activity inclusion and literacy skills for these same groups of people within the context of school-based physical education programs (Haegele et al., 2020).

One of the major foci of APA, and APE by extension, is making a wide range of physical activity accessible for those who face barriers to movement. Physical activity offers many potential benefits, and while physical activity is frequently cited as highly beneficial for one's physical health (Warburton & Bredin, 2021), many may choose to participate in physical activity for other reasons such as personal enjoyment, socializing, or as a way to manage stress (Ling & Robbins, 2017; Seymour et al., 2009; Xiao et al., 2019).

While a large focus of APA is centered on facilitating physical activity for reasons related to physical health or rehabilitation (ex. Tyler, Joyce, & MacDonald, 2020; Ferguson, 2010), the aims of APA stretch beyond this. Indeed, some have argued that an equally important focus of APA is facilitating dignity for those interested in physical activity (Goodwin et al., 2014; Johnston et al., 2015). One such way to facilitate dignity is by supporting choice around which physical activities one participates in, in which ways, and for which reasons. Further, Reid (2003) wrote that beyond advocating for access to physical activity, APA is also about "promoting self-advocacy... self-determination...choice, and teaching self-regulation" (p. 20). Sherrill (2004) shared similar sentiments in the introductory chapter to their APA textbook, stating that because disabled individuals are part of a social minority, APA professionals must strive to go beyond simply providing APA services and seek to empower disabled individuals as well. Empowerment, according to Sherrill (2004) refers to "the process by which individuals gain control over their lives, a sense of power equitable with that of others, and a feeling of responsibility for self, others, and the environment" (p. 3). The aspects of APA that Reid (2003) wrote above (promoting self-advocacy, self-regulation, and ultimately choice) all contribute to empowerment and are a vital part of what APA is about.

Most recently, APA scholar Eales (2018) has echoed this need to center choice by linking this key APA value to trauma-informed practice. Trauma-informed practice involves having the practitioner carry an understanding that those they are working with may be trauma-survivors (Eales, 2018). As Eales (2018) wrote, "key principles of trauma-informed practice include: trauma awareness, safety and trustworthiness, choice and control, connection and collaboration, and a strengths-based empowerment approach" (p. 174).

Eales (2018) mentions that the principles of trauma-informed practice align with many foundational principles of APA (i.e. choice, empowerment, collaboration, safety, and trustworthiness). Thus, trauma-informed practice shows great promise as a means to uphold the values of APA in practice. Eales (2018) writes that considering trauma-informed practice is particularly relevant when seeking to support Autistic folks because disability communities and Autistic individuals very likely have in the past, and present, experienced trauma in the form of ongoing-oppression and iatrogenic trauma—trauma enacted within and through medical systems and 'treatments.'

Many APA and APE practitioners are likely to work with Autistic individuals at some point in their career, given the relatively high prevalence of Autism (approximately 1 in 59 children) in Western societies (American Psychiatric Association, n.d.). Further, Autistic individuals tend to face many barriers when attempting to access mainstream physical activity settings. Hiller et al. (2020), for example, found through a questionnaire that Autistic individuals perceived cost, lack of motivation, and preferring other activities over physical activity more often compared to their non ASD diagnosed counterparts. Also, Menear and Neumeier (2015) reported barriers to accessing physical activity for Autistic individuals can result from factors such as sensory stimulation, social anxiety, and physical barriers and disabilities. Thus, it may not be uncommon for APA and APE experts to step in and facilitate more accessible physical activity experiences for Autistic individuals.

As will be discussed in the literature review, there is significant tension around the definition of, and language around, Autism. In the context of contemporary APA research, person-first language is most commonly used. Further, in current APA literature, Autism is most commonly referred to as "autism spectrum disorder" and defined as "a neurodevelopmental disorder characterized by impairments in social-communicative skills and restricted or repetitive behaviors and interests" (Tyler, Joyce, & MacDonald, 2020, p. 21; also see Ketcheson, Felzer-Kim, & Hauck, 2020). By contrast, Nick Walker (2014a), an advocate of the neurodiversity paradigm uses identity-first language, and defines Autism as "a genetically-based human neurological variant...simply part of the natural spectrum of human biodiversity" (n.p.). I found that most Autistic self-advocates use language similar to Walker (2014a) when talking about themselves.

In this manuscript I have made the deliberate decision to use identity-first language, the language that is in alignment with the majority of Autistic self-advocates I encountered in my study. This decision to use identity-first language is also consistent with the paradigm my research comes from, the critical paradigm, which I write more on in the methods chapter. Working from this paradigm, I deeply respect the language many Autistics prefer to be used when someone talks about their experiences. Some may argue that not all Autistics prefer identity-first language, and many even find it offensive (as found by Bury, 2020). However, there is a large number of Autistics that do prefer identity-first language and find person-first language (the language most prominent in APA literature) to be offensive (also found by Bury, 2020). It is precisely the lack of identity-first language (and Autistic knowledges and preferences) in APA research in present and past that I have chosen to center it in my work.

For many APA, and specifically APE, practitioners who do not have previous exposure to Autistic folks, their first formal introductions to Autism likely come from chapters in APA and APE textbooks. Makkawy and Moreman (2019) argued that textbooks represent the face of the discipline; they write that oftentimes, textbooks introduce undergraduate students to new topics, serve as a guiding tool for novice teaching assistants, and act as reference books for those both in and outside the field. Given that they are often the first learning resources that students access in our field, pedagogical textbooks can set the epistemological and axiological framing through which all subsequent knowledge is judged and incorporated. Thus, how APA and APE textbooks introduce Autism is likely to inform all future interactions with those who experience Autism.

Beyond being a key resource in student learning, textbooks play an important role in the identity narrative of any discipline (McGarrity, 2010). That is, what our APA and APE textbooks say about Autism, serves to construct a specific version of what (and who) Autism is. They also serve to construct a specific version of what APA is and who its practitioners are, producing particular disciplinary investments, including in expertise around "best practices" (Goodwin & Rossow-Kimball, 2012; Peers, 2018; Standahl, 2008). Both of these sets of knowledges—e.g.,

who 'We' are and who 'They' are can have significant impacts on the ways emerging APA and APE practitioners engage with Autistic individuals.

In this study, I conducted a comparative thematic analysis (Braun & Clark, 2006) between two kinds of sources: 1) emic sources: online self-advocacy resources (i.e. Blogs and videos) created by and for those who explicitly identify as Autistic, and 2) etic sources: that is, APA and APE textbooks written by APA scholars (note: no etic authors have explicitly selfidentified as Autistic in these texts).

The purpose of the study was to compare the ways in which Autism was represented in the neurodivergent community, in comparison to the ways Autism was represented in APA textbooks. I wanted to learn about the ways in which Autistic individuals represented their lives, needs, desires, knowledges, and strategies for inclusion in comparison to how the most widely circulated APA and APE textbooks represent the same Autistic lives, needs, desires, knowledges and inclusion strategies. In so-doing I asked two questions: 1) *what are the biggest similarities and differences between how etic APA experts and emic Autistic experts talk about and strategize around Autism-related inclusion*? And 2) *What can this thematic comparison teach us about how APA and APE textbooks are constructing and promoting the APA values of self-advocacy, selfdetermination, and choice for Autistic individuals*?

The format of this thesis is paper-based. In the second chapter I share the relevant literature that informed my study. In the third chapter, I discuss my methods and how certain methodological decisions were made. In chapter four you will find the full research paper that will be prepared for submission to a research journal, with joint efforts from my research supervisor. Please note that there is some repetition between chapters two and three with chapter four as much of the literature review and methods section were relevant to include in the research

Chapter Two: Literature Review

Medical Perspective on Autism

Within the medical (pathology) paradigm, being Autistic is often associated with a diagnosis of "autism spectrum disorder" (ASD). 'ASD' was first characterized in 1943 by a child psychiatrist named Leo Kanner, who described common characteristics found between 11 children he was studying (Houston-Wilson, 2017). These children showed characteristics such as preferring isolated activities and non-verbal communication, and showed uncommon body movements such as hand flapping. As a result, Kanner noted that these children had characteristics unique enough to warrant its own diagnosis. The term *Autism* was originally coined by a Swiss psychiatrist to refer to a type of schizophrenia in adults, and Kanner identified the children he was studying as having "early infantile Autism" (Houston-Wilson, 2017). Indeed, similar to schizophrenia, Autism was thought of as a form of 'mental illness' (Houston-Wilson, 2017).

Around the same time the Autism diagnosis was being defined by Kanner, an Austrian pediatrician, and Nazi Holocaust collaborator, named Dr. Hans Asperger described children similarly who had typical communication skills but 'difficulty' with social interactions. He coined the term *Asperger syndrome* to define these children (Houston-Wilson, 2017). Similarities between Autism and 'Asperger syndrome' were noted by a British researcher named Dr. Lorna Wang (Houston-Wilson, 2017).

In 1964, Dr. Bernard Rimland challenged the theory that Autism was a 'mental illness,' and instead considered it a biological neurodevelopmental disorder (Houston-Wilson, 2017). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) currently defines both Autism and 'Asperger syndrome' under the same umbrella term of 'autism spectrum disorder'(ASD), a neurodevelopmental disability characterized through 'deficits' observed in social communication, and restricted or repetitive patterns of behaviours or interests (American Psychiatric Association, n.d.). Today, 1 in 59 children are estimated to have been diagnosed with 'ASD' (American Psychiatric Association, n.d.).

'ASDs', as would be implied by its name, describes a large spectrum of experiences. The American Psychiatric Association (n.d.) notes that "Autism differs from person to person in severity and combinations of symptoms. There is a great range of abilities and characteristics of children with autism spectrum disorder—no two children appear or behave the same ways" (n.p.). Professionals mention that while children are not usually 'cured' of 'ASD', 'symptoms' can 'improve' with early diagnosis and treatment (American Psychiatric Association, n.d.). One form of 'treatment' is applied behavior analysis (ABA), which is cited as "intensive skillbuilding and teaching educational sessions" (American Psychiatric Association, n.d., n.p.). However, Kapp (2020) states that ABA was "designed to 'recover' Autistic children" (Preface i.x.). Indeed, one of the most famous Autistic individuals among non-Autistic communities, Temple Grandin, is frequently cited as having "recovered" from Autism (see Sherrill 2004). Grandin, themself, was one of the first Autistic-identified people to write for neurotypical audiences. In their book *Emergence: Labeled Autistic*, they present the narrative of how they were "able to 'emerge' (recover) from Autism" (Pripis-Kapit, 2020, p. 25). Despite the American Psychiatric Association (n.d.)'s statement that children are not usually 'cured' of "ASD," cure is very much sought out and written about in regards to Autism, still.

The medical (pathology) paradigm is currently the dominant paradigm from which Autism is understood in contemporary society. Within this paradigm, there is a relatively narrow range of "right" or "healthy" ways for human brains to be configured or function—this small range of brain/mind-function is constructed as *normal*. Those who diverge significantly from the dominant standard of "normal" are considered "impaired" and viewed through the pathology paradigm as 'broken,' 'defective,' and in need of 'cure' (Walker, 2013). Those who adopt the pathology paradigm would view being neurodivergent as 'undesirable,' 'tragic,' and 'in need of fixing.'

Neurodivergence and the Neurodiversity Paradigm

In this study, I center individuals who identify with adjectives such as Autistic or neurodivergent. Neurodivergent sociologist, Judy Singer, coined the term *neurodiversity* in 1998 to articulate that there is an infinite variation and diversity amongst human brains and minds that is, there is naturally a wide range of ways brains work (Walker, 2014b). To identify as neurodivergent is to have "a brain that functions in ways that diverge significantly from the dominant societal standards of 'normal" (Walker, 2014b). As neurodivergent individuals have brains that function differently from socially expected and policed norms, their ways of being are often targeted for normalization. To be clear, from a neurodivergent perspective, Autistic body/minds are not inherently problematic, rather, they are made problematic by dominant social norms that position Autistic bodyminds as '*abnormal*,' and thus *in need of 'fixing*.'

Against the medical (pathology) paradigm's rhetoric that neurodivergence is a 'problem' or 'deficit' in someone's body/mind, Autistic activist communities reclaimed the term, began explicitly and proudly identifying *with* neurodivergence (the state of being neurodivergent), and shifted towards the *neurodiversity paradigm* (Strand, 2017, n.p.). Within the neurodiversity paradigm, rather than ascribing to only a narrow range of body/mind-functioning as "healthy" or "normal," it purports that neurodiversity—the "infinite variation of neurocognitive functioning"

within the human species—is a natural form of human diversity, and that all bodyminds are valuable (Walker, 2014b, n.p.).

Neurodivergent people who ascribe to the neurodiversity paradigm and would have been diagnosed with 'disorders' (such as Autism or dyslexia) by the medical (pathology) paradigm reject these pathologizing labels, and understand themselves not as broken, wrong, or in need of fixing, but as simply having a variation of brain/mind that is naturally a part of human neurodiversity.

Beyond rejecting the pathologizing labels of the pathology paradigm, Nick Walker has talked explicitly about the ways in which the pathology paradigm is oppressive to Autistic individuals (Walker & Raymaker, 2021). Beyond neurodivergence being a natural part of human body/mind diversity, Walker (2021) argues that Autistic individuals are also a minority group he coined the term *neurominority* to describe this. Walker and Raymaker (2021) wrote:

...neurodiversity is an axis of human diversity, like ethnic diversity or diversity of gender and sexual orientation, and is subject to the same sorts of social dynamics as those other forms of diversity—including the dynamics of social power inequalities, privilege, and oppression. From this perspective the pathologization of neurominorities can be recognized as simply another form of systemic oppression. (Walker & Raymaker, 2021,

p. 6)

Similar to the ways other minority groups (like racial and gender minorities) experience oppression, the neurodiversity paradigm understands Autistic individuals as oppressed as well.

Neurotypical is a term used to describe individuals that have a "style of neurocognitive function that falls within the dominant societal standards of 'normal,'" and is not necessarily understood as a more desirable characteristic than neurodivergence (Walker, 2014b).

Neurotypicals make up the neuromajority, and experience a host of privileges (including choice, autonomy, credibility) not extended to neurominorities.

While I acknowledge that neurodivergence is currently used as an umbrella term to describe a wide array of neurodivergent individuals, I apply this paradigm, within this thesis, specifically to those who might also identify as Autistic, a person with Autism, or as someone 'on the spectrum'. Since the beginning of neurodiversity theorizing, conceptions of neurodiversity and neurodivergent identities have been "intimately intertwined with Autistic identities" (Strand, 2017, n.p.), and it is my intent to privilege these experiences of neurodivergence in my study.

This research study centres the paradigm(s) of the Neurodiversity Movement—a social justice movement that seeks civil rights, equality, respect, and full societal inclusion for neurodivergent people of all ages (Walker, 2014b, n.p.).

Autism in Adapted Physical Activity Research

Research related to Autism in APA has significantly increased over the last decade. For example, there were almost 300 articles referencing Autism in their keywords over the last 40 years within the journals of *Adapted Physical Activity Quarterly* (APAQ) and *Journal of Physical Education, Recreation, and Dance* (JOPERD). Roughly half of these publications were from the last 10 years.

Many publications published in the last 10 years vary from providing resources for teachers in APE, to exploring the perspectives of parents and teachers of Autistics, to studies *on* Autistic individuals. Few studies were conducted *with* or led by Autistic participants or researchers.

Published strategies for APE educators to use while working with Autistic students were plentiful (e.g., Grenier & Yeaton, 2019; Obrusnikova & Dillon, 2011; Weiner & Grenier, 2020). Wiener and Grenier (2020), for example, explored the impact of hyper or hypo-sensory responses on Autistic kids and provided teachers with sensory-balancing strategies to use with their Autistic students while in a physical education setting. Grenier and Yeaton (2019) shared how teachers could use cooperative learning in physical education to teach social skills and promote interdependence. These publications would be key to APE teachers seeking strategies for teaching Autistic children.

A couple studies explored the perspectives of parents of Autistic individuals. For example, Buchanan et al. (2017) interviewed nine parents from families with one adult Autistic child to garner their perspectives regarding physical activity in their adult Autistic children. The authors found that parents perceived multiple factors, such as intrapersonal, interpersonal, and community factors affected their Autistic children's participation in PA. Studies like these sought to help families and practitioners keep their Autistic clients and family members engaged in physical activity.

Other studies focused on teachers working with Autistic children (e.g., Beamer & Yun, 2014; Li et al., 2019). Beamer and Yun (2014) surveyed 142 general physical education teachers to learn about their beliefs and self-reported behaviors for including Autistic students in their physical education classroom. They then examined potential factors that affected the self-reported behaviours of the teachers regarding including Autistic students.

I generally found that many researchers conducted research *on* rather than *with* Autistic individuals. Common studies I found were related to assessing or developing movement skills for Autistic individuals (Pope et al., 2012; Lee & Porretta, 2013; Todd et al., 2021). Some of

these seek to compare the physical functioning of Autistic people to a neurotypical norm. For example, Todd et al. (2021) compared overhand throwing of 10 Autistic college students to the overhand throwing of 10 neurotypical college students. Others seek to use physical activity to normalize Autistic people or their *behaviours*. Lee and Porretta (2013), for example, published a piece on utilizing an aquatic environment to *enhance* Autistic children's "learning and performance" (p. 41). Decreasing stimming movements is listed as one of the "enhancements" that can come out of a pool-based movement approach.

Other studies attempted to correlate various aspects of movement to 'severity' of one's Autistic experience or focused on quantifying Autistic individuals' time spent doing PA (or not: sedentary time measured). MacDonald et al. (2014) assessed the relationship between gross and fine motor skills with Autism 'severity' of over 100 Autistic children. Lobenius et al. (2018) assessed both physical activity and sedentary time of four different groups of disabled youth, including Autistic youth, and found Autistic youth to be least active.

Further, exercise and physical activity was primarily explored in the majority of these studies as a form of intervention for 'challenges' that came with Autism (e.g. Bremer & Lloyd, 2016; Case & Jun, 2019; Colombo-Dougovito & Lee, 2021, Elliot et al., 2021; Garcia-Villamisar, Dattilo, & Muela, 2017, and more). For example, Bremer and Lloyd (2016) implemented a fundamental-motor-skill intervention to 5 Autistic children over two six-week blocks and monitored the changes that may have resulted from the intervention. Colombo-Dougovito and Lee (2021) conducted a scoping review on social skill development outcomes from physical activity for Autistic individuals.

Throughout my search of the APA and APE literature, only 3 studies focused on directly eliciting and learning from Autistic individuals. Stanish et al., (2015) verbally administered a

questionnaire to 35 Autistic adolescents to learn about their physical activity enjoyment, perceived barriers, beliefs, and self-efficacy. The same questionnaire was given to 60 neurotypical adolescents as a comparison (Stanish et al., 2015). The questionnaire deemed most appropriate to use in this study was one developed for adolescents with intellectual disability (Stanish et al., 2015). The results found that when compared neurotypical adolescents, Autistic adolescents were less likely to enjoy team sports, find physical activity easy to learn, and believe that physical activity was a way to make friends (Stanish et al., 2015). In another example, Blagrave (2017) collected data from 10 Autistic participants through drawing, an interview, and observing them in their APE setting to learn about their perception of APE experience. Blagrave (2017) identified three themes, one related to the Autistic participant's overall positive associations with participating in physical activity, another theme discusses both the positive and negative influence of peers on the participants' movement experience, and the third theme shares the Autistic participants' sensory experiences with physical activity participation (such as sweating and feeling hot, or having some sensory need met like helping one feel heavy).

It would be important to note that no authors of the mentioned studies in this section explicitly identified themselves in the articles as being Autistic. There is only one exception to this trend of having only neurotypical researchers. Blagrave et al. (2021) most recently interviewed 23 Autistic adults who communicated verbally to learn how physical activity could be made more accessible and enjoyable; in their article there is mention that both Autistic and neurotypical researchers reviewed the interview guide for clarity, however neither author selfidentified in the article as being Autistic.

APA Research that Frames Autism as Logical rather than Pathological

While most APA research approaches Autistic experiences from a pathological standpoint and view Autistic idiosyncrasies—that is, distinctive and peculiar characteristics of Autism (ex. stimming)—as 'symptoms' of Autism, one researcher considers the ways in which these idiosyncrasies hold meaning and are logical ways of communicating.

Connolly (2010) uses Laban Movement Analysis (LMA) to describe movements of Autistic children and ascribing meaning to those movements. They believe that movement has meaning and LMA is a strategy for 'seeing' the meaning (Connolly, 2010, p. 106). Here, movements such as stimming are viewed not simply as meaningless and problematic behaviours, but rather as movements of meaning. Connolly (2008) wrote that behaviors associated with Autism could be viewed as "embodied solutions to existential, neurological, sensory, or motor trauma or crisis rather than outbursts of deliberate deviance" (p. 243). Connolly's (2010) perspective on Autistic idiosyncrasies seem to echo similar sentiments to neurodiversity scholar M. Remi Yergeau, who once asked "what if childhood shit smearing was read as Autistic communication instead of Autistic behaviour?" (Yergeau, 2018, p. 7). Both Connolly (2010), Connolly (2008), and Yergeau (2018) ask us to suspend our assumptions about Autistic idiosyncrasies as problematic or meaningless misbehaviour and consider that peculiarly Autistic ways of moving through the world hold value and meaning.

Language and Autism in APA

Whatever the cause [of disagreements regarding how to describe experiences of Autism], the language that we use has the power both to reflect and to shape people's perceptions of Autism. (Kenny et al., 2016, p. 442)

The terminologies used to talk about disability in literature are highly contested, and differ by country, (sub)culture, impairment type, and research paradigm (Peers et al., 2014). Although sometimes these differences are written off as 'just semantics,' at the heart of such debates is the notion that certain language is (dis)respectful or can be harmful, and further, terminology has embedded within it particular histories, stories, paradigms, and theories that serve to shift the very heart of what 'disability' might mean (American Psychological Association, 2020; Peers et al., 2014). Autistic self-advocate (and blogger under the name Autistic Hoya), Lydia X. Z. Brown (2011) wrote on the importance of semantics, stating that "changing a phrase -- even if it holds the same literal meaning--alters the subtle connotations and nuances of the speech, and communicates a different meaning and context than the original phrasing" (n.p.). For example, medical (pathologizing) terminology, as discussed above, is preferred by some medical disciplines and inherent within it is the idea that Autism is undesirable and an illness. On the other hand, Person-first language was originally popularized to challenge medical (pathology) frameworks that defined people solely by their disability—e.g., the epileptic, the diabetic. By centering those experiencing disability as *people first*, person-first language upholds that disability communities are deserving or rights owed to all humans (Peers et al., 2014). The changeover to person-first language represented a cultural shift away from derogatory and harmful language and practices (Vivanti, 2020). Since the 1970s, various disability communities have come up with their own terminologies to define themselves. Many in the Autistic community adopted identity-first language to reflect their understanding that Autism is an inherent part of who they are, similar to how people refer to "Muslims," "Lesbian/Gay/Bisexual/Transgender/Queer," or "gifted" (Brown, 2011).

As such the journal, *Adapted Physical Activity Quarterly* has recently modified its own language policy to represent the importance of diverse disability terminology.

APAQ is a multidisciplinary and international journal. As such, it accepts a wide range of language around disability, gender, age, race, etc., provided that this language is both respectful and consistent with the theoretical or disciplinary perspective(s) of the manuscript. (Adapted Physical Activity Quarterly, n.d.)

Language and terminology used to talk about experiences of Autism, specifically, is equally contentious. Both within the communities of Autistic individuals and between Autistic communities and the professionals they work with, differing language is championed.

To date, there are a few studies that have looked at the terminology preferences of Autistic adults. Kenny et al. (2016) developed an online survey to learn about people's preference on terms used to talk about Autism. They received 4622 responses to their survey and found that Autistic individuals favoured identity-first terms (e.g., Autistic), while professionals preferred person-first language (e.g., person with Autism, or its medicalized variant person with 'autism spectrum disorder'). However, person-first language has been challenged by selfadvocates in recent years, in favour of identity-first terminology (e.g., "Autistic person"). This shift is based off two arguments, as stated by Vivanti (2020):

(a) Autism is a central, identity-defining feature that cannot be separated from the individual, and (b) the use of person-first language might perpetuate stigmatizing views, as desirable attributes are normally expressed through pronouns preceding nouns (e.g., "a smart child"), and alternative linguistic constructions might suggest undesirable attributes. (p. 691)

The difference in preferred terminology may reflect unique experiences and views of the Autistic individual, and without any universally accepted terminology to date, it is recommended that whenever possible, preferences of every Autistic individual be respected (Bury et al., 2020).

Bury et al. (2020) found that among Autistic adults in Australia, preferences for selfidentifying language were varied and at times polarizing. Identity-first, 'on the spectrum', and person-first language were all at times rated most and least desirable depending on the individual. However, overall, identity-first and 'on the spectrum' language were most often preferred. In the United Kingdom, Kenny et al. (2016) found that identity-first language was most frequently preferred by Autistic individuals along with their families; meanwhile, professionals more often endorsed person-first language. Consistent with Kenny's (2016) finding that professionals tended to prefer person-first language, in the field of APA in North America, person-first language is indeed the most prevalent and accepted terminology (Peers et al., 2014).

The words researchers choose to use in their work reflect their values, and thus, their axiological assumptions. Axiological assumptions, for researchers, can be thought of as the "...often-unexamined, unrecognized, or mistakenly universalized values that influence our work: Personal or disciplinary assumptions about what is good and bad, right and wrong, and more or less valuable, worth, desirable, and beautiful" (Hart, 1971, as cited in Peers, 2018, p. 268). For example, when functional labels such as "high-" or "low-functioning" are used by researchers when talking about different experiences of Autism, there is a connotation that one such experience is more desirable than the other (high-functioning over low-functioning). Autistics have said that viewing the variation of Autistic experiences in this way is "overly simplistic" and potentially harmful (Kenny et al., 2016, p. 449).

Peers et al. (2014) have also emphasized how terminology is directly connected to values and ideas articulated by the author's research. The language researchers use is reflective of what they know and believe to be true. Language has impact and meaning when it comes to the culture of physical activity and its relationship with Autistic individuals. Thus, while seeking to improve opportunities for Autistic individuals, care must be taken to consider what language is used and how the language can either build up or hurt the communities APA seeks to serve.

In the above-described literature search that I conducted on Autism in APA, most publication titles from the search used exclusively medical (pathologizing) language when referring to Autistic experiences (i.e. 'autism spectrum disorder') or person-first language (i.e. 'people with Autism'), and addressed Autism as a 'disorder.' Only two studies found during the literature search used language preferred by the neurodiversity paradigm (i.e. 'neurodivergent,'), and identity-first language ('Autistic person'). Blagrave et al. (2021) used identity first language in their paper ('Autistic person'). It is worth mentioning that Blagrave (2017) used person-first and pathologizing language ('autism spectrum disorder') in their work four years ago. This may represent a shift in paradigm in their research—I will discuss more on language and paradigm shifts later in this thesis.

The second example of using identity-first terminology is Connolly and Harvey (2018). The authors work through analyzing two case-based scenarios of APA students working with Autistic individuals, and propose that engaging with critical pedagogy could be highly valuable in providing an interdisciplinary understanding for future APA practitioners who will work with disabled individuals. While the focus of this work was on engaging with critical pedagogy in APA, the case-studies focus on Autistic participants, and throughout, the authors do not use pathologizing language to talk about Autism and make brief mention of neurodiversity in their abstract. This work served as a model for how I chose to talk about Autism in this thesis.

Critical Pedagogy and Adapted Physical Activity

In Connolly and Harvey's (2018) paper, they brought critical pedagogy into conversation with APA. They discussed three phases in which education could move learners through to facilitating their transition from one form of consciousness to another. Those three phases are: investigation (where the learner identifies where their beliefs lie in the archaeology of consciousness), thematization (where the learner goes from perception to reflection, where "implicit ideas are made explicit and then considered in relation to the social and political context"), and finally, problematization (where the learner realizes and unpacks their oppressive predicaments by exploring 'limit situations') (Connolly & Harvey, 2018, p. 300).

The three forms of consciousness students could move in between were naïve, superstitious, and critical consciousness. Naïve consciousness involves an "unreflecting acceptance of the absolute validity and unquestionability of the world as is and one's own views" (Connolly & Harvey, 2018, p. 301). Those with a naïve consciousness cannot comprehend a perspective that is different from their own and hold their assumptions and values unreflectively. A superstitious consciousness is "characterized by a recognition of cultural options but a concomitant sense of powerlessness to do anything about those options" (Connolly & Harvey, 2018, p. 301). Finally, a critical consciousness is described as an ability to recognize that:

...cultural institutions are created and sustained by human purpose, and action and language both shaped and reflects people's perceptions of cultural institutions...There is no innocent, separate "1" outside of or uninfluenced by culture. People shape and are shaped within culture. Culture can be analyzed, explicated, deconstructed and in principle, transformed by human action... (Connolly & Harvey, 2018, p. 301)

Connolly and Harvey (2018) wrote that if APA wishes to offer meaningful movement opportunities that do not compromise the "safety, dignity, or agency" of Autistic participants, blending critical pedagogy with APA is crucial (p. 305). This work made me wonder how pedagogical APA textbooks could better integrate critical pedagogy into their texts and provide more opportunities for learners to engage in it as well.

Chapter Three: Methods

Research Assumptions and Quality Research

A research paradigm is the set of beliefs and assumptions, values, and techniques that inform one's research approach (Markula & Silk, 2011). Paradigms typically include axiology (the nature of value and valuation), ontology (what there is for one to know), epistemology (how one comes to know), and methodology (the best practices for gaining knowledge) (Markula & Silk, 2011).

With the intention of actively including the perspectives of Autistic folks who identify with the neurodiversity paradigm, I position my research within a critical paradigm. That is, the research choices in this study were based on the epistemological assumption that all knowledge is subjective, and indeed, that the subjective (and often underexplored) perspectives of those on the margins are highly valuable in research about their lives (Markula & Silk, 2011). Importantly, research from the critical paradigm is explicit about its axiological commitments (Peers, 2018), specifically the valuation of social justice, the knowledges of the marginalized, and the commitment to challenge unjust power relations.

My decisions throughout this research process will be deliberate and intentional to prioritize neurodivergent knowledge, and far from trying to take an objective approach, this research centers my axiological assumptions and deliberately aims to critique (and call-in) power and knowledge structures that serve to pathologize and oppress Autistic people.

Critical paradigms tend to ontologically embrace "historical realism—an understanding that ideological constructions stemming from certain social, political, cultural, and economic reality shape identities" (Markula & Silk, 2011, p. 45). Individuals are not free from social

constraints and must be made aware of these constraints before they can truly understand themselves and be empowered in their lives (Markula & Silk, 2011, p. 45).

This paradigm fits well with my theoretical framework of the neurodiversity paradigm, which problematizes pathologizing labels, challenges dominant medical treatments of Autism, and places neurodivergent perspectives at the center. That is, neurodivergent theorists use critical thought to improve the lives of Autistic individuals (the marginalized class), which is an endeavor reflective of the critical paradigm (Asghar, 2013). As I will elaborate further in my methods section, I have chosen to use Braun and Clarke's (2006) approach to thematic analysis and the assumptions of the critical paradigm largely shaped the analysis of my data. Our job as researchers in this paradigm is not to present an objective or even balanced representation. Instead, I have sought to maximize quality by focusing on the following Big Tent criteria presented by Tracy (2010): *credibility, worthy topic*, and *sincerity*.

Credibility in qualitative research means conducting research that is trustworthy enough, such that those reading the study might feel convinced and compelled to act in alignment with the findings (Tracy, 2010). This may be done through using thick descriptions in the research and providing multiple perspectives in the research (Tracy, 2010). Further, credibility can result from immersing oneself in a culture enough that the research can notice their values. Through my thematic analysis I was able to learn about neurodivergent cultures and bring that into the work to inform the analysis of APA textbooks in this study. Through this process I was able to dive "beneath the surface to explore issues that are assumed, implicit, and have become part of... [the communities'] common sense" (Tracy, 2010, p. 843).

Worthy topics are timely and relevant topics (Tracy, 2010). This study's topic proves to be both timely and relevant in that it addresses the lack of Autistic self-representation in APA

pedagogical texts. This research challenges what the field of APA claims to know about Autistic individuals in relation to movement. In addition, neurodiversity and Autistic movements are gaining more traction in mainstream media today. Presently, the community is speaking out against applied behavioural analysis (ABA) with their #StopTheShock³ campaign (e.g. Autistic creator paige layle⁴ on Youtube). In addition, earlier this year, Autistic self-advocates spoke out against Sia's movie "Music," for casting a neurotypical individual to play the role of an Autistic person and for portraying Autism in an inaccurate stereotypical way. This past April also marked the 10th year of the annual Autism Acceptance Month which was created by Autistics for Autistics to shift the narrative away from being "aware" of Autism and towards acceptance for Autistics (Autistic Self Advocacy Network, 2021). With much thanks to the internet, Autistic individuals have been able to unite, and their movements are gaining much momentum. Now, more than ever, it is relevant to consider what APA can learn from neurodivergent Autistic self-advocates.

Sincerity is a quality that is rooted in the genuinity of the researcher. To have sincerity in qualitative research is to be honest and transparent about one's biases as one conducts the research. I struggled a lot with my decision to conduct work related to a group I am not a part of (I am a neurotypical researcher conducting this study related to Autistic individuals). I wondered if I may be perpetuating the current lack of Autistic self-representation in APA research by being another neurotypical researcher writing about Autism in APA. Meanwhile, I also contemplated

³ Early July 2021 there was an overturn on the Food and Drug Administration's ban on the use of electric shock devices for "developmentally disabled" individuals. The #StopTheShock Campaign is led by online activist communities, including Autistic self-advocate, to share the adverse effects of electric shock. Electric shock is a form of applied behavioural analysis. https://www.reuters.com/legal/litigation/dc-circuit-overturns-fda-ban-shock-device-disabled-students-2021-07-06/ See more at: https://linktr.ee/StopTheShock

⁴ <u>https://www.youtube.com/watch?v=94sy4YrUGRk&ab_channel=paigelayle</u>

how not doing the work would mean the continuation of leaving neurodivergent Autistic perspectives out of the narratives about Autism in APA. The biggest fear I had was doing this research poorly, misrepresenting the community, and causing further harm. I knew however, that doing the work with the understanding it might not be perfect was a worthwhile endeavor, and if I took care with what I was doing, I could lessen the mistakes made and maybe make the community proud. This would mean taking seriously the teachings I was receiving from Autistic self-advocates and being careful how I represented them moving forward.

For me, it was also important to let the desire for positive change for the Autistic community drive my work. About a year and a half into this master's program (I am about to hit the 3-year mark now), I began losing sight of why I was conducting this research. With my head so wrapped up in theory and removed from praxis, I started to question myself: could or would my research have any real-world impact on the Autistic community? Or am I just telling myself it will? Doing the work does not feel right to me when I don't have a grasp on whether or not change could come from it. I was not doing the work just to do the work and complete a program. It mattered to me that it would mean something. A little lost, I decided to spend some time volunteering with the Get Active Together program, an APA program for Autistic kids run by The Steadward Centre at the University of Alberta.

During my first session with this program, I was completely baffled with how teachers were interacting with the Autistic students. I saw a student yelled at and dragged out of the gym by two teachers holding their legs and arms. I saw a teaching assistant pull by hand a crying, screaming, and clearly distressed child back and forth across the gym to participate in a bean bag retrieval game. When I asked the assistant if maybe the child would like to take a break, they told me the kid was actually really enjoying it and it was good for the child to participate, despite
appearing distressed. I felt a big pit in my stomach and felt deeply disturbed. My Autistic brother had talked to me about abuse he had experienced while in school, and I wondered if it looked like what I was seeing that day. Seeing all that physically hurt me and I didn't know if I would be able to continue with the program after that day.

I reached out to the program coordinators with my reflections from the day. They said they understood where I was coming from and agreed with the points I was making; however, they could not have any control over how the teachers were treating the children unless they "notice something that deserves to be reported" (program coordinator, n.p.). It was clearly abuse to me that should have been reported. However, I know that "something that deserves to be reported" actually meant: *something that society deems necessary to report regarding the treatment of Autistic people*. Considering the United States allows professionals to use electrical shock on disabled people, I could not expect yelling, grabbing, and forced participation to be reported.

Despite not wanting to volunteer for a program that allowed Autistic children to be abused by their teachers, I came back for another session. This time, I took the liberty of breaking some quiet rules. For example, when moving with one of the kids who liked to pick up more than one bean bag, despite the rule only allowing us to pick up one at a time, I encouraged the child to pick up however many bean bags they wanted.

The highlight of my second day was working with the child who had previously been crying while being forced to participate in the last session. I was working with them one-on-one, and they started crying and screaming. I decided to go with them to a quiet corner and sit with them. I had remembered seeing rubber fish in the gymnasium storage room, so when they calmed down, I asked them if they liked fish. They nodded, so I asked if they wanted me to get a fish for them. They nodded again, so I bolted really fast to the storage to get the child the fish. They calmed down, were happy with the fish, and to my surprise, started running around the gym and somewhat participating in the activity while holding the fish. In that moment I saw how treating someone with compassion could make participating in an APA program more accessible. I also realized how much learning from Autistic individuals had changed my value system, and that my value system was very different from the current professionals facilitating APA for Autistic individuals in schools. Most importantly, I remembered why and how the work I was doing could help neurotypicals like myself relearn and unlearn what we think we know about Autistics in APA, and strive to do better as professionals for the Autistic communities we may work with.

Theoretical Framework

My [Autistic] personhood is intact. My selfhood is undamaged. I find great value and meaning in my life, and I have no wish to be cured of being myself. (Sinclair 1992, p. 302)

The theoretical lens used in this study is that of the neurodiversity paradigm. Walker (2014b) names three fundamental principles of this paradigm. The first is that "neurodiversity is a natural and valuable form of human diversity" (n.p.). In other words, Autism and other similarly pathologized conditions are not seen as problematic deviations, but rather a part of a broad range of value-neutral human sensory-cognition variation. The term "neurodiversity," itself, was coined in 1998 by an Autistic sociologist named Judy Singer to refer to the diverse and infinite variation of neurocognitive functioning amongst human minds (Walker, 2014b, n.p). Like social models of disability more generally (Withers, 2012), this principle is in stark contrast

to both medical (pathology) and charitable models of Autism, which presume Autism is a problem to be fixed.

Walker (2014b)'s second fundamental principle is that:

...the idea that there is one 'normal' or 'healthy' type of brain of mind, or one 'right' style of neurocognitive functioning, is a culturally constructed fiction, no more valid (and no more conducive to a healthy society or to the overall well-being of humanity) than the idea that there is one 'normal' or 'right' ethnicity, gender, or culture. (n.p.)

The hyper-valuation, and production, of human "normalcy" is a cultural construct and not, in itself, natural. This principle challenges the predominant medical (pathology) views of Autism as a neurological 'abnormality' in need of cure.

In the perspective of the medical (pathology) model, the right thing for a society to do is attempt to cure and eliminate these kinds of neurological differences (e.g., pharmaceutically, genetically, or through rehabilitation) so that individuals can live a 'better life' (read 'better life' as one that fits the ideals of the neurotypical society) (Rosqvist et al., 2020). However, Autistic self-advocates within the neurodiversity movement are explicitly against notions of cure and the idea that Autism is undesirable or scary. For example, one of the largest Autism organizations in North America, Autism Speaks, has been heavily criticized by self-advocates for funding research focused on finding the causes of and cures for Autism (Autistics 4 Autistics Ontario, 2020; The anonymous aspie, 2013; Brown, 2012 and more). Alongside that, the organization is also viewed poorly for producing commercials and movies that perpetuate stigma and stereotypes of Autism as sinister (see Autism Speaks' 'I Am Autism'⁵ commercial) or difficult to live with (see Autism Speaks' movie 'Autism Every Day'⁶ where a mother who shares that she

⁵ https://www.youtube.com/watch?v=9UgLnWJFGHQ&ab_channel=FindYaser

⁶ https://www.youtube.com/watch?v=O0vCz2KWMM0&ab_channel=MilestoneVideoNY

has contemplated driving off a bridge with Autistic child but didn't, only because she has a non-Autistic child) (George, n.d.a). Further, Lydia X. Z. Brown (2013) criticized Autism Speaks for listing the Judge Rotenberg Centre—a centre that has used punishments such as electric shock on neurodivergent folks—as a "service provider for Autistic people and their families" (n.p.).

Many Autistic self-advocates have also spoken out against other methods of 'cure' such as ABA therapy (George, n.d.b; Lynch, 2019; Celebration of Kat, 2020 and more). Despite being championed by many professional bodies (such as the American Psychiatric Association, n.d.), ABA has been viewed by Autistic self-advocates as abusive. Specifically, critics point out that conversion therapy (a widely banned behaviour modification program designed to "convert" gay and gender-non-conforming people into heterosexual and cis-gender citizens, which has been largely disavowed by psychiatry) has a deeply entwined history and methodology with ABA, and yet ABA continues to be celebrated by those who have vehemently disavowed conversion therapy. Sequenzia (2016) has thus suggested that this so-called 'treatment' be called "Autistic Conversion Therapy" (n.p.). Further in literature, it was found that Autistics that were exposed to ABA predicted a higher rate and more severe posttraumatic stress symptoms (Kupferstein, 2018)

By making explicit that a neurotypical brain is not the only valid way for minds to exist, Walker's (2014) second fundamental principle of the neurodiversity paradigm allows for neurodivergent brains to be understood as not broken or 'abnormal,' but rather, part of the normal human variation of neurocognitive function.

More than a neutral part of human variation, Autistic experiences can be deeply enjoyable and valuable, as is the case for any human. Autistic blogger, artist, and advocate, Kirsten Lindsmith (2014a) writes that Autistic minds often make for creative inventors, exceptional specialists, and a valuable "no-nonsense, straightforward approach to the world" (n.p.). That being said, Rosqvist et al. (2020) states that:

Acknowledging neurological difference does not imply that all difference is good in itself, or that human traits associated with neurodivergence are always desirable, but it accepts that there are 'good' and 'not so good' traits in all human beings. (p. 7)

Affirming neurodivergence and advocating for its existence does not mean there are not parts of the experience that are difficult or disabling. Rather, a key practice of the neurodiversity paradigm is to acknowledge that beyond these difficulties, there are aspects to neurodiversity that are enjoyable and valuable, as is the case for any human.

Whereas the dominant medical (pathology) view focuses on pathologizing the 'deficits' of neurodiversity, the neurodiversity paradigm makes visible, celebrates, and affirms the neutral and beautiful parts of neurodiversity while also acknowledging and supporting people through the hard things.

Although the neurodiversity paradigm is fundamentally in opposition to being cured as a response to Autism, this does not equate to being against the use of intervention. Autistic self-advocate Lindsmith (2014b) shares that while they do not view Autism as a disease, they still acknowledge that the differences that come with Autism can result in "varying levels of disability" depending on the situation one is in (n.p.). Thus, "where devices, legal protections, or medication can be helpful in tackling some of the impairments that result from societal demands, as long as these are consistent with some possibility of self-determination" (Rosqvist et al., 2020, p. 4) then it may be valuable to some proponents of the neurodiversity paradigm. In other words, neurodiversity theory affirms the rights of people to access supports and interventions that are actively desired and deeply consented to.

The third and final principle of the neurodiversity paradigm written by Walker (2014b) states that:

The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity (e.g., diversity of ethnicity, gender, or culture). These dynamics include the dynamics of social power inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential. (n.p.)

What this means is that the dominant medical (pathology) understanding of neurodivergence today is viewed as oppressive, and fighting against the erasure of neurodivergent individuals needs to be fought as a social justice fight.

The Neurodiversity Movement is a "social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent" (Walker, 2014b, n.p.). This movement began within the Autism Rights Movement, however, it is important to note that while there is much overlap between the two, the main difference is that the neurodiversity movement today seeks to include all neurodiverse individuals, not only Autistic individuals. In 1993, Sinclair (n.d.) wrote "Don't Mourn for Us," an essay that challenged medical (pathology) understandings of Autism, and that is considered a manifesto for the neurodiversity movement. Sinclair critiqued the tendency for parents of Autistic children to "mourn" their child's Autism status and dispelled myths about Autistics "being in their own world" (n.p.). Xe also advocated that Autism can not be separated from the individual, rather, Autism is a way of being.

As a theoretical lens, the neurodiversity paradigm attunes the reader towards differentiating between discourses of diversity and those of deviance, between consensual interventions and compulsive normalization, and between pathologization and politicalization. In short, it asks the reader to take as its fundamental premise, that the problem to be addressed at the intersections of Autism and physical activity is not how to "get" or even how to "let" Autistic people exercise, rather, it is how can we create deeply affirming, consensual, accessible, and supportive physical activity opportunities for a wide range of neurodivergent folks.

Methodology and Methods

This study was conducted through two subsequent thematic analyses (Braun & Clarke, 2006). The first was done for the purposes of understanding, reading, and learning about neurodivergent communication preferences, perspectives, and worldviews. Texts in the first data set consisted of sources (both academic and non-academic) from individuals who identified as neurodivergent or Autistic and were gathered from academic sources as well as websites hosted by and for Autistic and neurodivergent communities.

This first thematic analysis informed the second, where information regarding Autism in APA textbooks were analyzed both for how they aligned with or differed from the ways Autistics spoke about themselves. I also sought for research-based learnings that may have been potentially useful for neurodivergent individuals looking to access physical activity.

Sampling

For the first data set, I sought out toolkits and other instructional or self-help writings written by Autistic and neurodivergent writers. In essence, I looked for writings where Autistic individuals shared knowledges about how to create inclusive spaces, or how to successfully participate in mainstream spaces as someone who is Autistic. I named this the "emic" dataset because the aim of collecting this data was to learn about Autistic neurodivergent experiences from an insider's point of view, and emic perspectives are thought of as "shared views of cultural knowledge from the insider's 'normative' perspective'' (Fetterman, 2008, p. 2). The dataset was created through targeted snowball sampling (Dusek et al., 2015), followed by a broad Google Search. I began with websites that are known hubs for neurodivergent, self-advocate, and Autistic-led writings. These include the Autism Women and Non-binary Network website (https://awnnetwork.org/), and the Autism Self Advocacy Network

(https://Autisticadvocacy.org/). I then read their blogs, publications, and resources pages for signs of any "toolkits" or resources that articulate access or "how-tos" for Autistic individuals. Since many of these websites, and especially blogs, interlinked with other Autistic-lead blogs, I proceeded to use snowball sampling to search these websites for other useful sites.

To ensure that there were not major sources missed, I did broad Google and Google Scholar searches pairing search terms "neurodivergent," OR "Autistic" with terms like "toolkit", "self-advocate," "resource," and "workbook": I included any resources that fit my criteria above, and that were created by people who self-identified as Autistic or neurodivergent. The purpose of this search was not to create an exhaustive list of resources, but to analyse a collection of 12 well-circulated neurodivergent-produced resources from a variety of sites in order to get a sense of some key neurodivergent approaches to teaching and learning about tools for enabling greater, more accessible, or affirming participation in movement activities of meaning.

The second data set consisted of Adapted Physical Activity textbooks that were published in the last 20 years, with specific chapters related to Autism. I named this the "etic" data source because etic perspectives represent the "external social scientific perspective" (Fetterman, 2008, p. 2). That is, etic perspectives represent the outsider's view of a studied group (i.e., APA professionals' views of Autistic individuals). Textbook selection was done through a search on the Worldwide Library Database with keywords "Adapted Physical Activity" OR "Adapted Physical Education." Further, selected texts needed to contain at least one of the following search terms: "Neurodiverg* OR "Autism" OR "Autistic" OR "Developmental disability" OR "Behavioural issues" OR "Cognitive disability."

Findings were narrowed down to pedagogical texts, that is texts whose primary stated purpose is as a teaching tool within post-secondary classrooms. Only texts published in the last 20 years and that were widely circulated, that is, texts published between 2001 and 2021 with more than 100 worldwide holdings as noted in the WorldCat library, were selected. This search sequence yielded 5 distinct pedagogical textbooks. I only analyzed chapters from the textbooks in which Autism or neurodivergence were explicitly discussed. Where older editions of textbooks were available to use, I analyzed the sections to look for differences from newer editions.

Data analysis

The data sets were analysed through thematic analysis (TA): a paradigmatically, theoretically, and methodologically flexible mode of analysis that has been used often in the critical paradigm (Braun et al., 2016; Braun & Clarke, 2006). The phases of TA include: *familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report* (Braun & Clarke, 2006).

Thematic analysis gives way for researchers to identify patterns ("themes") in data sets and describe/interpret the meaning and importance of those patterns in ways that can be attuned to specific paradigms and research objectives (Braun et al., 2016). TA is useful when looking to either describe or interpret meaning out of a data set. While a data *corpus* refers to all data that has been collected for a research project, a data *set* describes the data from the data corpus that is being used in the particular analysis (Braun & Clark, 2006). Within this project, there are 2 data sets (the emic and etic data sets), both of which make up the data corpus for this project. Themes encapsulate some overarching pattern within a data set being analyzed, which helps answer research questions at hand.

Different types of analysis were used to analyze the different data sets. For the analysis of the emic data set, I sought to establish a rich, thematic description that could further inform my theoretical framework and offer nuanced descriptions of the dataset that has received minimal previous attention, and is likely not well known to the field. Through seeking a rich description of emic data set, I was able to learn about the viewpoint of Autistic self-advocates and neurodivergent cultures, an area under-researched and represented in the field of APA. Themes in this dataset were thus identified through a 'bottom-up' (inductive) approach, meaning the themes identified are strongly linked to the data set itself and not pre-organized by a particular theoretical frame (Braun & Clarke, 2006). My analysis was mid-way between semantic and latent. That is, I analyzed the literal things authors were saying, paying attention to some things I believed were inferred by the author, but otherwise not "reading into" the text's meanings beyond what I believed were intended by the authors. This analytic strategy was designed to learn about the ways in which emic Autistic self-advocates understood themselves and how they were strategizing for better inclusion for themselves and their communities.

For my analysis of the etic dataset, I used findings from my emic analysis to create a more deductive (top down) coding framework, thus looking for similarities and divergences in thematic content. In essence, the coded themes were sought after to answer specific questions, rather than letting the themes unfold during the analysis (Braun & Clarke, 2006). During this analysis, having just completed the TA for the emic data, I was interested in the ways in which APA textbooks' teachings on how to support Autistic individuals aligned or not with the ways in which Autistic self-advocates supported one another.

The data was analyzed and coded in a Word Document two-column chart with data extracts on the left column and codes on the right column (see Appendix A). Codes were then written by pen on Post-It notes, and stuck on my wall to look at holistically. Codes were moved around and themes were constructed. Once both analyses were completed and themes were created, the results of both analyses were written on Post-It notes again and analyzed together. From a holistic standpoint, I began analyzing the ways in which the etic texts promoted the values of APA as a field.

Collectively, this analysis enabled me to answer two important questions: 1) what are the biggest similarities and differences between how etic APA experts and emic Autistic experts talk about and strategize around Autism-related inclusion? And 2) What can this thematic comparison teach us about how APA and APE textbooks are constructing and promoting the APA values of self-advocacy, self-determination, and choice for Autistic individuals?

Ethical Issues

Gaining approval from my university's ethical review boards is a requirement for researchers that engage directly with people, but not required when research data consists exclusively of publicly available published texts available in libraries and on websites with no password or other procedures for limiting access. While my research is still subject to meeting research ethics standards more broadly, ethics in my work aimed to go beyond simply complying with required ethical procedures.

For a long time, research *on* disability communities has been largely done by outsiders without any input from their communities (Oliver, 1997); while the research would purport to

benefit the disability community, the work inadvertently oppresses them. "Nothing About Us Without Us" is a slogan that came from the ethical obligation that disability communities be included when "creating policies, decisions, activities, and knowledges that often affect them" (Peers, 2018, p. 279). Too often work has been done without the community's input and has led to harmful outcomes for their communities (Oliver, 1997). This is why learning from and centring the writings of neurodivergent knowledge holders is at the heart of my research study.

Living with and growing up with my brother who is Autistic and visually impaired, I have seen first-hand the violence that would result from society's (and my own family's) tendency to pathologize his existence. As an outsider doing work related to a neurodivergent community I was not a part of, I realized it would be likely that I could unintentionally and unknowingly cause harm to the community in some way. I approached the work humbly to learn from the Autistic community. As Peers (2018) wrote in their paper on engaging with axiology, "axiology is ethics" (p. 271). Engaging with axiological reflexivity throughout my work and understanding that ethics is an "ongoing, reflexive, and messy process" (Peers, 2018, p. 272). Approaching my analysis of the emic dataset humbly meant interrogating and consistently reflecting on my taken-for-granted axiological assumptions about Autistic experiences.

Ensuring I accurately represented the values and learnings I received from the Autistic self-advocates in my research was important to me as a neurotypical (outsider) researcher. As much as possible I tried to use and embed direct quotations in my emic data set. Further, I took a deep dive and immersed myself in large amounts of Autistic writing and work such that I could gain more than a shallow understanding of the values emulated in their self-advocacy works.

Perhaps one of the greatest challenges I had in trying to ensure I conducted my research ethically, was treating the etic textbooks fairly. When I conducted the thematic analysis on the etic APA textbook data set, after having just come out of analysing the emic Autistic selfadvocacy work data set, I often found myself feeling disturbed with what was written in the textbooks. So much of it felt violent to me that I unknowingly began developing a negative bias towards the textbooks and could not see the good that was in it. At that time, I had a talk with my supervisor about the difficulty I was having with reading the textbooks. All I saw was bad. The talk was helpful in that it let me vent to someone I knew would understand where I was coming from. However, what was more important was that the talk helped me realize the negative bias I had and that I was not treating the analysis of the textbooks fairly, nor was I doing the work ethically. I took a moment away and restarted my analysis again.

Knowledge Mobilization

The findings that resulted from this study will be published as a paper in a research journal. Further, witnessing the violence that could occur in an interactions' classroom, I am hoping to share these findings with APA and APE practitioners in the educational system through creating a workshop to be facilitated at events such a Teacher's Convention here in Edmonton. Perhaps the largest way in which the findings from this study will be mobilized is through myself as a future medical student and physician. Through completing this master's thesis, I have grown immensely as an individual and can say for certain that I am less ableist than I was when I started this program. Disability and medicine at this current time are deeply intertwined with one another. The medical field currently holds a lot of power over the lives of disabled people (e.g., the ability to administer shock therapy to Autistics in the United States is just one of many examples). Medicine has a hand in both causing and "curing" disability. My supervisor would always say that medicine saved them, and without the progress of medicine and its ability to conduct life-saving heart surgery, they may not have been alive today. On the other hand, the tendency to pathologize disability and difference (such as Autism) has led to harmful circumstances for many disabled individuals.

Moving forward into medical school, I intend to spend the first few months learning about where my medical school is in regards to confronting its own (nondis)ableist ways, and creating opportunities to question medicine's taken for granted values regarding disability for/with my classmates and fellow future medical professionals. Just as the field of APA celebrates the insecure APA practitioner (Standal, 2008), I hope to make space to celebrate insecure medical professionals with my medical community and myself as a future doctor as well. While I am formally leaving and will not be practicing in the field of APA, much of my learning from here will be carried into who I will be as a medical student and future medical professional. These knowledge mobilization activities are above and beyond the thesis requirements and will not form a part of this thesis document.

Chapter Four: Research Study

Introduction

Adapted physical activity (APA) is a cross-disciplinary field involving research, practice, and theoretical knowledge focused developing and implementing activity and environmental "adaptations that could facilitate physical activity across a wide range of individual differences" (Reid, 2003, p. 22). Adapted physical education (APE) can be defined as a subdiscipline of APA, which focuses on supporting physical activity inclusion and physical literacy skills for these same groups of people, but within the specific context of school-based physical education programs (Haegele et al., 2020).

One of the major foci of APA, and APE by extension, is making a wide range of physical activity accessible for underserved groups. Physical activity offers many potential benefits. While physical activity is frequently cited as highly beneficial for one's physical health (Warburton & Bredin, 2021), many may choose to participate in physical activity for other reasons such as personal enjoyment, socializing, or as a way to manage stress (Ling & Robbins, 2017; Seymour et al., 2009; Xiao et al., 2019). While a large focus of APA is centred on facilitating physical activity for reasons related to physical health or rehabilitation (ex. Ferguson, 2010; Tyler, Joyce, & MacDonald, 2020;), the aims of APA stretch beyond this. Indeed, some have argued that an equally important focus of APA is facilitating dignity for those interested in physical activity (Goodwin et al., 2014; Johnston et al., 2015). One such way to facilitate dignity is by supporting choice around which physical activities one participates in, in which ways, and for which reasons. Reid (2003), further wrote that beyond advocating for access to physical activity, APA is also about "promoting self-advocacy... self-determination...choice, and teaching self-regulation" (p. 20).

Autistic individuals are one of the groups that many APA and APE practitioners work with, given the relatively high prevalence of Autism (approximately 1 in 59 children) in Western societies (American Psychiatric Association, n.d.), and the many barriers they tend to face in mainstream physical activity settings (Hiller et al., 2020; Menear & Neumeier, 2015; Stanish et al., 2015). As will be discussed in the literature review, there is significant tension around the definition of, and language around, Autism. In the context of contemporary APA research, it is most commonly referred to as "autism spectrum disorder" and is defined as "a neurodevelopmental disorder characterized by impairments in social-communicative skills and restricted or repetitive behaviors and interests" (Tyler, Joyce, & MacDonald, 2020, p. 21; also see Ketcheson, Felzer-Kim, & Hauck, 2020). By contrast, Nick Walker (2014a), an advocate of the neurodiversity paradigm defines Autism as "a genetically-based human neurological variant...simply part of the natural spectrum of human biodiversity" (n.p.).

In this study, we have made the deliberate decision to use identity-first language, the language that is in alignment with the majority of Autistic self-advocates we encountered in our study. This decision to use identity-first language is also consistent with the paradigm our research comes from, the critical paradigm. Working from this paradigm, we deeply respect the language many Autistics prefer to be used when someone talks about their experiences. Some may argue that not all Autistics prefer identity-first language, and many even find it offensive (As found by Bury, 2020). However, there is a large number of Autistics that do prefer identity-first language most prominent in APA literature) to be offensive (also found by Bury, 2020). It is precisely the lack of identity-first language used in APA research in present and past that we have chosen to centre it in our work here.

For many APA, and specifically APE, practitioners, their first formal introduction to Autistic folks likely come from chapters in APA and APE textbooks. Makkawy and Moreman (2019) argued that textbooks represent the face of the discipline; they write that oftentimes, textbooks introduce undergraduate students to new topics, serve as a guiding tool for novice teaching assistants, and act as reference books for those both in- and outside the field. Given that they are often the first learning resources that students access in our field, they can set the epistemological and axiological framing through which all subsequent knowledge is judged and incorporated. Thus, how APA and APE textbooks introduce Autism is likely to inform all future interactions with those who experience Autism. Beyond being a key resource in student learning, textbooks play an important role in the identity narrative of any discipline (McGarrity, 2010). That is, what our APA and APE textbooks say about Autism, serves to construct a specific version of what (and who) Autism is. They also serve to construct a specific version of what APA is and who its practitioners are, producing particular disciplinary investments, including in expertise around "best practices" (Goodwin & Rossow-Kimball, 2012; Peers, 2018; Standahl (2008). Both of these sets of knowledges-e.g., who 'We' are and who 'They' are can have significant impacts on the ways emerging APA and APE practitioners engage with Autistic individuals.

In this study, we have conducted a comparative thematic analysis (Braun & Clark, 2006) between two kinds of sources: 1) Emic sources: online self-advocacy resources (i.e. Blogs and videos) created by and for those who explicitly identify as Autistic, and 2) Etic sources: that is, APA and APE textbooks—written by APA scholars who do not explicitly self-identify as Autistic. We set out to learn about the ways in which Autistic individuals represent their lives, needs, desires, knowledges, and strategies for inclusion. We then compared these learnings with how the most widely circulated APA and APE textbooks represented the same Autistic lives, needs, desires, knowledges and inclusion strategies. In so-doing we asked two questions: 1) *what are the biggest similarities and differences between how etic APA experts and emic Autistic experts talk about and strategize around Autism-related inclusion?* And 2) *What can this thematic comparison teach us about how APA and APE textbooks are constructing and promoting the APA values of self-advocacy, self-determination, and choice for Autistic individuals?*

Literature Review

Medical perspectives on Autism

Within the medical (pathology) paradigm, experiencing Autism is often associated with a diagnosis of "autism spectrum disorder" (ASD). ASD was first characterized in 1943 by a child psychiatrist named Leo Kanner, who described common characteristics found between 11 children he was studying (Houston-Wilson, 2017). These children showed characteristics such as preferring isolated activities and non-verbal communication, and showed uncommon body movements such as hand flapping. As a result, Kanner noted that these children had characteristics unique enough to warrant its own diagnosis. The term *Autism* was originally coined by a Swiss psychiatrist to refer to a type of schizophrenia in adults, and Kanner identified the children he was studying as having "early infantile Autism" (Houston-Wilson, 2017). Indeed, similar to schizophrenia, Autism was thought of as a form of mental illness (Houston-Wilson, 2017).

Around the same time the Autism diagnosis was being defined by Kanner, an Austrian pediatrician, and Nazi Holocaust collaborator, named Dr. Hans Asperger described children similarly who had typical communication skills but 'difficulty' with social interactions. He coined the term *Asperger syndrome* to define these children (Houston-Wilson, 2017). Similarities between Autism and Asperger syndrome were noted by a British researcher named Dr. Lorna Wang (Houston-Wilson, 2017).

In 1964, Dr. Bernard Rimland challenged the theory that Autism was a mental illness, and instead considered it a biological neurodevelopmental 'disorder' (Houston-Wilson, 2017). The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) currently defines both Autism and Asperger syndrome under the same umbrella term of 'autism spectrum disorder'(ASD), a neurodevelopmental disability characterized through 'deficits' observed in social communication, and restricted or repetitive patterns of behaviours or interests (American Psychiatric Association, n.d.). Today, 1 in 59 children are estimated to have been diagnosed with ASD (American Psychiatric Association, n.d.).

ASDs, as would be implied by its name, describes a large spectrum of experiences. The American Psychiatric Association (n.d.) notes that:

Autism differs from person to person in severity and combinations of symptoms. There is a great range of abilities and characteristics of children with autism spectrum disorder no two children appear or behave the same ways (n.p.).

Professionals mention that while children are not usually cured of ASD, symptoms can improve with early diagnosis and treatment (American Psychiatric Association, n.d.). One form of treatment is applied behavior analysis (ABA), which is cited as "intensive skill-building and teaching educational sessions" (American Psychiatric Association, n.d., n.p.). However, Kapp (2020) states that ABA was "designed to 'recover' Autistic children" (Preface i.x.). Temple Grandin is arguably one of the most famous Autistic individuals among non-Autistic communities, and is frequently cited as having "recovered" from Autism (ex. see Sherrill 2004). Grandin was one of the first Autistic-identified people to write for neurotypical audiences. In their book *Emergence: Labeled Autistic*, they present the narrative of how they were "able to 'emerge' (recover) from Autism" (Pripis-Kapit, 2020, p. 25).

Autism and Adapted Physical Activity

Research related to Autism in APA has significantly increased over the last decade. For example, there were almost 300 articles referencing Autism in their keywords over the last 40 years within the journals of *Adapted Physical Activity Quarterly* (APAQ) and *Journal of Physical Education, Recreation, and Dance* (JOPERD). Roughly half of these publications were from the last 10 years.

Many studies published in the last 10 years centre around strategies for APE educators to use while, as well as their perspectives on, working with Autistic individuals (e.g., . Li et al., 2019; Beamer & Yun, 2014; Grenier & Yeaton, 2019; Weiner & Grenier, 2020, Obrusnikova & Dillon, 2011). Of note, the strategies for engagement with Autistic individuals shared in these studies came from professionals who did not experience Autism. Further, some studies explored the perspectives of the parents of Autistic individuals (ex. Obrusnikova & Miccinello, 2012; An & Hodge, 2013; Buchanan, Miedema, & Frey, 2017). In addition, many researchers conducted research *on* rather than *with* Autistics. Common studies found were related to assessing, or developing movement skills for those on the spectrum (Pope et al., 2012; Lee & Porretta, 2013; Todd et al., 2021). Other studies attempted to correlate various aspects of movement to 'severity' of one's Autism experience or focus on quantifying their time spent doing PA (or not: sedentary time measured) (MacDonald et al., 2014; Lobenius et al., 2018). Generally, very few studies focused on directly eliciting and learning about the perspectives of Autistic individuals (Stanish et al., 2015). Further, exercise and physical activity was primarily explored in the majority of these studies as a form of intervention for 'challenges' that came with Autism (ex. Bremer & Lloyd, 2016; Case & Jun, 2019; Garcia-Villamisar, Dattilo, & Muela, 2017; Colombo-Dougovito & Lee, 2021, Elliot et al., 2021, and more).

Most publication titles from the search used medical (pathology) language when referring to experiences of Autism (i.e. 'autism spectrum disorder') or person-first language (i.e. 'people with Autism'). Only two studies found used language preferred by the neurodiversity paradigm (i.e. 'neurodiverse,'), or identity-first language ('Autistic person') (Blagrave, 2021; Connolly & Harvey, 2018).

APA Research that Frames Autism as Logical rather than Pathological

While most APA research approaches Autistic experiences from a pathological standpoint and view Autistic idiosyncrasies—that is, distinctive and peculiar characteristics of Autism (ex. stimming)—as 'symptoms' of Autism, one researcher considers the ways in which these idiosyncrasies hold meaning and are logical ways of communicating.

Connolly (2010) uses Laban Movement Analysis (LMA) to describe movements of autsitic children and ascribe meaning to those movements. They believe that movement has meaning and LMA is a strategy for 'seeing' the meaning (Connolly, 2010, p. 106). Here, movements such as stimming are viewed not simply as meaningless and problematic behaviours, but rather as movements of meaning. Connolly (2008) wrote that behaviors associated with Autism could be viewed as "embodied solutions to existential, neurological, sensory, or motor trauma or crisis rather than outbursts of deliberate deviance" (p. 243). Connolly (2010)'s perspective on Autistic idiosyncrasies seem to echo similar sentiments to neurodiversity scholar M. Remi Yergeau, who once asked "what if childhood shit smearing was read as Autistic communication instead of Autistic behaviour?" (Yergeau, 2018, p. 7). Both Connolly (2010), Connolly (2008), and Yergeau (2018) ask us to suspend our assumptions about Autistic idiosyncrasies as problematic or meaningless misbehaviour and consider that peculiarly Autistic ways of moving through the world hold value and meaning.

Language and Autism in APA

Whatever the cause [of disagreements regarding how to describe experiences of Autism], the language that we use has the power both to reflect and to shape people's perceptions of Autism. (Kenny et al., 2016, p. 442)

The terminologies used to talk about disability in literature are highly contested, and differ by country, (sub)culture, impairment type, and research paradigm (Peers et al., 2014). Although sometimes these differences are written off as 'just semantics', at the heart of such debates is the notion that certain language is (dis)respectful or can be harmful, and further, terminology has embedded within it particular histories, stories, paradigms, and theories that serve to shift the very heart of what 'disability' might mean (American Psychological Association, 2020; Peers et al., 2014). As such the journal, *Adapted Physical Activity Quarterly* has recently modified its own language policy to represent the importance of diverse disability terminology.

APAQ is a multidisciplinary and international journal. As such, it accepts a wide range of language around disability, gender, age, race, etc., provided that this language is both respectful and consistent with the theoretical or disciplinary perspective(s) of the manuscript. (Adapted Physical Activity Quarterly, n.d.)

Language and terminology used to talk about experiences of Autism, specifically, is equally contentious. Both within the communities of Autistic individuals and between these communities and the professionals they work with, differing language is championed.

To date, there are a few studies that have looked at the terminology preferences of Autistic adults. Kenny et al. (2016) developed an online survey to learn about people's preference on terms used to talk about Autism. They received 4622 responses to their survey and found that those Autistic individuals favoured identity-first terms (e.g., Autistic), while professionals preferred person-first language (e.g., person with Autism, or its medicalized variant person with 'autism spectrum disorder'). However, person-first language has been challenged by self-advocates in recent years, in favor of identity-first terminology (e.g., "Austistic person") . This shift is based off two arguments, as stated by Vivanti (2020):

(a) Autism is a central, identity-defining feature that cannot be separated from the individual, and (b) the use of person-first language might perpetuate stigmatizing views, as desirable attributes are normally expressed through pronouns preceding nouns (e.g., "a smart child"), and alternative linguistic constructions might suggest undesirable attributes. (p. 691)

The difference in preferred terminology may reflect unique experiences and views of the Autistic individual, and without any universally accepted terminology to date, it is recommended that whenever possible, preferences of every Autistic individual be respected (Bury et al., 2020).

Bury et al. (2020) found that among Autistic adults in Australia, preferences for selfidentifying language were varied and at times polarizing. Identity-first, 'on the spectrum', and person-first language were all at times rated most and least desirable depending on the individual. However, overall, identity-first and 'on the spectrum' language were most often preferred. In the United Kingdom, Kenny et al. (2016) found that identity-first language was most frequently preferred by Autistic adults along with their families; meanwhile, professionals more often endorsed person-first language. Consistent with Kenny (2016)'s finding that professionals tended to prefer person-first language, in the field of APA in North America, person-first language is indeed the most prevalent and accepted terminology (Peers et al., 2014).

The words researchers choose to use in their work reflect their values, and thus, their axiological assumptions. Axiological assumptions, for researchers, can be thought of as the

...often-unexamined, unrecognized, or mistakenly universalized values that influence our work: Personal or disciplinary assumptions about what is good and bad, right and wrong, and more or less valuable, worth, desirable, and beautiful. (Hart, 1971, as cited in Peers, 2018, p. 268)

For example, when functional labels such as "high-" or "low-functioning" are used by researchers when talking about different experiences of Autism, there is a connotation that one such experience is more desirable than the other (high-functioning over low-functioning). Autistic individuals have said that viewing the variation of Autistic experiences in this way is "overly simplistic" and potentially harmful (Kenny et al., 2016, p. 449).

Peers et al.(2014) have also emphasized how terminology is directly connected to values and ideas articulated by the author's research. The language researchers use is reflective of what they know and believe to be true. Language has impact and meaning when it comes to the culture of physical activity and its relationship with Autistic people. Thus, while seeking to improve opportunities for those who experience Autism, care must be taken to consider what language is used and how the language can either build up or hurt the communities APA seeks to serve.

Critical Pedagogy and Adapted Physical Activity

In Connolly and Harvey's (2018) paper, they brought critical pedagogy into conversation with APA. They discussed three phases in which education could move learners through to facilitating their transition from one form of consciousness to another. Those three phases are: investigation (where the learner identifies where their beliefs lie in the archaeology of consciousness), thematization (where the learner goes from perception to reflection, their ideas become explicit and considered in relation to the cultural context) and finally, problematization (where the learner realizes and unpacks their oppressive predicaments by exploring 'limit situations') (Connolly & Harvey, 2018).

The three forms of consciousness students could move in between were naïve, superstitious, and critical consciousness. Naïve consciousness involves an "unreflecting acceptance of the absolute validity and unquestionability of the world as is and one's own views" (Connolly & Harvey, 2018, p. 301). Those with a naïve consciousness cannot comprehend a perspective that is different from their own and hold their assumptions and values unreflectively. A superstitious consciousness is "characterized by a recognition of cultural options but a concomitant sense of powerlessness to do anything about those options" (Connolly & Harvey, 2018, p. 301). Finally, a critical consciousness is described as an ability to recognize that:

...cultural institutions are created and sustained by human purpose, and action and language both shaped and reflects people's perceptions of cultural institutions...There is no innocent, separate "1" outside of or uninfluenced by culture. People shape and are shaped within culture. Culture can be analyzed, explicated, deconstructed and in principle, transformed by human action... (Connolly & Harvey, 2018, p. 301)

If APA practitioners can realize a critical consciousness when thinking about their understanding of Autistic communities, they may better understand that the current culture around understanding Autism in the field of APA is culturally constructed and sustained. Through understanding this, they may better position themselves to unlearn harmful ways of viewing Autism and begin orientating their actions towards a more affirmative culture in APA that accepts and celebrates Autism. Connolly & Harvey (2018) wrote that if APA wishes to offer meaningful movement opportunities that do not compromise the "safety, dignity, or agency" of Autistic participants, blending critical pedagogy with APA is crucial (p. 305).

Theory

My [Autistic] personhood is intact. My selfhood is undamaged. I find great value and meaning in my life, and I have no wish to be cured of being myself. (Sinclair 1992, p. 302)

The theoretical lens used in this study is that of the neurodiversity paradigm. Walker (2014b) names three fundamental principles of this paradigm. The first is that "neurodiversity is a natural and valuable form of human diversity" (n.p.). In other words, Autism and other similarly pathologized conditions are not seen as problematic deviations, but rather a part of a broad range of value-neutral human sensory-cognition variation. The term "neurodiversity," itself, was coined in 1998 by an Autistic sociologist named Judy Singer to refer to the diverse and infinite variation of neurocognitive functioning amongst human minds (Walker, 2014b, n.p). Like social models of disability more generally (Withers, 2012), this principle is in stark contrast to both medical (pathology) and charitable models of Autism, which presume Autism is a problem to be fixed.

Walker (2014b)'s second fundamental principle is that:

...the idea that there is one 'normal' or 'healthy' type of brain of mind, or one 'right' style of neurocognitive functioning, is a culturally constructed fiction, no more valid (and no more conducive to a healthy society or to the overall well-being of humanity) than the idea that there is one 'normal' or 'right' ethnicity, gender, or culture. (n.p.) The hyper-valuation, and production, of human "normalcy" is a cultural construct and not, in itself, natural. This principle challenges the predominant medical (pathology) views of Autism as a neurological "abnormality" in need of cure.

In the perspective of the medical (pathology) model, the right thing for a society to do is attempt to cure and eliminate these kinds of neurological differences (e.g., pharmaceutically, genetically, or through rehabilitation) so that individuals can live a 'better life' (read 'better life' as one that fits the ideals of the neurotypical society) (Rosqvist et al., 2020). However, Autistic self-advocates within the neurodiversity movement are explicitly against notions of cure and the idea that Autism is undesirable or scary. For example, one of the largest Autism organizations in North America, Autism Speaks, has been heavily criticized by self-advocates for funding research focused on finding the causes of and cures for Autism (Autistics 4 Autistics Ontario, 2020; The anonymous aspie, 2013; Brown, 2012 and more). Alongside that, the organization is also viewed poorly for producing commercials and movies that perpetuate stigma and stereotypes of Autism as sinister (see Autism Speaks' 'I Am Autism'⁷ commercial) or difficult to live with (see Autism Speaks' movie 'Autism Every Day'⁸ where a mother who shares that she has contemplated driving off a bridge with her Autistic child, but didn't only because she has a non-Autistic child) (George, n.d.a). Further, Lydia X. Z. Brown (2013) criticized Autism Speaks for listing the Judge Rotenberg Centre—a centre that has used punishments such as electric shock on neurodivergent folks—as a "service provider for Autistic people and their families" (n.p.). Many Autistic self-advocates have also spoken out against other methods of 'cure' such as ABA therapy (George, n.d.b; Lynch, 2019; Celebration of Kat, 2020 and more). Despite being championed by many professional bodies (such as the American Psychiatric Association, n.d.),

⁷ https://www.youtube.com/watch?v=9UgLnWJFGHQ&ab_channel=FindYaser

⁸ <u>https://www.youtube.com/watch?v=O0vCz2KWMM0&ab_channel=MilestoneVideoNY</u>

ABA has been viewed by Autistic self-advocates as abusive. Specifically, critics point out that conversion therapy (a widely banned behaviour modification program designed to "convert" gay and gender-non-conforming people into heterosexual and cis-gender citizens, which has been largely disavowed by psychiatry) has a deeply entwined history and methodology with ABA, and yet ABA continues to be celebrated by those who have vehemently disavowed conversion therapy. Sequenzia (2016) has thus suggested that this so-called 'treatment' be called "Autistic Conversion Therapy" (n.p.). Further in literature, it was found that Autistics that were exposed to ABA predicted a higher rate and more severe posttraumatic stress symptoms (Kupferstein, 2018)

More than a neutral part of human variation, Autistic experiences can be deeply enjoyable and valuable, as is the case for any human. Autistic blogger, artist, and advocate, Kirsten Lindsmith (2014a) writes that Autistic minds often make for creative inventors, exceptional specialists, and a valuable "no-nonsense, straightforward approach to the world" (n.p.).

By making explicit that a neurotypical brain is not the only valid way for minds to exist, Walker (2014)'s second fundamental principle of the neurodiversity paradigm allows for neurodivergent brains to be understood as not broken or 'abnormal,' but rather, part of the normal human variation of neurocognitive function.

That being said, Rosqvist et al. (2020) states that:

Acknowledging neurological difference does not imply that all difference is good in itself, or that human traits associated with neurodivergence are always desirable, but it accepts that there are 'good' and 'not so good' traits in all human beings. (p. 7)

Affirming neurodivergence and advocating for its existence does not mean there are not parts of the experience that are difficult or disabling. Rather, a key practice of the neurodiversity paradigm is to acknowledge that beyond these difficulties, there are aspects to neurodiversity that are enjoyable and valuable, as is the case for any human.

Whereas the dominant medical (pathology) view focuses on the deficits of neurodiversity, the neurodiversity paradigm makes visible, celebrates, and affirms the neutral and beautiful parts of neurodiversity while also acknowledging and supporting people through the hard things.

Although the neurodiversity paradigm is fundamentally in opposition to being cured as a response to Autism, this does not equate to being against the use of intervention. Autistic self-advocate Lindsmith (2014b) shares that while they do not view Autism as a disease, they still acknowledge that the differences that come with Autism can result in "varying levels of disability" depending on the situation one is in (n.p.). Thus, "where devices, legal protections, or medication can be helpful in tackling some of the impairments that result from societal demands, as long as these are consistent with some possibility of self-determination," (Rosqvist et al., 2020, p. 4) then it may be valuable to some proponents of the neurodiversity paradigm. In other words, neurodiversity theory affirms the rights of people to access supports and interventions that are actively desired and deeply consented to.

The third and final principle of the neurodiversity paradigm written by Walker (2014b) states that:

The social dynamics that manifest in regard to neurodiversity are similar to the social dynamics that manifest in regard to other forms of human diversity (e.g., diversity of ethnicity, gender, or culture). These dynamics include the dynamics of social power

inequalities, and also the dynamics by which diversity, when embraced, acts as a source of creative potential. (n.p.)

What this means is that the dominant medical (pathology) understanding of neurodivergence today is viewed as oppressive, and fighting against the erasure of neurodivergent individuals needs to be fought as a social justice fight.

The Neurodiversity Movement is a "social justice movement that seeks civil rights, equality, respect, and full societal inclusion for the neurodivergent" (Walker, 2014b, n.p.). This movement began within the Autism Rights Movement, however, it is important to note that while there is much overlap between the two, the main difference is that the neurodiversity movement today seeks to include all neurodiverse individuals, not only Autistic individuals. In 1993, Sinclair (n.d.) wrote "Don't Mourn for Us," an essay that challenged medical (pathological) understandings of Autism, and that is considered a manifesto for the neurodiversity movement. Sinclair critiqued the tendency for parents of Autistic children to "mourn" their child's Autism status and dispelled myths about Autistics "being in their own world" (n.p.). Xe also advocated that Autism can not be separated from the individual, rather, Autism is a way of being.

As a theoretical lens, the neurodiversity paradigm attunes the reader towards differentiating between discourses of diversity and those of deviance, between consensual interventions and compulsive normalization, and between pathologization and politicalization. In short, it asks the reader to take as its fundamental premise, that the problem to be addressed at the intersections of Autism and physical activity is not how to "get" or even how to "let" Autistic people exercise, rather, it is how can we create deeply affirming, consensual, accessible, and supportive physical activity opportunities for a wide range of neurodivergent folks.

Methods

Research Assumptions and Quality Research

This research project embraced the critical paradigm. That is, our research choices were based on the epistemological assumption that all knowledge is subjective, and indeed, that the subjective (and often underexplored) perspectives of those on the margins are highly valuable in research about their lives (Markula & Silk, 2011). Importantly, research from the critical paradigm is explicit about its axiological commitments (Peers, 2018), specifically the valuation of social justice, the knowledges of the marginalized, and the commitment to challenge unjust power relations.

This paradigm fits well with our theoretical framework of the neurodiversity paradigm, which problematizes pathologizing labels, challenges dominant medical treatments of Autism, and places neurodivergent perspectives at the center. That is, neurodivergent theorists use critical thought to improve the lives of Autistic individuals (the marginalized class), which is an endeavor reflective of the critical paradigm (Asghar, 2013). As a result of this paradigm, our job as researchers is not to present an objective or even balanced representation. Instead we have sought to maximize quality by focusing on the following Big Tent criteria presented by Tracy (2010): *credibility, worthy topic*, and *sincerity*.

Sampling

This project involved the thematic analysis of two distinct datasets.

For the first data set, we sought out tool-kits and other instructional or self-help writings written by Autistic and neurodivergent writers. In essence, we looked for writings where Autistic individuals shared knowledges about how to create inclusive spaces, or how to successfully participate in mainstream spaces as someone who is Autistic. We named this the "emic" dataset because the aim of collecting this data was to learn about Autistic neurodivergent experiences from an insider's point of view, and emic perspectives are thought of as "shared views of cultural knowledge from the insider's 'normative' perspective" (Fetterman, 2008, p. 2). The dataset was created through targeted snowball sampling (Dusek et al., 2015), followed by a broad Google Search. We began with websites that are known hubs for neurodivergent, self-advocate, and Autistic-led writings. These include the Autism Women and Non-binary Network website (https://awnnetwork.org/), and the Autism Self Advocacy Network

(https://Autisticadvocacy.org/). We then read their blogs, publications, and resources pages for signs of any "toolkits" or resources that articulate access or "how tos" for Autistic individuals. Since many of these websites, and especially blogs, interlinked with other Autistic-lead blogs, we proceeded to use snowball sampling to search these websites for other useful sites.

To ensure that there were not major sources missed, we did broad Google and Google Scholar searches pairing search terms "neurodivergent," OR "Autistic" with terms like "toolkit", "self-advocate," "resource," and "workbook": we included any resources that fit our criteria above, and that were created by people who self-identified as Autistic or neurodivergent. The purpose of this search was not to create an exhaustive list of resources, but to analyse a collection of 12 well-circulated neurodivergent-produced resources from a variety of sites in order to get a sense of some key neurodivergent approaches to teaching and learning about tools for enabling greater, more accessible, or affirming participation in movement activities of meaning.

The second data set consisted of Adapted Physical Activity textbooks that were published in the last 20 years, with specific chapters related to Autism. We named this the "etic" data source because etic perspectives represent the "external social scientific perspective" (Fetterman, 2008, p. 2). That is, etic perspectives represent the outsider's view of a studied group (i.e., APA professionals' views of Autistic individuals). Textbook selection was done through a search on the Worldwide Library Database with keywords "Adapted Physical Activity" OR "Adapted Physical Education." Further, selected texts needed to contain at least one of the following search terms: "Neurodiverg* OR "Autism" OR "Autistic" OR "Developmental disability" OR" Behavioural issues" OR "Cognitive disability."

Findings were narrowed down to pedagogical texts, that is texts whose primary stated purpose is as a teaching tool within post-secondary classrooms. Only texts published in the last 20 years and that were widely circulated, that is, texts published between 2001 and 2021 with more than 100 worldwide holdings as noted in the Worldcat library, were selected. This search sequence yielded 5 distinct pedagogical textbooks. We only analyzed chapters from the textbooks in which Autism or neurodivergence were explicitly discussed. Where older editions of textbooks were available to use, we analyzed the sections to look for differences from newer editions.

Data analysis

The data sets were analysed through thematic analysis (TA): a paradigmatically, theoretically, and methodologically flexible mode of analysis that has been used often in the critical paradigm (Braun et al., 2016; Braun & Clarke, 2006). The phases of TA include: *familiarizing oneself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report* (Braun & Clarke, 2006).

Thematic analysis gives way for researchers to identify patterns ("themes") in data sets and describe/interpret the meaning and importance of those patterns in ways that can be attuned to specific paradigms and research objectives (Braun et al., 2016). TA is useful when looking to either describe or interpret meaning out of a data set. While a data *corpus* refers to all data that has been collected for a research project, a data *set* describes the data from the data corpus that is being used in the particular analysis (Braun & Clark, 2006). Within this project, there are 2 data sets (the emic and etic data sets), both of which make up the data corpus for this project. Themes encapsulate some overarching pattern within a data set being analysed, which helps answer research questions at hand.

Different types of analysis were used to analyse the different data sets. For the analysis of the emic data set, I sought to establish a rich, thematic description that could further inform my theoretical framework and offer nuanced descriptions of the dataset that has received minimal previous attention, and is likely not well known to the field. Through seeking a rich description of emic data set, I was able to learn about the viewpoint of Autistic self-advocates and neurodivergent cultures, an area under-researched and represented in the field of APA. Themes in this dataset were thus identified through a 'bottom-up' (inductive) approach, meaning the themes identified are strongly linked to the data set itself and not pre-organized by a particular theoretical frame (Braun & Clarke, 2006). My analysis was mid-way between semantic and latent. That is, I analyzed the literal things authors were saying, paying attention to some things I believed were inferred by the author, but otherwise not "reading into" the text's meanings beyond what we believed were intended by the authors. This analytic strategy was designed to learn about the ways in which emic Autistic self-advocates understood themselves and how they were strategizing for better inclusion for themselves and their communities.

For my analysis of the etic dataset, I used findings from my emic analysis to create a more deductive (top down) coding framework, thus looking for similarities and divergences in thematic content. In essence, the coded themes were sought after to answer specific questions, rather than letting the themes unfold during the analysis (Braun & Clarke, 2006). During this analysis, and having just completed the TA for the emic data, we were interested in the ways in which APA textbooks' teachings on how to support Autistic individuals aligned or not with the ways in which Autistic self-advocates supported one another.

Once both analyses were completed, the results were pasted on Post-It notes and analyzed together. From a holistic standpoint, we began analysing the ways in which the etic texts promoted the values of APA as a field.

Collectively, this analysis enabled us to answer two important questions: 1) what are the biggest similarities and differences between how etic APA experts and emic Autistic experts talk about and strategize around Autism-related inclusion? And 2) What can this thematic comparison teach us about how APA and APE textbooks are constructing and promoting the APA values of self-advocacy, self-determination, and choice for Autistic individuals?

Results

Through our comparative TA of 12 neurodivergent self-advocates' works and 5 pedagogical APA textbooks, we constructed 4 themes, which collectively answered our research questions. These themes were titled: 1) *Writing in Categorical Imperatives*, 2) *Excluding Autistic Perspectives*, 3) *Problematizing Autistic Characteristics*, and 4) *Promoting ABA and Autism Speaks*.

Writing in Categorical Imperatives

Through our analysis of the etic data, we found that oftentimes APA texts spoke in categorical imperatives, that is, they made broad statements about all or most people across the

spectrum, and then offered specific advice for this full (or most of the full) classification of people. For example:

Most children with Autism appear to be functionally deaf, in that they do not seem to hear noises or speech. The only way to get their attention is through firmly taking hold of one or both shoulders. Firm pressure is better than light touch because many children are tactile defensive to light touch stimuli. (Sherrill, 2004, p. 608)

...daily vigorous aerobic exercise is critical because it reduces self-stimulatory and offtask behavior, increases time on academic and vocational tasks, and, as important, improves gross motor performance. (Auxter et al., 2010, p. 410)

These texts used very strong language such as "the only way to" or declared that a particular strategy "is critical." Such language, first of all, suggests that despite the group of Autistic people being referred to as 'on a spectrum'—a term that explicitly acknowledges immense variation—they should all (or at least 'most') be dealt with in exactly the same way. Relatedly, it instructs future practitioners—the target of university-level APA and APE textbooks—to do a predetermined specific intervention, rather than negotiate interventions consensually and adaptively with individuals they are working with.

In contrast, we found emic texts almost always spoke in more contextualized, nuanced, and invitational ways. In lavender-sprinkles' (n.d.) "Meltdowns: A Survival Guide," they take care to respect the unique experiences of those they are speaking to by sharing tips for managing a meltdown in ways that maintain the individual's autonomy and ability to choose:

If you can tell you're approaching meltdown mode, try explaining to others that you need to go somewhere quiet and dark. (n.p.)
Lavender-sprinkles (n.d.) uses phrases "if you can,...try," multiple times in their meltdowns survival guide. This phrase is a kind of *invitatory language*. Invitatory language evolved out of trauma-sensitive yoga and is used with the intention to *invite* rather than *command* students during instruction (Eales, 2018; see also Emerson et al., 2009). Eales (2018) wrote that invitatory language is "one way in which choice is deeply integrated" (p. 258).

By way of weaving invitatory language into their survival guide, lavender-sprinkles (n.d) prioritizes choice for the individual reading their guide. Invitatory language inherently allows the individual reading the text autonomy and assumes their expertise to contextualize the advice given. In essence, invitatory language recognizes the individuality of every person's experience. This acknowledgment of expertise of those with lived experience, through the use of invitational language is used by many of the Autistic emic authors.

Through using this language authors are able to share tips that may potentially work for someone rather than having their words be depicted as imperative. Autistic Changeling (2018), is explicit about this in their "Executive Dysfunction and Organization Tips video":

First I think it's important to remember that executive dysfunction contains a lot of different types of difficulties, and not everyone who deals with executive dysfunction will deal with every single type of difficulty it can include. So I think it's important to keep in mind what specific things that you deal with when trying to find a solution. Just because something may help someone else it does not mean it will help you...I also want to point out that everything is subjective, what helps me might not help you...this is

advice but not necessarily like 100% guaranteed to work in your life, or in my own. (n.p.) This emic author explicitly invites viewers and listeners to contextualize the advice given in the moment and to remember that everyone's experience is unique—and thus there is no catch-all solution that will work for everyone. It invites the reader to adapt their learnings to their own unique circumstance, rather than offering a categorical generalization or imperative.

Exclusively Including Medical Understandings of Autism

Generally, all APA textbooks defined experiences of Autism exclusively in medical (pathological) ways—as "autism spectrum disorder" (ASD). Characteristics of Autism were viewed as "symptoms," and there was often talk of treatment or interventions. For example: "In general ASD is a life-long disability; however, with early intervention and treatment ASD symptoms can substantially improve, although results do vary" (Horvat et al., 2019, p.186).

However, there exist neurodivergent definitions of Autism which stray heavily away from medical (pathology) definitions. Nick Walker wrote an extensive 6-paragraph definition of Autism in his blog post called "What is Autism?" The definition starts off by stating that: "Autism is a genetically-based human neurological variant" (n.p., Walker, 2014a). Despite the availability of this definition online, no textbooks have included neurodivergent definitions of Autism in their textbooks.

While etic APA textbooks not once mention neurodivergent understandings of Autism, emic authors did not shy away from addressing the pathology paradigm's perspective on Autism on their platforms. Aside from definitions of Autism and neurodiversity coming from the neurodiversity paradigm on Nick Walker's blog, *Neuroqueer: The Writings of Dr. Nick Walker* (previously named *Neurocosmopolitan*), one can also find interpretations and definitions of the pathology paradigm.

Problematizing Autistic Characteristics

When APA textbooks discuss Autism, they often concentrate on what they frame as "problematic" behaviours: Horvat et al. (2019), for example, articulates that "problems in motor behavior... include repetitive behaviours, such as hand flapping..." (p. 182). Hand flapping—a form of stimming that has been suggested to provide multiple benefits to the individual (Kapp et al., 2019)—is framed as "problematic." In essence, movement patterns that have been thought of as potentially valuable for sensory regulation and as coping mechanisms are being targeted for elimination by way of referring to them as "problematic." Similarly, Sherrill (2004) writes about "problems of echolalia" as part of their section on "Language and Speech Impairments" characteristic to Autism (p. 609). Echolalia is thought simply as a problem and impairment, with no further presumed function or benefit. Both these forms of stimming, hand flapping and echolalia, are classified as non-normative and thus characteristic to Autistics.

In contrast, emic writers point out that non-normative and 'problematic' behaviours associated with Autism are not even that non-normative. Even non-Autistic individuals will partake in them. Lindsmith (2014c), for example, discusses how common stimming actually is:

Everybody does it. It's perfectly normal, but often embarrassing—something we encourage our children to suppress, or do in private. Existing on a continuum from

healthy, to bad habit, to scandalizing, stimming is as diverse as humanity itself. (n.p.) When Lindsmith (2014c) says everybody stims, they are referring to the fact that many neurotypicals will bob their head to a song they like, tap their feet or fingers when feeling anxious, or jump for joy when something excites them. They point to the fact that we all stim in some way whether we realize it or not, but perhaps because of the specific way in which those experiencing Autism stim, we have problematized it (Lindsmith, 2014c). By pointing out that everyone stims, Lindsmith (2014c) makes it comprehensible that stimming is indeed very ordinary, and can potentially be harmless or even helpful.

Further, emic authors write about these stimming actions as non-problematic variations that, indeed, can be useful and adaptive tools:

Echolalia can be functional communication, similar to the way a subset of Gen-X-ers considers lines from the movie Caddyshack perfectly acceptable responses during casual conversation. Echolalia can also be a form of verbal stimming: it can be reassuring and self-soothing to repeat phrases either to one's self, or in a call-and-response fashion with other people. Yet parents, teachers, and therapists often try to squelch or redirect Autistic echolalia. If this attempted squelching happens, just say no. And then say it again! (Des Roches Rosa, 2017, n.p.)

Beyond advocating for echolalia as not a problem and not an impairment, emic authors take it a step further to say that there are many functionalities to echolalia such as being an important means of self-soothing. Further, by comparing echolalia to trendy communication styles of Gen-X-ers, the author asks readers to expand what they have once thought of as acceptable forms of communication. Those using echolalia are encouraged to resist conforming to any external pressures to suppress this form of communication, further emphasizing echolalia as a harmless form of communication that also has valuable function.

While emic authors would emphasize the harmlessness of their non-normative traditions, etic APA textbook authors would encourage physical activity as a form of intervention to "fix" these non-normative traits such as stimming.

For example:

Vigorous aerobic exercise on a motorized treadmill is sometimes effective in preventing stereotypic and hyperactive behaviours. (Elliot et al., 1994; Grandin, 1995, as cited in Sherrill, 2004, p. 611)

Exercise interventions appear to have a very positive effect on stereotypical behaviors... (Horvat, et al., 2019, p. 187)

In both examples above, exercise is offered as a means to "prevent" or "positively effect" (i.e. decrease) stimming behaviours. Exercise is offered as an intervention to decrease what are thought of as "symptoms" of Autism. Movement is not offered as a means of enjoyment and meaning making, rather as a way to eliminate stimming behaviours, and ultimately Autistics.

Promoting ABA and Autism Speaks

Throughout our analysis of emic texts, we found that many self-advocates showed outward and direct disapproval to organizations such as Autism Speaks, and the therapeutic practice of Applied Behavioural Analysis (ABA).

Amy Sequenzia (an Autistic activist) has written extensively about ABA for the Autistic Women and non-binary-Network. Sequenzia (2016) has compared ABA to Gay Conversion Therapy, proposing ABA be called more specifically "ABA: Autistic Conversion Therapy that uses torturous methods" (Sequenzia, 2016, n.p.). Further, they remind readers that both ABA and Gay Conversion Therapy have the same "father—Ivar Lovaas" (Sequenzia, 2016, n.p.). Just as Gay Conversion Therapy has been experienced by many as violent, ABA can be experienced in similar ways. Sequenzia (2016) states that adults who experienced ABA are against it: "ABA is bad...it hurts and...is violence against who we are" (n.p.). They further are not convinced when parents say their children claim to love ABA: "They are children, being manipulated through rewards, being taught that pleasing adults makes them 'good'" (Seqeunzia, 2016, n.p.). Sequenzia asks us to listen to Autistic adults who have survived ABA because children currently undergoing ABA are not allowed to have their own voice. They themself 'failed' ABA and wrote:

If you want something from me, if you want me to do something, respect who I am, respect my way of doing things, listen to me and allow me to disagree and to find my own way. ABA rejects all of this and that's why I failed it. (Sequenzia, 2015, n.p.)

ABA does not respect who they are. As it is often advertised as "treatment" for Autism, ABA inherently does not respect Autism; it is a method of trying to eliminate Autism. Sequenzia is asking that instead of forcing Autistics to comply and do things in ways ABA wants them to, let them find their "own" way—perhaps more Autistic ways. ABA is focused on eliminating Autistic tendencies in Autistic children, and Sequenzia points out that nurturing their unique ways of doing things may actually prove a better method.

In terms of Autism Speaks, Lydia X. Z. Brown, an Autistic advocate also known as Autistic Hoya, wrote against supporting Autism Speaks to the President of an organization:

...I am very disappointed to see that you have chosen to support an organization that nearly all Autistic adults do not support and cannot condone. I cannot condemn Autism Speaks strongly enough...I strongly encourage you to consider alternative means of supporting Autism and Autistic communities... (Brown, 2012, n.p.)

In addition, in a letter to the co-founder of Autism Speaks, Amy Sequenzia alluded to the work done by Autism Speaks as a form of oppression and signed off the letter with: "Oppression will eventually lose, and so will you and Autism Speaks." (Sequenzia, n.d., n.p.) Both letters written by Brown (2012) and Sequenzia (n.d.), condemn Autism Speaks for the harm they've caused through offensive marketing that instill attitudes of fear towards Autism, the exclusion of Autistic voices from their organization, and more.

Despite our findings of disapproval for ABA and Autism Speaks within Autistic communities, we still found APA textbooks that promoted ABA. Houston-Wilson (2017) stated under their recommendations for interventions and behaviour management techniques:

The token economy system and the Premack principle, described in chapter 6, are also

effective behavior management strategies to use with students with ASD. (p. 212) The chapter 6 they are referring to here is a chapter in their textbook titled "Behavior Management," and it spends well over half its chapter fleshing out the details of ABA, with both the token economy system and Premack principle described as procedures for increasing desired behavior and a type of reinforcer in ABA, respectively. Essentially, while not overt, ABA is being promoted as a form of intervention for Autistic individuals in Houston-Wilson (2017)'s text.

Interestingly, between the 11th and 12th edition of the *Developmental/Adapted Physical Education: Making Ability Count* textbook, the authors removed mention of ABA under their recommended teaching strategies. Auxter et al. (2010) listed and described ABA under their section titled "Teaching Strategies" (see page 406), but it has since been removed from the same section in the 12th edition.

ABA is described and recommended in etic texts as a form for intervention to use while working with Autistic individuals. While this information might be shared with good intention, more thought needs to be given when many Autistic adults claim their experiences with ABA as harmful. While not explicitly stated, Roth et al. (2017) may have removed ABA for this reason, and we urge other textbook writers to do the same.

Further, two of the second most recently published textbooks from our data set, both from 2017 (most recent is 2019), cite or referenced Autism Speaks:

Autism Speaks maintains a database of apps for students with Autism. (Roth, et al., 2017, p. 428)

Because ABA requires between 25-40 hours per week for changes in behavior to occur...The goal of this [ABA] intervention is to provide an abundance of positive reinforcement for demonstrating useful and socially appropriate skills and ignoring inappropriate behaviours. (Autism Speaks, 2015, as cited in Houston-Wilson, 2017, p. 203)

Further, Houston-Wilson (2017) listed Autism Speaks as a recommended online resource, stating:

Autism Speaks is dedicated to funding global biomedical research into the causes, prevention, treatments, and cure for Autism; to raising public awareness about Autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. (p. 214)

One of the most problematic aspects of Autism Speaks is that they heavily fund research that seeks to find the "causes, preventions, treatments, and cure for Autism." This is problematic because much of the Autism community does not wish to be cured. Cure, to them, can feel violent and genocidal in ways (Clare, 2017). Further Autism Speaks has been criticized for the ways in which it views Autism as a tragic experience, full of "hardships." Recommending Autism Speaks and embedding this whole description in ways that infer support for the cause

demonstrates just how far some APA textbooks are from the worldviews and self-stated best interests of Autistic people.

Discussion: Implications for the Field of APA

In the theme titled *Writing in Categorical Imperatives*, we noted how, in contrast to emic authors, etic authors of APA textbooks tended to generalize across the 'Autism spectrum' and offered strategies that were treated as *the* right choice across all or most Autistic people. This generalization across a full spectrum of people runs counter to one of the primary skill sets of APA practitioners, that is, adapting physical activity contexts according to *individualized* needs (Sherrill, 2004). Further, the use of categorical imperatives about predetermined actions practitioners must make, we argue, runs counter not only to neurodivergent knowledges, but also counter to APA's own stated values. As discussed above, APA has been argued to be about promoting self-advocacy and choice for people with disability (Reid, 2003). However, this kind of imperative language teaches practitioners *not* to engage adaptively and consensually with participants, but rather to generalize predetermined interventions across a large group of highly diverse people as though they were a relatively homogenous group undeserving of autonomy or choice.

Contrastingly, through both implicit and explicit ways, emic authors emphasized choice and autonomy for the communities they intend to benefit. The ways in which emic authors more often wrote in conditional and invitational ways may be reflective of trauma-informed practice (Eales, 2018). Eales' (2018) states that APA has yet to engage with the ways in which our field and practitioners can incorporate trauma-awareness and therefore engage in trauma-informed practices. They write that we have yet to think about how "we might be causing trauma by virtue of the very ways we understand and engage with disability and bodies doing physical activity" (Eales, 2018, p. 180). By way of writing in categorical imperatives, APA textbooks have left little room for learners to give choice to Autistic individuals in physical activity settings, which may end up "retraumatizing" the very people APA practitioners aim to benefit (Eales, 2018). We ask APA pedagogical textbook writers to consider teaching trauma-awareness to APA practitioners and using invitatory language in their textbooks when discussing Autistic experiences. Through these efforts we believe that APA may better engage with their own stated aims and values, as well as with trauma-informed practice, and lessen the chance of retraumatizing Autistic individuals we may work with.

The second theme, titled *Excluding Autistic Perspectives*, notes the general absence of any acknowledgement of neurodivergent perspectives on Autism in etic APA textbooks. Rather, the textbooks rely solely on the pathology paradigm. Walker (2011) points out that dominant paradigms, such as the pathology paradigm, involve assumptions that are oftentimes:

so widely taken-for-granted that most people never consciously reflect upon them or articulate them (and sometimes it can be a disturbing revelation to hear them plainly articulated). (n.p.)

Pedagogical textbooks are trusted resources for learners, and to teach about Autism without including the knowledge of Autistic individuals themselves would be doing textbook users a disservice. Through only providing dominant pathology paradigm narratives, etic authors miss out on a vital opportunity to *plainly articulate* alternative understandings of Autism and allow APA students and professionals the opportunity to *consciously reflect*.

By excluding neurodivergent perspectives from APA textbooks, etic authors may also be missing the opportunity to challenge the taken-for-granted assumptions of the pathology paradigm that many APA learners with a *naïve consciousness* will hold, and thus miss the

opportunity to engage with critical pedagogy and bring students into a *superstitious consciousness*, and later to a *critical consciousness* (Connolly & Harvey, 2018). If APA textbooks simply included neurodivergent perspectives in their textbooks, they could be taking one step towards engaging with critical pedagogy, and putting future APA practitioners in a better position to provide "meaningful movement to participants anywhere on the spectrum without compromising their safety, dignity, or agency" (Connolly & Harvey, p. 305).

At the minimum, APA textbooks should offer alternative understandings of Autism, especially when these perspectives are widely popular within, and come directly from, Autistic advocacy communities. The fact that even textbooks published as recently as 2 years ago have no mention of neurodivergent perspectives is extremely problematic and would be working in opposition to APA's goals to provide meaningful and safe movement opportunities for Autistic individuals.

In our third theme titled *Problematizing Autistic Characteristics*, we contrasted the ways in which emic and etic authors framed Autistic characteristics. Whereas emic authors tended to see function, sense, and normalcy in their non-normative Autistic traits, etic APA textbook authors problematized them.

Within APA, one scholar challenges the field's assumption that peculiar Autistic ways of moving are problematic. Laban Movement Analysis (LMA) was used by Connolly (2010) to describe movements of Autistic children and ascribe meaning to those movements. Connolly (2010) believe that movement has meaning and LMA is a strategy for 'seeing' the meaning (p. 106). Here, movements such as stimming are viewed not simply as meaningless and problematic behaviours, but rather as movements of meaning. Our hope is that our field of APA can follow in Connolly's footsteps and learn from Autistic communities to begin viewing stimming in ways similar to LMA—movement with inherent meaning and value.

Rather than viewing stimming as the culprit preventing Autistic individuals from participating in life fully, we could consider that stimming might make way for Autistics to better participate in activities they desire. Kapp et al. (2019) shared that for some, stimming was a way to help Autistics better concentrate. By way of helping individuals better regulate their senses, it allowed them to participate in whatever activities it was that they wanted to partake in.

Further, movement and physical activity itself could be viewed as a form of stimming. Houston-Wilson (2017) describes *sensorimotor activities* as kinesthetic activities that can benefit Autistic individuals. Examples they included were trampoline jumping and crawling through a tunnel (Houston-Wilson, 2017). Rather than viewing physical activity as a means to eliminate existing (non-normative) stimming behaviours, exercise movement could be offered as an alternative means of stimming, in addition to already existing and preferred stims. Further, if physical activity is defined as movement, then stimming could be referred to as a form of physical activity and would provide benefits that come with partaking in physical activity.

It is important to note that we recognize that some forms of stimming are in fact dangerous and harmful, however, we uphold the belief that individuals should still have choice around what to do about those harmful stims (if anything at all). There are techniques and tips which can be offered to those who wish to eliminate certain kinds of stims if they want. For the most part, many stims are not inherently harmful and emic thinkers argue that these should be affirmed as valid ways to move.

Physical activity, rather than always a means to "intervene" and "fix problematic behaviours," can be offered to students as an alternative and new way to stim, if they so choose

to. Rather than offering physical activity in exclusively prescriptive ways, incorporating choice around physical activity participation can change the relationship Autistic individuals have with physical activity, from an intervention to change integral parts of who they are to an activity one can choose to partake in and derive joy from.

In the final theme titled *Promoting ABA and Autism Speaks*, we point out the prevalence of support some etic authors had for applied behavioural analysis (ABA) therapy and the organization Autism Speaks. This support is in stark contrast to emic authors, who, across the board, condemn both ABA and Autism speaks emphatically.

By citing and referencing Autism Speaks in their textbooks, without even offering the Autistic movement critique, etic authors signal to their readers that Autism Speaks is a reliable source to go to when looking to learn about Autism. As it has been argued again and again in Autistic communities, Autism Speaks is an organization that harms the Autism community and should never be referenced as an authority on Autism and Autistic lives.

As a field, it is important to rethink the organizations and practices we continue to engage with when Autistic self-advocates almost universally view them as abusive. We should consider the ways that our continual and uncritical engagement with Autism Speaks and ABA therapy might alienate, further exclude, and actively harm those we as a field are seeking to include and support.

Conclusion

This study sought to learn about the ways in which Autistics who ascribe to the neurodiversity paradigm represent and understand their experiences, and then to compare this to the ways in which Autistic experiences were represented in APA pedagogical textbooks. Through this comparative thematic analysis, we were able to find ways in which APA textbooks can better work towards supporting Autistic communities, and that is through including the neurodivergence paradigm's definitions of Autism, teaching and exemplifying trauma-informed practice, acknowledging and affirming aspects of the Autism experience that are simply different or desirable, and finally, not promoting Autism Speaks or ABA.

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Chapter Five: Conclusion

Implications of this work

This research is the first in the field of APA to analyze pedagogical textbooks in comparison to self-advocacy works by Autistic neurodivergent authors. It is also one of few studies in the field of APA to use language from the neurodiversity paradigm (Connolly & Harvey, 2018), and the only study in APA to forefront the neurodiverse ways of knowing when discussing experiences of Autism.

My hope is for pedagogical textbook writers in the field of APA to consider the perspectives and knowledges of Autistic individuals when writing about Autism in their books. Through greater representation of neurodivergent knowledges in APA, professionals in the field may become better set up to create neurodivergent affirming spaces more often. This work may also pave the way for more researchers in the field of APA to strive towards learning *from* Autistic individuals directly. My hope overall is that we as a field will learn how to better meet the needs and desires of Autistic communities when it comes to accessing opportunities for meaningful movement. In the end, I think the intentions of APA are in the right place, and I believe that learning from neurodivergent communities and adapting a neurodiversity paradigm in APA will only progress us forward to meet our goals as a field.

Personal reflections

I never expected nor planned to enter graduate school. While it technically was my decision, I often feel like I had no choice. I was in the woods, found a trail of crumbs, and followed. That trail of crumbs led me to become a person committed to seeking out and challenging ableism in myself and the structures around me. I am forever grateful for that.

The trouble is that once you see it, you can't unsee it. And once you've seen it, keeping quiet, saying nothing, becomes as political an act as speaking out. There is no innocence. Either way, you're accountable. (Roy, 2001, p. 7)

I learnt a lot of theory during this program. I really loved the ways the theory helped me make sense of some experiences I had had or seen in real life. It helped me imagine how I could view disability differently than I had previously, and allowed me to confront ways in which my ways of thinking about disability were problematic and harmful. For me, once I realized the ways in which my thought process and actions relating to disability were problematic, it was impossible to not act on it. I've changed a lot, but I still have a ways to go. I think there will always be (un)learning for me to do. Once I had realized that there were structures creating a world that is ableist, it was hard not to see the ways these structures also made my world a sexist, racist, sanist, or transphobic world as well.

I've gone from an unknowingly complicit individual who perpetuated ableist values, to a person frozen by guilt, disgust, and hopelessness, and now to an individual who still feels anger and complicity at times but is more-often able to hold multiple complex realities together, open to learning and growth, and optimistic for a better future.

My hope for this work is not to point fingers at, blame, or shame anyone. Rather, I am hoping to start a conversation about whose voices are not being included in the field of APA, in relation to experiences of Autism. Whose voices had I not ever acknowledged prior to completing this project? What voices have APA as a field missed learning from?

Stories About My Awesomely Autistic Brother

In my prologue I problematized stories from my childhood where my autistic brother was viewed as a tragedy, inspiration, and incapable. Here, I want to take the opportunity to share some alternative stories about my brother.

There are so many things about my brother that are just plain awesome. If you ever met Thomas, you would know that he is an incredibly passionate person. When he develops a new hobby, he is going to love it in a deep, focused, and generous way. When we were kids his main interests included creating recordings on cassette tapes and playing with trains. He had hundreds of cassette tapes where he would record himself singing, telling stories, and capturing memories. I hardly remembered him as a kid without his tape recorder. He was deeply invested in the things that brought him joy and creating tape records was one of those things. As adults today, my brother's passions have shifted, but are distinct all the same (these days he's most passionate about swearing at COVID-19 in Vietnamese and purchasing Crowns to wear). As someone who hardly indulges myself in hobbies because I am so tethered to 'adulting,' I think it's awesome that my brother commits to and clearly derives such deep pleasure from his passions. It reminds me that there is more to life than work and school, and that we can stop to find pleasure in the small moments if we let ourselves.

Another thing I always admired about my brother is his steadfast sense of self. He always knows who he was and what he likes and does not like. He is never afraid to voice his opinion and is firm about his desires. I respect how my brother is so easily able to advocate for his needs and desires and is not afraid of how others might judge him. As an indecisive and often anxious people pleaser myself, I have had a lot to learn from him when it comes to loving myself and asking for what I need. Finally, Thomas is incredibly honest. Even when the honesty can hurt, I can count on him to tell me things like it is and share the truth. He has a no-nonsense way of communicating and does not see the point in talking around things. His blunt honestly has at times felt jarring, but I have grown to realize the value in directness and honesty. Despite being a blunt and logical person, as well, my brother is also incredibly empathetic. When I went through a difficult experience of suddenly losing someone close to me, Thomas wrote me poems about how that loss hurt him too. His ability to feel for others is deep, and I think that makes him awesome.

Final Reflections

For transparency, just 30 minutes ago (after completing my first round of major revisions for this thesis) I was made aware that in my *Personal Reflections* section (about two sections up from here), I had used ableist disability metaphors, not once, not twice, but three times.

I had also previously written that I had become a "less ableist person" whilst working my way through this program as well, as if challenging one's own ableism is an escalator moving only up where you become less and less ableist until you are no longer ableist at all (it has since been removed with comments and teachings from my supervisor). I am reminded that challenging my own biases is an ongoing journey, and that I must constantly work to question my thoughts and actions. I am also encouraged to surround myself with mentors that will both teach and hold me accountable—this can be books, keeping up with disability self-advocacy blogs, or others committed to similar journeys (thank you, Danielle).

It is somewhat ironic that I followed up my previous "I'm less ableist!" remark with the three ableist metaphors to conclude my thesis that feels heavily centred around challenging ableism in APA. However, I also kind of think it is the perfect way to exit my masters program because it reminds me that the work with myself and my ableism does not stop here. I will always have to catch myself, and if I am lucky, I will have others who catch me and will call me in. And in those moments, I hope I will be ready and up for doing the work to try and do better.

For anyone interested in learning more about ableism and language, Lydia X. Z. Brown (Autistic Hoya), who I reference multiple times in this thesis, has a page⁹ dedicated to this. Their page is constantly updated, and very informative and educational.

⁹Link to Autistic Hoya's Ableism/Language page: <u>https://www.Autistichoya.com/p/ableist-words-and-terms-to-avoid.html</u>

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Appendix A

Sample of Coding Process

Data Extract	Code
The employment shift: Tips for autistics by Jeanette Purkis, O	oct 17, 2017
Autistic people can find it very hard to break into the labor market (Purkis, 2017)	 Identity first language Non-absolute language
There are many <u>reasons why people on the Autism spectrum</u> find <u>ourselves</u> out of work. We may have left the workforce du to health reasons, such as anxiety or depression, we might have been retrenched or made redundant from a previous job be unhappy in our current job, taken time out to raise children or we could have never had a job. There is nothing shameful or embarrassing about being unemployed. Even if mainstrear society tends to view unemployment as being a failing or lack it is in fact a very common part of life for many people – and not just those of us on the spectrum. It is important to value yourself if you are unemployed and to avoid blame and shame. Most of us do want a job though and hope that unemployment will be a temporary state. (Purkis, 2017)	Inguage Educating on Autistic truths teaching about autistic people's m
Autistic people can find it very hard to break into the labor market. We might be <u>extremely anxious about working or the</u> job application process, have had a traumatic experience in the workplace, be very anxious around people or have low <u>self-esteem</u> . If one of these things is an issue for you, you car often find help to assist with things like anxiety, past trauma o social and communication difficulties. Your local Autism association or organization may be able to help you with thing	teaching about autistic people's experiences r Useful tip that may be relevant to
Data Extract	Code
Sherrill (2004) sixth edition	
"Autistic disorder is a severe, lifelong developmental disability that is diagnosed by impaired functioning, with onset before age 3 years, in (a) social interaction, (b) language as used in social communication, (c) imaginative or social imitative play, and (d) repetitive, stereotyped patterns of behaviour" (p. 604)	 Medical model Stimming as "impaired functioning" Frames differences to the norm as impairment Autism framed as problematic/langauge
"Degree of autism varies from child to child; descriptors indicate level of functioning (e.g., high, low)" (p. 604)	 Uses functional labels Language implies autism is a problem
"Causes of Autism" (p. 606)	 Relative focus on "Cause" of autism; in alignment with the medical model?
"About one third of persons with autism are able to live and work fairly independently by adulthood. The other two thirds remain several disabiled "	 Person first language Emphasis on importance of independence Deficit framing/debilitating

 work fairly independenctly by adulthood. The other two thirds remain severely disabled."
 independence

 "Traditionally autism is a life long condition, but an increasing number of books by parents describe partial or total recovery from classic autism as a result of intensive, structured early childhood intervention programs (e.g., Kaufman, 1994; Maurice, 1993)." (P. 606)
 Medical language