

APPLIED BEHAVIOUR ANALYSIS (ABA): A TRANSFORMATIVE MIXED METHODS
ANALYSIS OF EXPERIENCES AND PERSPECTIVES FROM AUTISTIC PEOPLE,
PARENTS, AND ABA PROVIDERS

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Abstract

The following mixed methods dissertation examines experiences of Applied Behaviour Analysis (ABA) from the perspective of autistic people, parents, and ABA providers in Canada. Using survey and interview analysis, this study explores a growing divide in standpoints regarding ABA as a method of treating and supporting autistic young people. Autistic people across the globe have shared their lived experiences of the ways ABA has caused them harm, and often trauma, due to the rigidly applied reward and punishment strategies that were used to make them appear less autistic and more neurotypical. Yet, ABA remains the most recommended autism intervention in Ontario. To understand this problem more in-depth, the methodology adopts a Critical Autism Studies (CAS) framework, and transformative explanatory sequential mixed methods design, to seek autistic justice. The four-staged methodology (surveys – interviews – analysis – participatory dissemination with co-authorship of policy and practice directions with autistic participants) responds to Damian Milton’s (2014) call for “interactional expertise” between non-autistic researchers and autistic people to improve autism practice and policies through a strength-based understanding of autism. Eight participants with either positive or negative experiences with ABA (4 autistic people, 2 parents, and 2 ABA providers) were purposively sampled for interviews from a total of 100 survey respondents.

Using a mix of quantitative analyses followed by open text box responses and eight “Stories Behind the Statistics”, the research aimed to explore the questions: What are the impacts of ABA services on autistic people’s well-being and quality of life (QoL)? Are ABA services meeting the needs of autistic people? As the research progressed, two new research questions emerged: In what ways do power and stigma influence experiences with ABA interventions? How can diverse autistic expertise transform autism intervention practices and policy? Findings did not reveal compelling evidence that ABA is an approach that improves the quality of life or

wellbeing of autistic people. While some respondents shared positive experiences of ABA, findings revealed evidence of harm, which raises ethical concerns about the services received by autistic people in capitalist colonial societies. The dissertation concludes with recommendations co-authored with four autistic recipients of ABA.

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Table of Contents

Abstract.....	ii
Acknowledgements	iv
Table of Contents	v
List of Tables.....	ix
List of Figures.....	x
Chapter 1: Preface	1
<i>Objective.....</i>	<i>1</i>
<i>Research Questions</i>	<i>2</i>
<i>Format of Thesis.....</i>	<i>3</i>
Chapter 2: Power, Stigma, and Emancipation: A Justice-Oriented Critical Autism Studies (CAS) Literature Review and Theoretical Framework.....	4
<i>Power</i>	<i>9</i>
Humanising/Dehumanising Autism.....	10
Discipline and Control: Operant Conditioning and the Methods of Rewards/Punishments ..	16
The Neo-asylum Era and Institutions Without Walls	29
Intersectional Experiences	33
The Autism Industrial Complex (AIC).....	39
<i>Stigma.....</i>	<i>45</i>
<i>Emancipation</i>	<i>52</i>
Chapter 3: A Transformative Mixed Methods Design.....	55
<i>Rationale</i>	<i>56</i>
<i>Critiques of Quantitative Methods and Mixed Methods</i>	<i>57</i>
<i>Ontology.....</i>	<i>57</i>
<i>Study Design: Overview</i>	<i>59</i>
Positionality in Research	61
Ethics Approval	62
Timeline Disruptions	62
<i>Stage 1: Surveys</i>	<i>63</i>
Sampling and Recruitment	65

Trustworthiness.....	65
<i>Stage 2: Interviews</i>	<i>66</i>
Purposive Sampling.....	67
Interview process	69
Anonymity	71
Transcription.....	71
<i>Stage 3: Analysis</i>	<i>72</i>
<i>Stage 4: Participatory Collaborations for Dissemination</i>	<i>75</i>
Chapter 4: Respondent Views: A Synopsis of Identity and Standpoints	78
<i>Views of Autism: Autism as a Disorder or Neurotype, Spectrum, and/or Culture</i>	<i>78</i>
<i>Views of Functioning Labels</i>	<i>79</i>
<i>Views of ABA Interventions as a Support Model for Autistic Young People</i>	<i>81</i>
Autistic and Parent Perspectives.....	81
Providers.....	82
<i>Views of Whether ABA Has Improved</i>	<i>84</i>
Conclusion.....	85
Chapter 5: Autistic Allies of Autistic Recipients of ABA: Speaking Up and Speaking Out	
Against Harms.....	88
Overview.....	88
<i>Do Autistic Allies' Perspectives Matter?</i>	<i>92</i>
<i>Concern #1: ABA is Based on a Faulty Premise.....</i>	<i>94</i>
<i>Concern #2: ABA is Conversion Therapy</i>	<i>104</i>
<i>Concern #3: ABA is Compliance Training.....</i>	<i>108</i>
<i>Concern #4: ABA is Not Actually Evidence-based.....</i>	<i>114</i>
<i>Concern #5: ABA is Harmful and Abusive.....</i>	<i>119</i>
Conclusion.....	125
Chapter 6: Perspectives of Autistic Recipients of ABA	127
Overview.....	127
<i>Differences Between Views of Autism as a Disorder or Neurotype and ABA Effectiveness: A</i>	
<i>Cross Analysis</i>	<i>134</i>
Stories Behind the Statistics 1: Russel's Experience:.....	135

<i>Self-identified Race and Perceptions of ABA Effectiveness for Achieving Personal Goals: A Cross Analysis at the Intersections.....</i>	<i>141</i>
Stories Behind the Statistics 2: Clara’s Experience:.....	143
<i>Cross Analysis at the Intersections: Self-identified Queer Identity and Perceptions of ABA Effectiveness for Achieving Personal Goals</i>	<i>150</i>
<i>Wellbeing Outcomes</i>	<i>153</i>
Risk-Benefit Analysis: What is The Emotional Impact of ABA?	153
Current Overall Emotional Wellbeing	157
Feelings of Suicide	158
Stories Behind the Statistics 3: Kendra’s Experience:.....	161
<i>Quality of Life (QoL) Outcomes.....</i>	<i>168</i>
Education outcomes.....	170
Stories Behind the Statistics 4: Damon’s Experience:.....	171
Employment Outcomes	176
Feelings of Preparedness	177
<i>Experiences of Consent, Reward and Punishment Procedures.....</i>	<i>180</i>
Consent	181
Frequency of Rewards and Punishment Procedures Received.....	185
Types of Rewards and Consequences.....	186
Perceptions of Effectiveness.....	188
Perspectives on Rewards and Punishments: Open Text Box Responses.....	189
Years and Types of Punishments Received	192
<i>Conclusion.....</i>	<i>196</i>
Chapter 7: Parent and Provider Perspectives	201
Overview.....	201
Parent Perspectives	202
Social Validity and Wellbeing.....	203
Reasons for Enrolling in ABA.....	213
Stories Behind the Statistics 5: Alex.....	216
Provider Perspectives.....	222
Quality of Life (QoL)	223

Stories Behind the Statistics 7: Cassidy	230
Wellbeing	237
Questioning Effectiveness	241
Stories Behind the Statistics 7: Dina	242
<i>Parent and Provider Experiences of Consent, Reward, and Punishment Procedures</i>	254
Consent	254
Rewards and Punishment Procedures	259
Stories Behind the Statistics 8: Brynn	269
Conclusion	273
Chapter 8: Final Thoughts and Future Directions	275
<i>Co-authored Recommendations for Policy and Practice</i>	276
Damon: Involve Autistic People in Policy and Practice Decisions	277
Clara: Practice with Love and Care	281
Russel: Create Safety and Acceptance in the Environment	282
Kendra: Understand What Underlies Behaviours	284
Everyone: Foster Feelings of Belonging	287
<i>Future directions</i>	290
<i>Limitations</i>	293
References	295
Appendix A: Ven Diagram	348
Appendix B: Inclusion and Exclusion Criteria for Interviews	349
Appendix C: Example Interview Questions	350

List of Tables

Table 5.1. Demographic Characteristics of Autistic Allies Who Did Not Receive ABA (n=46)...	88
Table 5.2. Autistic Allies Who Have Not Received ABA: Feelings of ABA Effectiveness	92
Table 5.3. Open Text Box Responses of “No” to the Question, “Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?”	93
Table 6.1. Demographic Characteristics of Autistic ABA Recipient Respondents (n=22).....	127
Table 6.2. Perspectives of ABA Effectiveness for Achieving Personally Valid Goals	131
Table 6.3. Example Perspectives Shared by Autistic Recipients of ABA.....	132
Table 6.4. Perceptions of Autism (as a disorder or neurotype) and ABA Effectiveness.....	134
Table 6.5. “Do you feel the ABA or IBI you received has ever made you feel sad, angry, anxious, or depressed?”: Open Text Box Responses	156
Table 6.6. Education, Employment and Feelings of Preparedness	178
Table 6.7. Consent: Open Text Box Responses	182
Table 6.8. Perspectives on Rewards and Punishments	189
Table 6.9. Type of Punishment Procedure by Range of Years Received and Example Comments	195
Table 7.1. Demographic Characteristics of Parent Respondents (n=12)	202
Table 7.2. Parent Perspectives on ABA Effectiveness and Wellbeing Outcomes.....	205
Table 7.3. Reasons For Enrolling Child in ABA or IBI	214
Table 7.4. Demographic Characteristics of Provider Respondents (n=20).....	222
Table 7.5. Provider Perspectives and Example Comments.....	225
Table 7.6. Provider Perspectives Regarding Wellbeing	238
Table 7.7. Have you ever questioned the effectiveness or appropriateness of the ABA interventions you used?: Open Text Box Responses	242
Table 7.8. Can your child/client/student complete or maintain the skills without the continued use of the reinforcement?	261
Table 7.9. Parent and Provider Perspectives on Punishment Procedures	265

List of Figures

Figure 3.1. Stages of the Sequential (and brief concurrent) Mixed Methods Design.....	60
Figure 4.1. Proportions of Respondents' Views of Autism as a Disorder.....	79
Figure 4.2. Respondents Who Use Functioning Labels to Describe Autistic Experiences	81
Figure 4.3. Perspectives of ABA Effectiveness: Autistic and Parent Views Compared	82
Figure 4.4. Provider Perceptions of ABA Effectiveness in Schools and Improving Life Skills....	83
Figure 4.5. Respondent Views of Whether ABA Has Improved Over Time	85
Figure 5.1. Number of Autistic Respondents Who Received and Did Not Receive ABA Interventions	90
Figure 5.2. Autistic Ally Respondents Who Agree or Disagree with the use of Functioning Labels	97
Figure 6.1. Do you feel ABA and/or IBI is an effective treatment or support model? Autistic Allies and ABA Recipients Compared	130
Figure 6.2. Perspectives of ABA Effectiveness by Self-Identified Race	142
Figure 6.3. Perspectives of ABA Effectiveness Shared by Self-Identified Queer Autistic Respondents.....	152
Figure 6.4. Cross Analysis: Perceptions of ABA Effectiveness and Likert Scale Feelings of Sadness, Anger, Anxiety, or Depression	155
Figure 6.5. Allied Autistics' and ABA Recipients' Feelings of Emotional Wellness.....	158
Figure 6.6. Autistic Allies and ABA Recipients' Feelings of Suicide.....	159
Figure 6.7. Highest Level of Education: What is the highest level of education you have completed to date?	170
Figure 6.8. Employment Outcomes: Have you ever been employed?.....	176
Figure 6.9. Factors That Have Contributed to Independence and Success.....	177
Figure 6.10. ABA Recipients who Consented to Interventions Received	182
Figure 6.11. Frequency of Rewards and Punishment Procedures Received.....	186
Figure 6.12. Types of Rewards and Punishments: Response Frequency	187
Figure 6.13. Did Respondents Feel the Positive Reinforcements (rewards) or Consequences (punishment procedures) were Effective?	188

Figure 7.1. Parent Perceptions of Social Validity and Impact on Wellbeing	204
Figure 7.2. Comparative Perceptions of ABA Effectiveness Between Autistic and Parent Respondent Groups.....	213
Figure 7.3. Provider Respondents' Perceptions of ABA for QoL.....	224
Figure 7.4. Provider Respondents' Perceptions of ABA for Wellbeing.....	238
Figure 7.5. Have you ever questioned the effectiveness or appropriateness of the ABA Interventions you used?	241
Figure 7.6. Parent and Provider Responses Regarding Consent.....	255
Figure 7.7. Parent and Provider Perceptions of Reward Effectiveness for Maintaining Skills ...	261
Figure 7.8. Frequency of Punishment Procedures Used: Parent and Provider Responses	263
Figure 7.9. Were punishment procedures effective? Parent Perspectives	264
Figure 7.10. Could students/clients effectively maintain a decrease in problem behaviours without the continued use of punishment procedures? Provider Perspectives	264

Chapter 1: Preface

Objective

The following participatory mixed methods dissertation project examines experiences of Applied Behavior Analysis (ABA) from the perspective of autistic people, parents, and ABA providers in Canada. The key problem explored throughout the dissertation relates to the growing evidence of harm experienced by ABA recipients worldwide (Ask an Autistic, 2019b; Neuroclastic, 2021) along with the conflicting data and ethics of ABA as an effective form of autism treatment and support (Bottema-Beutel et al., 2021; Bottema-Beutel & Crowley, 2021; Dawson & Fletcher-Watson, 2021; King, 2020; Sandbank et al., 2020; Wilkenfeld & McCarthy, 2020). My inquiry builds on a key concern regarding the wellbeing of ABA recipients, which was raised by an autistic participant during my master's thesis study who asked: "Have we even followed these kids well into adulthood? How are they doing?" (Marshall et al., 2018). Using methods of survey analysis, interviews, and participatory dissemination of recommendations with autistic recipients of ABA, the methodology adopts a justice-oriented Critical Autism Studies (CAS) framework to inform practice and policy for the betterment of autistic people's wellbeing and quality of life.

The Ontario Scientific Expert Task Force for the Treatment of Autism Spectrum Disorder (OSETT-ASD) (2017) defined ABA as a "professional field" that incorporates "the majority of evidence-based interventions" for autism spectrum disorders (p. 113). In Ontario, comprehensive ABA is known as Intensive Behavioural Interventions (IBI) delivered 20 to 40 hours per week by private service providers (Perry et al., 2016). Focused ABA interventions "address one or few targets" (i.e., social interaction, toileting) "and typically involve fewer hours of service" (p. 5). Focused ABA methods are usually administered in school and residential care settings in Canada (OSETT-ASD, 2017). Researchers, ABA practitioners, and ABA programs often refer to Ivar

Lovaas (1987) as the forefather of current ABA practices (particularly in the IBI form) adapted from the behavioural theory applications of B.F Skinner (1957, 1974). While Lovaas's (1987) adaptation of behaviourism included the use of punishment to shape behaviours, Skinner (1974) believed solely in the use of positive reinforcement (i.e., reward-based learning) as an effective means of shaping behaviour through methods of operant conditioning.

Autistic people across the globe have shared their lived experiences of the ways ABA has caused them harm, and often trauma, due to the rigidly applied reward and punishment strategies that were used to make them appear less autistic and more neurotypical (see Ask an Autistic, 2019b; Neuroclastic, 2021). The field of ABA has been listening and responding to these stories by acknowledging the concerns raised (e.g., Allen et al., 2024; Leaf et al., 2021; Mathur et al., 2024; Pritchett et al., 2021) and, in some cases, reforming ABA methods to be more neurodiversity-centred and/or trauma-informed (e.g., Hanley, 2021; Mindful Behavior, 2024; Rajaraman et al., 2022). In the province of Ontario, it does not appear as though the ABA industry has, or will, suffer great losses as a result of recent ABA opposition. In fact, the field is in the process of becoming a regulated profession under the new *Psychology and Applied Behaviour Analysis Act, 2021* (College of Psychologists of Ontario, 2023) with a new PhD program launched at Brock University (Brock University Academic Programs, 2024). These discussions are explored in more detail alongside the findings and analyses throughout this dissertation.

Research Questions

The research began with the following research questions: What are the impacts of ABA services on autistic people's well-being and quality of life (QoL) in Ontario? Are ABA services meeting the needs of autistic people? Throughout the survey design stage, new research

questions emerged as I explored themes related to the ways power and stigma influenced experiences with ABA interventions. While keeping autistic wellbeing and quality of life in mind, two new research questions guided the analysis of this study: In what ways do power and stigma influence experiences with ABA interventions? How can diverse autistic expertise transform autism intervention practices and policy?

For the purposes of this study, indicators of wellbeing and QoL were determined through a lens of disability and autistic justice (see Chapter 2) that values the importance of self-determined goals by neurodivergent and autistic individuals regarding the treatment or education interventions they receive. Through this lens, wellbeing and QoL are determined by each individual as opposed to by caregivers or ABA providers (e.g., obtaining employment, establishing long-term relationships, accessing community and educational settings, etc.).

Format of Thesis

Because the histories of autistic justice and ABA are so inextricably linked, it was difficult to separate the literature review from the theoretical framework chosen for this project. For this reason, Chapter two includes both the theoretical components and review of the literature pertinent to the analyses and discussions that follow throughout this manuscript. Chapter 3 outlines the transformative mixed methods design I employed. Chapter 4 presents an overview of all 100 survey respondent views and perspectives related to autism and ABA. Chapter 5 extrapolates the themes included in the justice-oriented Critical Autism Studies (CAS) framework introduced in Chapter 2 from the perspective of autistic survey respondents who, despite not having received ABA interventions themselves, shared deeply thoughtful insights into the impacts of ABA on autistic wellbeing and QoL. Chapters 6 and 7 explore the findings and analyses from autistic recipients of ABA, parents and ABA providers. Chapter eight concludes

the thesis with final thoughts, future research directions, and education and practice recommendations co-authored with four autistic participants.

Chapter 2: Power, Stigma, and Emancipation: A Justice-Oriented Critical Autism Studies (CAS) Literature Review and Theoretical Framework

This study is grounded in the grassroots activism, advocacy, and theories that have arisen from the field of Critical Autism Studies (CAS). In many respects, CAS is rooted in Critical Disability Theory (CDT), which interrogates medicalized disability frameworks that a) view disabilities as deficits and b) “privilege normalcy over the abnormal” (Pothier & Devlin, 2006, p. 2). Much like CDT, the growth of CAS would not be possible without political activism driven by disabled and/or autistic people who expertly interrogate power-driven and pathology-laden definitions of autism as a ‘disorder’ (Orsini & Davidson, 2013; Ryan & Milton, 2023; Walker, 2016, 2021). The roots of this activism have created what is now known widely as the neurodiversity movement (see Botha et al., 2024; Kapp, 2020), which draws on theories of social constructionism (e.g., Goffman, 1963) to differentiate between constructions of neurotypical and neurodivergent brains (e.g., autistic, ADHD, dyslexia, etc.). The goal of the neurodiversity movement is to push back against the socially constructed stigmatization of neurodivergence resulting from comparisons to idealized neurotypical norms—what CAS scholars have referred to as “neuronormativity” (Chapman, 2023; Walker, 2021).

Over the histories of their activism, both CDT and CAS have had to contend with two distinct and polarizing models of disability—the social model and the biomedical model (Orsini & Davidson, 2013; Runswick-Cole, 2016; Ryan & Milton, 2023). The social model of disability has gained renowned respect within disability studies for its emphasis on dismantling the environmental and attitudinal barriers that exclude disabled people, rather than burdening disabled people with the responsibility of adapting to ableist societies through individualized

cures and treatments (Orsini & Davidson, 2013; Pothier & Devlin, 2006). While useful as a framework for equitable inclusion, the social model of disability has also been critiqued for its emphasis on disability as entirely socially constructed, which can devalue disabled people's own understandings of their disablement (e.g., bodily impairments) from a natural biological perspective (Oliver, 2013; Thomas, 2004).

Both CDT and CAS have evolved to explore the space between and beyond dichotomies of social and biomedical models of disability (Hodge et al., 2023; Orsini & Davidson, 2013; Thomas, 2004; Titchkosky, 2011). CDT includes thinking about disability within a social relational model (Thomas, 2004) whereby equitable inclusion and belonging are understood to be restricted by both individual impairments and by a lack of awareness about child and disability rights (Hodge et al., 2023). Pertinent to the discussion of autistic experiences is the biomedical definition of autism as a 'disorder' located in the Diagnostic and Statistical Manual of Mental Disorders [DSM-5] (American Psychiatric Association, 2013). This deficit-based construction of autism has been produced through the hegemony of standardized child development tools—what Davies et al. (2022) refer to as “an emphasis on developmentalism” through “discourses and practices of normalcy” (p. 371). Tools used to measure the ‘success’ of ABA interventions have been developed and administered within the hegemony of developmentalism (see forthcoming discussions in Chapter 5), leaving little room to explore possibilities of what healthy neurodivergent development might look like for autistic children. To date, there exist very few resources for educators and practitioners to rely on when assessing autistic, as opposed to non-autistic, development. Autistic people are filling this gap through the collecting and sharing of their lived experiences (e.g., Autistic Collaboration, 2019) or by creating their own strength-based assessment tools with their combined lived experience and

clinical diagnostic expertise (Engelbrecht, 2024). One way toward bridging the socially constructed view of autism as a deficit-based disorder in need of normalization, and the biological reality of autism as a valid human experience in its own right, is through an understanding of the ways stigma operates in systems of power (discussed later in this chapter). Additionally, an understanding of the ways power and stigma operate together, as discussed within CAS scholarship, can create pathways toward understanding the ways binary constructions of autism as either a disorder in need of treatment, or a difference in need of acceptance, sometimes polarize the lived experiences of autism and autism care (Orsini & Davidson, 2013; Ryan & Milton, 2023).

More recently, disability studies has been exposed for formulating narrow definitions of disability through a lens of white scholarship that has missed critical issues of oppression experienced by queer and racialized disabled people (Annamma et al., 2013; Bell, 2006; Berne, 2015; L. X. Z. Brown, 2016; Sins Invalid, 2019). These critiques share an important element in common in that they both understand the detrimental impacts of excluding particular populations of disabled voices who are often the most marginalised by stigma and oppression due to their layered lived experiences of race, sexuality, gender nonconformity, disability, and neurodivergence (L. X. Z. Brown, 2016; Sins Invalid, 2019).

Some disability activists and scholars have responded to these issues by adopting frameworks that extend disability theory to include issues of disability justice, which emphasize the need for authentic engagement with all disabled and neurodivergent people particularly when they face multiple intersectional barriers to inclusion and access to information (Ashburn & Edwards, 2023; L. X. Z. Brown, 2016; Sins Invalid, 2019). The disability justice framework, developed by Patty Berne and their team of queer, gender non-conforming, and racialized

scholars, artists, and activists known collectively as Sins Invalid (2019) , highlights the ways human rights legislation (e.g., United Nations, 1990, 2006) developed within colonial settler societies fail to protect those most impacted by racism, ableism, and other forms of discrimination because these societies have yet to “truly understand ableism by tracing its connections to heteropatriarchy, white supremacy, colonialism, and capitalism.” (Sins Invalid, 2019, p. 18). Without this deeper understanding of the ways ableism is enacted within Western colonial settler societies, human rights discourses and protections cannot break free of the entrenched “neoliberal principles of individual freedom”, which are principles honoured only in relationship to one’s ability to contribute to the aims of capitalist production (Roscigno, 2019, p. 406). As Jules Edwards (2021b) explained, disability rights cannot be realised within our existing colonial-capitalist worldview because disabled people who cannot contribute to capitalism will always be neglected. In contrast, a disability justice framework embraces all disabled people as valuable citizens who deserve access to basic rights (e.g., housing, water, necessities of life) regardless of their ability to contribute to the aims of capitalism (Sins Invalid, 2019). Edwards described this latter framework as a natural component of the Indigenous “relational worldview” that has been devalued by centuries of colonial power (Ashburn & Edwards, 2023, p. 42).

While this study is limited its capacity to fully adopt a disability justice framework due to my limitations as a student researcher to enact deep systemic change, not to mention my own positionality as a white non-autistic person (see “Positionality in Research” section on p. 66), there are important aspects of the disability justice movement that guide this research. Namely, these include recognizing the ways that ABA is justified as an effective approach within the colonial-capitalist worldview vis-à-vis aims of autistic conformity to ableist societies and the promise of freedom through independence (i.e., a dependency free life) whilst ignoring

humankind's need for collective care and interdependence (Berne, 2015). With this in mind, the aim of the justice-oriented CAS framework is to explore the experiences of autistic people, and those who care for them, from a variety of standpoints (i.e., perspectives within the social model, biomedical model, and the spaces in-between), which has been identified as an integral aim of CAS scholarship (Orsini & Davidson, 2013). To provide a brief history, CAS grew from autistic activism in the early 1990s (Ryan & Milton, 2023) and was first articulated as a field of scholarship in 2012 through the publication of *Autonomy, the Critical Journal of Interdisciplinary Autism Studies* (Arnold, 2012). A year later, the field of CAS was definitively coined and defined by Joyce Davidson and Michael Orsini (2013) in the introduction of their edited volume, *Worlds of Autism, Across the Spectrum of Neurological Difference*, which identified three components complementing the important tenets of CDT:

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

In 2018, the definition of CAS was further developed by Richard Woods, Damian Milton, Larry Arnold, and Steve Graby (2018) who came together to create what they envisioned as “a more inclusive interpretation” of CAS after noticing the rise in interest taken up by non-autistic

(allistic) scholars (p. 974). The definition proposed by Woods and colleagues places emphasis on the need for autistic-led scholarship and expertise, which has since been articulated as a fourth strand of CAS scholarship (Ryan & Milton, 2023).

In careful consideration of this fourth component, I return to Davidson and Orsini's (2013) description of CAS as a collection of works created by "autistics and the individuals who love and care for them" who bring "'critical' perspectives on autism into the social and political worlds that make a difference in the lives of people on the spectrum" (p. 21). As an allistic (non-autistic) scholar in CAS discourse, I have taken care to seek partnership with autistic participants in my research methods¹. Because many autistic people face barriers to equitable education, I have further taken care to include autistic voices outside of academic arenas in my own definition of CAS scholarship, including social media posts, blogs, and books by activist authors.

In essence, this framework adopts the theory of neurodiversity that sees all ways of thinking and being as necessary for healthy societies, economies, and communities to thrive (Chapman, 2023). I have aimed to engage with CAS scholarship, activism, and allied educational perspectives as a collective analytic framework through which I can thoroughly investigate the impacts of ABA on autistic lives. To do so, I adhere closely to all four strands of CAS by dividing my framework into three main areas: 1) power; 2) stigma; and 3) autistic emancipation, all with emphasis on autistic expertise (Orsini & Davidson, 2013; Ryan & Milton, 2023).

Power

CAS scholars have discussed the analytics of power, as they pertain to the lives of autistic people, in numerous important and complex ways. The following section draws on several key

¹ See the following chapter for the transformative participatory methods I employed

constructs in particular: dehumanising/humanising autism; discipline and control; the neo-asylum era; intersectional experiences; and the Autism Industrial Complex (AIC).

Humanising/Dehumanising Autism

No discussion of humanisation, as it relates to autism, can begin without mention of the dehumanization of autistic people that has occurred throughout the decades. As Paulo Freire (1970) famously wrote: “Concern for humanization leads at once to the recognition of dehumanization, not only as an ontological possibility but as an historical reality” (p. 43). When facts are laid bare, it is impossible to deny the historical reality of autistic dehumanization, which is a reality that continues to the present day. Inextricably, this history is linked to the history of behaviourism as a treatment for autism. Tracing the history of autistic dehumanisation is necessary when examining the root of the problems surrounding ABA because the very premise of ABA as a therapy for autism was founded on the premise that autistic children were not human. In the widely circulated Psychology Today interview, Ivar Lovaas (1974) stated:

You have a person in the physical sense—they have hair, a nose and a mouth—but they are not people in the psychological sense. One way to look at the job of helping autistic kids is to see it as a matter of constructing a person. You have the raw materials, but you have to build the person. (para. 11)

Lovaas’s dehumanizing assumptions about autistic children did not emerge suddenly. The history of pathologizing autistic children reaches back (and beyond) initial medical formulations of autism as articulated by Leo Kanner (1943) and Hans Asperger (1991) who described autism to be a disturbing and psychopathic disorder. Accounts as far back as the 16th century have described children with autistic traits as possessed, disturbed, psychotic, severely impaired, and in need of radical treatment (or death) to free them (and their families) from what was believed

to be a hopeless condition (Wing, 1997). From the time it was first articulated as a medical condition in 1911 by the Swiss doctor Eugen Bleuler, pathologized and stigmatized views of autism have contributed to the narrative of autism as some “thing” that has robbed children of their humanity (McGuire, 2016). McGuire (2016) argued that this pervasive view of autism as a “something” as opposed to seeing the autistic child as a “someone” has exposed autistic young people to the pervasive normalisation of harmful treatments and violence. Citing Jim Sinclair’s (1993) poem, *Don’t Mourn for Us*, McGuire reflected on the efforts of autistic activists and scholars who have had to undertake the work of challenging assumptions that define autism as separate from the human experience. Credit for current understandings of autistic human experiences belongs to the seminal work of critical autism activists, like Sinclair (1993), who wrote: “It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with” (para. 5). Globally, autistic people continue to raise awareness about autistic experiences as an identity and “a way of being” as opposed to a tragic disorder that can be treated through intervention (Autistic Collaboration, 2019, para. 5). Applying the concepts of autistic humanisation and dehumanisation enables a framework to examine the ways ABA measures (or does not measure) up to calls for ethical autistic care and education.

Behaviourism and Dehumanisation. Lovaas’s (1987) approach to applied behaviour analysis (ABA) as an intervention for autism evolved from John B. Watson’s (1913, 1994) experiential applications of behaviourist theory—a stimulus-response analysis of behaviour change that focused on observable results without regard for emotional human development. Before Lovaas developed ABA as an intervention for autism, behaviourism gained legitimization through studies such as the foundational ABA experiment conducted by Wolf, Risely & Mees

(1963) that treated a pre-school aged boy in a hospital setting for “problem behaviours” including refusal to wear eye-glasses, inability to eat or talk “normally”, and self-injury (p. 305). The researchers used the operant conditioning methods of “mild punishment” procedures (e.g., verbal reprimands, food deprivation, and being left in the bedroom without attention) and “reinforcement procedures” (e.g., rewards such as food and attention) to decrease and increase specifically targeted behaviours (see Chapter 5 for further discussion of this study). At no time did the researchers consider why the boy refused to wear glasses or have tantrums. Instead, the premise of intervention was to categorize and objectify behaviours as either problematic or desirable – behaviours became ‘things’ that could be decreased or increased outside the realm of emotional human experiences.

Over the next 20 years, similar studies produced efficient results of behaviour change that leveraged momentum for the field of ABA. As a treatment for autism specifically, ABA gained the most popularity following Lovaas’s (1987) randomized control study measuring the observable behaviour change of autistic children. Lovaas’s goal was to condition autistic children to be “indistinguishable” from their “normal” peers using intensive methods of positive reinforcements and punishment procedures including food, hugs, praise, skin shocks, verbal reprimands, and physical slaps on the thigh (LIFE Magazine, 1965; Lovaas, 1981). Lovaas (1981) rationalised that the operant conditioning procedures of rewards and punishments were necessary to eliminate what he felt were abnormal or problematic behaviours (e.g., hand flapping, self-injury). Similar to the methods of Wolf, Risely and Mees (1963), Lovaas focused solely on measurable behaviour without consideration of autistic children’s inner thoughts or emotions. Simply by changing the autistic child’s outward behaviour in the most efficient way possible, Lovaas and his colleagues felt confident in their theory that they were “building a

person where little had existed before” (Lovaas & Smith, 1989, p. 24). Today in Ontario, Lovaas’s (1987) methods continue to be cited in recent ABA literature as evidence that ABA is effective (OSETT-ASD, 2017).

Over time, the field of ABA moved on from John B. Watson’s reductionist stimulus-response/cause-effect theory of behaviourism to the more radical behaviourism of B.F. Skinner (1957, 1974), which acknowledged mental unobservable “private events” (i.e., thoughts and emotions) as significant internal behaviours. Skinner’s (1957, 1974) approach to behaviourism has been considered both progressive and humanistic by behaviourists for its focus on emotions, thoughts, positive reinforcements (as opposed to punishment procedures), and helping people to achieve happiness (Newman, 2020). However, similar to Watson (1994), Skinner’s (1957, 1974) approaches were reductionist in that they concluded human behaviours, including inner thoughts and emotions, were determined by stimuli in the environment and not as a result of innate human characteristics or free will. Skinner’s advancements in behavioural theory, as they relate to autism education and therapy, continue to be scrutinized by scholars and advocates who argue that all forms of behavioural interventions are counterproductive to autistic children’s development of self esteem, autonomy, and inclusion in society because the interventions value one standardization of human behaviour without attention to the unique characteristics of autistic human development (Chown, 2017; Collis, 2019; Lynch, 2019; Memmott, 2023; Swan, 2017; Vivanti, 2022; Wilkenfeld & McCarthy, 2020). Many scholars have also challenged Skinner’s work over the decades, including Noam Chomsky (1967) who critiqued Skinner’s (1957) theory that behaviour is shaped by external reinforcements (rewards that are received after a behaviour occurs in order to increase the probability that the behaviour will occur again) rather than by natural intrinsic learning processes. Because Skinner’s deterministic theory of behaviour sees all

behaviour as shaped by external reinforcements in the environment, ABA therapists often rely on reward systems to change the behaviour of autistic children without first considering autistic children's agency and autonomy to resist normatively defined developmental trajectories so that they can develop into their genuine autistic selves (Wilkenfeld & McCarthy, 2020).

Neo-behaviourism and Humanisation. Historically, the theories underlying humanistic and behaviourist psychology have been at odds with one another (Decarvalho, 1990; Hayes, 1995; Newman, 2020). Decarvalho (1990) explained that humanistic learning theories arose in the years following World War II. An important foundation of humanistic psychology, called the “Third Force”, arose out of frustration with the behaviourist and psychoanalytic dominance of psychology at the time. The Third Force school of psychology deeply critiqued Watson's (1913) stimulus/response theory and “argued that human motivation was purposive, choice-oriented, intentional, and self-motivated” (Decarvalho, 1990, p. 33). Several historical critiques of behaviourism remain strong today, such as its data-driven emphasis on quantifiable results that objectify human experience and ignore underlying social and emotional causes of human behaviour (Delahooke, 2019; Kohn, 2018; Laurent & Fede, 2020a; Shanker, 2017; Tolley, 2021).

Humanistic psychology has played a role in influencing “neo-behaviourists” to practice outside of Watson's (1913) extreme reductionist views of stimulus/response theory and to acknowledge the more complex influences of cognition and social environments on human behaviour (Hayes, 1995). As a result, the field of ABA has undergone a continued process of transformation since Lovaas' (1981, 1987) dehumanizing applications of behaviourism. Recently, a trend toward a trauma-informed, autonomy-focused, and person-centered ABA has emerged (Hanley, 2021; Kolu, 2021a; Rajaraman et al., 2021; Stack, 2021). Several current forms of ABA interventions promise to enhance autistic children's choice and consent by:

allowing them to leave the therapeutic environment whenever they choose (Rajaraman et al., 2021); listening to their needs and desires (Hanley, 2021); and considering the effects of trauma on autistic people's ability to meet behavioural goals (Kolu, 2021a; Stack, 2021). The common link between these newer and more traditional forms of ABA is the unwavering adherence to Skinner's (1974) theories of positive reinforcements to produce evidence of behaviour change. Treatment rooms and classrooms using person-centered or enhanced choice models of ABA (Rajaraman et al., 2021) emphasize the need to keep autistic children "happy, relaxed, and engaged" by creating rewarding learning environments (Hanley, 2021, para. 3).

Autistic critics closely monitor newer forms of ABA by signalling the problematic "rebranding" of a more "compassionate" ABA that continues to inform its own science without inclusion of autistic people's lived experiences (Kupferstein, 2023). Autistic perspectives highlight the ways autistic children's development is negatively impacted by the power dynamics involved in ABA sessions when a child's favourite things are used as a tool to motivate autistic children to comply with adult expectations (Kayleen, 2019; Lynch, 2019; Real Social Skills, 2015). As one autistic blogger explained:

ABA programs give the therapist massive power over the person. That power in itself can cause people to look happy, through a more subtle reinforcement mechanism than takes place on a behavior plan:

- If you have power over someone in the way that behavior therapists do, they're going to be highly motivated to please you
- If they figure out that you want to believe that they are happy, they are very likely to act like they are

- If you treat them better when they display the affect you want or praise you, they're likely to act happy.
- It doesn't mean they're actually happy
- Or that what you're doing is good for them (Real Social Skills, 2015, para. 3).

Outside the field of ABA, humanistic approaches to education and therapy that are neuro-affirming have gained considerable momentum and endorsement from autistic people (Brown, 2018; Delahooke, 2019; Foundations for Divergent Minds, 2024; Laurent & Fede, 2020a; Prizant et al., 2003; Therapist Neurodiversity Collective, 2020b; Tolley, 2021). These approaches expand upon humanistic learning theory to consider the whole of autistic personhood (e.g., cognition, emotion, environment, neurology) without reliance on reward-based learning. With these alternative schools of thought established, it is important to consider whether newer forms of ABA can find their place amongst humanistic approaches to autistic care and education. Is a trauma-informed ABA possible (or even necessary) given its roots in medical pathology, autistic dehumanisation, and lack of understanding of autistic experiences? The possibility of merging behaviourist and humanistic psychologies—two fundamentally opposing schools of thought—remains up for discussion, particularly when the vantage points of autistic recipients of ABA practices have yet to be prioritized.

Discipline and Control: Operant Conditioning and the Methods of Rewards/Punishments

Rewards. For over 20 years there have been documented trends in ABA literature that point to a decrease in the use of punishment procedures (Hanley et al., 2005; Pelios et al., 1999). Today's ABA practitioners are trained to focus instead on the use of “differential reinforcement strategies”, which are defined as a process of “withholding reinforcers in the presence of challenging behaviour, a procedure also known as extinction; while providing access to

reinforcement when some predetermined criteria has been met” (Ontario Scientific Expert Task Force for the Treatment of Challenging Behaviour [OSETT-CB], 2019, p. 40). The field of ABA considers this shift toward positive reinforcements to be a progressive improvement over the more disciplinary control measures of punishment used by ABA practitioners in the past (OSETT-ASD, 2017). However, within the context of dehumanisation and power discussed thus far, ABA has been criticized for its manipulating of reward-based learning to achieve behavioural compliance (Kohn, 2020), which is particularly risky when conducted without regard to autistic neurodevelopmental differences (Collis, 2019; Memmott, 2023; Vivanti, 2022). When used in this way, reward-based learning is similar to punishment in that it becomes a form of power, discipline, and control over children that impedes natural development of self-determination (Deci, 1971; Kohn, 2018; Lepper & Greene, 2015; Ryan & Deci, 2000). Autistic children’s bodies and minds think and move in ways that compliance-based education systems view as problematic and difficult to cope with (Wharmby, 2022). Erevelles (2000) explained that, “In an attempt to control these ‘disruptive excesses’ of unruly bodies, schools have developed elaborate practices that support the rigid organization of classroom space and time, the overriding emphasis on discipline, and the careful monitoring of the curriculum” (p. 33). With regard to autistic students, rewards are an integral part of the education system’s “elaborate practices” and that can become a control tactic to tame autistic students’ “unruly bodies” (e.g., self-stimulatory behaviours that are a common trait of autistic experiences).

Skinner’s (1948, 1974) theories of radical deterministic behaviourism based on the behavioural reactions of pigeons and rats in laboratory experiments (which would not be approved by ethical standards today), created the foundation for the widespread use of reinforcement schedules in treatment programs for autistic young people (Cooper, Heron, &

Heward, 2020; Geneva Centre for Autism, 2019). As the theory goes, human behaviour is shaped, conditioned and strengthened by the environmental consequences (i.e., reinforcers) that follow any given behaviour (Skinner, 1974). Within an ABA treatment or education program, practitioners and educators use positive reinforcement schedules to teach autistic children skills deemed necessary for their development, including (but not limited to): sitting at a desk, dressing independently, toileting, completing academic-related tasks, verbal communication, etc. (see recent studies: Mantzoros et al., 2023; Milne et al., 2017; Owen & Rodriguez, 2023; Wergeland et al., 2022; Wójcik et al., 2023). The problem with externally reinforcing these skills relates to the gaps in understanding the unique neurological needs of autistic children, which creates situations wherein children are enticed by their favourite things (e.g., snacks, games, screentime) to perform tasks that are often extremely uncomfortable or unnatural for them (Kohn, 2020; Lynch, 2019; Swan, 2017).

Alfie Kohn's (2018) discussion of the ways control is exerted over children through the use of positive reinforcements is an important lens through which to examine the argument that, although autistic children may enjoy their reward-laden ABA sessions, this does not mean the sessions are ethical (Real Social Skills, 2015; Swan, 2017). In Kohn's (2018) book, *Punished by Rewards*, he explained the ways Skinner's (1974) theory of operant conditioning through positive reinforcements are detrimental to all children's learning because: "rewards are often successful at increasing the probability that we will do something. At the same time, though ...they also change the *way* we do it" (p. 35). Citing decades of science and scholarship on the theory of self-determination (see Ryan & Deci, 2000), Kohn (2018) described the ways rewards provide effective (and often short-term) results that satisfy adults' desires for compliance more so than they satisfy children's intrinsic motivation to learn. To briefly summarize this perspective,

rewards quicken the way children perform tasks that they would either learn in their own time and space, or that they had no desire (or need) to learn in the first place. This is particularly problematic when applied to autistic ways of learning due to the common assumption underlying ABA treatments for autism that autistic children are not intrinsically motivated to learn (e.g., see Geneva Centre for Autism, 2019)². More on this discussion follows in Chapter 5.

Indeed, there are two basic premises of ABA psychology that have contributed to the pervasive presumption that autistic children have little motivation to learn. First, ABA psychology itself is rooted in Skinner's (1974) theories of behavioural determinism that concludes "behavioral variability is the result of environmental influence" (Cooper, Heron, & Heward, 2020, p. 183). With particular regard to people with disabilities, Skinner stated in a 1977 televised interview that, "... defectives of one kind or another, retarded people, psychotic people, they're not sensitive to contingencies of reinforcement. So, what we need to do is to make the reinforcements more conspicuous. This is done with a token economy ..." (Biophily2, 2016, 9:35). Second, behavioural analysts began treatment for autism with the assumption that autistic children were "close to tabula rasa" (Lovaas & Smith, 1989, p. 23)—in other words, autistic children were blank slates in need of external reinforcements to fill up their 'slates' with more humanistic behaviours.

Even when well-intentioned, this blend of theoretical assumptions has led to the creation of misguided interventions that rely on reward systems as covert mechanisms for control (Gates, 2019; Kohn, 2018). Indeed, in the same interview noted above, Skinner agreed that positive reinforcements are mechanisms of control; but, according to Skinner, rewards are a suitable alternative to coercion because they cause people to *feel* free: "we feel free when we are

² This ABA training manual is cited here and in Chapter 5 but it is not in the public domain. Readers can contact the author of this dissertation for a copy of the referenced page of the document.

controlled through positive reinforcement. We don't feel free when we are being coerced or threatened with punishment" (Biophily2, 2016, 3:17). The *feeling* of freedom as opposed to *actual* freedom was an important theoretical frame for Skinner, which he extrapolated at length in his book *Beyond Freedom and Dignity* (Skinner, 1971). While the differences between *feeling* freedom and *actualizing* freedom are beyond the scope of my own discussion, the point of whether autistic children even *feel* free when conditioned by positive rewards, particularly when they are viewed as blank slates not capable of intrinsic motivation, is an important area for further examination in the discussions and analyses that follow throughout this dissertation study.

ABA interventions for autistic children further maintain a focus on a good rapport, referred to as the "pairing process", through which ABA therapists learn what reinforcers best motivate a child, and then build rapport with the child by 'pairing' themselves with the reinforcer by limiting access to those reinforcers for use only within therapy sessions (Barnett, 2020; Special Learning, 2021). In an ethnographic study involving interviews with ABA therapists, Gruson-Wood (2016) discovered that rapport-building and relationship-building were defined differently by the field of ABA; in fact, the ABA therapists in her study were deterred from relationship-building with autistic children due to the risk of skewing the practitioner's ability to record objective behaviour change results. Instead, therapists were trained to remain focused on the "carefully managed" process of "rapport", which became a quantifiable process of enhancing the therapists' "ability to generate replicable effective behavioural performances" through processes of reinforcement strategies (p. 50). For this reason, bioethics researchers have determined that ABA-based reward systems are a form of covert control that infringe on autistic children's rights to autonomy (Wilkenfeld & McCarthy, 2020). When rights to autonomy are considered in these ways, Kohn (2018) explained that when it comes to teaching children skills

within compliance-based societies, “rewards and punishments are not opposite at all” (p. 50). Recently, ABA providers have published numerous stories online explaining their decisions to leave the field of ABA after tiring of the power-driven ways they were expected to manage autistic children’s behaviours, which conflicted with their initial intent to support autistic wellbeing (Anxiousadvocate, 2015; Autistic Allies, 2018; Ram, 2020; Stay, 2021).

Punishments. Despite insistence that the field of ABA is a progressive science due to its more flexible approach to behaviour that contrasts the “reductionist ABA” proposed by Ivar Lovaas and others in the past (Leaf et al., 2016), rigid compliance-based methods in the form of both rewards *and* punishment procedures persist. Punishing procedures that are considered to be less intrusive than the disciplinary methods of the past remain relatively common practice for use with autistic children. These include time outs, verbal redirections, planned ignoring, and the withholding of food or other favoured items (see Cooper, Heron, & Heward, 2020; Matson, 2023; Slocum et al., 2022; Verriden & Roscoe, 2019). The field of ABA defines punishment as a “basic principle of learning” (Cooper, Heron, & Heward, 2020, p. 363) through a method of delivering or taking away a stimulus that “decreases the likelihood that the behaviour will happen in the future in similar situations” (OSETT-ASD, 2017). But context is important. ABA punishment procedures are enacted within societies that have used discipline and control measures over young people for centuries as a means of advancing colonial and capitalist agendas to produce more independent, moral, and productive humans (Broderick, 2022; Edwards, 2021a).

In the introduction of their edited volume, *Decolonizing Discipline: Children, Corporal Punishment, Christian Theologies, and Reconciliation*, Valerie Michaelson and Joan Durrant (2020) explained the ways that the colonization of North America brought with it the Western

European Christian moral values of disciplinary child rearing. When coupled with the views held by the white Western European colonizers who believed Black, Brown, and Indigenous cultures were inferior to their own, these disciplinary values were enacted through forceful measures, such as electric shocks, in efforts to normalize and Westernize Indigenous children within residential school systems (Edwards, 2021a). Skin shock “therapy” continues to be used as an evidenced-based ABA therapy that disproportionately punishes Black and Indigenous autistic and disabled young people in treatment centers in the United States (L. X. Z. Brown, 2016; Edwards, 2021a). The Association for Behavior Analysis International (ABAI) continues to justify the use of contingent electric skin shock (CESS) intervention vis-à-vis a special task force to monitor (as opposed to discontinue) painful skin shock as a treatment to correct autistic young people’s behaviours (ABAI, 2022). Within the context of Canada, colonial Christian values condoning the discipline of children are evidenced through Section 43 of the Criminal Code, which continues to allow for “‘reasonable force’ in correcting the behaviour of children” (McDonald, 2020, p. 21). Discipline in the form of physical restraints and seclusion are disproportionately justified in both the United States and Canada for use with marginalised and traumatized students, including autistic children in ABA-informed special education classrooms (Alliance Against Seclusion and Restraint, 2022; Autistics for Autistics [A4A] Ontario, 2023; Bartlett & Ellis, 2021; Provincial Advocate for Children and Youth [PACY], 2016; Snow, 2016).

One basic principle of behaviour theory that underlies the meaning of “positive punishment” in ABA practice is important when situated within this colonial history. This principal is explained by behaviourists Cooper, Heron, & Heward (2020) as such: “Learning from consequences that produce pain, discomfort, or the loss of reinforcers has survival value for the individual and for the species. Punishment teaches us not to repeat behaviors that cause

harm.” (p. 363). The logic of punishment as a “natural phenomenon”—i.e., the natural consequence of an action—has shaped the ways discipline has been used as a teaching tool for compliance throughout the centuries (Cooper, Heron, & Heward, 2020, p. 363). In the colonial capitalist context, punishment procedures have become an efficient means of changing behaviour for the benefit of societies within which both conformity and productivity are prioritized. Historically, the use of punishment for capital gain in colonial North America is largely rooted in actions of power and control over Black slaves and Indigenous people (Tuck & Yang, 2012), which is further tied to fears of anyone whose looks and/or actions diverge from white European neurotypical norms (Erevelles, 2011). Returning to Jules Edwards’ articulation of the differences between the “colonial-capitalist worldview” (that values bodily and mental abilities to produce labour) and the “Indigenous relational worldview” (that values all members of community regardless of their mental and physical abilities), it is important to remain vigilant of the ways some punishment procedures justified by ABA (in much the same ways as reward systems) are reproduced through systems that value normativity (Ashburn & Edwards, 2023, p. 42).

Granted, the use of punishment procedures in current ABA practice, also referred to as “aversive or unfavourable consequences” are only recommended as a means of reducing harmful behaviours (e.g., aggression, self harm) when all other options for treatment have been exhausted by the ABA practitioner, including a functional analysis “geared toward changing the environmental conditions that have fostered the socially unacceptable behaviour” (OSETT-CB, 2019, p. 23). However, with outdated knowledge concerning the sensory, communication, and emotional needs of neurodivergent children, ABA practitioners are limited in their ability to accurately change the environment to meet autistic children’s needs (Memmott, 2023; Vivanti, 2022). Autistic activists and researchers have provided evidence of the ways even less intrusive

methods are experienced as harmful and pose great risk to autistic children's long-term emotional wellbeing (Lynch, 2019; Sandoval-Norton & Shkedy, 2019; Swan, 2017). Again, this is due to ABA therapists receiving little to no training in the unique inner neurological developmental needs of autistic children (Sandoval-Norton & Shkedy, 2019). Without training in autistic lived experiences, ABA practitioners may use interventions (e.g., the elimination of flapping hand behaviours) that deny autistic children the freedom to develop into their authentic autistic selves with healthy autistic behaviours (Lynch, 2019; Swan, 2017; Wilkenfeld & McCarthy, 2020). Punishment procedures of all kinds (whether intrusive or not) cause autistic children to feel that their needs are not valid (Broderick, 2022; Collis, 2019; Memmott, 2023; Sandoval-Norton & Shkedy, 2019; Vivanti, 2022). Despite well-researched accounts from autistic scholars who explain the ways intrusive punishment procedures, such as skin shock, are akin to abuse (L. X. Z. Brown, 2014; Collis, 2022; Neumeier & Brown, 2020; Shields, 2019), some ABA practitioners echo Lovaas' (1981) rationale that intrusive procedures are necessary for the treatment of serious problem behaviours (e.g., self-injury, refusal to eat, and aggression) that impede autistic people's quality of life (Blenkush, 2017; Israel et al., 2008).

Rewards, punishments, and the promise of independence. The justification of both reward and punishment procedures for the purpose of achieving normatively defined visions of quality of life within power-driven societies is one reason disability activists call for more robust disability justice frameworks. Using a medical lens of disability, proponents of ABA adhere to article 26, "Habilitation and rehabilitation", of the United Nations Convention on the Rights of People with Disabilities (UNCRP) that stipulates "States Parties shall take effective and appropriate measures to... enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and

participation in all aspects of life” (United Nations, 2006, p. 19). ABA’s particular focus on early behavioural intervention (before the age of four) as critical for autistic children to achieve optimal developmental functioning (Klass, 2020) further adopts the UNCRPD stipulation that “... services and programmes: a) Begin at the earliest possible stage ...” (article 26, p. 19). For example, when it comes to intrusive punishment procedures, ABA manuals and standards of care must contend with the ways enshrined rights to habilitation and rehabilitation conflict with article 15 of the same Convention: “No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his or her free consent to medical or scientific experimentation” (p. 12). Children under the age of four cannot consent to any form of treatment, let alone punishment procedures; nor can many nonspeaking autistic youth and adults who have not been given access to Augmentative and Alternative Communication (AAC) (see A4A 2019a). To contend with this, the Ethics Code for Behavior Analysts emphasizes the need for behaviour analysts to obtain informed legal guardian consent and to “recommend and implement restrictive or punishment-based procedures only after demonstrating that desired results have not been obtained using less intrusive means” (Behavior Analyst Certification Board [BACB], 2023, p. 12). In sum, if an intrusive punishment procedure is deemed to have improved a child’s quality of life, the procedure is justified (Blenkush, 2017; McFadden et al., 2021).

ABA procedures such as punishment, when rationalized through a rights-based medicalized lens of habilitation and rehabilitation, create vague distinctions between what can be considered humanizing (e.g., the right to a full and independent life) and dehumanizing (e.g., the administration of skin shock treatments or time-out procedures that ignore children’s signs of pain and distress). As the collective authors of *Sins Invalid* (2019) explained, “A single-issue

civil rights framework is not enough to explain the full extent of ableism and how it operates in society.” (p. 18). Within a capitalist worldview, behaviourists argue that a dependency-free life (i.e., non-reliance on government, special education, or health care assistance) is a marker of a good quality of life that further reduces financial strain on society (California Association for Behavior Analysis, 2011; Chasson et al., 2007; Larsson, 2012; Motiwala et al., 2006). Yet, to date, there is no evidence that ABA programming prevents institutionalisation or 24-hour care (this issue is discussed in more detail in Chapter 5). Within this context, disability rights frameworks allow for emphasis to be placed on single issues such as a dependency-free life, and create risk for autistic people worldwide who continue to be dehumanized by traditional reward-punishment applications of behaviourism (Neuroclastic, 2021; Stop ABA, Support Autistics, 2019b). Thus, when human rights are enacted in societies that value dependence-free lives as markers of improved quality of life, behaviourists (and many parents) may view the operant conditioning procedures of ABA as “medically necessary” for autistic children (Busch, 2019b; Dawson, 2021; Kavchak, 2020; Shepherd & Waddell, 2015). This framework impedes the development of systems that value autistic people for their humanity regardless of their ability to produce and conform.

Many autistic people have described the ways it is inherently ableist to assume that they need behavioral interventions to avoid life-long reliance on their necessary 24 hour care (Ashburn & Edwards, 2023; Baggs, 2021; Schaber, 2021). Yet, current resources in Canada offer very little in terms of affordable, supportive, and safe housing that guarantees their right to support with dignity (Canadian Academy of Health Sciences [CAHS], 2022; Randle & Thurston, 2022; Slaughter, 2016; Tran, 2023). Without adequate supports, there remains little choice but for families to seek interventions that promote or provide the promise of an independent life for

their child. The ABA industry continues to profit from the promise of independence (Broderick, 2022).

The similarities and parallels between ABA and historical discipline/control measures cannot be overlooked. Foucauldian analytics of power have assisted CAS scholars to examine the ways biopolitics (see Foucault, 2007) operate in liberal capitalist societies to control, surveil, and discipline anyone whose behaviours are deemed too deviant to be of value in modern production-oriented societies (e.g., Gibson & Douglas, 2018; Gruson-Wood, 2016; Roscigno, 2019). Gibson and Douglas (2018) applied Foucault's (1980, 1995) analytics of power, control, and sexual/gender deviance to Amy Sequenzia's (2015) discussion of ABA as modern-day "autistic conversion therapy", which explained how "any 'expert' intervention that attempts to slap, shout, reward, shock, and ignore autistic and gender non-conforming behaviors out of children" are justified for the benefit of future society (p. 4). Gruson-Wood (2016) discussed Foucault's (1995) concept of disciplinary power to examine the ways both autistic young people and behaviour analysts themselves become mechanical objects "created to serve functional purposes" through programmed engagement in regimented behavioural procedures (p. 46). Roscigno (2019) examined the ways behaviourist practitioners are seduced through the aims of biophilanthropy (see Schuller, 2017)—the philanthropist mission to help autistic people modify their behavior so that they can "be made includable in liberal capitalist society" (p. 408). These discussions align with basic tenets of disability theory and justice that have long understood "efficiency and productivity are irretrievably ableist discourses" (Pothier & Devlin, 2006, p. 18).

Disparities revealed by the COVID-19 pandemic have led the field of ABA to critically examine the ways their applied science has failed "to enable and expand human rights" due to its historically narrow focus on human productivity and independence (Pritchett et al., 2021, p.

1074). In their systematic study of ABA literature over the past 50 years, Pritchett and colleagues (2021) discovered that ABA studies overwhelmingly reflect “colonial, rather than collaborative, research practices” due to: limited reporting of informed consent; lack of goals decided upon by the community it serves; lack of demographic information, including race and ethnicity; and lack of outcome measures that examined “improvements in participants’ lives outside of the research context” (p. 1080). While the field of ABA may be surprised by these findings, many autistic advocates and activists are not. Autistic people in Western colonial settler societies have understood the ways they are dehumanized by behaviour modification tactics used to condition them to become neoliberal versions of a worthwhile human, meaning they are only deemed includable when able to meet the production aims of capitalist society (Roscigno, 2019).

Because the field of ABA has only begun to scrutinize its own practices, it will take time to know whether ABA can decolonize itself in meaningful and actionable ways. As discussed earlier, the decolonization of ABA practice will involve understanding the ways that the operant conditioning methods of reward and punishment are linked to, and enacted through, the legacy of colonial moral values that define a good quality of life as one that is normative, productive, and dependence-free. Actionable steps toward undoing the harm caused by the colonial moral values entrenched in behaviourism will require both personal and systemic work on the part of ABA practitioners, researchers, and ethics boards to transform the goal-setting and practices of ABA (more on this is discussed in forthcoming chapters). In this sense, decolonization is not a metaphor for social justice (Tuck & Yang, 2012). Decolonizing ABA requires the same commitment to decolonizing the field of education as a whole through an understanding and undoing of the ways neurotypicality and neuronormativity have been falsely constructed as an ideal way of being within the capitalist-colonial worldview (Ashburn & Edwards, 2023;

Chapman, 2023; Edwards, 2021b). Until autistic ways of being are understood by ABA practitioners, autistic activists, scholars, and allies will advocate for a ban on all forms of compliance and control-based reward/punishment procedures that disregard autistic children's developmental autonomy in pursuit of independence measured against neurotypical standardized norms (Bettin et al., 2021).

The Neo-asylum Era and Institutions Without Walls

In liberal welfare states (like Ontario) that treat disabled people as clients dependent upon financial government support due to their inability to contribute to the means of production (Spagnuolo, 2016), parents and guardians of autistic children often feel they have few options beyond: a) supporting their child to reach conventional development norms so they can become employable or b) placing their child in “mini-institutions” including group homes, senior homes, or hospitals (Slaughter, 2016; Spagnuolo, 2016; Spagnuolo & Earle, 2017; Tran, 2023). Canada continues to undergo a process of deinstitutionalization after Ontario closed its final institution that formally housed and educated people with intellectual disabilities—the Huronia Regional Centre—in 2009 (Slaughter, 2016). In the same ways that colonial history is important, the history of institutionalisation in North America is equally as important. The Christian values that accompanied the colonialism of Canada became amplified throughout the industrial era during 18th and 19th century in various ways that impacted the lives of disabled people. Both humanitarianism and eugenics worked together to create societies wherein disabled people who were once deemed incapable of learning could finally be ‘properly’ cared for and educated through the use of “well-equipped asylums away from the unhealthy conditions of the dirty and crowded cities” (Brown & Radford, 2015, p. 10). The basic life skills programming provided within institutions, along with the segregation and sterilization policies of the eugenics

movement, meant that societies no longer had to concern themselves with the unproductiveness of disabled citizens in ways that made people without disabilities feel charitable and good (Brown & Radford, 2015).

Once it was clear in the mid to late 20th century that institutionalisation had failed to protect the rights of disabled citizens due to understaffing and high costs of care needs, behaviourism regained powerful legitimacy. Many psychologists and parents became convinced that the efficiency of ABA methods to change autistic children's behaviours, as promoted by Ivar Lovaas (1981), was the best answer to ending the inhumane institutionalisation of autistic children (Silberman, 2015; Yergeau, 2018). Thus, the purported purpose of both institutionalisation and later deinstitutionalisation were to provide health, dignity, and safety to disabled people (Brown & Radford, 2015). Under a guise of benevolence, institutions of the past sustained the status quo of unbalanced power through the disciplinary control of non-normative citizens who were kept hidden away, abused, and subjugated due to poor conditions. Foucault (1973) explained the ways institutionalization was never destined to be more humane than the pre-institutionalization era because those who held power remained focused on maintaining power-driven production gains. Foucault insisted that history be scrutinized for better practice in the future—a future which disability activists point out has yet to become suitable or safe even after the last of the formal institutions for disabled people closed in Canada (Brown & Radford, 2015; Carpenter, 2007; Spagnuolo, 2016). Carpenter (2007) used the term “institutions without walls” (p. 1) to describe systems holding onto the “pervasive belief that people with disabilities are ‘sick’, ‘deficient’, ‘dependent’ and requiring ‘care’ by professional healthcare experts who work within authority-driven, institutionalized systems” (Member of Parliament Audrey King as quoted in Carpenter, 2007). Historians have reiterated the ways institutionalisation is a “state of

mind” that cannot be undone by closing the institutional buildings alone (Brown & Radford, 2015, p. 8). And autistic activists have described the ways “community institutionalisation” is reproduced through an inadequate disability support system “where all the features of an institution still exist, but instead of walking from building to building the person is driven from program to program” (Baggs, 2021, 6:27). To explain the lingering institutional mindset more clearly, Pat Worth (n.d.) explained that an “institution is not just a place; it is the way people think” (para. 10).

In many ways, disabled people remain stuck in what disabled activist, Sandra Carpenter (2007), has termed the “neo-asylum era”—an era of well-meaning yet misguided rights-based efforts to integrate disabled citizens into production-oriented societies via unsuitable life-skills/education programs or inadequate housing. When very little has been done to dismantle the ableist idea that disabled citizens are of lesser value to society, community education programs sustain the same disempowering and freedom-limiting aims of the live-in institutions of the past—disabled people must be controlled and surveilled until the day they are able to assimilate, which is an impossibility for so many (Carpenter, 2007).

The institutionalization, segregation, and subjugation of disabled and neurodivergent people are a product of colonialism, capitalism, and industrialisation. Fears of bodily and behavioural differences are documented in narratives that date back to 15th century when colonialists were shocked by encounters with humans whom they immediately categorized as “the Other” because they perceived them as radically different from themselves (Erevelles, 2011, p. 49). The moral and religious customs of Western European society have sustained several institutional practices that surveil/contain anyone perceived as the ‘other’ or unable to contribute to capitalist society. This includes (as mentioned earlier) corporal punishment based on the

British colonial practice of correcting ““what is evil” (a.k.a., different or troublesome) in children who do not conform (Freeman, 1999; as cited in Michaelson & Durrant, 2020, p. 1). A colonial-capitalist worldview values an individualistic hierarchy of power by which anyone who does not conform to ancient moral colonial European norms and behaviours (e.g., autistic people) are deemed less valuable and less worthy of power, which simultaneously disregards the need for interconnected relationships with land and communities (Ashburn & Edwards, 2023). In drawing a parallel between Lovaas’s (1974) notion that autistic children “are not people”, and Richard H. Pratt’s motto, “Kill the Indian, save the man”, Edwards (2021a) stated, “Both are dehumanizing, relegating Indigenous and autistic people as “other” subhumans who need to be trained to be real humans.” (para. 13). For this reason, Edwards (2021) designated ABA as a form of “forced assimilation, reminiscent of the boarding school [i.e., residential school] era” (para. 15). In these ways, connections between neo-asylum and colonial mindsets resulting in the existence of behaviourism become clearer.

Existing systems of disability support have been found to dehumanize individuals through teaching skills in segregated settings that are menial, underpaid, undervalued, or not transferrable nor relevant to disabled people’s everyday needs (Baggs, 2021; Carpenter, 2007). Within systems that operate under these ableist mindsets, human rights become “institutionalized and bureaucratized” (Carpenter, 2007, p. 3), which again speaks to the need for more comprehensive justice-oriented disability frameworks (Berne, 2015). Rights to fair wages, life choice, and dignity are all at risk, and too often denied, under our current system of deinstitutionalisation (Spagnuolo & Earle, 2017). Within this system, therapy and education programs such as ABA insist that their methods provide autistic people with opportunities to improve their quality of life (Cooper, Heron, & Heward, 2020; OSETT-ASD, 2017), yet there is

minimal long-term outcome data to back up these claims (Koudys et al., 2018; Pritchett et al., 2021).

Intersectional Experiences

Justice-oriented disability perspectives remind us that not every disabled person experiences disability as a single issue barrier in their lives (Sins Invalid, 2019). Disabled people who cannot contribute to capitalism are neglected in favour of disabled people who can, and the disabled people who can are often white or white-passing (Ashburn & Edwards, 2023). Price (2022) uses the term “masked Autism” to refer to the exclusion of intersectional experiences within the conventional medical model framing of autism that is defined not by autistic people, but by therapists, researchers and autism organizations who too often represent white and non-disabled experiences (p.5). Masked autism shows up in service delivery and education plans that are tailored to narrowly defined autistic experiences determined by the overrepresentation of autism diagnoses in male and predominately white children (American Psychiatric Association, 2013; D’Mello et al., 2022; Rubey, 2017). With representational gaps in analyses related to intersectional experiences of autism, interventions such as ABA (much like special education itself) perceive the needs of every autistic child as neutral, irrespective of race, sexuality, and gender.

Race. CAS scholarship has only begun to consider the impacts of white supremacy on the lives of racialized autistic people. Majority white autism advocacy and autistic activist communities have historically ignored, silenced, and erased racialized autistic perspectives (L. X. Z. Brown, 2017; Giwa Onaiwu, 2017, 2020; Lewis et al., 2022; Simmonds, 2023). This has occurred despite the many statistics and news headlines that reveal racialized autistic and disabled people are much more likely to be victims of police violence due to racial profiling (L.

X. Z. Brown, 2016; Erevelles, 2011; Rubey, 2017; Spagnuolo & Earle, 2017) and are disproportionately harmed in institutional settings compared to their white autistic and nondisabled peers (L. X. Z. Brown, 2016, 2017; Spagnuolo & Earle, 2017). Over 75% of residents subjected to painful skin shock treatments at the Judge Rotenberg Centre (JRC) are racialized (L. X. Z. Brown, 2016, 2017).

Centuries of scientific attempts to prove the ways Black and Brown people are inferior to white people have created a deeply ableist “legacy of historical beliefs about race and ability” that segregates racialized citizens from everyday society (Annamma et al., 2013, p. 2). Until recently, disability theorists have failed to examine the intersectional impacts of race on perceptions of disability (Annamma et al., 2013; Erevelles et al., 2006). Newer theories, such as Annamma, Connor, and Ferri’s (2013) Dis/ability Critical Race Studies (DisCrit), are important for understanding the reasons why Black and Brown students are disproportionately more likely to be labelled with intellectual, behavioural, and emotional disabilities than white students due to entrenched systemic biases of intelligence based on race (Dolmage, 2018; Gould, 1996; Habib, 2018; Parekh, 2022). Racialized autistic students face unique complexities: they may not receive an autism diagnosis due to pervasive ableist attitudes toward Black and Brown people’s intelligence and behaviours (Gardiner, 2023; Giwa Onaiwu, 2017); they have to work harder than their white autistic peers to mask (i.e., suppress) their autistic traits due to the compounded impacts of racism and ableism (Lewis et al., 2022; Simmonds, 2023; The Black Autist, 2022; Thornton, 2021); and they must contend with everyday code-switching within white-dominated environments in addition to suppressing their autistic traits (The Black Autist, 2022).

Pritchett and colleagues’ (2021) review of ABA literature over the past 50 years found that no ABA studies considered the unique experiences of Black or racialized recipients of ABA.

Until recently, very few ABA researchers or therapists had attempted to address this issue in the ABA literature base, nor had many ABA providers advertised decolonization efforts toward their practices with autistic young people. A few notable exceptions exist including emerging ABA graduate scholars (e.g., Rubey, 2017), and trauma informed, Black neuro-affirming Board Certified Behavior Analysts (e.g., see Mindful Behavior, 2022—Nyetta Abernathy). ABA organizations such as Mindful Behavior (2024), collaborate with justice-oriented Black and queer autistic activists (e.g., Jude Afolake Olubodun) to inform their professional development and practice methods; yet these collaborations remain rare within the field of ABA.

There are varied reactions to the advancements of ABA from Black autistic activists. Cheyenne Thornton (2021), a female-identified Black autistic activist and blogger, expressed frustration with the popular “race-based excuses” (para. 11) provided by ABA therapists who argue that it is imperative for Black autistic children to learn compliance and autistic masking skills (i.e., suppressing autistic traits) if they are to survive the racial and ableist profiling exhibited by police, educators, and community members in racist societies. At the same time, Black autistic activists and scholars agree that asking a Black autistic child to *stop* masking is asking them to expose themselves to danger in white-dominated spaces (Hammond, 2022a; Lewis et al., 2022; Simmonds, 2023). The prevalent theme among these perspectives is that ABA is merely a “leaf” of a much bigger problem that ignores the roots of historical racial and racialized autistic oppression (Hammond, 2022a, p. 3).

The overwhelming majority of ABA opposition is generated from white autistic people (see Ask an Autistic, 2019b; Autistic Collaboration, 2022; Neuroclastic, 2021). Tiffany Hammond is a Black autistic activist, author, and mother of an autistic son who holds a nuanced perspective of ABA. In a recent interview on a popular Canadian ABA podcast, Hammond

admitted she becomes frustrated with people who accuse Black parents of abusing their kids when they place them in ABA programs, particularly when that is the only therapy option available (Hammond, 2022b). Hammond (2022b) argued that while ABA programs are indeed harmful and traumatic, they are no more traumatic than the everyday experiences of being Black and autistic in America. The tragic reality is that the intersections of being Black and autistic ultimately requires children to learn to comply; it *is* often a matter of survival in the face of police, threat of incarceration, and other encounters with authority (Hammond, 2022a; Lewis et al., 2022; Simmonds, 2023).

In the interview, Hammond (2022b) recalled the important history discussed earlier in this chapter—white people have used compliance-based conformity and control measures to enslave Black people for centuries, long before Ivar Lovaas’s (1981, 1987) advent of ABA therapy for autistic children. Indeed, the basic tenets of stimulus/response control measures in behaviourism have existed for centuries as a way to control and discipline racialized bodies. Thornton (2021) explained the problem with ABA this way: “A lifetime of subservience and discomfort is not the answer to racism, and no amount of torture disguised as therapy will make a neurodivergent child neurotypical” (para. 13). Only Black autistic people understand the experience of living in a world where they cannot mask their skin colour, but they can mask their autistic traits as needed on a near daily basis (Gardiner, 2023; Hammond, 2022a; Simmonds, 2023). This reality creates a paradox for racialized autistic people as ABA programs cyclically perpetuate and respond to the power structures in place. Many Black autistic parents become “the oppressor out of love and necessity” because white dominated education settings are much too “unsafe for Black Autistic children and parents to even contemplate reducing their masks if they wish to improve their long-term health outcomes” (Simmonds, 2023, p. 105). Black and

racialized autistic activists have argued that the work is to both fight the system and work within the system at the same time, which has always been the colonial burden placed on racialized individuals (Hammond, 2022a, 2022b; Lewis et al., 2022; Simmonds, 2023). Thorton (2021), however, disagrees with the idea of working with the ABA industry by providing examples of times when masking put her in further danger (e.g., police believing she was neither disabled nor autistic). Thorton concluded that, “the solution to keeping minority autistic children safe in these situations is to educate society—not force a lifetime of pain and discomfort on them” (para. 35).

Similar to the ways ableism is reproduced in the neo-asylum era, ableism and racism are reproduced through liberal education policies that create symbolic structural reforms (e.g., partial integration of Black, Indigenous, and disabled students alongside large populations of white and nondisabled students) without attention to the normative structures and stereotypes legitimizing “both White supremacist and ableist society” (Erevelles et al., 2006, p. 93). When solutions are symbolic, rather than genuinely transformative, students with disabilities experience feelings of being “a problem”, which are compounded for Black, Indigenous, and racialized students, and can manifest into behaviours deemed “morally degenerative” simply because they resist the productive capitalist aims of education (Erevelles et al., 2006, p. 85). The intersectional lived experiences of Black, Indigenous, and racialized autistic people reveal the ways in which educational systems create conditions wherein multiply marginalised autistic children are disproportionately susceptible to disciplinary forms of behaviour change. Importantly, these experiences point to the need for efforts that can dismantle systems of oppression that pathologize all neurodivergent ways of being human.

Queer identities. Within the context of power, it is further important to consider the field of ABA’s “twin shared history with LGBT conversion therapy” (Pyne, 2020, p. 348). Prior to

Lovaas's (1981, 1987) experimental applications of ABA with autistic children, he worked closely with George Rekers on a doctoral research project that used the principles of ABA and operant conditioning to treat the "deviant sex-role behaviours in a male child" (see Rekers & Lovaas, 1974, p. 173). Several CAS scholars and activists have discussed the harmful results of this experimental study that led to the widespread popularity of gay conversion therapies in North America and beyond (e.g., Gibson & Douglas, 2018; Pyne, 2020; Sequenzia, 2016; Yergeau, 2018). One common thread in all of these discussions includes the efficiency and effectiveness of operant conditioning as a method of forcing young people to suppress (i.e., mask or camouflage) their queer and natural ways of being for the purposes of assimilation at the expense of their wellbeing. Pyne (2020) discussed the irony of Canada's recent criminalization of ABA as conversion therapy (Government of Canada, 2021) while the exact same principles of ABA remain firmly in place for the treatment of autism. Pyne's (2020) analysis confirmed autistic scholar, Remi Yergeau's (2018) position that the practice of ABA as a treatment for autism is a form of autistic "cultural annihilation" – i.e., an eradication of autism vis-à-vis a suppression of autistic traits.

The twin histories of gay conversion therapy and ABA for autism is of particular concern considering the vast number of autistic people who identify as queer. In a recent study, 56% of 7,491 autistic respondents identified as LGBT+ while only 35% identified as heterosexual (Bonello, 2022). There are further stories about the intensified negative impacts of ABA therapy for those who identify as both autistic and queer/trans (Adams & Liang, 2020). It is further unsettling to consider the parallels that might exist between queer young people (see Truth But No Logic, 2011) and autistic young people (e.g., Young, 2016a, 2016b) who became suicidal after receiving years of ABA therapy. Research that examines links between gay conversion

therapy and suicide is now well established (Forsythe et al., 2022). To date, there is limited research that examines a link between ABA and suicidality for autistic people. However, there are plenty of autistic ABA survivor stories to be found on social media and online blogs that illuminate lived experience accounts of ABA and connections to suicide (Alexanderstreasuresblog, 2020; art twink [@art_twink], 2021; Kupferstein, 2016; Unbound Books: Autism Acceptance Library, n.d.; Young, 2016a, 2016b).

Analyses of queer and/or autistic ABA experiences reveal the ways ABA methods have been used to erase young people's unique ways of being by adhering to constructions of developmental normality/abnormality as defined by those who hold power in their societies (Gibson & Douglas, 2018; Sequenzia, 2016). Advancements in the field of ABA as a treatment for autism have led to the recent legislative approval for ABA regulation in Ontario (College of Psychologists of Ontario, 2023) and mandated use of ABA in Ontario special education programs (Ontario Ministry of Education, 2007). These advancements of ABA for autism, when ABA is simultaneously criminalised as a treatment for gender and sexual nonconformity, speaks to the ways in which disability rights in the neo-asylum era continue to be undervalued (Carpenter, 2007). Efforts from within the field of ABA to reform its practice of normalising autistic children are admirable (Allen et al., 2024; Mathur et al., 2024; Mindful Behavior, 2024; Pritchett et al., 2021). However, the risks associated with operant conditioning as a method to treat or teach autistic children in a neurotypically-dominated world remain great.

The Autism Industrial Complex (AIC)

The final CAS analytic of power in relation to the practice of ABA is the Autism Industrial Complex (AIC) (Broderick, 2022; Broderick & Roscigno, 2021; McGuire, 2013, 2016). In their article of the same name, Broderick and Roscigno (2021) explained that the AIC

was first coined as a definitive term a decade ago by Anne McGuire (2013). Prior to that, the realisation of ABA as an “autism/ABA industry” was articulated by Michelle Dawson (2004) in her seminal work, *The Misbehaviour of Behaviourists: Ethical Challenges to the Autism-ABA Industry* (Broderick & Roscigno, 2021, p. 81). Over the years, multiple other CAS scholars have discussed the phenomenon of the autism industry in various ways (see Grinker, 2018; Latif, 2016; Mallett & Runswick-Cole, 2016; Milton & Moon, 2012). Each discussion centers the problems associated with the ways ABA has become a powerful and profitable industry benefitting from investment dollars (more than any other autism intervention) due to its reputation as medically necessary treatment for autism (Morris, 2018). Through tracing a record of this history, Broderick & Roscigno (2021) discussed how, over time, the AIC has worked within capitalist structures to produce two distinct outputs, “... autism as commodity and the normative cultural logic of intervention in relation to it” (p. 77). ABA has benefitted from the commodity of autism within capitalist societies that hyper-focus on the productivity of its citizens (Roscigno, 2019). Because autistic people think, move, and speak differently from the accepted and valued norms of modern society (i.e., able-bodied, able-minded, and productive), behavioural interventions for autism have become a non-contested (and thusly lucrative) logic within a linear neoliberal worldview (Broderick, 2022; McGuire, 2016; Roscigno, 2019).

Roscigno (2019) refers to Mitchell and Snyder’s (2015) term “inclusionism” to demonstrate the way ABA interventions work within bureaucratized human rights agendas that do little to change exclusionary environments (e.g., school systems) while autistic rights are defined by the ways autistic children need to fit in. Profits gains from deficit-based views of disability are not new to special education (see Brantlinger, 2006; Erevelles, 2000). ABA interventions have become comfortably situated within the market of special education that

benefits from the sustainment of exclusion (Brantlinger, 2006; Shyman, 2014) at the price of genuine disability justice (Parekh, 2022).

Despite extensive research that found very little in terms of wellbeing outcomes for autistic people in ABA research, nor evidence of self determined treatment goals, ABA researchers Pritchett and colleagues (2021) concluded that “It is hard to tell who the main beneficiary of applied behavior analytic research is” (p. 1086). Critics of ABA have known for some time that quite clearly, the beneficiary of ABA is the AIC. Critical discussions of the ways ABA does not benefit its recipients have existed within the fields of philosophy, psychology, and education for decades. Since the time of Chomsky’s (1967) famous critique of Skinner’s (1957) assumption that behaviour is shaped by external reinforcements, decades of studies have revealed the ways that rewards-based learning diminishes children’s self determined intrinsic curiosities and passion for learning (Kohn, 2018; Lepper & Greene, 2015; Ryan & Deci, 2000) for the benefit (and profit) of educational industries in capitalist society (Brantlinger, 2006; Broderick, 2022). Indeed, evidence from autistic lived experiences has demonstrated that self-determined autistic individuals report having a better quality of life (Kim, 2019).

The popularity of ABA continues to rise due to, in part, its literature-base defining the operant conditioning strategies used in ABA as an evidence-based practice (EBP) for teaching autistic children skills (see Hume et al., 2021; OSETT-ASD, 2017; Steinbrenner et al., 2020). One key element of ABA as an evidence-based practice is “Reinforcement (R) —The application of a consequence following a learner’s use of a response or skills that increases the likelihood that the learner will use the response/ skills in the future” (Hume et al., 2021, p. 4025). What the systematic reviews of ABA studies have been quite successful at demonstrating are the ways autistic children attain goals, through measures of observable data, when positive reinforcements

are used (Hume et al., 2021; National Autism Center, 2015; Odom et al., 2010; Steinbrenner et al., 2020; Wong et al., 2015). What is missing from these reviews is the evidence of autistic people setting their own self-determined goals (Chown & Murphy, 2022; Ferguson et al., 2019; Leaf et al., 2021). In fact, foundational ABA studies have emphasised the value of ABA interventions in terms of the ways society (including caregivers) benefits from the behaviour change achieved by the recipients of the intervention (e.g., Baer et al., 1968, 1987; Wolf, 1978). With a lack of studies demonstrating that autistic people are invested in their selected behaviour goals (Chown & Murphy, 2022), the AIC thrives on the rhetoric of evidence-based practice that excludes the self-determination of autistic people (Broderick, 2022; Dawson, 2004; Yergeau, 2018).

Largely, the problem with ABA interventions as a measure of better autistic functioning is the absence of autistic neurodevelopmental knowledge and absence of autistic assessors in ABA research who do not challenge the values of neuronormativity (Sandoval-Norton et al., 2021); when assessors are not autistic themselves, they cannot determine the abilities and talents of autistic people (Bascom & Perry, 2022; Burgess, 2016; Burns, 2019; Collis, 2023; Flynn, 2018; Williams, 2019). These concerns, along with the vast amount of literature exposing the myriad reasons ABA interventions as a whole have a weak evidence base (King, 2020; Zamzow, 2022), have prompted student members of the American Medical Association (AMA) to recommend a “removal of AMA support” for ABA interventions (AMA House of Delegates, 2023, resolution 706). A more in-depth analysis of ABA’s weak evidence base will be discussed in Chapter 5.

Despite limitations to its evidence-base, ABA has the marketing power to persevere as the best (often sold as the *only*) evidence-based practice for autism (Alderson, 2011; A4A Ontario, 2018; Prizant, 2009; Shyman, 2014). When society maintains a narrow definition of normative

development within a linear worldview, behaviourism becomes a desirable and hopeful cure for perceived deficiencies in behaviour (i.e., behaviors that veer away from the path of developmental norms). As Broderick (2022) explained, behavioural interventions quickly became hopeful “*technologies*” “... to effect change on people in spite of their inner deficiencies” (p. 68). Broderick further explained that this marketing of hope serendipitously emerged at a time when reductive nativist ideologies had influenced the dominant view that undesirable human qualities could not be changed. The possibilities of behaviour-shaping technologies provided renewed insight into the nature versus nurture debate. For example, psychologists came to understand how environment played a significant role in the behaviour of incarcerated people whose behaviours, once deemed innate and incurable malicious tendencies, were a product of their environment and could be rehabilitated through the method of operant conditioning (Biophily², 2016; Kubina & Kostewicz, 2021).

At the same time, deficit-based views of disability continued to permeate social consciousness. The practical applications of behaviourism created hope for parents who believed their autistic children could be cured of their innate autistic traits (Silberman, 2015). As narrow visions of normative behaviour persisted, ABA became valued by parents more than autistic people themselves (Kohn, 2020; Sparrow, 2015) and effectively sold to parents as the best alternative to institutionalization or a life of financial burden (Broderick, 2022; Silberman, 2015; Yergeau, 2018). This promise, made by early behaviourists (Lovaas, 1981, 1987), persists today. In a recent blog post titled, *How to Enroll More ABA Clients by Overcoming Parent Objections... Without Being Pushy or Sales*³, ABA therapist Reece Epstein (2019) used what he called a “doctor frame” to appease parents’ worries that they could not afford his ABA services:

³ The post was removed due to protests by autistic advocates (ABA PBS Controversy Autism Discussion UK, 2020) but can be viewed on an archive:

... getting your child the services he/she needs right now, you will actually save many tens or even hundreds of thousands of dollars on therapy, support services, and financial support you may have to provide to your child when he or she is an adult. That's because if you don't get your child the help he/she needs now, he/she will need a lot more help later. And he/she may not be able to get a good job.

As this example illustrates, therapists can covertly manipulate parents into spending thousands of dollars on a therapy that falsely promises a life of independence using the rhetoric of "help" to incite panic and guilt.

The capitalist power of the AIC has been extremely successful at marketing hope despite behaviourism's now outdated and reductionist theories, which Skinner (1974) himself admitted were limited by science's inability to observe the inner mental process of the mind (Broderick, 2022). Broderick convincingly concluded that "With the advent of neuroimaging and the ability to observe internal states and processes, behaviorism's sole claim to scientific legitimacy on the terms of logical positivism is now outdated" (p. 54). In other words, we now have a deeper understanding of innate human behaviour, neurology, and neurodiversity that was not available during the rise of Skinner's behaviourist era. Advancements in neuroscience have helped us to understand that neurological difference does not equate to neurological deficit. These advancements have further helped us to understand that not all autistic children's behaviour can, or should, be targeted for therapeutic intervention. Nor should they be shaped by external reinforcement strategies when we consider our advanced understanding of the inner emotional world of the autistic child.

In sum, a key focus of my forthcoming analysis explores the impacts of operant conditioning, punishment procedures, and positive reinforcement strategies within power-driven capitalist societies. The following CAS section explores the theory of stigma, which scholar, Roy Richard Grinker (2020) theorized is not a natural dehistoricized human phenomenon as once previously believed (see Goffman, 1963), but has come to exist within the historical context of who is valued as productive within capitalist and individualist modern societies. A risk-benefit analysis of ABA interventions reveals the AIC is clearly driven by the interests of capitalist profit over the interests of autistic wellbeing (Broderick, 2022). Autism is reduced to a stigmatized “thing” that is “produced, consumed, and commodified” by and through the autism/ABA industry (Runswick-Cole et al., 2016, p. 7).

Stigma

While I have made clear the ways that analytics of power are key areas of exploration when examining the impacts of ABA on autistic people’s lives, I have yet to explore the important ways that stigma drives the success of power and capitalism through operations of discrimination, ableism, and marginalization. Erving Goffman (1963) discussed the ways stigma impacts identity formation through publication of theoretical essays in his book, *Stigma: Notes on the management of spoiled identity*. Of course, Goffman was not the first sociologist to discuss stigma in Western culture. Gordon Allport (1954), among others, had been writing and theorizing about stigma and prejudice for several years prior to Goffman’s work. The following remains focused on Goffman’s conceptualization of stigma, and the ways in which CAS scholars have applied the theory of stigma to autistic lives.

Goffman (1963) explained stigma through an etymology of the term dating back to ancient Greece when the Greeks used the term (*stizein* in Greek language) to “...refer to bodily

signs designed to expose something unusual and bad about the moral status of the signifier” (p. 11). Goffman explained that during his era of the 1960s, the term stigma was used in much the same way as in ancient times but was “...applied more to the disgrace itself than to the bodily evidence of it” (p. 11). Several CAS scholars and activists agree that stigma is a violent reality of their lived experience that is tied not only to physical evidence of their differences (e.g., motor, speech, and movement differences), but also to their cognitive and sensory differences. Citing Goffman’s concept of “spoiled identity”, CAS scholars and autistic health professionals explained that autistic stigma occurs in relation to autism itself as opposed to physical markings or differences, which creates a need for autistic people to mask (sometimes referred to as a need to camouflage) their autistic traits (Gates, 2019; Pearson & Rose, 2021; Price, 2022). The experience of autism involves sensory and behavioural neuro-differences which, initially labelled as childhood schizophrenia (Bleuler, 1950), are firmly rooted in the historical stigmatization of mental illnesses during the rise of capitalism (Grinker, 2020). The stigma associated with autistic traits has continued to exclude autistic people from everyday participation in Canadian society (Canadian Academy of Health Sciences [CAHS], 2022).

Gordon Gates (2019), autistic author and therapist, discussed what he called “invalidation trauma”, which he described as a significant, often invisible, outcome of autistic stigma (p. 16). In his book, Gates defined trauma in more expansive ways than are generally accepted in contemporary trauma-informed resources. For example, he stated, “Trauma is not always so extreme and is not necessarily related to single catastrophic events. It can also be associated with poverty, harassment, bullying, loss and chronic invalidation” (p. 17). For autistic people in particular, Gates explained that everyday experiences of autistic discrimination “generates a daily treadmill of micro-stigma with socioconventional others” (p. 72). Maintaining a

“neurotypical mask” perpetuates a cycle of stigma due to the exhaustion that results from upholding that mask (Price, 2022, p. 7). As Price explained it, exhaustion from autistic masking can lead to behaviours that are deemed challenging (e.g., melt downs due to overwhelm; depression; aggression) that further stigmatize the autistic individual.

Autistic people have made clear the harm that results when ABA interventionists force autistic people to hide, mask, and manage their natural and stigmatized autistic traits (Dawson, 2004; Gates, 2019; Pearson & Rose, 2021; Price, 2022; Sequenzia, 2015; Stop ABA, Support Autistics, 2019b). Goffman’s (1963) concept of “passing” is referred to as “camouflaging” or “masking” by autistic people, which has been linked to increased risk of suicide (Cassidy et al., 2019). Depression and suicidal ideations experienced by autistic people result from the “impact that conscious and unconscious norms and societal expectations place upon stigmatized persons and the lengths they might go to conceal their otherness” (Pearson & Rose, 2021, p. 54). In contrast to this, evidence from self-reported surveys completed by autistic people worldwide have found that autistic self-acceptance is associated with improved mental wellness (Keating et al., 2024). It is important to query the relationship between autistic stigma and ABA interventions. For example, what evidence is there that ABA causes autistic people harm through its focus on fixing or erasing stigmatized autistic traits? And is it possible for the field of ABA to establish a role for itself in addressing autistic stigma in trauma-informed ways?

The impacts of daily autistic micro-stigma have yet to be thoroughly researched nor addressed in ABA or special education literature. However, there has been recent acknowledgment from within the field of ABA that autistic people may experience an increased risk of trauma (Kolu, 2021b; Stack, 2021; Stack & Lucyshyn, 2019) and that ABA interventions have been the cause of significant trauma and harm for autistic individuals (Allen et al., 2024;

Mathur et al., 2024; Pritchett et al., 2021). Other ABA researchers are examining the intersectional impacts of racial stigma within autism service provisions, along with the responsibility of ABA practitioners to respond effectively (Čolić et al., 2021; Pritchett et al., 2021; Rubey, 2017).

One thing is for certain, the AIC, with its focus on ABA as a treatment for autism, would not exist without stigma. It is clear that ABA, as it is most currently delivered, profits from the social process of stigma. This is evidenced by the following rationale written by ABA researchers for treating and reducing the stereotypic behaviours of autistic children:

"...behavior analysts also have an obligation to best prepare their clients for the world in which they currently live, which is, unfortunately, less accepting than desired. Research has documented that engaging in stereotypic behavior often has a negative impact on the person engaging in the stereotypic behavior... as well as negative perceptions from those observing the person engaging in the stereotypic behavior...To align with the research and best prepare clients for the environments in which they will find themselves, behavior analysts will likely be required to address stereotypic behavior." (Leaf et al., 2021, p. 2845)

To revisit the earlier discussion of inclusionism (Roscigno, 2019), it is clear that the perceived necessity for autistic children to fit in stems from the deficit-based medical model of disability that stigmatizes disabled bodies, character traits, and behaviours (Brantlinger, 2006; Erevelles, 2000; Parekh, 2022). Indeed, ethics research into the historical past of ABA has concluded that "Goals have become somewhat more democratic... but it would be difficult to deny that the ultimate goal of ABA is to get autistic children to fit into society, without placing corresponding burdens on society to adapt to autists as they are" (Wilkenfeld & McCarthy, 2020, p. 52).

Naturally, parents can be drawn to medicalized approaches to autism therapies as they worry about deficits in their children's development and the associated stigma that can come with it. Parents are told by doctors that if they do not secure early comprehensive ABA interventions for their children, they may be depriving their children of their needs (Shepherd & Waddell, 2015). In this way, the ABA industry profits from what Goffman (1963) referred to as "courtesy stigma", a type of stigma experienced by those (e.g., parents or relatives of autistic children) who are stigmatized through their relationship and association to stigmatized people (p. 43), which is partly the reason why ABA attracts families of autistic children with more visible neuro-differences, communication needs, or support needs (Carey et al., 2020; Gillespie-Lynch et al., 2017; Williams, 2019). The prognosis of a more productive and desirable life promised by early autism interventions preys on overwhelmed parents who fear a lifetime of barriers and stigma for their autistic children (Carey et al., 2020; Shepherd & Waddell, 2015). Stigma is thusly sustained in these ways by the medical model perspective that financially benefits the status quo.

An analysis of stigma gets to the heart of harm caused by the ABA industry. Autistic people and researchers point out that ABA interventions targeting harmless behaviours such as solitary play and stimming impede on autistic people's human rights to freedom of expression, play, acceptance, and neurodivergent development (Dawson, 2004; Mottron, 2017; Sandoval-Norton & Shkedy, 2019; Wilkenfeld & McCarthy, 2020). Nonspeaking autistic people point out that the focus on teaching conventional verbal speech by ABA therapists undermines their intelligence (Kedar, 2012; Reyes & Reyes, 2018) and denies their right to non-speaking modes of communication such as facilitated typing or Augmentative and Alternative Communication (AAC) devices (A4A Ontario, 2019a).

Autistic scholars studying the effects of stigma further contend that autistic young people may engage in challenging behaviours in response to the emotional trauma caused by stigma, lack of accommodations, and abuse (Gates, 2019), which can make it difficult for educators and other practitioners to discern which behaviours are the result of autistic sensory experiences, and which are the result of trauma (Price, 2022). Because ABA intervention literature views challenging behaviours such as aggression and self-harm to be common symptoms of autism (OSETT-ASD, 2017; OSETT-CB, 2019), it is important to explore the role of ABA in relation to Gates' (2019) postulation that, "Emotional pain does not come from autisticcy itself so much as stigma, accumulated traumas and microtraumas of not being accepted, and being different in an unforgiving world built to accommodate the conventional mainstream" (p. 138). For example, in contrast to its intended purpose, ABA therapies can exacerbate nonspeaking autistic people's frustration and meltdowns due to stigmatization and inaccessibility of autistic communication (see Chang, 2019; Dixit, 2019; Kedar, 2012). Conversely, a closer look at the evidence may show (but not always) that ABA interventions 'work' to decrease challenging behaviours, but what 'works' must be viewed within the context of compliance-based systems that exhaust autistic children "to a point where the child has shut down because they believe there is no longer any point expressing their desires, needs or distress. This is called 'improved behaviour'" (Swan, 2017, para. 6). In other words, it is possible that in its attempts to treat challenging behaviours, ABA interventions perpetuate harm in covert ways through its own means of stigmatizing autistic behaviours.

Appearances of compliance and cooperation from autistic children may convince proponents of ABA that autistic people enjoy and appreciate their ABA interventions (Durling, 2022; Swan, 2017). In response to this view, Taryn Jaye (2021), an autistic writer and activist,

observed that some autistic people appreciate the skills they learn in ABA due to their chronic experience of stigma and wish to appear normal. In their analysis of autistic masking due to spoiled identity stigma, Amy Pearson and Kieran Rose (2021) explained the ways the “cognitive dissonance” involved in “masking as a self-protective mechanism rather than a necessarily conscious choice” can lead to burnout if the cognitive dissonance is not solved (p. 55).

Finally, proponents of ABA argue that autistic opponents of ABA are made up of only those autistic people who have fewer support needs (i.e., not as stigmatized), and thus have never received nor needed ABA in the first place (Busch, 2019a; Dawson, 2021; Kavchak, 2020). This claim has been named the “double bind” (Rothwell, 2020) and the “no true Scotsman fallacy” (Collis, 2023, p. 1) of the AIC: nonspeaking or minimally-speaking autistic people are considered too low-functioning to write books, blogs, or advocate for themselves, and autistic people with verbal speaking abilities are considered too high-functioning to understand the experiences or challenges of nonspeaking autistic people (Busch, 2019a; Dawson, 2021; Kavchak, 2020; Vivian et al., 2019). Autistic advocates with high support needs (whose families were covertly and overtly coerced into enrolling them into ABA programs) have contested these claims to be both ableist and unfounded (see, for example, Alexanderstreasuresblog, 2020; Bascom, 2011; Boskovic, 2018; Kedar, 2012; Melnychuk, 2019; Sequenzia, 2015).

The double bind phenomenon aimed at silencing the most stigmatised disabled people is not new. For decades, psychiatrists have defended medical model treatments for psychiatry patients when faced with criticism from patient advocacy groups who identify as “psychiatric survivors” of abusive medical treatments (Reaume, 2002; Torrey, 1997). E. Fuller Torrey (1997), a well-known American psychologist, claimed that the antipsychiatry movement was led by self-proclaimed oppressed “psychiatric survivors” who were less disabled (i.e., less stigmatized) than

the half a million “profoundly disabled individuals who have no insight into their illness or their need for treatment” and who needed “involuntary hospitalization or involuntary medication” in order to survive (p. 143). This commentary was strongly refuted by activists at the time who accused Torrey of making unsubstantiated claims (Reaume, 2002).

The social theory and history of stigma provides a useful framework through which to explore the ways the social process of stigma fuels the medicalized ABA industry that silences the autistic voices it aims to serve. ABA attracts families of autistic people with high support needs who often have limited means of effective communication (Sandoval-Norton & Shkedy, 2019). For this reason, autistic people who have not received ABA (and there are many) may feel compelled to voice strong opinions against the practice regardless of whether they had not participated in the interventions themselves. All autistic people have a shared invested interest in dismantling autistic stigma *through* a dismantling of ABA, which many feel is an ableist intervention that exacerbates stigma, dehumanization, and trauma for them all (Broderick, 2022; Gates, 2019). Emancipation efforts will rely on ABA experiences that have both been told and untold in order for ethical and helpful autistic education to be made possible in Ontario and around the world.

Emancipation

The third and final tenet of CAS analytics is autistic emancipation from persistently misguided and harmful interventions. Neither autistic expertise (Milton, 2014) nor meaningful autistic participation in research (Chown et al., 2017; Raymaker & Nicolaidis, 2013; Rosqvist et al., 2019) have yet to be valued in medical models of autism, including ABA intervention research. CAS scholarship and autistic activism highlight the ways that emancipation can be

realised through new directions in research that value genuine participation with autistic people⁴ and a commitment to transparency.

Many autistic people, particularly those involved in the neurodiversity movement, call for strength-based approaches that affirm autistic differences as natural and accepted ways of being, and oppose any intervention that assumes they need to be cured or fixed in order to be considered human (Autistic Collaboration, 2022; Gardiner, 2019; Stop ABA, Support Autistics, 2019b). Erevelles (2000) called for “a critical pedagogy that provides the intellectual tools that can render visible the material structures and ideological discourses that have different effects on black, white, lesbian, working-class, disabled, and third world students” (p. 47). This philosophy adopts Paulo Freire’s (1970) conscientization, which has been identified in the field of education as an essential component of emancipation for all marginalised students (Brantlinger, 2006; Erevelles, 2000; Grinker, 2018). For example, ABA critics call for an end to covert tactics (e.g., coercion) adopted by the ABA industry to mislead the public and caregivers into believing that enrolling in ABA is the only way to help autistic people fit in (Therapist Neurodiversity Collective, 2020c). Indeed, ableism has yet to be thoroughly dismantled in education (Dolmage, 2017; Mitchell, 2015; OHRC, 2018; Parekh, 2022; PACY, 2016; Shyman, 2014). And ableist environments pose great risk to autistic people when capitalist power sustains exclusion through ableism and stigma. As the ABA industry continues to benefit from the sustainment of ableism, emancipation efforts remain difficult.

In 1977, Skinner himself expressed his fear that behaviorism could be weaponized if placed in the wrong hands and suggested: “... the best way to make sure that you’re not going to be abused by a controller is to understand all of the possible techniques of control so you can see

⁴ See the transformative methods approach in the following chapter for details on this approach

what’s going on. People are not aware of how they are being controlled” (Biophily2, 2016, 15:52). Skinner’s concerns about the ways people are unaware they are being controlled clearly apply to autistic people who are at risk of subjugation through behavioural therapies they receive without conscious consent nor attention to personally relevant and neuro-affirming goals (Chown & Murphy, 2022; Collis, 2019; Dawson, 2004; Memmott, 2023).

What does it take to realise autistic rights and disability rights within bureaucratic systems that are slow to change? Foucauldian thought is useful when thinking through the biopolitics of power and stigma. However, a critical aspect missing from Foucault’s analyses is the voices of disabled, mad, and oppressed people themselves (Reaume, 2017). A justice-oriented CAS approach highlights the importance of what Gates (2019) described as “authentic, open-minded listening”, which he further described as “the most important tool of stigma control” (p. 138). CAS scholarship and autistic activism reminds us that dismantling autistic oppression involves authentically listening to autistic people by allowing them to be the authors of their own stories, representations, and experiences (Communication First, 2021; Hodge et al., 2023; Milton, 2014; Peña, 2019; Shields et al., 2022; Sutton, 2015).

ABA researchers are beginning to see how the science of ABA “was developed within a Western hegemonic structure. It is a discipline that operates within a larger structure that is racist, sexist, and ableist” (Pritchett et al., 2021, p. 1088). A commitment to authentic listening by those who wield power in the AIC seems a momentous ask. However, it is evident that a paradigm shift is occurring in autism related sciences. Autistic voices have played a significant role in the transformation of health sciences that now acknowledge the importance of identity-first language (American Psychological Association [APA], 2015) and the harmful impacts of stigma (Public Health Agency of Canada [PHAC], 2023). Organizations such as the Autism Alliance of Canada

(formerly the Canadian Autism Disorder Alliance) have attended to stigma by officially removing the word “disorder” from their name (Autism Alliance of Canada, 2022).

In reference to the hegemonic structure of Western culture, Pritchett and colleagues (2021) admitted that “Our work is to understand how that happens, to imagine how that can change, to produce changes, and to learn how the change process works” (p. 1088). ABA has been exposed for violating its ethical obligation to do no harm (Sandoval-Norton et al., 2021; Sandoval-Norton & Shkedy, 2019; Wilkenfeld & McCarthy, 2020). Autistic emancipation involves families, educators, practitioners, autistic people, and society coming together to dismantle ableist notions that autistic people are incapable of defining their own non-capitalist and unconventional quality of life (Schaber, 2021). Emerging theories in neuroscience affirm that the behaviours of all young people can be destigmatized using trauma-informed approaches (Delahooke, 2019; Desautels, 2020), which, in turn, can improve the quality of educational and therapeutic approaches that support the wellbeing and inclusion of autistic people (Shyman, 2014). More on the emancipatory possibilities of these theories follow in subsequent chapters and the co-authored recommendations that conclude this study.

Chapter 3: A Transformative Mixed Methods Design

The methodology for this dissertation study adopts Donna Mertens’s transformative explanatory sequential mixed methods (Mertens et al., 2015; Teddlie & Tashakkori, 2009) to seek disability justice by means of authentic participation with autistic people at each stage of research (Nicolaidis et al., 2019; Raymaker & Nicolaidis, 2013; Rosqvist et al., 2019). The four-staged methodology (surveys – interviews – analysis – participatory dissemination with co-authorship of policy and practice directions with autistic participants) responds to Milton’s (2014) call for “interactional expertise” (Collins & Evans, 2007) between non-autistic

researchers and autistic people in order to improve autism practice and policies and unlearn pervasive deficit-based misconceptions about autism through a strength-based understanding of autistic culture.

Rationale

Rosqvist and colleagues (2019) defined emancipatory research with autistic people as “...the inclusion of the participants within the research process in such a way that they benefit from it and it expresses their opinions and experiences” (p. 1088). Only recently has this form of participatory research become a well-established approach adapted from the early work of Stone and Priestley (1996), pioneers of emancipatory knowledge production in disability studies (Rosqvist et al., 2019). Milton (2014) adds to this point by calling for an emphasis on autistic expertise and agency regarding the knowledge production that concerns autistic people. Mertens’s (2009) transformative paradigm (originally named “emancipatory” but changed to “transformative” to take emphasis away from the idea that marginalised communities could be emancipated *by* researchers) places emphasis on the responsibility of researchers to work *with* research participants and respect “the agency role for the people involved in the research” (p. 2). The shared goal of community agency within emancipatory autism research (Chown et al., 2017; Raymaker & Nicolaidis, 2013; Rosqvist et al., 2019) and Mertens’s (2009; 2015) transformative paradigm has created opportunities to collaborate with autistic people toward future justice.

My rationale for choosing a transformative mixed methods approach further rested on my awareness that neither quantitative nor qualitative analysis would be sufficient for my study. Researchers who are drawn to mixed methods intuitively understand that their research questions cannot be answered through a single method (Mertens, 2015) and will thusly benefit from

moving “beyond the either-or stance in terms of method to the both-and stance” (Mertens, 2009, p. 165).

Critiques of Quantitative Methods and Mixed Methods

It is not uncommon for researchers of human behaviour to view quantitative analysis within mixed methods studies as reductionist when evidence produced through findings are objectified and left unproblematized through a philosophical lens (Mertens, 2015). Science fields such as ABA are rife with statistical analyses that rely on standardized results from autism severity scales, IQ tests, and adaptive functioning assessments without regard to philosophical assumptions of truth outside the realm of medical model positivist aims (see Cooper, Heron, & Heward, 2020; Matson, 2023). Unlike more pragmatic forms of mixed methods research, quantitative analyses in transformative research are an effective means of critically interrogating unproblematized claims about objective reality (Mertens, 2015). For the purposes of this dissertation study, inferential quantitative hypothesis tests can reveal relational trends between stigma and power, such as how stigmatized views of autism as a disorder are related to perceptions of ABA effectiveness. Statistical findings are further explained by qualitative analyses of real lived experiences.

Ontology

Similar to poststructural and social constructionist theories that underly CAS and critical disability theory (CDT), the transformative paradigm adopts the ontological assumption that reality is constructed through one’s lived experience of the world and that ‘truth’ claims can and should be interrogated when one considers the complexities involved in the dynamics of power and privilege afforded to some and denied to others (Mertens, 2009, 2015). Subsequently, as the emphasis is placed on social change and disruptions to power that create oppression, the

transformative paradigm allows for certain basic truths to exist, particularly those truths related to the lived experiences of harm caused by a disproportion of power. Mertens et al. (2015) explained the transformative ontology this way:

the transformative ontological belief emphasizes that which seems “real” may instead be reified structures that are taken to be real because of historical situations. Thus, what is taken to be real, needs to be critically examined via an ideological critique of its role in perpetuating oppressive social structures and policies (Mertens et al., 2015, p. 8).

In this way, the disruption of positivist claims to ‘truth’ complements the CDT and CAS theoretical frameworks I have chosen for this study.

A CAS lens applied to transformative research allows for the researcher to hold a positionality of truth outside the realm of positivism. For example, my own truth position in this research is that dominant power dynamics cause harm to those who diverge from mainstream society; this occurs through the unproblematized investment in positivist ‘facts’ (e.g., disability is a disorder in need of intervention) through which profitability is sustained for those in power (Broderick, 2022; Grinker, 2018; McGuire, 2016). Truths about marginalization created by pervasive comparisons to cognitive and bodily norms within special education policies and practices (Brantlinger, 2006) are basic truths that many can agree on when provided with evidence. ABA researchers themselves have come to acknowledge that the field of ABA has a history of harming autistic young people through its attempts to normalize autistic behaviours (Allen et al., 2024; Leaf et al., 2021; Mathur et al., 2024; Pritchett et al., 2021). It is therefore my position that when evidence of harm has been acknowledged, it is the responsibility of transformative researchers to make clear to all research participants (regardless of their personal standpoints or worldviews) that the research goal is to investigate the causes of harm experienced

by the marginalised communities involved in the study. It is equally as important to remain open to new possibilities and to check in with personal biases while maintaining focus on research questions (Mertens, 2015).

To make my own standpoint clear to participants, I added a purpose statement to the online surveys I distributed in the first stage of the study:

The purpose of this study is to examine whether Applied Behaviour Analysis (ABA), and its more intensive approach known as Intensive Behavioural Intervention (IBI), contribute to improved quality of life for autistic people in Ontario. This research question has emerged in light of recent opposition to ABA and IBI from autistic people, their families, and their allies who have been advocating for an end to ABA and IBI in Ontario and around the world.

With this statement clearly stated on the survey, and then reviewed with participants in the interview, I made clear my intention was to engage in open dialogue with a certain truth laid bare—the truth that ABA has harmed many autistic people. With this articulated, I stayed focused on my research standpoint that harms caused by ABA must be mitigated, and that one way to achieve this is through knowledge mobilization with autistic people and with those who love and care for autistic people.

Study Design: Overview

Explanatory sequential mixed methods use a quantitative-to-qualitative sequential analysis approach to explain possible connections and correlations related to discoveries made in the quantitative phase of research (Mertens, 2015; Teddlie & Tashakkori, 2009). Following this method, the stages of the following research occurred in chronological order with each stage dependent on the strand of methods and data that precede it (Teddlie & Tashakkori, 2009).

insight into the reasons different respondent groups support or oppose ABA methods; and c) disseminate important results and recommendations for the betterment of autistic people, from autistic people themselves. The quantitative, qualitative, and participatory approach allowed me to explore phenomenon not often considered nor discussed in studies concerning ABA (e.g., that all autistic voices matter regardless of whether they have received ABA or not; that a diverse population of autistic people oppose ABA; that listening to positive experiences of ABA are just as important as negative experiences of ABA; etc.).

Positionality in Research

In transformative research, it is important for researchers to consider “insider-outsider” issues when conducting research alongside marginalised communities (Mertens, 2015, p. 318). As an outsider researcher who is not autistic myself, I maintain awareness of the space that I take up in this area of research. I chose to embark on this project as a result of my experiences as a researcher and educator who has witnessed harm caused by ABA-based programs. My own identity as a neurodivergent person with ADHD has further helped me to empathise with some of the challenges faced by autistic young people. At the same time, I value autistic people as the *only* experts on their lives. I know that autistic people are too often expected to provide free labour, often without due credit, toward the betterment of autism research, policy, and practices. As such, I attempted to leverage my academic privilege by leading this research in a manner that respects the expertise, time, and energy of autistic participants.

It is further important to note that I am a novice mixed methods researcher. Mertens (2015) encourages students to become confident in the mixed methods approaches before a study begins. I took risks as a novice researcher while also taking great care to understand the steps required thoroughly within my capacity as a PhD student. I took time to engage with autistic

people in meaningful ways and to learn the new skills I required until I was confident in my approach. My decision to focus on this research topic resulted from several years of listening, learning, and collaborating with autistic people to mitigate harm caused by ABA. This kind of authentic engagement is an important tenet of the transformative framework: “Transformative researchers who work with communities with disabilities place high priority on developing relationships with members of the community, building trust, and recognizing the expertise that community members have” (Mertens, 2015, p. 298).

Ethics Approval

All stages of research received ethics approval from York University’s Office of Research Ethics (ORE) Human Participants Review Sub-Committee beginning in October 2021.

Amendments to the original research plan were made at several steps throughout the research process. Each amendment is noted at the corresponding research steps throughout this chapter.

Timeline Disruptions

The COVID-19 pandemic has impacted the timeline and interview process of this project. Originally, I had planned to defend my thesis proposal and submit my ethics protocol to York University’s Office of Research Ethics (ORE) Human Participants Review Sub-Committee in the Fall semester of 2020. However, due to restrictions placed on in-person interviews and the personal impacts of the pandemic, I allowed extra time to amend my proposal (defended in April 2021). After several more disruptions to the research due to personal circumstances during the analysis stage in the Summer and Fall of 2022, I required extra time—one year longer than expected—to complete all stages in a thorough manner.

Stage 1: Surveys

In April 2021, I consulted with trusted autistic community members (e.g., *Re•Storying Autism Collective*, 2023) to assist in the development and review of survey questions covering themes important to autistic communities (e.g., pathologized or strength-based perceptions of autism; popular claims made by the ABA industry; and ABA outcomes related to wellbeing and quality of life). I then created three comprehensive online surveys that recruited three groups of participants to share their lived experiences and perceptions of autism and ABA. These groups included as follows: 1) autistic people aged 16 and older who had either received ABA services in Ontario or had not received ABA services but who wanted to share their opinions of ABA; 2) parents and caregivers of autistic people who had received ABA services for at least 6 consecutive months in Ontario; and 3) ABA providers who had provided ABA services for at least 6 consecutive months in Ontario. My decision to include autistic people who had not received ABA was important for two reasons: 1) all autistic people's views matter on this issue because even those autistic people who have not received ABA have articulated carefully researched views on ABA (e.g. Sparrow, 2015); and 2) comparing the wellbeing and QoL outcomes of ABA recipients to those who had not received ABA was an important question.

I consulted statistical guidelines to create questions appropriate for inferential hypothesis testing (Agresti, 2018) and accessibility guidelines to create survey instruments that optimized accessibility for autistic or disabled respondents (Nicolaidis et al., 2020).

Included in the questionnaire were demographic questions pertaining to gender, age (at attendance of program and now), race, ethnicity, socioeconomic status, communication needs, concurring disabilities (e.g., intellectual disabilities) and duration of the ABA program they attended. I carefully reviewed articles, reports, and blog posts within the field of ABA, autism studies, and autistic activism to develop questions that would produce variables that could be

analysed for diverse experiences of ABA interventions. I further included a checkbox for autistic respondents who wished to be contacted for a 45-60 minute interview in stage two.

Broadly, I covered themes pertaining to stigma, perceptions of autism, popular claims made by the ABA industry, and well-being and quality of life outcomes. I utilized parallel quantitative (multiple choice and Likert scale) and qualitative (open-ended short answer) questions (Creswell & Plano Clark, 2018) to allow for an in-depth analysis. My aim in this first stage was to work deductively from general theories (Teddle & Tashakkori, 2009) identified in my literature review to make both major and minor hypotheses and predictions (Mertens, 2015) about how survey respondents think and feel about autism and ABA services in Ontario. The survey answers provided a “snapshot in time” of my variables and correlations of interest (Mertens, 2009, p. 191). For example, one correlation of interest is that autistic people have noted compliance-based behavioural therapies are problematic in that they do not value self-determination as a defined goal (Everett, 2019; Gardiner, 2019). Each survey question was carefully chosen to test such theories, along with other key elements identified within the literature included in my theoretical CAS framework.

I invited autistic and non-autistic colleagues with various positive and negative views of ABA to review the survey questions for accessibility, clarity, non-ableist language, elimination of bias and leading questions, and inclusion of key themes and concerns about ABA practices in Ontario. After all necessary edits were complete, I distributed the surveys online in late November of 2021⁵. I used the online survey software Lime Survey to host and distribute my surveys. Each survey had approximately eight groups of questions with ten or more specific questions in each. Respondents took an average of 45 to 60 minutes to complete their survey.

⁵ Edits were approved by York University Office of Research Ethics

The “save and resume later” option was enabled so that respondents could take breaks and return to the survey as needed.

Sampling and Recruitment

I used a random sampling method (Teddlie & Tashakkori, 2009) to recruit my three distinct groups of participants with open invitations to complete the online survey. I also used a purposive snowball sampling method that consisted of sending surveys via email to peers and colleagues who then circulated the survey to others who wished to participate (Tashakkori & Teddlie, 2010). I aimed to reach 150 or more participants in total (50 respondents from each group) to ensure I collected enough data to capture a snapshot of ABA/IBI outcomes in Ontario. By the time I closed the recruitment and data collection phase on June 1st, 2022, I had received 102 completed surveys. Of the 102 completed surveys, 100 met the inclusion criteria of the study: 68 autistic respondents; 12 parent/guardian responses; and 20 ABA provider responses.

Trustworthiness

All three surveys were pilot-tested at least twice by various colleagues and autistic community members to test for accessibility and feasibility of answering my research questions, which is a key recommendation in survey development for transformative research (Mertens, 2015).

The Lime Survey software included several security features including protecting respondent anonymity. Respondents were not required to enter their email address, but many chose to. To protect against fake submissions, I created a detailed survey that required thought, time, and energy to complete. For example, in order to move through each section of the survey, respondents were forced to complete questions within each series. My aim was to optimize assurances that respondents would take time to carefully read each of the questions and

corresponding choices. Question areas that included sensitive content (e.g., feelings of suicide) did not require forced completion. I collected and reviewed survey completion time stamps and IP addresses to ensure respondents took their time without completing the survey more than once. No compensation was offered for completion of surveys. To further mitigate bias, I was careful to consider the ways my surveys could be accessed equally by participants who had positive and negative experiences with ABA. I targeted recruitment on a wide range of autistic people, parents, and ABA practitioners from across the province of Ontario via flyers posted to social media, and emails to Ontario autism organizations that support ABA interventions.

Stage 2: Interviews

From March to June 2022, the interview stage took the form of eight 60-minute (approximately) semi-structured exploratory interviews with four autistic recipients of ABA in Ontario and British Columbia; two parents of children who had received ABA in Ontario; and two providers of ABA services in Ontario. This phase of the research required a further amendment to my ethics protocol to request the inclusion of four autistic interviewees instead of my original plan to include only two. I decided on this amendment after my initial scan of the survey data in March of 2022 revealed that only ten autistic respondents had received ABA services in Ontario (including IBI), while five had received ABA services elsewhere in Canada. The original scope of my thesis analysis was to focus only on those respondents who had received ABA in Ontario; I was planning to save data from other provinces for future research. Given the small number of respondents who had received ABA, I decided to widen the scope of interviewees. Additionally, the initial sample pool of ABA recipients represented a diverse community of autistic people who varied in terms of race, gender, support needs, and types of

ABA received. The addition of two more diverse autistic voices added further rigour to the research.

Purposive Sampling

I used a purposive sampling method to select the eight participants from my pool of survey respondents who offered further insight into the themes reflected in my research questions and survey analysis (Tashakkori & Teddlie, 2010). The process began with a set of inclusion and exclusion criteria (see Appendix B). To be considered for an interview, survey respondents needed to have stated a clear motivation to be interviewed and to have (preferably) been unknown to me in order to reduce any confirmation bias of my own stated positionality regarding ABA practice. Autistic respondents must have had received some form of ABA services to qualify for an interview. Once these first criteria were met, I scanned each survey for respondents who met the next set of inclusion criteria items (e.g., racial diversity; positive or negative experiences associated with ABA, etc.; see Appendix B: Inclusion and Exclusion Criteria for Interviews).

From the autistic respondent sample, I selected four respondents—two with positive experiences receiving ABA and two with negative experiences. From the parent and ABA provider samples, I selected a parent and ABA provider who had positive experiences with ABA and a parent and ABA provider who had negative experiences. In my initial recruitment phase, one autistic survey respondent did not reply to my email invitation after two attempts, which resulted in my choice to invite an autistic respondent known to me. This respondent was the most suitable choice due to her insights on more ubiquitous forms of informal ABA practices in schools, homes, and public spaces. What was further significant about the inclusion of this respondent was that her perspectives allowed for a critical, yet nuanced, analysis of ABA that

offered a deeper understanding into commonly taken for granted assumptions about autism interventions (e.g., that reward-based is always acceptable).

I made the best attempts possible to select a diverse representation of racial, gender, cultural, and marginalized identities in all three sample respondent groups. Within the autistic respondent sample, there were no non-binary or gender non-conforming recipients of ABA who agreed to an interview. This resulted in the selection of cis-gender respondents—two self-identified male recipients who were minimally-speaking or nonspeaking and who identified as white, one self-identified female who identified as white, and one self-identified female who identified as Black. Few parents and ABA provider respondents with diverse racial, gender, or marginalised identities agreed to an interview or did not respond to email invitations. This resulted in my selection of three self-identified white female participants and one gender non-conforming participant.

At the time of recruitment, only two parents with mainly positive experiences with ABA (one father and one mother) had agreed to an interview. Both of my attempts to recruit these parents by email were met with no responses. This resulted in a purposive sampling decision to recruit a mother who had shared some positive experiences with ABA in her survey but also shared that she questioned its effectiveness. I also recruited a parent with negative experiences with ABA who was known to me due to their high motivation to participate and share information that was important for my research questions. My provider survey respondent pool resulted in the selection of two female ABA providers—one in a formal ABA provision centre and one in a publicly funded high school. As per my inclusion criteria, one provider shared an overall positive experience of delivering ABA services while the other shared negative experiences.

Transformative mixed methods research requires the researcher to remain open to new insights and discoveries (e.g., that ABA can be helpful; it is becoming more trauma-informed; etc.) despite their own biases, worldviews, and positionality on the research topic (Mertens, 2015). When selecting two respondents known to me, I was careful to consider the ways they could provide perspectives of ABA that extended my thinking and did not contribute to confirmation bias.

Interview process

I followed the flexible semi-structured interview guidelines offered by Mertens (2015), which aimed to eliminate leading questions and to allow for unsolicited open-ended responses (see Appendix C: Example Interview Questions). After my selected participants had agreed to interviews, I adapted my interview guide by referring back to each participant's survey data to ensure I could attain the clarifications and elaborations I needed for further insight into statistical findings. A coding method allowed for correlations from my survey data in stage one to deductively formulate general questions for my interviewees. I focused the questions on similar themes and hypotheses that I had selected for testing during the survey creation stage while allowing for inductively formulated themes to arise through open questions without my preconceived agenda (Skjott Linneberg & Korsgaard, 2019).

My revised interview guide was re-submitted to ethics for approval in February of 2022, and I began interviews in March 2022. All questions and consent forms were emailed to participants ahead of time for assurance of accessibility and informed consent. All interviews were conducted over Zoom. I interviewed two autistic participants twice due to internet connectivity issues and the need for further clarifications of their experiences. Each participant received a \$25 gift card after each interview.

I used a phenomenological inquiry style of interviewing (Van Manen, 1990) to interpret my participants' lived experiences from each of their particular vantage points (Mertens, 2015). Phenomenology derives from the transcendental hermeneutic style of Edmund Husserl (1970) who argued it is important for researchers to bracket their own preconceived biases. Van Manen's (1990) view of transcendental phenomenology holds that researchers "must describe what is given to us in immediate experience without being obstructed by pre-conceptions and theoretical notions" (p. 184). This approach to interviewing can often be at odds with researchers who hold preconceived positionalities within a critical theory framework. However, I was drawn to phenomenological inquiry due to its roots in the constructivist paradigm that considers reality as a social construction that varies from person to person. Knowing that my own reality is as socially constructed as my participants', I aimed to bracket my positionality in order to remain open to new discoveries (Van Manen, 1990).

Mertens (2009) offers examples of a phenomenological approach to inquiry within a transformative research lens (see, for example, Gubrium & Holstein, 2002) that allows critical researchers to take "cultural, historical, and institutional concerns" into consideration when using phenomenological inquiry (p. 181). Each of my respondents had clear views and positionalities about autism and ABA services that, at times, differed from my own. While interviewing, I took heed of Mertens's (2015) important reminder of the tension that exists "between engaging in a true dialogue with the respondent and possibly biasing responses by triggering "expected" responses" (p. 32). The transformative lens to phenomenological inquiry allowed me to listen to a variety of perspectives with an understanding of the ways stigma and power influence all of our daily lives.

Anonymity

The four participants from the autistic ABA recipient sample waived anonymity for the purpose of participatory dissemination of research (see stage 4 later in this chapter). Two autistic participants (Clara and Russel) requested to present and publish our co-created work under single names only; one autistic participant (Kendra) chose to publish under a pseudonym with permission to release her true name to closed audiences (e.g., conference presentations and guest speaking opportunities). All anonymity choices were approved by the York University Ethics Review Board and made explicitly clear on participant consent forms (see stage 4 later in this chapter). The parent and provider interviewees remained anonymous with assigned pseudonyms.

Transcription

I drafted my interview transcriptions using the secure automated transcription service offered by the NVivo automation technology. I then reviewed the interview drafts to fix errors and add utterances that the automation had left out (e.g., pauses, chuckles, moments of sadness). One nonspeaking participant used an augmentative and alternative communication (AAC) device to type out his answers, which I left unaltered.

I reviewed my interviews several times as I coded for important themes. I adhered to what Bucholtz (2000) referred to as a “reflexive transcription practice” (p. 1462), which meant I stayed conscious of how I interpreted what was relayed by my participants while making careful decisions about what to include in my analysis. Commensurate with a phenomenological and transformative interview process, I tried to remain transparent and aware of my own impact on the data. I knew I could not completely separate myself from the data as I have my own preconceived assumptions and points of view. I checked in with my biases carefully as I edited the data (Bucholtz, 2000; Mertens, 2015). I asked myself questions such as, “did I lead the

participant to say this? Am I leaving this utterance out for a reason?” etc. I used a combination of naturalized transcription for purposes of clarity (i.e., text that conforms to accurate grammar and spelling conventions) and denaturalized transcription for authenticity of voice (i.e., participant speech style remains largely unaltered to capture the essence of the interviewees’ natural communication style).

Stage 3: Analysis

I used SPSS, NVivo, and Microsoft Excel software to analyze the statistical and qualitative results. The first stage of statistical descriptive analyses revealed an unexpected finding that changed the direction of my original analysis plan—only a small proportion of autistic survey respondents had actually received ABA interventions. This realisation led to my decision to keep surveys open while I conducted interviews. By the time surveys closed in June 2022, I had received 68 completed surveys in the autistic respondent pool that met the inclusion criteria of the study: 22 respondents had received ABA and 46 had not. This underrepresentation of autistic ABA recipients made it difficult to do comparisons of wellbeing and quality of life between recipients and non recipients of ABA as I had originally planned.

After careful examination of open text box answers provided by respondents who did not receive ABA, a new analytic method emerged, which is common in mixed methods research due to the complexity of triangulated data collection (Teddle & Tashakkori, 2009). Teddle and Tashakkori (2009) explained that “all MM [mixed methods] researchers can do is to establish a set of ideal types or “families” of MM research designs, which researchers can then creatively manipulate in specific research settings” (p. 125). As many of the non-recipients of ABA shared very detailed concerns about ABA, I used a method of thematic analysis (Teddle & Tashakkori, 2009) to organize five emergent themes, which mirrored the concerns raised by CAS scholars in

my theoretical framework (see Chapter 5). These thematized findings prompted a further question: in what ways do the perspectives of autistic non-recipients of ABA matter? The findings acted as an anchor for the remaining analysis of responses provided by autistic recipients of ABA, parents, and ABA providers (see Chapters 6-7). Because transformative research designs often employ a “cyclical use of data to inform decisions for next steps” (Mertens, 2007, 2009 as cited in Mertens et al., 2010, p. 9), I cycled back to the concerns of the 46 non-recipients of ABA to discuss findings from ABA recipients, parents, and ABA providers.

For the statistical analysis of autistic ABA recipients, parents, and ABA providers, I used a combination of descriptive and inferential statistics (Mann-Whitney U test of mean ranks and Chi-square tests of association) to test hypotheses that emerged within my CAS theoretical framework. I then used the NVivo software to code and select interview data from stage two that I felt provided deeper explanatory insight into the statistical findings (see “Stories Behind the Statistics” in Chapters 6 through 7). To create qualitative tables of survey respondents’ open text box answers, I used Microsoft Excel to perform the sequential explanatory method of selecting and organizing a balanced representation of perspectives that deepened the understanding of the statistical findings (Mertens, 2015; Teddlie & Tashakkori, 2009).

Similar to the method of selecting open text box responses, I reviewed each of the eight interviews to code and select key examples from the lived experiences of interviewees that illuminated findings from statistical data. I reported these experiences in the form of eight *Stories Behind the Statistics* following carefully selected statistical findings related to each story’s main themes (see chapters 6 and 7). I nested each story under statistical findings that closely matched the emergent themes from their lived experiences (e.g., Damon’s story followed statistical findings about educational outcomes, etc.).

My primary aim through this stage of analysis was to maintain the integrity and phenomenological vantage point of participant experiences (whether I personally agreed with their standpoints or not) with an understanding that their experiences are shaped by the context of their social environment (Berger & Luckmann, 1966). To maintain flow and emphasis on participant experience, I opted to remove my own voice (e.g., specific interview questions) as much as possible. I used two specific methods of reporting style – 1) chronological reporting and 2) reporting of critical/key events. These reporting choices were dependent upon each participant's interview engagement style (Mertens, 2015). For Russel and Clara's stories, I presented interview findings in chronological order of themes that emerged from my open-ended questions (e.g., personal views and lived experiences of autism; their positive experiences of ABA; their feelings of distress caused by some ABA interventions; their overall feelings about ABA; and their future hopes for autism services). For the other six participants who adhered less strictly to the interview guide and had specific experiences they wished to share, I reported on key experiences of ABA that were important to each of them.

A further aim at this stage was to reduce my data into manageable chunks by labelling "excerpts of data that conceptually 'hang together'" (Mertens, 2015, p. 512). I also recognized that it would be important to use inductive reasoning to seek patterns in my thematic analysis to formulate new possible theorizations of ABA based on diverse experiences (Mertens, 2015; Teddlie & Tashakkori, 2009). I kept memos with the NVivo software to keep track of any additional curiosities and clarifications that emerged as interviews proceeded (Teddlie & Tashakkori, 2009). I remained observant for outliers and disruptions to my preconceived ideas and theories and not just phenomenon known to me (Skjott Linneberg & Korsgaard, 2019). For example, one parent introduced me to the concept of autistic disinhibition (behaviour that is not

communication), which I had previously not been aware of. In another interview, an autistic participant mentioned he was somewhat hopeful about a new form of trauma-informed ABA developed by Greg Hanley (2021). Memos proved to be a useful way to keep track of my reflections to re-visit with participants at later dates through email or additional interviews (Skjott Linneberg & Korsgaard, 2019).

Finally, in transformative mixed methods research, it is often important to maintain a cyclical and iterative flow to knowledge production (Mertens et al., 2015). I maintained an iterative flow and trustworthiness of my data through a method of “member checks” that I conducted through email exchanges and Zoom calls. I asked participants to review and edit their stories to ensure their experiences were relayed in the way they had intended (Mertens, 2015, p. 519). All participants thoroughly reviewed, clarified, and edited the interview stories and audio/video materials for conferences and publications (see stage 4 that follows).

Stage 4: Participatory Collaborations for Dissemination

Mertens (2015) emphasized “catalytic authenticity” as an important criteria for transformative mixed methods, which she described as “the extent to which action is stimulated by the inquiry process” (p. 336). The action stimulated by this dissertation research involved inviting the four autistic participants I had interviewed in stage two to create presentations that included prerecorded audio clips and videos for use in conference proceedings and workshop training for educators or ABA providers. All four participants agreed to engage in this stage. I supported each participant via 5 individual one-hour Zoom sessions spanning the months of August 2022 to March 2024. Each participant received \$125 in gift cards for their participation.⁶

⁶ None of the participants worked together or met each other during this stage of research

In the Summer months of 2022, I sought out conference opportunities in the field of Education, Child and Youth Work, and autism policy. The first conference proceeding was the *National Child and Youth Care conference: Reaching for a Better Tomorrow* in Canmore, AB, Canada in October of 2022. Two of the participants (Russel and Clara) prepared audio files, which we selected together from select moments in their interviews and adapted for the purpose of presenting to an audience. The other two participants (Damon and Kendra) prepared videos on their own time with minimal support from me. I provided each participant with the following prompts: What did you like and/or dislike about receiving ABA services? What recommendations do you have for autism policy and practice in Canada? Each set of audio clips and videos were approximately 6 minutes each in length. I further supported two participants (Clara and Russel) in selecting licensable images and graphics (e.g., from Pixabay and Canva) for the purpose of adapting their audio files into streamlined video files which could be used in future workshop and/or conference proceedings.

In March of 2023, I included the audio files and videos in a digital poster presentation at *The Rosa Bruno-Jofré Symposium in Education* at Queen's University in Kingston Ontario and the 10th Biannual *Provoking Curriculum Conference* at Western University in London, ON. During the former presentation, one participant (Kendra), presented her own recommendations for educators together with me in person. To meaningfully optimize research benefits and reciprocity for participants, I supported each participant to add these conference experiences to their resumes, LinkedIn pages, and curriculum vitae (CVs). All four autistic participants have plans to pursue academic careers, guest speaking opportunities, or coaching support for parents/practitioners in neurodiversity-affirming care. The hope is that these experiences become valuable for their future career aims.

In tandem with transformative and cyclical mixed methods research designs, the aim is for these conference proceedings and publishing opportunities to generate critical discussions about ethical approaches to autistic care (see the Deaf community study by Mertens et al., 2015, p. 11, for a similar participatory dissemination of results). The conference proceedings from 2022 and 2023 generated much enthusiastic engagement and discussion from audience members who were interested in improving mental health and behavioral services for autistic people. I reviewed presentation materials and feedback from audience members with all four participants via email and Zoom calls.

In February 2024, I received confirmation of acceptance to have my dissertation findings published in a proposed special issue of the peer-reviewed *Journal of the Society for the Psychological Study of Social Issues (SPSSI): Using Neurodiversity-Affirming Intersectional Approaches to Build More Equitable Societies and Shape Public Policy*. The expected publication date is December 2024. As part of this publication, I supported my four autistic research participants to write and edit their recommendations for autism policy and practice. These recommendations are expected to be published in co-authorship with me in both the journal submission and/or forthcoming publications.

In March of 2024, I further amended my ethics protocol to receive editing support from a local autistic filmmaker and video editor to adapt Clara and Russel's audio files and selected images/graphics into streamlined videos (see acknowledgments at the beginning of this dissertation). Current plans in 2024 onward include making participant videos available upon request for ongoing invited guest speaking engagements, workshops and conference opportunities. The autistic participants will be credited for their contributions and invited to attend panel discussions.

Non-participatory dissemination also included digital posters presented at the annual *Canadian Autism Leadership Summit (CALs)* and The American Educational Research Association (AERA) in April of 2024. In each of these presentations I promoted the expertise of my autistic participants and encouraged future networking and guest speaking opportunities.

Chapter 4: Respondent Views: A Synopsis of Identity and Standpoints

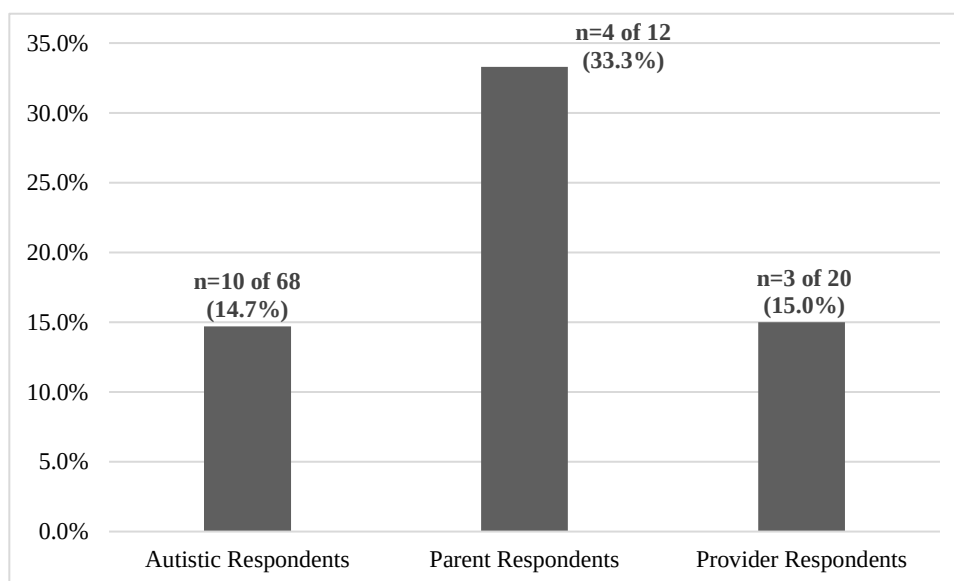
The goal of a transformative paradigm is to effect social change through an understanding of personal standpoints within the context of power and social constructs (Mertens, 2015). It is therefore important to provide an overview of perspectives provided by the 100 respondents surveyed. This chapter explores an analysis and discussion of the 100 survey respondent perspectives related to: autism identity; functioning labels; ABA effectiveness as a support model for autistic young people; and whether the field of ABA has improved over time. For demographic details of each respondent group, see demographic tables presented in Chapters 5, 6, and 7.

Views of Autism: Autism as a Disorder or Neurotype, Spectrum, and/or Culture

The first point of analysis examined respondents' views of autism or autistic identity. All three of the survey respondent groups were asked the same multiple-choice question: "*Choose the statement(s) that best fits your view of autism*". There were six selections available: a) "Autism is a culture and/or an identity shared by many autistic people"; b) "Autism is a disorder"; c) "Autism is a naturally occurring brain difference/neurodivergence/neurotype, and not a disease or disorder"; d) "Autism is a spectrum – it affects different people in different ways"; e) "Autism is a spectrum within a person – it affects a person differently in different ways on different days"; and f) "other". For the purposes of analysis, the six selections were divided into a binary variable

of views representing “autism is a disorder” and “other view”⁷. Of the 100 responses, only 17.0% (n=17) selected that they viewed autism as a disorder. Ten of the respondents who made this selection were from the autistic group (14.7% of n=68), four were parents (33.3% of n=12), and three were providers (15.0% of n=20). A Chi Square test of association found no statistically significant difference in proportions across the three groups of respondents, $\chi^2(2, N=100) = 2.579, p = .275$. This result indicates that, despite the persistent description of Autism Spectrum Disorder (ASD) in diagnostic manuals (American Psychiatric Association, 2013), only a small proportion of respondents across all groups viewed autism through a deficit medical model of disability. See Figure 4.1.

Figure 4.1. Proportions of Respondents’ Views of Autism as a Disorder



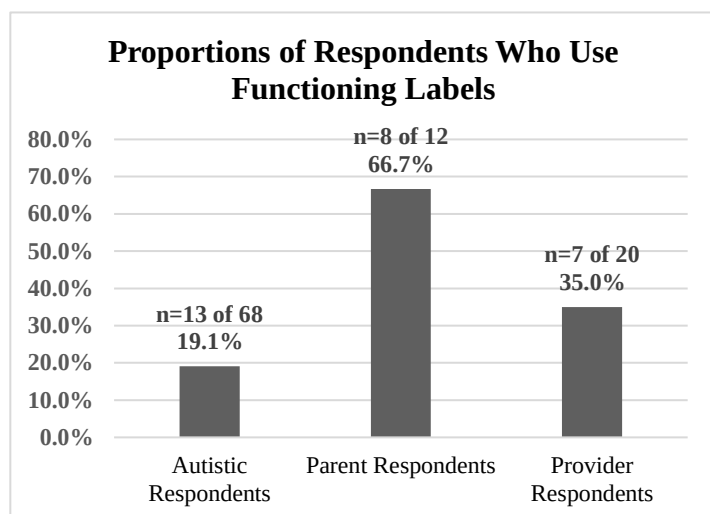
Views of Functioning Labels

Similarly, I asked all three respondent groups the following question: “Choose the statement(s) that best fits your view of autism functioning labels. Explain further in the space

⁷ Note that some respondents who selected “autism is a disorder” also selected other options.

provided if needed.” Respondents could choose from the multiple-choice selections: a) “Autistic people can be high or low functioning, moderately or more severely affected, depending on the person”; b) “I don’t agree that there are high or low functioning labels or severe, moderate, or mild forms of autism.”; or c) “I have no particular view of autism functioning labels.” Results indicated that only 28 of 100 respondents (28.0%) selected that they felt autistic people can be defined in terms of high or low functioning labels. Thirteen of these respondents were from the autistic group (19.1% of n=68); eight were from the parent group (66.7% of n=12); and seven were from the provider group (35.0% of n=20). Over two thirds of total respondents (70.0%, n=70) selected that they did not agree with functioning labels, and two selected that they had no particular view. A Chi Square test of association revealed a statistical difference existed between respondent groups: $X^2(4, N=100) = 13.360, p = .010$. This result indicated that, while the majority of respondents did not agree with the use of functioning labels, parents and providers were more likely to agree with functioning labels than autistic people themselves. When broken down further, results revealed that ten respondents from the parent and provider respondent groups identified as neurodivergent or autistic (two parents and eight providers); all ten of these respondents disagreed that there are high or low functioning forms of autism. This additional finding suggests that autistic and neurodivergent respondents are less likely to agree that functioning labels are accurate descriptors of autistic support needs despite being outlined as such (i.e., levels 1, 2, and 3 – low to high support needs) in the DSM 5 (American Psychiatric Association, 2013). See Figure 4.2.

Figure 4.2. Respondents Who Use Functioning Labels to Describe Autistic Experiences



Views of ABA Interventions as a Support Model for Autistic Young People

To analyse views about ABA, I asked respondent groups different questions dependent on their stakeholder status as either autistic people, parents (i.e., the consumers of ABA) or ABA providers.

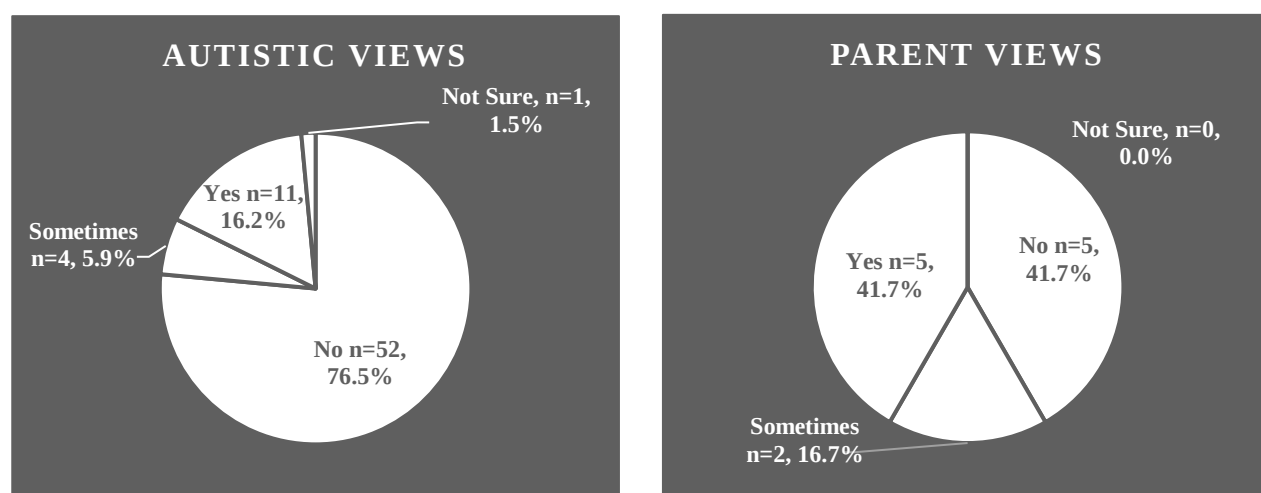
Autistic and Parent Perspectives

To gain a consumer's perspective, I asked both autistic⁸ and parent respondents the question, "*Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?*" Respondents could choose from the options, "yes", "no", "sometimes", or "I'm not sure". Results revealed that close to three quarters (71.3%; n=57) of the 80 autistic recipient and parent respondents combined did not feel ABA interventions are an effective support for autistic young people. When compared by group, results showed that over three quarters (76.5%) of autistic respondents (n=52) selected "no". This compared to close to half (41.7%) of parents (n=5) who selected "no" and another 41.7% (n=5) who selected "yes". A Chi Square test of

⁸ Note that for this initial overview of standpoints, all 68 autistic responses were included in the analysis whether they received ABA or not

association did not find a statistically significant difference between the groups, $\chi^2(3, N=80) = 6.806, p = .078$. This result negates a common hypothesis posed by some autistic activists and education scholars who suggest that parents are more likely to find ABA to be effective than autistic people themselves (Kohn, 2020; Sparrow, 2015). However, given the sizable differences in response proportions between groups, further studies with larger samples are needed to make stronger inferences. See Figure 4.3.

Figure 4.3. Perspectives of ABA Effectiveness: Autistic and Parent Views Compared



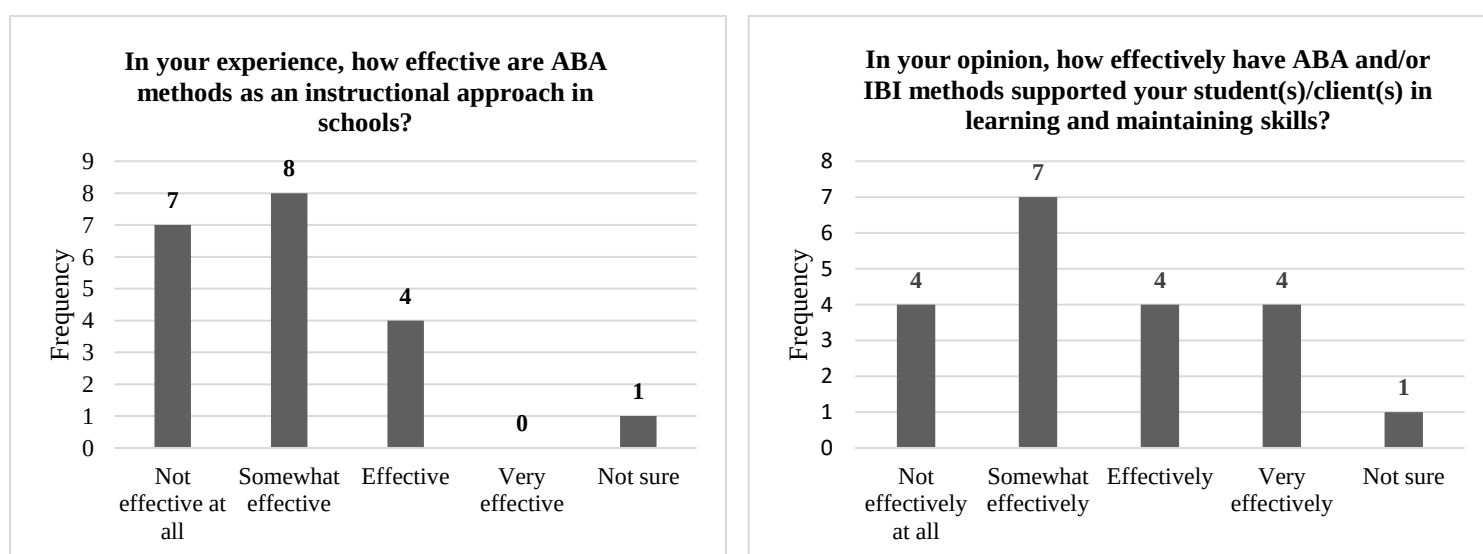
Providers

To further examine ABA effectiveness from the provider standpoint, I asked ABA provider respondents (n=20) different questions than autistic respondents and parents, including a series of specific questions related to their own ABA practices. The following analysis focused on one question in this series that asked, “*In your experience, how effectively have ABA and/or IBI methods supported your student(s)/client(s) in learning and maintaining skills in the following general areas?*” Respondents could rate 14 different areas of skill development using the Likert scale options of, “very effectively”, “effectively”, “somewhat effectively”, “not effectively at all” or “not sure/not applicable”. I chose one of the 14 areas that is commonly

identified in ABA literature as an indicator of improved quality of life: “*learning independence and life skills (e.g., toileting, hygiene, public transit, self-help skills, etc.)*”⁹ (see Ontario Association for Behaviour Analysis [ONTABA], 2020). Results revealed that less than half (40.0%) of the provider respondents (n=8) felt that ABA either very effectively (n=4) or effectively (n=4) supported their clients or students with life skills.

Due to the large proportion of the provider respondents who delivered ABA interventions in schools (see Demographic Table 7.1 in Chapter 7), I further decided to examine providers’ perspectives from one key question related to ABA practices in the Ontario education system: “*PPM 140 states that ABA is an effective instructional approach in the education of many students identified with autism. In your opinion, how effective are ABA methods as an instructional approach in schools?*” Results revealed that only 20.0% (n=4) of ABA providers felt that ABA was an effective approach in schools. Of particular note, none of the respondents selected that they felt ABA was “4 - very effective”. See Figure 4.4.

Figure 4.4. Provider Perceptions of ABA Effectiveness in Schools and Improving Life Skills



⁹ The remaining 13 indicators will be saved for analysis in future studies

These comparative results suggest that while some provider respondents felt ABA interventions could support autistic young people's quality of life in terms of learning life skills, fewer were confident that ABA could be a supportive instructional approach to support the educational success of autistic students in schools. This is an important finding given the Ministry of Education's mandate to support the success of autistic students with ABA strategies in Ontario special education programs (Ontario Ministry of Education, 2007).

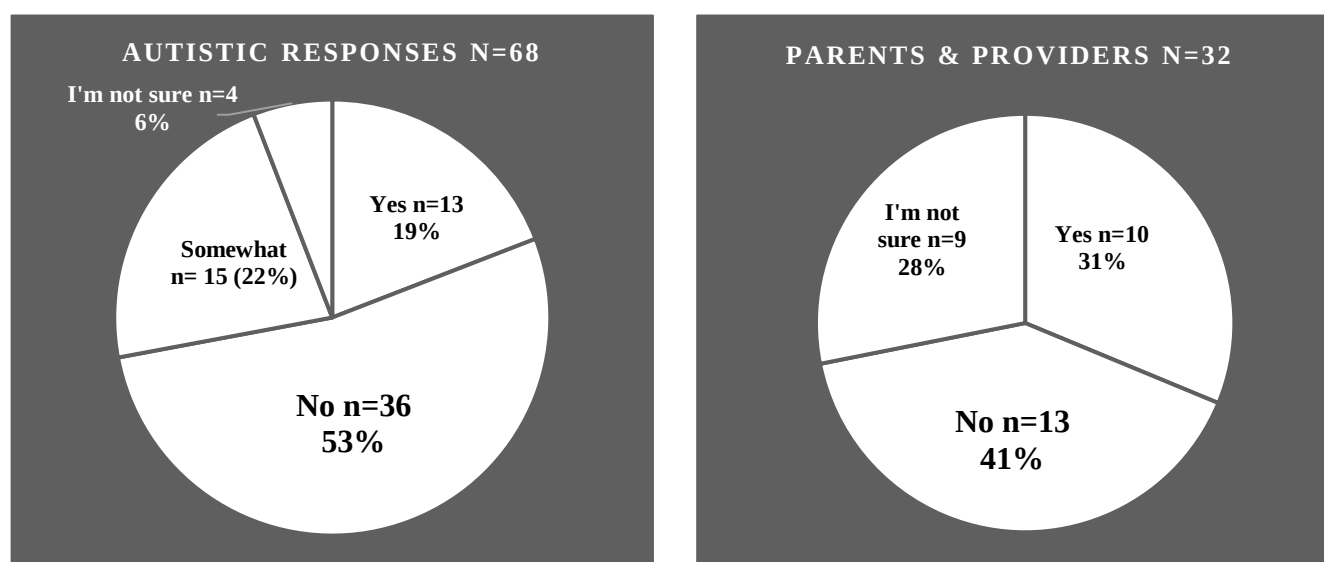
Views of Whether ABA Has Improved

In response to the many critiques and concerns about the compliance-based nature and troubled history of punishment-based procedures in ABA, the field is currently undergoing transformation. Most recent transformations include the development of trauma-informed, (Kolu, 2021a; Rajaraman et al., 2022; Stack, 2021), autistic-centered (Do Better Collective, 2023; Hanley, 2021), and neurodiversity-informed ABA practices (Mindful Behavior, 2024). There has also been a historical shift away from punishment based procedures recorded in research since the late 1990s (Hanley et al., 2005; OSETT-ASD, 2017; Pelios et al., 1999). However, some punishment procedures, such as contingent skin shock therapy for extreme problem behaviours or planned ignoring/withholding favourite items for less extreme behaviours, continue to be endorsed and practiced (Blenkush, 2017; Blenkush et al., 2023; Cooper, Heron, & Heward, 2020; Israel et al., 2008; Matson, 2023; Slocum et al., 2022; Tarbox, 2018).

To examine whether respondents of this study felt that ABA has improved over time, I analysed responses to the following question, *“In your opinion, has the field of ABA/IBI improved over time?”* Autistic respondents were given the options to select answers ranging from “yes”, “no”, “somewhat”, or “I’m not sure”. Parents and providers were given three options

of “yes”, “no”, or “I’m not sure”.¹⁰ Results revealed that over half (53%; $n=36$) of the autistic group selected a definitive “No” compared to 41% ($n=13$) of the parent and provider group combined. To test whether there was a significant difference of definitive answers between groups, I conducted a 2x2 Chi-square test of analysis that compared binary selections of “no” and “other selections” (i.e., selections of yes, somewhat, and not sure). Results revealed no significant difference between groups, $\chi^2(1, N=100)=1.321, p = .250$. See Figure 4.5.

Figure 4.5. Respondent Views of Whether ABA Has Improved Over Time



Conclusion

With respect to autism identity, a majority of respondent views reflected recent neurodiversity standpoints (e.g., autism is a neurotype)¹¹ that oppose the pathologized medical model framing of autism as a ‘disorder’ (Autistic Collaboration, 2019; Walker, 2016). Similarly, over two thirds of respondents did not agree with the use of functioning labels for describing autistic experiences. This finding may reflect a population sample skewed toward a justice-

¹⁰ The difference in answer options occurred unintentionally during the creation process of the surveys.

¹¹ A later finding in Chapter 7 revealed that some autistic people do not view use the word ‘autism’ as a noun, but rather prefer the adjective form ‘autistic’ to describe their identity (i.e., “I am autistic”; “my identity is autistic”)

oriented CAS paradigm comprised of autistic activists and scholars who reject the usefulness of functioning labels due to their dehumanizing and inaccurate portrayal of autistic abilities, needs, and strengths (Bascom & Perry, 2022; Burgess, 2016; Williams, 2019). Recent studies, such as the regression analysis of functioning ability predictors in 2,225 autistic young people (Alvares et al., 2020), have provided evidence to support an end to the use of functioning labels. Alvares and colleagues' (2020) study concluded that standardized measures of functioning abilities used for autism diagnoses and ABA treatment recommendations are inaccurate, particularly for those participants labelled as "high functioning" whose life skill support needs go unnoticed due to having an average or higher IQ. Their findings support the lived experiences of autistic people labelled as 'high functioning' who express frustration at the assumption they have better life skills and need less support simply because they can speak, write, or perform academically (Burgess, 2016; Singh Chawla, 2019; Williams, 2019). The inaccuracy of functioning labels has further been challenged by autistic people labelled with "severe" or "low functioning autism" whose capabilities are underestimated due to presumed incompetence or lack of access to augmentative and alternative communication (AAC) (Biklen & Burke, 2006; Communication First, 2021; Habib, 2018; Higashida, 2016; Kedar, 2012; Kirsebom, 2020; Mukhopadhyay, 2011; Peña, 2019).

Similarly, with regard to perceptions of ABA effectiveness, a majority of respondents did not feel ABA interventions were always an effective support for autistic young people, which aligns with the activism and scholarship found in CAS literature (see Chapter 2). What was surprising was that this finding included parents and ABA providers who are more often believed to support ABA interventions than autistic people themselves (Kohn, 2020; Sparrow, 2015). This result highlights a possible shifting of community perspectives once dominated by the medical

model worldview that “prescribes” ABA as the best available treatment for Autism Spectrum Disorder (OSETT-ASD, 2017). In fact, similar results have been found elsewhere. In a study asking the opinions of 7,491 autistic people worldwide, Chris Bonello (2022), autistic researcher, educator, and activist found that a large majority of respondents (79%; n=5,195) strongly disagreed with the use of ABA for autistic children. Another study found that 78% of 824 autistic people surveyed (mainly from countries in Europe with small percentage from the United States and elsewhere) were against or strongly against ABA (The European Council of Autistic People [EUCAP], 2022). Interestingly, Bonello’s (2022) study further found that over half of 787 non-autistic professionals (60.0%; n=472) and over one third of 622 parents/caregivers of autistic children who have experienced ABA (34.7%; n=216) either disagreed or strongly disagreed with the use of ABA for autistic children. Similarly, fewer than 20% of all Bonello’s respondents felt that autism was a definitively a ‘disorder’, which reflected findings reported earlier in this chapter that revealed medicalized and deficit-based definitions of autism within the public consciousness are on the decline.

Lastly, with respect to whether respondents of my surveys felt ABA has improved over time, over half of the autistic respondents and close to half of the parent and provider respondents (combined) selected a definitive “no”. This suggests that considerable opposition to newer forms of ABA continues to persist despite efforts by the field of ABA to transform their practices. Again, Bonello’s (2022) survey revealed similar results – 63.5% of autistic respondents who were likely to have received newer forms of ABA (i.e., respondents who were ABA recipients between the ages of 0-19) either disagreed or strongly disagreed with the use of ABA for autistic children¹².

¹² Further analysis and discussion of these respondents’ open text box responses will be made available in future publications.

The following chapters explore several specific analyses of the reasons respondents either support, or do not support, ABA as an appropriate method of intervention for autistic young people in Ontario and elsewhere. Chapter 5 begins this exploration with an analysis of autistic respondents who, despite not personally receiving ABA interventions themselves, had several important perspectives to share.

Chapter 5: Autistic Allies of Autistic Recipients of ABA: Speaking Up and Speaking Out Against Harms

Overview

In this chapter, I introduce findings from 46 of the 68 autistic survey respondents who I have named, *autistic allies* of autistic recipients of ABA. These respondents are autistic people who, despite not receiving ABA interventions themselves, care enough about the wellbeing of autistic recipients of ABA to share deeply thoughtful views about the practice of ABA as they understand it. Key demographics of these respondents are detailed in Table 5.1.

Table 5.1. Demographic Characteristics of Autistic Allies Who Did Not Receive ABA (n=46)

Characteristics	n	%
Gender		
Agender; Transgender; Nonbinary	19	41.3%
Female	20	43.5%
Male	7	15.2%
Sexual Orientation		
Queer (gay, lesbian, pansexual, Two Spirit, questioning, asexual, etc.)	32	69.6%
Heterosexual ¹	14	30.4%
Race		
White	40	87.0%
Black	0	0.0%
Varied (e.g., Mixed background, South	6	13.0%

East or East Asian, Middle Eastern, Metis)		
Highest level of education ²		
Elementary and/or middle school	2	4.3%
High School	6	13.0%
College or Technical/Trade School	11	23.9%
University+ (undergraduate degree or above)	26	56.5%
None of the above	1	2.2%
Autism Diagnosis		
Received diagnosis from a doctor/psychologist	29	63.0%
Self diagnosed/faced barriers to diagnosis	17	37.0%
Identity Preference		
Identity First Language (IFL) Only	36	78.3%
Person-First Language (PFL) Only	0	0.0%
Either IFL and/or PFL	7	15.2%
Other (e.g., neurodivergent, Asperger's Syndrome, 'on the spectrum')	3	6.5%
Co-occurring Identifications/disabilities ³		
Intellectual Disability	0	0.0%
Intermittent/minimally speaking with Learning Disability (LD)	2	4.5%
Other Neurodiverse identities (e.g., ADHD, LD, Gifted, Behavioral/emotional challenges, etc.)	42	95.5%
Place of Current Residence		
Ontario	30	65.2%
Elsewhere in Canada	14	30.4%
United States	2	4.3%
Age at time of survey		
20-30 years old	15	32.6%
30-40 years old	18	39.1%
40 years +	13	28.3%

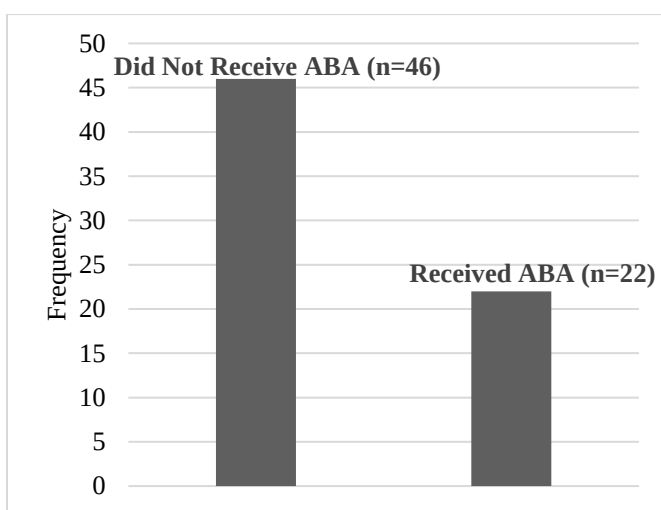
¹ Note. Three respondents selected both heterosexual and asexual

² Note. There were 2 missing cases

³ Note. Only one respondent identified with a 'Gifted' diagnosis specifically

The analysis begins with parallel quantitative and qualitative mixed-methods results from two survey questions: 1) *Have you ever received ABA, IBI, or ABA-informed services for 6 consecutive months or more in the province of Ontario?* And 2) *Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?* Results from the first question revealed an unexpected finding: over two thirds (67.6%; 46 out of 68) of autistic respondent surveys were completed by autistic people who did *not* receive ABA interventions (See Figure 5.1). Given the number of emerging blogs, stories, and studies that highlight the motivation of ABA survivors to speak out about their experiences (e.g., Ask an Autistic, 2019b; Neuroclastic, 2021), I had expected that the majority of my respondents would have received ABA themselves.

Figure 5.1. Number of Autistic Respondents Who Received and Did Not Receive ABA Interventions



To accompany their responses, many of the 46 autistic allies provided in-depth and well researched concerns about ABA interventions in the open text box areas of the survey. My own careful analysis of their concerns, coupled with the myriad concerns I had discovered through my review of CAS literature (see Chapter 2), provided me with an opportunity to interrogate the common argument that those who critique ABA are too ‘high functioning’ to be in need of ABA

and therefore have no say (Busch, 2019a; Dawson, 2021; Kavchak, 2020). This argument, levied by proponents of ABA (mainly parents or ABA providers), is summed up by Peter Dawson (2021), father of an autistic son whom he describes as “at the severely affected end of the spectrum” (p. 4):

... those who don’t need IBI/ABA treatment frequently denounce both the treatment and those parents who try to help their kids who need the treatment get access to it. Many of these people can function very well without the treatment and don’t need any” (p. 56).

Autistic scholar, Ryan Collis (2023), described this argument as a “no true Scotsman fallacy” by which proponents of ABA attempt to create “a model of a true” advocate (i.e., only those considered to be severely autistic), “while any autistic who can argue against the model is clearly not that kind of autistic and has no business commenting” (p. 1). Collis (2023) pointed out the irony of this argument from non-autistic parents who arguably, by terms set out in their own rationale, have ‘no business’ speaking on behalf of autistic people either.

Autistic responses to this common criticism from parents and ABA providers include the position discussed in the previous chapter that functioning levels are inaccurate descriptors of autistic needs and strengths and cannot be determined by non-autistic people (Bascom & Perry, 2022; Burgess, 2016; Burns, 2019; Collis, 2023; Flynn, 2018; Williams, 2019). Autistic people and other opponents of ABA have further emphasized that *no* autistic child, regardless of support needs, require ABA interventions (Rosa, 2020; Sequenzia, 2015; Sparrow, 2015; Williams, 2019).

The viewpoints shared by these 46 autistic ally respondents reflect perspectives from within critical autism studies (CAS) in such a way as to contextualize the findings discovered throughout my entire study. The qualitative thematic analysis of open text box responses includes

one key example shared by selected respondents within five identified themes (see Table 5.3). These themes are explored alongside commentaries, historical literature, and studies that exist both within and about the field of ABA in an attempt to answer the question, do the perspectives of autistic people who have not received ABA matter?

Do Autistic Allies' Perspectives Matter?

To answer this question, I analysed the 46 autistic allies' responses of "yes", "no", "sometimes", and "not sure" to the question, *"Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?"* Results revealed that the vast majority of these respondents (89.1%; n=41) selected "no". See Table 5.2 for results.

Table 5.2. Autistic Allies Who Have Not Received ABA: Feelings of ABA Effectiveness

Response Category	n	%	Cumulative %
1 No	41	89.1%	89.1%
2 Sometimes	3	6.5%	95.7%
3 Yes	2	4.3%	100.0%
4 Not sure	0	0%	
Total	46	100.0%	

Mean and Standard Deviation: M=1.15, SD=.470

Of the 41 respondents who selected "no", 34 chose to elaborate on their answer using the open text box area provided. Four of these respondents did not consent to having their responses published, and three provided answers without enough detail to be considered for analysis (e.g., "Not as it currently stands"). Two of the three respondents who selected "sometimes" chose to respond briefly in the open text box area, but only one consented to have their comment

published and wrote, “I do not personally believe in it, but I know people who have received ABA and they feel it works for them.” Only one of the two respondents who selected “yes” chose to respond briefly with the comment, “Yeah very efficient”.

The remaining 27 open-text responses (all accompanying selections of “no”) have been organized into five themes: 1) ABA is based “on a faulty premise”; 2) ABA is conversion therapy; 3) ABA is compliance training; 4) ABA is not actually evidence-based; and 5) ABA is harmful and abusive. See Table 5.3¹³. The analysis of these themes are explored through a “politics of truth” (Broderick, 2022, p. 47) that understands the ways positivist ideologies that make claim to evidence-based ‘truths’ are invested in the scientific aim of autism ‘recovery’ as opposed to autistic wellbeing.

Table 5.3. Open Text Box Responses of “No” to the Question, “Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?”

Theme	Comment Count Within Theme	Example Comment
ABA is based “on a faulty premise”	3	“It starts out on a faulty premise that autistic people are less than neurotypical people and reinforces that idea through it’s practice.”
ABA is "akin to conversion therapy" that aims to normalise autistic children	5	“... It is akin to conversion therapy and it’s roots are the same (see Lovaas’ Feminine Boys Project). While conversion therapy is now widely condemned, ABA continues to be held as the ‘gold standard treatment’ for autistic people.”
ABA is compliance training	5	“...[ABA] focuses more on compliance with dominant social/behavioural norms (or simply the demands of authorities) than on developing useful skills and autonomy...”

¹³ Note that several comments overlapped across themes; I counted responses according to the major theme respondents articulated and chose one example comment from each theme.

ABA lacks a sufficient evidence-base	2	“it’s not nearly as 'evidence-based' – as far as I know there still have yet to be any studies comparing long-term outcomes for people who’ve had ABA/IBI therapy and people who haven’t, calling into question whether 'intensive intervention' in autistic children’s development produces any significant benefits at all.”
ABA is harmful and abusive	12	“it is essentially based around coercion (whether through punishment or rewards) and commonly employs physically and emotionally abusive tactics that have traumatized many people subjected to them and/or made them susceptible to further abuse.”
Total	27	

Concern #1: ABA is Based on a Faulty Premise

To analyze the first concern that “[ABA] starts out on a faulty premise”, I explored several common assumptions about autistic experiences derived from the pathology paradigm of autism (Walker, 2021)¹⁴. The first assumption relates to the commonly argued notion that ABA is a medically necessary treatment for autistic children, particularly those children labelled as ‘low functioning’, or ‘severely/profoundly’ autistic (Busch, 2019b; Dawson, 2021; Kavchak, 2020; Shepherd & Waddell, 2015). This assumption directly relates to the argument presented by proponents of ABA in the conclusion of Chapter 4 who claimed that the anti-ABA activism is driven by ‘high functioning’ autistic people who do not need ABA. To further this claim, ABA proponents have argued that efforts to limit access to ABA services “explicitly excludes the voices of children and families impacted on the severe end of the autism spectrum” (Busch, 2019a para. 1). This argument presumes that if autistic people “on the severe end of the

¹⁴ It is important to note that these five assumptions are not intended as a comprehensive list as a more thorough discussion would exceed the scope of this project.

spectrum” or their families were included in policy decisions, they would have different (i.e., good) things to say about ABA. This assumption is not backed by evidence.

Countless autistic advocates labelled with ‘severe’ autism, along with their families, have shared lived experiences of the ways in which ABA interventions caused harm through a misinterpretation of needs and cognitive abilities (e.g., Autistic Strategies Network, 2022; Clinton, 2019; Kedar, 2012; Kirsebom, 2020; Melnychuk, 2019; Reyes & Reyes, 2018; Rosa, 2020; Sedgwick, 2019; Sequenzia, 2015; Summers, 2022). Furthermore, a recent review of ABA literature found evidence that directly contradicted assumptions about ABA effectiveness for autistic children labelled with ‘low functioning’ or ‘severe’ autism (Sandoval-Norton & Shkedy, 2019). In their in-depth analysis of the ABA evidence base, Sandoval-Norton and Shkedy (2019) noted that ABA studies often show behaviour change and skill building efficacy (e.g., life, speech, and academic skills) for autistic children who score higher on pre-intervention IQ measurements of 70 or above (e.g., Virués-Ortega, 2010). Despite the many problems with skill building, IQ scores, and behaviour change as indicators of ABA efficacy (more on this discussion to follow), the fact that ABA studies lacked these efficacy outcomes for autistic children with lower IQ scores indicates a possibility that ABA has not been a helpful support for nonspeaking autistic people in the ways it was intended (Sandoval-Norton et al., 2021; Sandoval-Norton & Shkedy, 2019).

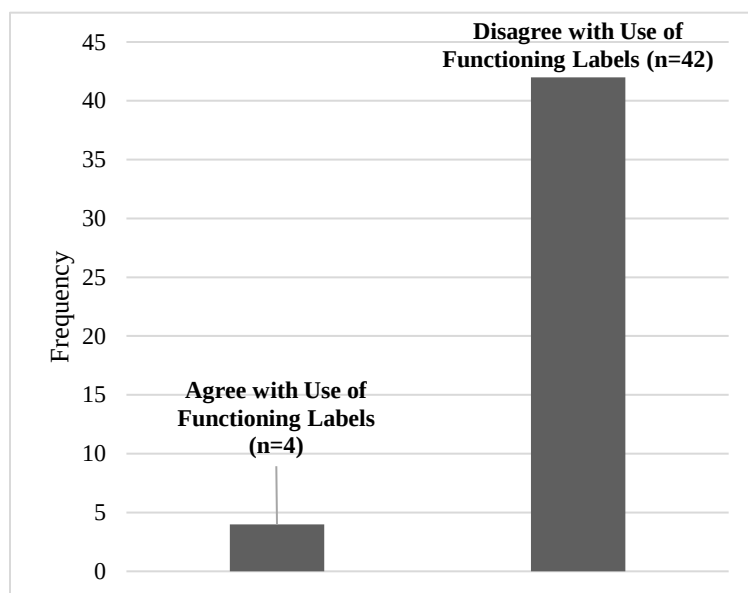
Indeed, several of the Ontario studies included in the OSETT-ASD (2017) report of best evidence for ABA efficacy with large autistic populations in community settings (e.g., Flanagan et al., 2012; Perry et al., 2008, 2011, 2019) found that children with higher IQ and behaviour scale scores at treatment outset responded better to the behaviour goals targeted (e.g., non-specified daily living skills, reduced autism symptoms, IQ scores, etc.). Perhaps most

importantly, there is little evidence to support the claim that ABA is medically necessary for any autistic child, regardless of support needs (see Ackley et al., 2019; Falligant et al., 2022; King, 2020; McGlade et al., 2023; Mitteer et al., 2022; Reichow et al., 2018; Rogers et al., 2021; Sandbank et al., 2020; Strydom et al., 2020; Tachibana et al., 2017; Zamzow, 2022). More on the gaps and problems with ABA evidence will be discussed under Concern #4.

Additionally, there is little evidence to support the assumption that autistic people who critique ABA online have fewer support needs than others. Over 90% of the 46 autistic ally respondents of my survey agreed that functioning labels inaccurately reflect their needs (see Figure 5.2). In fact, 44 of the 46 respondents identified with co-existing disabilities, neurodivergences, and challenges, which may indicate they have significant support needs. As autistic people, and even parents, have pointed out (see conclusion section of Chapter 4), it is unreasonable to base an opinion about an autistic person's functioning level or support needs solely on their presumed IQ level or ability to use their voice/type online (Bascom & Perry, 2022; Williams, 2019).

Indeed, the survey results of this study revealed that 67.6% of the autistic respondents who did not receive ABA were largely critical of ABA, which may seem to lend truth to the argument that those who have not received ABA are overrepresented in advocacy that denounces ABA interventions (see Dawson, 2021; Kavchak, 2020). Nonetheless, it is unfair to suggest that these respondents have no say in the matter. As the remainder of this chapter reveals, autistic people who have not received ABA have well-researched justifications to support their concerns about ABA interventions. Further discussion on this overrepresentation of non-ABA recipients will be discussed in Chapter 6.

Figure 5.2. Autistic Ally Respondents Who Agree or Disagree with the use of Functioning Labels



The second assumption underlying the concern that ABA is “based on a faulty premise” explores the idea that autistic children have certain deficits in comparison to neurotypical children (Milton et al., 2023; Walker, 2021). ABA literature is comprised of experimental studies measuring improvement in three aspects of young autistic children’s development: adaptive functioning, reduction of autism severity or symptomology, and IQ (see Cooper, Heron, & Heward, 2020; Flanagan et al., 2012; Freeman & Perry, 2010; Perry et al., 2008, 2019; Wójcik et al., 2023). To justify their methods, ABA researchers have held firm to their belief that the credibility of ABA evidence cannot be disputed due to their empirically validated and scientific focus on increasing the quality of life of autistic people through “objective, standardized measures” (Leaf et al., 2021, p. 2842). As introduced in Chapter 2, this view of empirical validity has become a “rhetoric of positivist science” (a.k.a., “scientism”) that has evolved as a branding campaign for the Autism Industrial Complex (AIC) for decades (Broderick, 2022, p. 44). In other words, the ABA evidence-base was formulated within an agreed upon ‘truth’ of autistic deficits

defined over time through medical, cultural, and economic influences that aim to serve the needs of a society that refuses to include anyone who does not fit within the capitalist vision of normal productive (i.e., ideal) human bodies.

Common measurement tools used by behavioural psychologists for the purposes of autism diagnoses, assessments, treatment recommendations, and outcomes include the Vineland Adaptive Behaviour Scales (VABS) (Sparrow et al., 2016); the Childhood Autism Rating Scale (CARS) (Schopler et al., 2010); and the Wechsler Preschool and Primary Scale of Intelligence for Children (Wechsler, 2014). Both VABS and CARS measure behaviour skills deemed to be lagging in autistic children (e.g., academic skills, play skills, social skills, etc.) (Schopler et al., 2010; Sparrow et al., 2016). However, even by positivist standards of what constitutes improved behaviour skills, these tools are not as objective as the ABA literature suggests (see Cooper, Heron, & Heward, 2020; Hume et al., 2021; Matson, 2023; Odom et al., 2010). Much of the established ABA evidence base reveals behaviour change targets chosen by ABA researchers or parents (e.g., Flanagan et al., 2012; Hume et al., 2021; Perry et al., 2008, 2008, 2019; Wójcik et al., 2023; Wong et al., 2015). To determine outcomes, VABS relies on a semi-structured interview assessment based on answers from parents/caregivers and teachers that include items such as “Responds politely when given something”, “Acts appropriately when introduced to new people”, “Keeps her promises”, “Responds to parent/caregiver’s voice by looking”, etc. (Sparrow et al., 2016). There is no way to determine whether the child has a choice in these behaviour targets or whether the parents/guardians set their own goals for their children based on normatively defined versions of ‘politeness’ or ‘appropriate’ behaviours. Similarly, the CARS assessment tool utilizes a clinical observation of behaviours that determines autism severity through scores from 1 to 4, which measures improvements in areas such as “appropriateness of

body movements”; “frequency and intensity of bizarre body use”; “strange finger movements”, etc. (Schopler et al., 2010). Yet, these may well be harmless behaviours deemed in need of correction or management due to the historical existence of stigma and ableist power (Goffman, 1963).

In addition to these identified biases embedded within VABS and CARS, the use of IQ scores as an indicator of ABA effectiveness presents several concerns. First, children’s natural maturation and growth, particularly in regard to IQ development, is often not effectively controlled for in early intensive behaviour intervention studies (e.g., Perry et al., 2008). Second, IQ tests have long been exposed for their eugenic, racist, and ableist legacy (Chapman, 2023; Dolmage, 2017; Ellis, 2013). Third, research demonstrates the ways in which IQ testing underestimates autistic and disabled children’s intelligence (Courchesne et al., 2015; Dawson et al., 2007; Habib, 2018; Nader et al., 2016). It has been pointed out that the standardized format of IQ tests make them prone to measure a child’s increased “improvement in compliance rather than in cognitive functioning” (Schopler et al., 1989, p. 162). Experimental studies have revealed how the required verbal responses to questions on Wechsler IQs tests (e.g., “What is the thing to do if you find an envelope in the street that is sealed, addressed, and has a new stamp on it?”) are particularly challenging for autistic children (Dawson et al., 2007, p. 657). Therefore, increased scores on post ABA intervention treatments may reflect an autistic child’s increased “test-taking skill” as opposed to “improved intellectual functioning” after having: exposure to standardized methods of testing; training in complying to therapists’ demands during treatment; and a better understanding of what is expected of them (Schopler et al., 1989, p. 162).

Standardized tools that compare autistic children’s development to neurotypical development continue to be used as evidence of ABA effectiveness (see Wójcik et al., 2023)

despite significantly lagging behind current understandings of autism as an identity, not a disorder, in need of social acceptance (Canadian Academy of Health Sciences [CAHS], 2022; Vivanti, 2022). Arguably, the inherent subjectivity of these scales warrants the first concern shared in the example comment in Table 5.3 that ABA presumes autistic people to be “less than neurotypical”. Some ABA therapists have rationalized the use of ABA methods for extinguishing stereotypic behaviours (i.e., stopping autistic people from engaging in stimming behaviours via reward and punishment procedures) due to “social stigmatisation” that leads to bullying, isolation, and loneliness (Leaf et al., 2022, p. 3). This rationalization persists despite evidence from lived experiences that has found that extinguishing stimming behaviours can violate bodily autonomy and deny autistic people access to their natural coping mechanisms for stress (Anderson, 2022; Bascom, 2011; Gardiner, 2019; Kapp et al., 2019). When ABA interventions continue their reliance on standardized measures, autistic behaviours risk being judged as unproductive, less than ideal, and therefore in need of treatment even when the behaviours are harmless. This judgment reflects the power of stigma to maintain an autism treatment industry that benefits from the commodification of autism as a deficit-based disorder (Broderick, 2022; McGuire, 2016).

The third assumption related to Concern #1 examines the ABA research surrounding what are deemed as harmful or “challenging behaviours” (e.g., aggression, self-harm) as common traits of autism shared by many autistic young people (American Psychiatric Association, 2013; OSETT-CB, 2019; Schopler et al., 2010). Although both the DSM 5 (American Psychiatric Association, 2013) and CARS (Schopler et al., 2010) recognize that challenging behaviours can be caused by an autistic child’s inability to communicate their needs in ways that others understand, there remain gaps in ABA research that prioritize self-determined neurodivergent

communication skills through the use of tools such as augmentative and alternative communication (AAC) (Therapist Neurodiversity Collective, 2020a). In fact, many ABA researchers and providers (e.g., Holehan & Zane, 2020) contest the evidence base of ACC (sometimes referred to as facilitated communication) as an effective means of supporting autistic people's communication (Alabood et al., 2022; Biklen, 1990; Crossley & Remington-Gurney, 1992; Jaswal et al., 2020; Krishnamurthy et al., 2022; Williams, 2020). The reason for this contestation is skepticism around whether autistic people independently do the typing or pointing needed for AAC without influence from a support worker, trainer, or assistant (Williams, 2020). Yet, nonspeaking autistic people have shown time and time again that the words and thoughts they type are theirs alone (e.g., Communication First, 2021; Ngeow et al., 2017; Sedgwick, 2019; Srinivasan, 2018). Nonspeaking autistic people and their families have further shared the ways in which their (or their children's) aggressive behaviours/meltdowns decreased substantially once they had access to AAC and could better express frustrations in ways that others could finally understand (e.g., Carey et al., 2020; Chang, 2019; Dixit, 2019; Kedar, 2012).

Although nonspeaking autistic rights to assistive communication access have been affirmed by the United Nations (United Nations, 2019), faulty assumptions about nonspeaking autistic incompetence continues to force nonspeaking autistic people and families to advocate for AAC training and support that they rarely receive (Autistic AAC Underground, 2019; A4A Ontario, 2019a; Therapist Neurodiversity Collective, 2020a). Instead of assistive communication support, nonspeaking autistic people commonly receive ABA interventions that focus on methods of positive behavioral support (PBS) and operant conditioning to increase verbal speaking skills or change behaviour (Sandoval-Norton & Shkedy, 2019; Schopler et al., 2010), despite numerous studies that have revealed weak evidence of these interventions' effectiveness

for reducing challenging behaviour (Falligant et al., 2022; Mead Jasperse et al., 2023; Mitteer et al., 2022; Strydom et al., 2020). There further remain gaps in trauma informed and lived-experience informed ABA interventions that treat discrimination, bullying, and/or sensory/bodily distress as underlying causes for challenging behaviours displayed by autistic children (Gates, 2019; Memmott, 2023; Stack, 2021). These gaps in ABA research risk the implementation of faulty behaviour plans that view challenging behaviours as a symptom (or trait) of autism rather than as a symptom of the normative discriminatory environment.

A final assumption relating to the concern that ABA is based on a faulty premise is the assumption that external rewards or methods of positive reinforcement are necessary for autistic children to develop motivation to learn. Since the popularization of Skinner's use of positive reinforcements in North American institutions (Biophily2, 2016), ABA programs have relied on operant conditioning methods as a teaching tool for autistic young people who are deemed unable to learn things on their own. An example of this is found in a practitioner's story shared within The Geneva Centre ABA for Educators training module (2019):

Real Story – The Power of Reinforcement:

So I worked with students with Autism Spectrum Disorder for years. One of the things I found was that it was very challenging to get them to do just regular everyday things: putting on a coat or going to their desk. Eventually I realized that there wasn't anything in it for them, so I started using reinforcers and that made a real difference in terms of their willingness to do the things that needed to be part of their daily routine. (p. 9).

In this example, no attempt has been made to find the reasons why a student would not go to their desk or put on their coat—there could be sensory issues related to the coat or difficult emotions related to the desk work. The ABA practitioner seems to have made the assumption that

autistic young people are incapable of learning the skill of putting on a coat or doing desk work without some kind of tangible reinforcement or reward. This assumption, without basis in evidence beyond what the non-autistic practitioner observes, is common in ABA practice. A similar example is found in a blog on a recent ABA therapy website: “[autistic children] may have different motivations from neurotypical children. For example, children with autism may not have the desire to please people” (Songbird, 2022, para. 6).

Currently, there are no standards or mandatory training for ABA providers to understand the communication and neurological differences between autistic children and non-autistic children (Memmott, 2023). As such, the behaviours practitioners observe are based on neurotypical assumptions about motivation that signal a misalignment, or what Damian Milton (2012) referred to as the “‘double empathy problem’... a disjuncture in reciprocity between two differently disposed social actors” (p. 884). Put simply, without an understanding of autistic communication and sensory differences, behavioural assessments of autistic children’s motivations risk becoming “wildly inaccurate” (Milton, 2012, p. 884).

When a target skill has been identified in ABA practice (e.g., put on a coat or go to desk), the practitioner performs an assessment of what are called motivating operations (MOs), which are defined as “an environmental variable that has two effects: value-altering and behavior-altering effects” (Cooper, Heron, & William, 2020, p. 413). In laymen terms, an MO is described this way: “an MO changes how much you “want” something and how hard you will “work” to get it” (Langthorne & McGill, 2009, para. 4). Once an MO has been identified, it is common practice to use treats, such as Skittles or other types of candy or preferred activities such as iPad time, that a practitioner has determined autistic children will work hard for (Songbird, 2022). For

the student identified in the example above, the practitioner might give the child a piece of candy or time on a digital game each time they put on their coat or go to their desk.

When the reinforcer (i.e., candy or game time) is motivating enough, it risks undermining autistic capabilities by teaching autistic children to mask their true feelings in efforts to receive tangible rewards (Dawson, 2004; Gates, 2019; Price, 2022; Yergeau, 2018). Importantly, refusal and resistance are communicative of a child's need for something different (Delahooke, 2019; Greene, 2018; Kohn, 2018). Article 7 of the UNCRPD (2006) states that: "In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration ... States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them" (p. 8). Autistic children communicate in ways that are much different than non-autistic adults may be used to (Milton, 2012). By relying on rewards for compliance instead of responding to the child's refusal behaviour as a valid form of communication, ABA practitioners may risk dismissing the child's right to resistance when an intervention does not meet their needs (Roscigno, 2019).

As the remaining four concerns will exemplify, the ABA focus on changing external behaviour through reinforcement strategies sends the message that autistic people are the ones in need of change as opposed to the environment itself. In this way, ABA becomes a symptom of an ableist system that does little to challenge compliance-based, ableist, and discriminatory norms (Dolmage, 2017; Kohn, 2020; Mitchell, 2015; OHRC, 2018; Parekh, 2022; PACY, 2016).

Concern #2: ABA is Conversion Therapy

The second concern raised by the 27 respondents who shared their views arises from an assumption that underlies the faulty premises of ABA discussed thus far; this assumption holds that autistic children can "recover" from autism (Lovaas, 1987). As discussed in Chapter 2, Ivar

Lovaas's (1987) research was steeped in the dehumanizing idea that autistic children are born with abnormal behavioural deficits (e.g., lack of eye contact, inappropriate play skills/behaviours, lagging vocal communication, etc.) all measured with standardized measurement tools such as the IQ test, VABS, and CARS. John Cooper and colleagues, authors of a foundational ABA textbook for researchers and practitioners, emphasised the importance of using normative assessment measures as markers for improved behavioural development: "Comparing subjects' behavior to ongoing probes of the behavior of a normative sample provides a formative assessment measure of how much improvement has been made and how much is still needed" (Cooper, Heron, & Heward, 2020, p. 265). This comparison to "a normative sample" is at the root of autistic ally respondents' concerns that ABA is a treatment "akin to conversion therapy".

Autistic activists have noted the parallels between gay conversion therapy and ABA for some time. In 2016, nonspeaking autistic activist, Amy Sequenzia (2016), boldly named ABA as a form of "autistic conversion therapy" that forces autistic people "to comply with erroneous assumptions, and to act in ways that go against our identity ..." (para. 5). Contrary to the common claim that ABA interventions are mainly used to address harmful or "aberrant behaviors" (Leaf et al., 2021, p. 2842), many ABA interventionists continue to target harmless neurodivergent body movements or vocal stereotypy with the justification that these behaviours interfere with academics and/or socialization (Akers et al., 2020; Callahan et al., 2023; Leaf et al., 2021; Mantzoros et al., 2023). The DSM 5 continues to define autistic children in terms of their deficits measured against neurotypical norms, and ABA is "prescribed" as a treatment through which these deficits can be treated (OSETT-ASD, 2017, p. 28).

It was not that long ago that gender identity disorder and homosexuality were included in the DSM as medical diagnoses, both measured against cisgender and heterosexual norms (Pyne, 2020). The commonly prescribed treatment for these perceived ‘disorders’ included the operant conditioning strategies of positive reinforcement and punishment procedures pioneered by George Rekers and Ivar Lovaas (1974) at the University of California, Los Angeles (UCLA) (Gibson & Douglas, 2018; Pyne, 2020). The parallels between gay conversion therapies and ABA therapies for autistic children cannot be ignored when, as Sequenzia (2016) pointed out, both treatment modalities share “the same ‘father’—Ivar Lovaas” (para. 10). The harms of these treatments cannot be ignored either. One long term outcome of Rekers and Lovaas’s study that is rarely discussed by ABA researchers is the eventual suicide of one participant of their study who was conditioned to suppress his feminine behaviours using many of the same methods of operant conditioning prescribed to autistic children today (see Truth But No Logic, 2011). Research into the risk factors of suicide within autistic populations has revealed links between masking (i.e., suppressing) of autistic traits and increased risk of suicide (Cassidy et al., 2019). Goffman (1963) identified similar psychological risks in his observations and theorizations of stigmatized individuals who feel the need to “pass” as normal in fear of being discredited and excluded from society: “The phenomenon of passing has always raised issues regarding the psychic state of the passer. First, it is assumed that he must necessarily pay a great psychological price, a very high level of anxiety, in living a life that can be collapsed at any moment” (p. 107). When operant conditioning strategies result in an autistic child’s need to suppress their autistic traits from a young age, risk of prolonged psychological strain may naturally follow (see Anderson, 2022; Kupferstein, 2018; McGill & Robinson, 2020; Sibley, 2015). Studies have found that both suicide rates and suicidal thoughts are disproportionately high (66% versus 17%) for autistic

people in comparison to the general population (Cassidy & Rodgers, 2017). Other studies have found suicide attempts to be at 3.9% compared to only 0.7% for neurotypical populations (Chen et al., 2017).

While no conclusive links have been made between ABA and autistic risk of suicide, one study did find a link between ABA participation and risk of post traumatic stress symptoms (PTSS) (Kupferstein, 2018). Kupferstein's (2018) study has since been critiqued for its methodological limitations related to the use of leading questions, ambiguity of ABA intervention type, and implied causation claims without concrete evidence, among other concerns (Broderick, 2022; Leaf et al., 2018). Despite these limitations, Kupferstein's study provides valuable insight into the plausible traumatic effects of suppressing autistic traits due to societal stigma, which have been further validated by independent reviews of the study (see Chown et al., 2019). As will be discussed in more detail later in this chapter (see Concern #4), the evidence produced from this study is arguably just as strong (in some cases stronger) than the evidence produced by ABA research itself. Given the potential of increased risk of suicide and depression as a result of suppressing autistic traits (Cassidy et al., 2019), more investigation into the impacts of behaviour modification on autistic wellbeing is needed and further research will be valuable to determine connections between ABA and suicide.

ABA researchers agree that the impact of ABA interventions on long term psychosocial and wellbeing outcomes for autistic children have yet to be followed-up in meaningful ways (Koudys et al., 2018; Pritchett et al., 2021). Although reform in the field of ABA is underway (see, for example, Hanley, 2021; Mindful Behavior, 2024; Rajaraman et al., 2021), ABA research has historically paid little attention to the ethics involved in behaviour modification techniques

that condition autistic children to mask their authentic ways of being in the world (Dawson, 2004; Memmott, 2023; Wilkenfeld & McCarthy, 2020).

ABA therapists have claimed that their obligation is to support autistic people to prepare for a less than desirable world (Leaf et al., 2021). As the evidence has revealed thus far, this kind of support risks infringing on autistic people's rights to become their authentic selves when compliance to societal norms is valued over addressing societal stigma, discrimination, and trust in lived experiences (Gates, 2019; Price, 2022; Wilkenfeld & McCarthy, 2020). Until these issues are attended to, the concern that ABA is a form of conversion therapy that is harmful to autistic children seems warranted.

Concern #3: ABA is Compliance Training

As an extension of their concerns about autistic conversion therapy, the 27 respondents who shared views in the open text box areas were concerned about the ways ABA interventions demanded “compliance with dominant social/behavioural norms” as opposed to supporting the development of “useful skills and autonomy” (See example comment in Table 5.3). The crux of this concern can be found in the therapeutic aim of ABA, which the Ontario Association of Applied Behaviour Analysis (ONTABA) (2020) defines this way: “ABA aims to increase behaviours that are important to the individual, their family, and/or the community, to a meaningful degree” (p. 1). This aim is often referred to as “social validity”, which has become the hallmark of ABA first conceptualized by early ABA scholars (i.e., Baer et al., 1968, 1987; Wolf, 1978) in response to demand from “consumers” and community members (mainly parents) to ensure behaviour change targets meet their own (i.e., parents’) desired goals, as opposed to the predetermined goals of the psychologists and researchers administering the interventions (Wolf, 1978). Since this time, little evidence has been found in ABA literature of including “the

individual” (i.e., autistic person) in the therapeutic aims defined by ONTABA. In a recent article addressing concerns raised about ABA from autistic people, a team of ABA researchers admitted that, due to the scant amount of social validity measures identified in ABA studies “... there is validity to the concern that autistics/individuals diagnosed with ASD are not commonly included in the goal selection” (Leaf et al., 2021, p. 2846). Systemic literature reviews of social validity within ABA studies found that only 12% of articles between 1999 and 2016 collected data that included social validity measures (Leaf et al., 2020). This means that there is no comprehensive evidence-base to suggest that the goals chosen by parents and ABA practitioners are meaningful or socially significant to the autistic child receiving the interventions. Recent reviews of current ABA practices have found that autistic people continue to be left out of the consent process (Chown & Murphy, 2022; Memmott, 2023). Therefore, it is reasonable to conclude that ABA intervention goals continue to be centered around what is important for the family or community, and not autistic people themselves. This lack of consent and goal identification from recipients of ABA has been a concern raised by researchers and activists for decades (Dawson, 2004; Sandoval-Norton & Shkedy, 2019; Wilkenfeld & McCarthy, 2020).

Some ABA practitioners and researchers have responded to the above concern by claiming that “there is no normalizing agenda at the heart of ABA” (Dillenburger & Keenan, 2023, p. 203) and that newer forms of ABA do not force autistic children to comply with demands the same way as in the past (Lamb, 2019; Leaf et al., 2021). Yet, evidence from ABA literature shows otherwise. A recent early intervention study identified an approximate total of 63 behavioural goals for preschool aged autistic children to work on at home and at school (Wójcik et al., 2023). Behaviour targets were identified using VABS, CARS and PEP-R (Psychoeducational Profile Revised) and included “stereotyped and ritualistic behaviors” among

other subjective measures (Wójcik et al., 2023, p. 15). Children were taught new skills using methods that included discrete trial training, shaping, errorless learning, chaining, and differential reinforcement strategies, all of which required the child to comply with therapist requests for an average of 22.5 hours per week.

A vast majority of the ABA evidence base consists of similar early intervention studies that measure standardized norms related to IQ, adaptive functioning, verbal communication, and behaviour skills after complying with adult instructions (see Hume et al., 2021; National Autism Center, 2015; Odom et al., 2010; Wong et al., 2015). The OSETT-ASD (2017) cites numerous Ontario studies that base treatment effectiveness and efficacy on children's ability to meet standardized norms after intensive interventions that require many hours of compliance to therapist requests (e.g., Flanagan et al., 2012; Freeman & Perry, 2010; Perry et al., 2008). Insistence on compliance is a valid concern when the behaviours deemed in need of change are assessed in response to societal stigma—e.g., “bizarre body use”; “strange finger movements”, etc., (Schopler et al., 2010)—but are otherwise harmless to the autistic individual and others. Current policy aims further advise that autistic children receive immediate access to early intervention by cautioning that “‘wait and see’ approach can have significant negative consequences for developmental trajectories of children with this disorder” (Autism Alliance of Canada, 2020, p. 4). This priority risks the continuation of compliance-based strategies that are used to change young autistic children's behaviours even when the behaviours (e.g., stimming for emotional and physical regulation) are now understood to be necessary for autistic wellbeing (Bascom, 2011; Kapp et al., 2019; Kupferstein, 2016; Laurent & Fede, 2020a).

In a recent analysis of ethics within the field of ABA, bioethics researchers Daniel Wilkenfeld and Allison McCarthy (2020) agreed, in part, with the field of ABA's claim to “thirty

years of research” supporting evidence of behaviour change in autistic children (p. 38). However, they point out that the problem is that the research does not support evidence of deep or meaningful behaviour change for the betterment of autistic lives. Rather, the thirty years of research reveals evidence of how therapists “...can successfully get children to act *as if* [italics in original] they belong in a particular social construct” (e.g., social constructs within compliance-based school systems) (p. 39). Ryan Collis’s (2019) undergraduate thesis furthered Wilkenfeld and McCarthy’s point. Through investigating the meaning of evidence produced by autism interventions from the perspective of autistic expertise, Collis aptly concluded that the meaning of evidence, or successful outcomes, are not the same for ABA providers, parents, governments, and autistic people. As one participant of Collis’s study surmised, “If you’ve proved that a group of children are scared and compliant, did you really prove program ‘success’?” (p. 52). In other words, the evidence produced by ABA signals evidence of compliance to conform at the expense of autistic wellbeing, which benefits educators and parents more than autistic people themselves (Kohn, 2020).

Recall the common technique of “pairing” introduced in Chapter 2 through which autistic children are given rewards in order to optimize behaviour change within the therapeutic relationship (Special Learning, 2021). One therapist described the process of pairing this way:

You are now the ultimate reinforcer or the giver of all good things!!!... he will see you as he sees his favorite toys and activities... he will want to engage with you, and will be more likely to comply with instructional demands. Does your learner walk away from you or attempt to escape instruction frequently? If so, it’s time to pair! (Barnett, 2020 para. 2)

Carol Millman (2019), an autistic behaviour psychologist, described this particular use of rewards as a form of blackmail: “It focuses on training children by holding their sources of happiness hostage and using them as blackmail to get the children to meet goals which are not necessarily in the best interest of their emotional health” (section 10: The Rights of All Living Things).

Pairing in this way is akin to assessments of motivating operations (MOs) discussed earlier in this chapter. The history of assessing what motivates a child, and then strengthening that motivation through methods of operant conditioning, dates back to B.F. Skinner’s (1948) experiments that involved keeping pigeons hungry at 75% of their body weight. These experiments were later adapted for use with children in experimental studies such as Wolf, Risely & Mees’s (1963) study. In this experiment, researchers reinforced a young boy’s behaviour of “glasses-wearing” by limiting his breakfast and lunch intake so that rewards such as ice cream “were much more powerful” (p. 310). The researchers then coached parents to use these methods at home and deemed the intervention a success after a 6-month follow up. Similar to other operant conditioning experiments that had been gaining popularity at the time (see Pritchett et al., 2021), no other follow-up outcomes nor investigation into the boy’s inner emotional well-being was conducted.

Tracing the roots of pairing and MO methods in ABA practice is important because these are methods of operant conditioning produced through dehumanizing experiments that discovered the motivation power of food and pleasure deprivation to increase or decrease behaviours. As some autistic activists have pointed out, it can often seem like a child is happily motivated to complete tasks in ABA therapy when, in fact, they may simply be happy and relieved to gain access to their favourite things (Real Social Skills, 2015; Sparrow, 2015).

Autistic lived experiences of ABA (e.g., Autistic Strategies Network, 2022; Watkins, 2021; Young, 2017) have revealed how the use of reinforcers in this way is dangerous as it teaches the child from an early age that they have no choice but to comply with adult demands if they are to get what they want, regardless of their inner feelings of distress or discomfort. This covert form of control puts autistic students at risk for future abuse because they are not empowered with the choice to say ‘no’ (e.g., Autistic Strategies Network, 2022; Watkins, 2021; Young, 2017).

Since the time of Wolf, Risely & Mees’s (1963) study, long term follow-up investigations into children’s inner emotional well-being after ABA interventions of this kind are rarely, if ever, conducted (Pritchett et al., 2021). As discussed in Chapter 2, ABA interventions risk prioritizing target behaviours as objectifiable measurable ‘things’ that, when successfully modified, determine an intervention’s success.

Several researchers have signalled the many ethical issues related to rewarding children for compliance (Dawson, 2004; Kohn, 2018; Roscigno, 2019; Sandoval-Norton & Shkedy, 2019; Wilkenfeld & McCarthy, 2020). The risks involved in compliance-based therapy are indeed concerning. The diminishing effects of reward-based learning on the development of self-determination, freedom of choice, and autonomy have been thoroughly researched (Deci, 1971; Kohn, 2018; Lepper & Greene, 2015; Ryan & Deci, 2000). Research has further found an increased risk of sexual abuse, and other forms of abuse and maltreatment among autistic children (Dike et al., 2022; Pecora et al., 2021; Sullivan & Knutson, 2000). For this reason, recent research from the perspectives of autistic lived experiences have called for an immediate focus on autistic self-determination and rights to autonomy in regard to their treatment, including autistic children’s rights to resist unreasonable demands placed on them by adults (Gardiner, 2019). Arguably, this right can only be realised when the use of positive reinforcement for the

purposes of compliance is removed from ABA interventions. As long as ABA continues to rely on the “the strategic use of positive reinforcement” (OSETT-ASD, 2017, p. 113), autistic ally concerns about compliance-based goals seem justified.

Concern #4: ABA is Not Actually Evidence-based

The fourth concern shared by autistic ally respondents was the concern that ABA is “not nearly as 'evidence-based'” as the field claims it to be. Currently, Autism Ontario (2022) bases their intervention recommendations for autistic children and their families on three research reviews of evidence-based practices (see Hume et al., 2021; OSETT-ASD, 2017; Steinbrenner et al., 2020). All three of these reviews selected studies (all prior to up until 2017) that were invested in the positivist paradigm of scientific objectivity (e.g., reliance on VABS, CARS, and IQ tests as mentioned in the concerns above). This positivist ontological standpoint has created a rhetoric of evidence-based practice (EBP) formulated “within the cultural logic of intervention” based on one narrowly defined view of evidence (Broderick, 2022, p. 77) through which “the strategic deployment of scientism” legitimizes treatments for stigmatized behaviours deemed to be disordered or abnormal (Broderick, 2022, p. 44).

Research reports, such as those recommended by Autism Ontario (2022), further continue to cite Lovaas’s (1987) study as a gold standard example of efficacy in ABA intervention outcomes. This research claims Lovaas provided the first concrete ‘evidence’ of ABA as a treatment for autism recovery (OSETT-ASD, 2017) despite discovery of research flaws in his 1987 study that included (but were not limited to): a lack of concrete behavioral, social and communication outcome measures; a lack of discussion on the effects of parental advocacy impacting the mainstream classroom placements of the autistic children claimed to be “recovered”; and a lack of discussion on IQ scores that may have reflected improvements in

compliance rather than cognition (Schopler et al., 1989). Indeed, there are numerous limitations to Lovaas's (1987) 'efficacy' study, which found only 47% (9 children out of 19 in the experimental group) achieved the target aims of "normal intellectual and educational functioning" (p.3). Over half, or 53% (11 of the children), did not achieve the "best outcomes" the intervention was intended to produce including "normal range IQ scores and successful first grade performance in public schools" (p. 3). In short, the evidence from this study, which is considered to have produced "encouraging research findings" (OSETT-ASD, 2017, p. 10), is based on a very small number of children influenced by researcher bias. There are further concerns from within the field of Education regarding the practical limitations of intensive behavioral interventions like Lovaas's due to the experimental designs of the interventions implemented solely within clinical research labs (not school settings) up to 40 hours per week (Edward Ritvo as cited in Larsson, 2014). These exposed gaps in Lovaas's influential study are the first of several valid critiques of the ABA evidence-base.

The OSETT-ASD (2017) stated that Lovaas's (1987) 'encouraging' findings were duplicated in a number of "well-controlled studies" in the United States (e.g., Cohen et al., 2006; Howard et al., 2014; Sallows & Graupner, 2005; Smith et al., 2000). A careful examination of this claim reveals that Cohen et al. (2006) and Howard et al. (2014) were the closest to replicate Lovaas's study in that they were the only two studies of the four that compared children receiving IBI to those children attending only special education (Cohen et al., 2006) or "eclectic treatments" (Howard et al., 2014). Neither of these studies used random selection for participation in the study and both used very small samples in each of their groupings—21 children and 16 children respectively. Both studies reported only moderate gains in IQ score and adaptive functioning compared to their control groups: Cohen and colleagues (2006) found no

differences in expressive language or non-verbal cognitive skills between their groups, while Howard and colleagues (2014) found heterogeneous results on a variety of other measures with statistically significant improvements on IQ and adaptive scores only in year one of their three-year study. Both of these studies reported that the parents in the IBI treatment groups were better educated on average than the parents of their control groups. As such, the researchers could not rule out important influencing factors such as successful parent advocacy for regular education inclusion (Cohen et al., 2006) or the influence of other “individual components to the outcomes” that compromised the integrity of the findings (Howard et al., 2014, p. 3342).

In recent years, a significant number of meta-analyses and independent studies have discovered methodological flaws and limited academic rigour within ABA research. ABA studies have been found to have an insufficient evidence-base due to issues including small sample sizes, single case study designs, lack of randomized control trials (RCTs), and research bias (French & Kennedy, 2018; McGlade et al., 2023; Reichow et al., 2012, 2018; Sandbank et al., 2020; Virués-Ortega, 2010; Weitlauf et al., 2014). The reviews conducted by the OSETT-ASD (2017), Hume et al. (2021) and Steinbrenner et al. (2020) included many non-randomized studies, single subject studies, and quasi-experimental designs that have been disputed to produce reliable evidence (Sandbank et al., 2020). The Cochrane Handbook for Systematic Reviews of Interventions stipulates that if a research team decides to include non-randomized designs in their reviews, risk of bias should be assessed using tools such as the Risk Of Bias In Non-randomized Studies of Interventions (ROBINS-I) assessment (Sterne et al., 2022). None of reviews cited in the OSETT-ASD (2017), nor reviews conducted by Hume et al. (2021) or Steinbrenner et al. (2020), made use of such tools to assess risk of bias. When a risk of bias tool was used in one recent meta-analysis of early intensive behaviour intervention (EIBI) studies,

namely the Cochrane Risk of Bias 2 (Sterne et al., 2019), the analysis determined that EIBI has a limited impact on the neurodevelopmental outcomes of young children (McGlade et al., 2023).

Smaller reviews of ABA interventions have reported a lack of consistent evidence related to intended outcomes (Ackley et al., 2019; Rogers et al., 2021; Sandoval-Norton et al., 2021; U.S. Department of Defense, 2019, 2020, 2021; Warren et al., 2011). Studies have found significant persistence, resurgence, and renewal of participants' problem behaviours (e.g., hitting, kicking, self injurious behaviour, yelling, etc.) during and after treatment with no evidence of intended treatment goals being met (Mead Jasperse et al., 2023; Mitteer et al., 2022). Between the years of 2019 and 2021, The US Department of Defence published three quarterly reviews of ABA services received by up to 16,160 beneficiaries of the Effectiveness of the Comprehensive Autism Care Demonstration (ACD) covered under the Department's TRICARE program (U.S. Department of Defense, 2019, 2020, 2021). The reviewers analyzed outcome measures for the autistic children of beneficiaries each year. In each report they concluded that autistic children in ABA treatment programs showed little to no change in targeted behaviour goals with a small percentage each year developing worsened outcomes.

Other 'evidence' claims made in favour of ABA effectiveness include lifetime cost-saving measures based on predicted (i.e., hypothetical) monetary savings related to autistic children's future independence as a result of ABA interventions (California Association for Behavior Analysis, 2011; Chasson et al., 2007; Jacobson et al., 1998; Larsson, 2012; Motiwala et al., 2006; Penner et al., 2015; Piccininni et al., 2017). To date, these predictions have no grounding in actual research outcomes. In fact, a recent study framing autism as a "burden" on society due to predicted lifetime costs for the government was retracted due to misinterpretation of autism

“incidences”, use of unrepresentative data, lack of valid justification, arbitrary choice of birth cohort (1931), and assumptions that inflate predicted costs (Blaxill et al., 2023).

Finally, the ABA literature is clear in its claim that ABA is an evidence-based approach that improves the quality of life (QoL) of the individuals under care (Cooper, Heron, & Heward, 2020; OSETT-ASD, 2017). Yet, there remain few, if any, long-term follow-up studies related to autistic wellbeing and QoL in ABA research (Koudys et al., 2018; Leaf et al., 2021; McGill & Robinson, 2020).

It is worth repeating that any ‘evidence’ that does exist for ABA is based on outdated objective behavioural measures in light of our current understandings of lived autistic experiences and wellbeing outside of the positivist science (Vivanti, 2022). Perceived improvements in adaptive functioning are achieved through objective recordings of behaviour through compliance-based methods that provide evidence of a child’s ability to perform for an adult without a full understanding of whether the child’s inner needs were met (see Concern #3). ABA research holds the positivist view that “self-report data” is “unreliable” (Leaf et al., 2022, p. 8), which limits validation of lived experiences. Yet, when it comes to IQ measures, for example, nonspeaking autistic people have proven their capabilities, creativity, and intelligence time and time again despite being labelled as ‘low functioning’ (see Biklen & Burke, 2006; Communication First, 2021; Habib, 2018; Higashida, 2016; Kedar, 2012; Kirsebom, 2020; Mukhopadhyay, 2011; Peña, 2019). The eugenic, racist, and ableist legacy of IQ tests compounds this issue (Chapman, 2023; Dolmage, 2017; Gould, 1996; Parekh, 2022), not to mention the inaccessibility of IQ tests for autistic children resulting in an underestimation of their abilities and talents (Courchesne et al., 2015; Dawson et al., 2007; Nader et al., 2016). In fact, the invention of IQ tests—as Chapman (2023) extensively explained through a detailed

history of eugenics and the invention of normality—have done little more over history than to value a narrow standard of neuronormativity to support capitalist and industrial aims. The positivist belief that IQ and ability are quantifiable genetic traits (i.e., fixed, innate, and biologically determined) has been debunked time and time again (Parekh, 2022). Yet, similar to the ABA industry, intelligence testing in education has become big business (Brantlinger, 2006) and continues to authorize placements in educational settings without consensus amongst researchers as to “what intelligence is or means” (Parekh, 2022, p. 42). No singular test can measure the vast diversity of innate human qualities. Abilities and talents of all kinds can and should be valued on their own terms regardless of standardized results produced by tests invented through ableist mindsets long ago.

Finally, there exist numerous problems with the ethics and conflicts of interest of ABA researchers involved in the ABA literature base as a whole (Bottema-Beutel et al., 2020; Bottema-Beutel & Crowley, 2021; Memmott, 2023; Wilkenfeld & McCarthy, 2020), which certainly warrants the concern that ABA is not “actually evidence-based” in meaningful ways that meet the needs of autistic people. A careful examination of the literature behind autistic concerns makes clear the ways ABA is able to maintain its reputation as ‘evidence-based’ through a justification of goals that change the individual rather than the ableist environment itself.

Concern #5: ABA is Harmful and Abusive

The fifth concern raised by the autistic ally respondents was summarized by the comment: “it is essentially based around coercion (whether through punishment or rewards) and commonly employs physically and emotionally abusive tactics that have traumatized many people subjected to them and/or made them susceptible to further abuse” (See Table 5.3 on p.

90). As demonstrated under Concern #3, the 27 autistic allies who chose to comment voiced their concerns about the covert harm resulting from seemingly innocent applications of pairing and other reward-based compliance strategies. In addition to this covert harm, ABA interventions have continued to use overt punishment procedures that include (but are not limited to): forced feeding procedures (e.g., McHugh, 2019; Peterson et al., 2016; Scotchie & Borrero, 2023); skin shock (Israel et al., 2008; McFadden et al., 2021); the purposeful ignoring of a child's distress, or allowing a child to remain in distress (i.e., tantrumming) through the application of planned-ignoring or time-out (Slocum et al., 2022; Tarbox, 2018); and the provocation of problem behaviour by the therapist to assess what are referred to as “antecedent interventions” for the purposes of assessing escape-maintained behaviours – for example, telling a child at a table to keep their “hands down for 30 seconds” while they show signs of distress by crying and screaming to try and escape the ‘hands-down’ expectation (see Axe, 2020, 7:51).

Despite the OSETT-ASD's (2017) claim that the use of punishment in ABA is a “misconception”, punishment procedures are at the root of ABA interventions with autistic children (p. 113). To their credit the OSETT-ASD (2017) admitted that “... in the very beginnings of the use of ABA for children with ASD, a punishment approach was included...” (p. 113). Yet, this statement also contradicted their claim that ABA is not “based on the use of punishment” (p.113). The fact remains that the purported ‘encouraging’ findings produced by Ivar Lovaas could not have been possible without the use of overt punishment procedures, which included withholding food, slapping, and electric skin shock (LIFE Magazine, 1965; Lovaas, 1981, 1987). An example of the “physical punishments” recommended by Lovaas (1981) is as follows:

... you may want to start with a loud "No!" and then use procedures that the child does not like but that appear relatively "innocent," such as 10 or 20 sit-ups, or 5 minutes of jogging around the block, or holding a telephone book for one minute with outstretched arms, contingent on the undesirable behavior. Or, if a child is very afraid of dogs, briefly showing him a picture of a dog when he acts up particularly badly may be enough of an aversive... Just as a good teacher can find many ways to reward her child, so she can find many socially acceptable ways to discipline him. If the milder aversives don't work, try a swat on the rear. At the other extreme, painful electric shock has sometimes been used, but we advise against this procedure except in cases where the child's life is in danger. (p. 26)

The OSETT-ASD (2017) further claimed that in today's ABA, "the routine use of aversive stimuli to change problem behaviours or teach new skills is seldom used" (p. 113). Once again, evidence from recent ABA studies and interventions prove otherwise. The following section details examples of aversive punishments that may be triggering; read with caution.

In his conference paper titled, *Learning From Violent Pasts and Presents A Future Where We Don't Hate Children*, Autistic scholar Ryan Collis (2022) discussed the harm experienced by autistic children who are forced to eat non-preferred foods through the methodical use of an ABA technique known as the "non-removal of the spoon" (NRS) that continues to be recommended as an evidence-based approach for the treatment of autistic children labelled with 'feeding disorders' (McHugh, 2019; Peterson et al., 2016; Scotchie & Borrero, 2023). In this intervention, ABA therapists are trained to place a spoon of either rejected or expelled food (i.e., food the child has spit out due to disgust) to the child's mouth and offer a reward of praise if the food is accepted (McHugh, 2019; Peterson et al., 2016; Scotchie & Borrero, 2023). If the child continues

to refuse the rejected or expelled food presented on the spoon, the therapist may then use physical hand-over-hand prompting (Peterson et al., 2016) and/or jaw or chin prompts that involve “placing their middle finger and thumb on the participant's mandibular joint” or “placing their thumb on the participant's chin with the fingers resting under the chin and applying slight upward pressure” (Scotchie & Borrero, 2023, p. 357). In some interventions, the therapist is trained to encourage the child by singing their favourite songs throughout the procedure (Peterson et al., 2016). Peterson et al., (2016) describe the procedure of the “nonremoval of the spoon and continuous interaction” as follows:

The therapist re-presented expelled bites by guiding the child’s hand to scoop up the bite and place it back in his mouth. If the child was expelling and the therapist was representing a bite 30 s after the bite entered the mouth initially, the therapist presented the next bite as soon as the previous bite remained in the child’s mouth for at least 3 s... Throughout the session, the therapist continuously interacted with the child by talking and singing. (p. 494)

In many procedures, therapists are trained to continue with the NRS treatment whilst ignoring the child’s communicative signals of distress and/or saying “no” (see Concern #1). Food rejection displayed in these ways by the child are labelled as “inappropriate mealtime behavior” (McHugh, 2019, p. 21). Arguably, the intrusive methods “nonremoval of the spoon” (NRS) procedures, in and of themselves, make clear Collis’s (2022) concerns about a violent world that seems to hate autistic children.

With regard to skin shock procedures, a federal court appeal overturned a recent ban on the use of electric skin shock devices by the Judge Rotenberg Center (JRC), an ABA-based educational centre, in 2021 (Pierson, 2021; Reed, 2023). Autistic people and families had fought

for this ban for years due to the tortuous nature of skin shock interventions, which are worn as backpacks by autistic students and controlled by therapists via a remote control device (L. X. Z. Brown, 2014; Shields, 2019). The ABA therapists at the JRC argue that the treatment allows for autistic people to have a better quality of life (Blenkush, 2017; Israel et al., 2008) as it aims “to correct aggressive or self-harming behavior” exhibited by autistic people (Pierson, 2021, para. 1). Survivor stories reveal that the skin shock devices (which are often accompanied by physical restraint, planned ignoring, and food deprivation) were used to correct behaviours as non-intrusive as standing up without permission, waving hands, refusing to take off a jacket, and crying (L. X. Z. Brown, 2014; Msumba, 2018). Survivors have further shared that whether the shocks were used to correct self-harming or aggressive behaviours or not, the procedures worsened their mental and physical health due to the pain caused by burning of their skin:

It lasts 2 seconds but it feels like 10-15 seconds. The feeling is like this pulsing, pulling, yanking, burning sensation that they get in your arm, leg, whatever spot they shock you in ...it will tear into it and your whole muscles will clench up and raise up ...It's a terrible pain. I have no idea how to describe it. (AutSciPerson
[@AutSciPerson@mstdn.social], 2021)

A recent review article discussing the risks and benefits of skin shock procedures described the intervention to have mainly “positive behavioral effects”, which were assessed by clinicians who observed “improvements in appropriate behaviors, overt happiness, and improvement in skill acquisition” (Blenkush, 2017, p. 5). No detailed description of the behaviours, happiness, or skills were provided in the review. It is clear that the ‘positive’ effects were determined through a positivist lens of achieving observable behaviour change without attention to the inner thoughts and feelings of the recipients under treatment. The author of the

review made no mention of the potential trauma effects resulting from skin shock procedures that can elicit fear-based responses including feigned happiness and compliance (Gates, 2019; Price, 2022).

Along with the overt procedures of skin shock punishments, the JRC uses a positive reinforcement system to reward compliant behaviour, delivered via a simulated “re-creation” of the Emerald City and Yellow Brick Road from the Wizard of OZ, which is utilized to playfully encourage behaviours deemed appropriate by therapists by way of an elaborate theatrical reward system—if the autistic person behaves in the ways expected of them, they earn entrance into the Emerald City where they can “access various rewards including trips to an indoor cinema, the use of a ball pit or an arcade, and access to an internet café furnished as a “Tiki bar” complete with synthetic palm trees” (JRC, n.d., as cited in Shields, 2019, p. 6). Shields (2019) described the “juxtaposition of this indoor amusement park with practices of extreme violence and inhumane treatment” as a covert and deceptive form of “psychological violence” that aims to justify harm through a veil of “fun” (pp. 6-7). This example is similar to the singing used during NRS feeding procedures explained by Collis (2022). The use of pleasure as a tool to tolerate punishment is a covert form of attaining compliance that amplifies harm for autistic young people through a manipulation of power.

Despite not having received ABA interventions themselves, Collis (2022) and Shields (2019) are skilled investigators of the obvious harm caused by both covert and overt behaviour modification procedures, whether combined or used in isolation, when the aim of the procedure is behavioural compliance. Their assessments are backed by others in education research, such as Alfie Kohn (2018) who convincingly made the argument that when the imbalance of power is taken into consideration, “rewards and punishments are not opposite at all; they are two sides of

the same coin” (p. 50); and Eric Shyman (2014) who exposed the “supremacy” of the ABA industry that makes claims to evidence using a positivist lens with a “de-emphasis of social justice and civil rights in education” (Introduction, para. 2).

Over and over again, autistic people have shared their trauma as a result of ABA (Anderson, 2022; L. X. Z. Brown, 2014; Gardiner, 2019; Kupferstein, 2018; Neuroclastic, 2021; Unbound Books: Autism Acceptance Library, n.d.). There is currently no system for meaningful consultations with autistic people, nor is there much (if any) focus on ethics or adverse effects in ABA research (Bottema-Beutel et al., 2020; Memmott, 2023). With the ban on skin shock procedures overturned, the risk of extreme harm continues at the JRC. The allowance of this violence in the name of ‘improving quality of life’ through a positivist interpretation of ‘appropriate’ behaviour sets a precedent for the continuation of harm. The autistic ally respondents of my study who have not received ABA themselves have valid reasons for concern.

Conclusion

To conclude this chapter, I have attempted to answer the question of how autistic voices regarding concerns about ABA matter regardless of whether they received ABA interventions or not. Evidence from literature within and about the field of ABA makes a strong case for the autistic ally respondent concerns raised in this chapter. All autistic people understand the impacts of stigma, along with the operant conditioning strategies (i.e., rewards and consequences) that harm autistic people within societies that value neurotypicality (Chapman, 2023; Chown et al., 2023; Gates, 2019; Gibson & Douglas, 2018; Price, 2022; Roscigno, 2019; Yergeau, 2018). The lived experience of stigma and power legitimizes the perspectives of all autistic people on matters that concern them.

Bioethics scholars in the field of health sciences (i.e., Wilkenfeld & McCarthy, 2020), further agree that the concerns raised by autistic advocates who may not have participated in ABA (e.g., Sparrow, 2015) are valid. To sum up this perspective in brief, Wilkenfeld and McCarthy argued that one does not need to have experienced ABA to know that traditional ABA methods violate the four basic principles of bioethics—1) beneficence: the evidence of ABA does not reveal empirical evidence of genuine autistic wellbeing as reported by autistic people themselves; 2) nonmaleficence: ABA therapies have caused harm to countless autistic people worldwide (Neuroclastic, 2021) and are time-consuming (up to 40 hours over week) thereby restricting children’s rights to play; 3) autonomy: ABA is compliance-based as discussed at length under Concern #3; and 4) justice: ABA stigmatizes autism vis-à-vis its treatment aims that require autistic children to fit in to society without emphasis on societal change toward acceptance.

Concerns about ABA have been shared by researchers and philosophers in the fields of Education and Psychology since (and well before) its widespread use with autistic children (Chomsky, 1967; Kohn, 2018; Larsson, 2014; Ryan & Deci, 2000). All of these critiques share a fundamental concern—the use of behaviour modification techniques risk significant loss of autonomy and self-determination, which are integral to the growth of children as they mature into adults. This concern is shared by ABA therapists who have begun to design “Enhanced Choice” models of ABA (Rajaraman et al., 2021) and “prevention practices” (Ala’i-Rosales et al., 2018) that allow autistic children to voluntarily leave therapy spaces and/or have free access to their favorite things (as opposed to holding these things back as rewards for compliance) (Hanley, 2021). Autistic ABA therapists have validated autistic people’s concerns related to loss of autonomy and lack of autistic lived experience knowledge in ABA practices by working

toward creating a field of ABA that “...values autonomy, and values neurodivergent traits or essence” (Cerdeña, 2021, para. 5).

The fact that large groups of researchers and scientists (whom presumably have not received ABA interventions themselves) share concerns about the problems with ABA highlights the ways in which the autistic allies’ voices of this study matter. At the same time, it is important to note that 87% of the autistic ally respondent group represented a white racial demographic, which may miss important considerations specific to Black and racialized autistic experiences (Hammond, 2022a; Lewis et al., 2022). The next chapter explores whether the concerns raised by this demographic were shared by autistic respondents who received ABA themselves.

Chapter 6: Perspectives of Autistic Recipients of ABA

Overview

The following chapter explores the question of whether autistic recipients of ABA agree with the critical perspectives and concerns about ABA shared by autistic respondents who did not receive ABA interventions. Demographics for the ABA recipient respondent group (n=22) are detailed in Table 6.1.

Table 6.1. Demographic Characteristics of Autistic ABA Recipient Respondents (n=22)

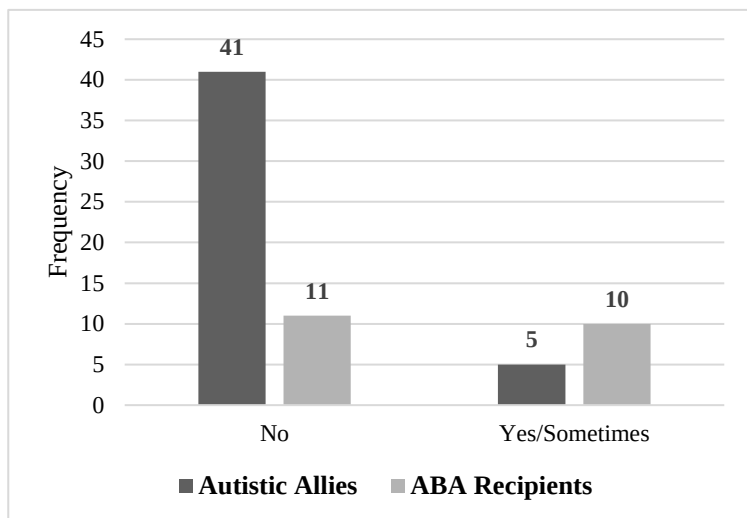
Characteristics	n	%
Gender		
Agender; Transgender; Nonbinary	4	18.2%
Female	5	22.7%
Male	13	59.1%
Sexual Orientation		
Queer (gay, lesbian, pansexual, Two Spirit, questioning, asexual, etc.)	9	40.9%
Heterosexual	13	59.1%
Race		
White	14	63.6%

Black	7	31.8%
Mixed background	1	4.5%
Highest level of education ¹		
Elementary and/or middle school	1	4.8%
High School	10	47.6%
College or Technical/Trade School	3	14.3%
University + (undergraduate degree or above)	6	28.6%
None of the above	1	4.8%
Autism Diagnosis		
Received diagnosis from a doctor or psychologist	19	86.4%
Self diagnosed/faced barriers to diagnosis	1	4.5%
Informed of diagnosis by parents	2	9.1%
Identity Preference		
Identity First Language (IFL) only	12	54.5%
Person-First Language (PFL) only	6	27.3%
Either IFL and/or PFL	3	13.6%
Other (neurodivergent or "on the spectrum")	1	4.5%
Co-occurring Identifications or Disabilities		
Intellectual Disability	3	13.6%
Nonspeaking/minimally speaking (including learning disability)	6	27.3%
Other neurodiverse identities, disabilities or identified challenges (e.g., ADHD, LD, behavioral/emotional challenges, etc.)	13	59.1%
Place of Current Residence ²		
Ontario	17	
Elsewhere in Canada	4	
Age at time of survey		
16-20 years old	1	4.5%
20-30 years old	17	77.3%
30-40 years old	2	9.1%
40 years +	2	9.1%

^{1 2}Note. There is one missing case in these categories

Contrary to the claim presented by ABA proponents in Chapter 5 who asserted that autistic people who believe ABA to be harmful have never received nor needed the interventions themselves (Busch, 2019a; Dawson, 2021; Kavchak, 2020), there are countless lived experience stories revealing the harms of ABA worldwide (Ask an Autistic, 2019b; Neuroclastic, 2021). For this reason, I hypothesized that similar to the autistic allies in Chapter 5, respondents who had received ABA would have largely critical perspectives of the interventions they received. To test this, I began with a Chi-square test of association to compare the autistic allied respondents' (n=46) and ABA recipient respondents' (n=22) answers to the question, "*Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?*". For the purposes of analysis, I created a binary variable of combined "yes"/"sometimes" responses and singular "no" responses. There was one response of "not sure", selected by a recipient of ABA, which was counted as a missing case for the purpose of statistical comparison. Contrary to my hypothesis, results revealed that proportionately *more* respondents in the group who received ABA interventions (n=10; 47.6%) felt that ABA was an effective support model for autistic young people than those who did not receive ABA interventions (n=5; 10.9%). The comparison between groups was statistically significant, $X^2(1, N = 67) = 11.206, p = <.001$. See Figure 6.1 (that follows) for a comparative graph of responses.

Figure 6.1. Do you feel ABA and/or IBI is an effective treatment or support model? Autistic Allies and ABA Recipients Compared



To further explore the perspectives of ABA recipients, I used a descriptive statistic to analyze Likert scale responses to specific question posed only to the ABA recipient group, “*How would you rate the overall effectiveness of ABA and/or IBI methods in helping you to achieve personally valid goals that meet your own needs and desires*”. Respondents could choose from the answers “1 - not effective at all”, “2 - somewhat effective”, “3 -effective”, and “4 - very effective”.

Results of this analysis were similar to the Chi-square test of association between respondent groups who did not receive ABA and who received ABA (presented above). Close to half (45.5%) of the respondents within the ABA recipient group (n=10) felt that the interventions they received were either, “3 -effective” (n=3) or “4 - very effective” (n=7) for them personally. This compared to just over half (54.5%) of ABA recipients (n=12) who felt the ABA interventions they received were either “1 - not effective at all” (n=10) or “2 - somewhat effective” (n=2). See Table 6.2.

Table 6.2. Perspectives of ABA Effectiveness for Achieving Personally Valid Goals

Likert Scale Category	n	%	Cumulative %
1 Not effective at all	10	45.5	45.5
2 Somewhat effective	2	9.1	54.5
3 Effective	3	13.6	68.2
4 Very effective	7	31.8	100.0
Total	22	100	

M=2.32, SD=1.4

Next, I explored these findings using a qualitative analysis of open text box responses accompanying answers to both questions, a) *“Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people?”*; and b) *“How would you rate the overall effectiveness of ABA and/or IBI methods in helping you to achieve personally valid goals that meet your own needs and desires?”* Results yielded 11 responses in total. Again, similar to the trend found in the surveys completed by 46 autistic ally respondents who did not receive ABA, only one comment reflected positive feelings toward ABA interventions. This comment accompanied a selection of “yes” in response to the first question and stated briefly, “Especially for those who need to learn life skills.” The ten remaining comments reflected critical or negative views of ABA, which accompanied answers of “no”, “3- somewhat effective”, or “1 - not effective at all”. Example open text box responses are listed in Table 6.3 (that follows). These responses reflect similar themes to those identified by the autistic ally respondents earlier in Chapter 5.

Table 6.3. Example Perspectives Shared by Autistic Recipients of ABA

Survey Question	Example Comment
How would you rate the overall effectiveness of ABA and/or IBI methods in helping you to achieve personally valid goals that meet your own needs and desires? Comment further in the space provided if needed.	“I never had any desire to learn the skills the professionals I saw claimed to teach me because none of them had anything to do with my actual wellness...” “It was always based on what works better for others and how my ways of being were burdensome to others.” “For me, the programming was not accomplishing what it was meant to accomplish because the BCBA didn't understand that I understood language completely, that I had Developmental Coordination Disorder and Severe, whole-body Apraxia; and that I was so extremely overwhelmed by sensory input. My "behaviours" were thought to be intentional, when they were often neurological responses which were beyond my control. Further, I am still stuck saying verbal scripts which were drilled into me.” “There were a couple of things that ABA did help me with, like allowing myself to eat a wide variety of foods instead of a narrow selection. However, I feel as though there could have been less traumatic ways to teach me the lessons that did stick with me.”
Do you feel ABA and/or IBI is an effective treatment and support model for autistic young people? Briefly explain in the space provided.	“Behaviourism alone has many philosophic limitations which prevent it from being applicable to cultures outside a western sphere. There is furthermore the issue of ABA itself being largely designed and defined by outsiders to the experiences it tries to "treat" leading it to have goals which are incongruent with the actual issues someone would have if they were autistic.” “It begins with the concept that Autistic people and behaviour are undesirable.”

“Please no. IBI and ABA were so stressful on my nervous system. Lack of neurology, and particularly polyvagal theory meant that the programming was all wrong for me.”

“No. Even if you have the very best of intentions, a modality that encourages "correction" (as determined by the practitioner) instead of investigation/accommodation/connection for children who are already struggling to be understood is going to have continued problems....”

“No I don't it's very harmful and scary.”

“It traumatizes and has a very negative impact on their mental health. I am speaking from lived experience.”

The comments shared in Table 6.3 make clear that several of the concerns raised by autistic ally respondents in Chapter 5 are also shared by close to half the autistic respondents who received ABA interventions. What is less clear, are the perspectives of the 10 ABA recipients who had positive feelings toward the ABA interventions they received. In fact, beyond what has been included in the analyses above, the 10 respondents who had positive experiences with ABA shared close to nothing else in the open text box areas provided throughout the survey. The gap in open-text box responses of those who had positive feelings toward ABA is a finding in and of itself that I explore later in the conclusion of this chapter.

To gain a deeper understanding of ABA recipient perspectives, the remainder of this chapter includes analyses in the form of descriptive statistics and statistical hypothesis tests derived from autistic activism, CAS literature, and ABA literature. Several of these analyses are deepened through qualitative analyses of open text comments and lived experiences of four autistic respondents who agreed to interviews and participatory dissemination of results. The first half of the chapter explores perspectives of diverse autistic ABA recipients. The latter half

examines ABA impacts on autistic wellbeing and quality of life (QoL), along with perspectives regarding consent, rewards, and punishment procedures.

Differences Between Views of Autism as a Disorder or Neurotype and ABA Effectiveness: A Cross Analysis

The first hypothesis test of this chapter analyzes an observation voiced by autistic justice activist, Taryn Jaye (2021) who noted:

An autistic person who views their autism as a disorder, while that is their choice, will more likely view ABA as a “solution” to their autism, meaning that they are more likely to view ABA as positive, if their original goal was to “appear less autistic.” (para. 3)

To test this, I divided autistic recipients of ABA into two groups: 1) those who perceived autism as a disorder (n=7; 31.8%); and 2) those who viewed autism as a neurotype/neurodiversity (n=15; 68.2%). I then compared each groups’ perceptions of ABA effectiveness. A Mann-Whitney U test of mean ranks revealed a significant difference between groups, $U=25.00$ $z = [-2.075]$, $p = [.038]$. The mean rank of responses within the autistic group who viewed autism as a disorder was 15.43 ($M=3.14$) compared to only 9.67 ($M=1.93$) in the group who viewed autism as a neurotype. The higher mean rank in the former group indicates that respondents who viewed autism as a disorder were more likely to perceive ABA to be effective than those who viewed autism as a neurotype. See Table 6.4 for a breakdown of results.

Table 6.4. Perceptions of Autism (as a disorder or neurotype) and ABA Effectiveness

Perceptions of Personal ABA Effectiveness Scale	View Autism as a Disorder (n=7)		View Autism as a Neurotype/ Neurodiversity (n=15)	
	n	% Within Group	n	% Within Group
1 - Not effective at all	0	0.0%	10	66.7%
2 - Somewhat effective	2	28.6%	0	0.0%
3 - Effective	2	28.6%	1	6.7%
4 - Very effective	3	42.9%	4	26.7%
Total	7	100.0%	15	100.0%

This result highlights the importance of stigma theory as it relates to the power of the autism industry (Goffman, 1963). While close to half of the ABA recipient respondents felt ABA was effective, these respondents may have also been impacted by stigmatized views of autism constructed as a disorder. In a world where autistic people are viewed as disordered or deficient because of their differences, autistic people may gravitate toward an intervention that helps them to appear ‘normal’ (see Concern #2 in Chapter 5). Recall from Chapter 5 that Goffman (1963) referred to this desire to appear normal as a matter of “passing”, which he defined specifically as an undertaking whereby “... the stigma is nicely invisible and known only to the person who possesses it, who tells no one” (p. 92). An understanding of stigma helps to explain some autistic people’s desire to invisibleize (i.e., mask or suppress) stigmatized autistic traits and pass as ‘normal’ in a society that is unaccepting of difference (Gates, 2019; Jaye, 2021; Pearson & Rose, 2021; Price, 2022). The following experience of Russel, drawn from the interview and participatory stages of my study, provides deeper insight into the impacts of stigma resulting in an appreciation of ABA.

Stories Behind the Statistics 1: Russel’s Experience:

Russel (he/him) identified as a white 28-year-old autistic male at the time of the interview. He selected that he felt ABA was a “very effective” approach for him personally. Russel shared that he earned an undergraduate degree in Business after high school, and currently worked part-time in a childcare centre for autistic children. He described his part time job as rewarding, but it was mostly a volunteer role that only recently began to pay him in stipends that were not enough to live independently. He was living with family as he prepared and made plans to apply for a master’s degree in Business. In response to my question about what motivated him to participate in this study, he responded: “I’ve kind of gotten in touch with

the survey as people living with autism. I'm technically a caregiver for persons living with autism so that is one of the things that really piqued my interest."

In response to my question about the challenges he has faced in life, Russel expressed how he has found it difficult to find sustainable work and to fit into society due to the discrimination he has faced throughout his life:

I think it's something where [paused]... everyone with my condition face, and this is conditions of facial expressions and eye contact, difficult[y] in lack of interest in relationship[s], making friend[s]... connecting with the world, and it's hard. People find it really difficult to connect with people like me. Some find people like me to be boring... people find people like me to be very difficult understanding.

In his survey, Russel indicated that he was diagnosed with autism "level 2" as a young child and had limited speech ability. In the interview he elaborated: "I have this mental instability, and I have issues of daily activity so yeah, quite a lot if I think about it." He admitted that he has not been comfortable with his autistic identity and does not particularly like autism due to the harsh discrimination and bullying he experienced as a child: "You get beaten up from other kids where, because of your condition, your disability, you feel bad you know? You really don't wanna be [paused] that fear of... being laughed at."

Russel remembered receiving several types of ABA services in schools and other centres throughout his childhood. He felt ABA helped him overcome the speech and behaviour difficulties that made him stand out as a kid. He admitted that he is tired of discrimination and would like to live a normal life with a wife and kids who see him as a good dad, one who does not have to suffer from discrimination: "So,... it's a goal for me where I could have a family of my own, where my kids wouldn't suffer what I did suffer and where they could not see me as

someone with autism. They could see me as a person and as a hero, just like I see my dad, like my hero.” When I asked Russel to explain how he felt ABA was effective, he responded:

Yeah, it’s really helped me be [paused]... have behavioural change. It’s helped me a lot to acquire skills and actions and being able to talk and play and live [long pause]... It really helped me on those specific behavioural and social skills... communications and, yeah, I would say academics.

For these reasons, Russel said that he would recommend ABA services to those hoping to improve their social, communication, and academic skills. He enjoyed many aspects of ABA, such as the rewards, praise and encouragement he regularly received. However, in his survey, he also indicated that these aspects of his ABA experience were only effective “sometimes” and that the interventions “always” made him feel sad, angry, anxious, or depressed. When I asked him to explain this further, he responded:

I think, I mean, it was certain protocols [paused]... it was the part where I... at the younger age, I kind of saw it like I am forced. To me it was like [paused]... forced to ignore my experience and my boundaries [long pause]. I kinda didn’t get to do the things I like or the things I, that I want.

I asked Russel to clarify what he meant when he said his boundaries were ignored. He replied: “It was just like [paused]... something you always wanna do, the way you always wanna [paused]... gonna express yourself was being ignored... You feel it’s a professional, so you have to do this so [paused]... Well, it was all good, it was also good ‘cause...” At this point in the interview, we paused as there were lots of kids yelling in the background. Russel then continued:

Being a kid at that point you wouldn’t really understand that you just felt... you’ve been forced... You know, being a child you wanna be free. You wanna get out and express

yourself, you see what's going on with that condition as just one more thing and you feel everyone else is like that, at that point, so... getting to the point at which you feel like, Why am I being like this when... why can't I just do the things I like? Why can't I get to sit here? Why can't I get to stand here? This is the kind of the boundaries that I am talking about.

Russel further indicated in his survey that his ABA therapists “sometimes” used consequences and punishments in the form of “aversive stimuli (e.g., verbal reprimands)”, “planned ignoring”, or “physical interventions” for behaviours such as getting out of his seat, demand avoidance, meltdowns or tantrums, and self harm. Without giving too many details, Russel clarified that these consequences were related to the boundaries he described above, that he felt were ignored:

... to me I felt like um my boundaries shouldn't be broken... but the therapist try to tell you 'sit' and you know, as a kid you try and behave... at some point I thought maybe they could do something different but I couldn't really figure out what they could do because they were professionals in the field and I couldn't really have any sort of say so I just had to obey them like “yes sir, yes sir” [then chuckled softly].

Throughout the interview, and several follow-up meetings (see Methods Chapter 3: Stage 3 - Participatory Collaborations for Dissemination), Russel continued to emphasise that the consequences he received, mainly in the form of firm verbal redirections, were “all good” because, as he explained: “It was also good 'cause, you know, being a child you wanna be free... sometimes you are sure these rules are just to break you. But actually, at the end... they just make you. They're there for your own good.” Russel did admit that: “I felt like maybe they could do something different. Sometimes I wish they could take me out on the field. Maybe I could get

to learn and play at the same time.” Overall, however, Russel emphasized that his ABA experiences were positive:

I think they did a good job getting me to make me believe in myself, getting this depression out... it gave me confidence to be able to stand up for myself. I think with them, I was able to get and find courage to make my first move about my changes. And that's led to a lot many change for me.

Russel’s experiences highlighted a key perspective underlying Jaye’s (2021) observation about autistic people who appreciate ABA for its focus on helping autistic people to “appear less autistic” (para. 3), and thereby experience less discrimination. The tone of Russel’s interviews throughout our several meetings on Zoom was quite positive. He repeated his appreciation for the ways ABA practitioners helped him improve his communication and academic skills so that he could be successful in high school and university. Russel’s appreciation for the ways he was supported to build confidence in his speech ability, feel more accepted, and “get his depression out” were key highlights of his story.

Russel’s main critique of his interventions was his inability to “learn and play at the same time.” His experience of being told to sit at his desk while learning exemplifies the more traditional form of intensive table-top ABA interventions that have been gradually replaced with “naturalistic teaching procedures” that allow children to play and learn in their day-to-day environments (OSETT-ASD, 2017, p. 115). As evidenced in Chapter 5, not all newer forms of ABA are naturalistic in nature (e.g., Wójcik et al., 2023); even when they are, they are not necessarily ethical (see Wilkenfeld & McCarthy, 2020). Autistic children’s rights to “equal access with other children to participation in play, recreation and leisure” are important (United Nations, 2006, article 30-d). When autistic children’s mental wellbeing is already impacted by

the traumatic effects of bullying, discrimination, and stigma (Gates, 2019), it is imperative that autistic children like Russel do not feel extra pressures, such as feeling “forced” to sit while learning normative skills that do not feel natural for them. Despite appreciating the skills he learned in his ABA programming, Russel’s experience of “always” feeling sad, angry, or depressed during his sessions reflects the practitioner’s misattunement to his inner needs.

Neuroscience has advanced our understanding of children’s needs to feel calm, happy, and connected in order to learn (Delahooke, 2019; Desautels, 2020; Shanker, 2017). Russel intuitively knew he needed to feel more calm and connected in his learning environments. He also had thoughts that “maybe they could do something different” but was unable to imagine “what they could do because they were professionals in the field.” This innocent trust in the teachers and practitioners that supported him aligns with the autistic allies in Chapter 5 who felt ABA was a form of compliance training that provides children with few opportunities to resist the demands placed on them. While Russel does not hold a critical view of ABA, he does agree that perhaps there are ways to teach children skills without a strong focus on compliance. He was simply unaware of the alternatives to behaviour-based table-top learning that would allow him to learn and play at the same time. He trusted the “professionals in the field” to know what was best for him. Freire (1970) explained that “As long as the oppressed remain unaware of the causes of their condition, they fatalistically ‘accept’ their exploitation” (p. 64). By virtue of the adult-child power imbalance, all children are vulnerable to exploitation; particularly autistic children who are marginalised by discrimination, which they may not yet see as the cause of their oppression.

In contrast to other autistic self advocates, Russel did not adhere to the neurodiversity movement. Russel’s discomfort with his autistic identity reflects the reality of a pathology paradigm of autism that exists in society (Walker, 2016). This is clear in Russel’s desire not to be

seen “as someone with autism” due to the stigma associated with his perceived deficits. It is understandable that some autistic people carry the burden of discrimination with them in ways that make them reject the pathologized label of autism. For Russel, it was important to learn skills that helped him to fit into a normative society. The differences between Russel’s perspectives and neurodiversity advocates’ perspectives are equally valid. Russel’s adherence to the pathology view of autism did not, in any way, impede his ability to provide expertise on improving autism services from his own lived experiences. Russel’s insightful recommendations toward dismantling stigma and creating safety for autistic young people are included in the conclusion chapter of this dissertation.

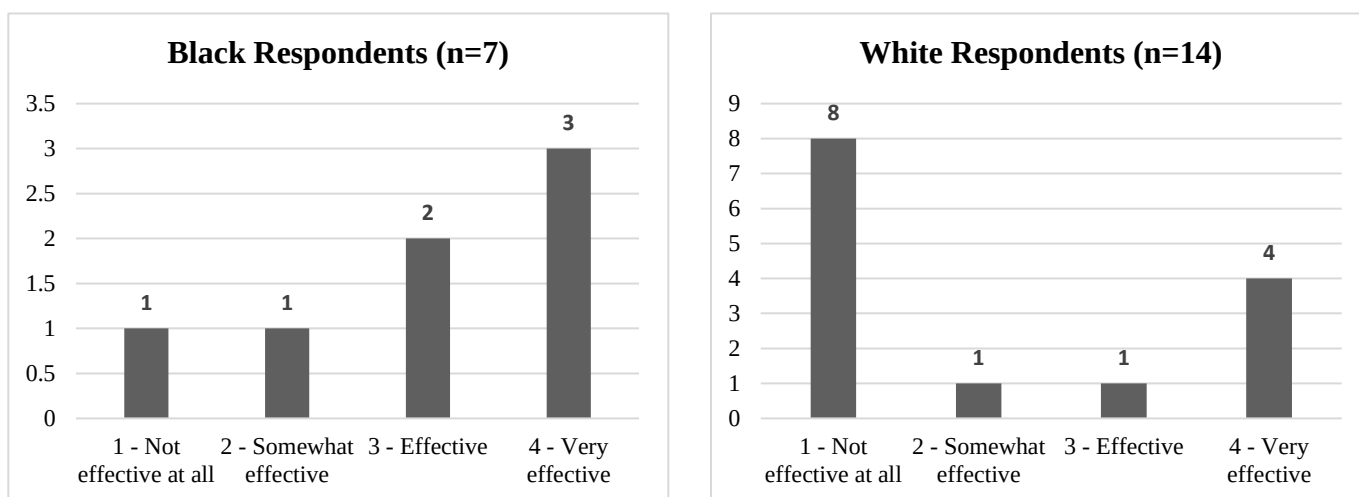
Self-identified Race and Perceptions of ABA Effectiveness for Achieving Personal Goals: A Cross Analysis at the Intersections

The next hypothesis explores a perspective shared by Black autistic activist and mother of Black autistic children, Tiffany Hammond (2022a), introduced in Chapter 2. This hypothesis is derived from Hammond’s experience that, while “even the ‘gentle’ ways are still harmful”, ABA has kept her and her children safe “within a racist, compliant based society” (para. 54). While Hammond does not condone the compliance-based methods of ABA, she understands that Black autistic people, their families, and people who care for them may indeed find ABA interventions to be effective or helpful due to centuries of white supremacy that have created conditions wherein ABA is the only accessible service available to support multiply-marginalised autistic children avoid the school-to-prison pipeline, police brutality, and other injustices (Hammond, 2022b). See Chapter 2 for more on this discussion.

With Hammond’s considerations in mind, I examined whether Black autistic recipients of ABA rated their perceptions of ABA effectiveness higher than white autistic recipients. I conducted a Mann-Whitney U test to analyze mean rank differences between self-identified

white (n=14) and Black (n=7) autistic respondents who received ABA (total n=21). Results revealed no significant difference between groups, $U=30.50$ $z = [-1.469]$, $p = [.142]$. Despite the lack of statistical significance, the mean rank difference between self-identified white autistic respondents (9.68; $M=2.07$) and Black autistic respondents (13.64; $M=3$) indicated that proportionally more Black autistic respondents felt ABA was effective compared to white autistic respondents. In addition, substantially more white autistic respondents felt ABA to be “not effective at all” than Black autistic respondents. See Figure 6.2.

Figure 6.2. Perspectives of ABA Effectiveness by Self-Identified Race



Only one Black autistic respondent chose to elaborate on their experiences in the open text box areas of the survey. Following the trend discovered throughout the survey analysis thus far, this respondent was critical of ABA and found the interventions to be “not effective at all”. This respondent chose to elaborate on their perspectives in response to only two questions on the survey. In response to the question, “*Did you consent to the ABA/IBI you received?*”, this respondent selected “Never” and wrote, “During my adolescence when I discovered how harmful it was to my emotional state, I tried getting out only to be denied that and be stuck in

that environment”¹⁵. In response to the question, “*How would you rate your enjoyment of your ABA/IBI program?*”, the respondent selected, “Not enjoyable at all” and elaborated with one word: “Traumatic.” This respondent, who also identified as a “semi-speaking (Part-Time AAC user)”, reflected Cheyenne Thornton’s (2021) concerns from Chapter 2 that, despite some hopes otherwise, ABA does not necessarily mitigate the harm caused by racist, ableist, and compliant-based societies.

The lack of elaborations from other respondents makes it difficult to determine the reasons why proportionately more self-identified Black autistic respondents perceived their ABA interventions to be effective than white-identified respondents. To explore these experiences more in-depth, I interviewed Clara, a Black autistic woman who selected ABA was “effective” for her personally.

Stories Behind the Statistics 2: Clara’s Experience:

At the time of the interview, Clara (she/her) identified as a 25-year-old Black autistic woman finishing up her high school diploma through an adult education program. She lived with her parents in Ontario but was born in California. Clara grew up in both California and Canada with immediate and extended family. She remembers attending ABA programs in both countries but received most of her ABA services in schools and in group settings on weekends in a large urban city in Ontario for about two or three years. Clara shared her motivation to participate in this study with the following response: “I wanted to share my experience and be heard because actually disclosing my situation, all what I’m passing through with others, is kind of, like, hard for me. It’s only my parents that I really kind of open up to. And so, I just wanted to share what I’ve been through.” She shared that she did not find out she was autistic until she was 16 years

¹⁵ This comment appears again later in Table 7

old when she began asking her parents more questions about why she was different from her peers. She confessed she had mixed emotions about learning she was autistic but that her parents were very supportive in her journey to accept herself:

They just, like, came into in my room one morning, and because I noticed I was not like other people [paused] the way I was behaving... I was wondering what was actually wrong with me. So, I kept asking them questions. Maybe they just wanted me to go to some certain stage before they kind of, like, disclose my kind of situation to me. So, one day they just came to my room, "Hey baby girl, this is what is happening to you. But it's not that bad because we are going to help you. We, your family, will support you. We will help you."

Clara explained that growing up different was difficult. It took many years of learning to love herself for who she is before she could fully accept herself. She was grateful for her parents' support: "Then I just embrace it [autism] because I just knew [paused] I knew that I can do what other people are doing... My parents, they told me not to give up on myself, that I can actually, like, achieve whatever I want to achieve... it [autism] it doesn't define me."

Clara stated that she had no preference between identity-first or person-first language, and felt, "People should be treated equally, no matter your agenda... society should learn to love everybody, no matter who they are, no matter their skin colour or the kind of situation they are going through... Just love people because you don't know what people are going through." Like Russel, Clara indicated in her survey that she perceived autism to be a disorder. When I asked her to clarify she responded:

Autistic people have a kind of disability. Like, you're not like normal people who [paused] the way you move [paused] there's this kind of awkwardness about you, not like

other kids. So, while growing up, I just noticed that I was not kind of moving the way I was supposed to be moving one part of my body. Kind of shifting to this side. I was wondering what was wrong? So, it's a disorder because it actually, like, limits you...

When I asked her to further clarify her selection of survey response option that stated, “autism doesn’t define me”, she explained:

Yeah, because as a person, I have dreams. I have what I want to be in life in the next ten years and the next five years. So, me having the disability doesn't, like, stop me... As a person, you have to stand up and face your fears. Like, just embrace who you are and kind of work towards achieving your career in love. So that is it. I wouldn't let anyone look down on me because I have this disability. I tried as much as possible not to let anybody talk down to me because if you allow people's opinion about you to get to you, that's when it really damages you. It might even cause depression.

Clara was one of the two Black autistic respondents who indicated that she felt ABA was “effective” (as opposed to “somewhat effective” or “very effective”) for her personally. When I asked her how ABA was helpful, she said:

I was taught how to use, like, vocally speak with words. Using complex language because I was always having difficulty in that. Expressing myself was always having this thing running through my head, but I can't really say it out. But with the help of the program, I was able to, like, speak and communicate very well with complex languages. Yeah.

Clara further indicated in her survey that the positive reinforcements she received “effectively helped” her to learn other skills such as “eating a variety of foods” and “keeping my hands still”. In both the survey, and in the interview, she shared that these goals were chosen for her by her

therapists. When I asked her to tell me more about the goal to keep her hands still, she explained: “I don't really know. According to them, it was not like, kind of too normal. Yeah, so I was advised to like, adjust.” Clara also emphasised how much she appreciated this support:

Before the program, I always have, like, difficulties—like cooking... I have to, kind of, pour the ingredients I'm not supposed to because my hands would be shaking. So, I actually adjusted and learned to have control, even if it was when it was even really, really hard. So now I can kind of feel relaxed and manage things in the kitchen.

Clara felt that other skills she learned, such as learning to “sit still”, were also helpful for her to not stand out as different:

I feel it [sitting still] is important because, you know, when you're out there with others, you [paused] it shouldn't be obvious that there's something wrong with this person. So, sitting still would kind of make you, like, kind of equal with others. So not being able to do it just attracts people's attention... So, it's very important.

Much like Russel, Clara expressed very positive feelings toward her ABA interventions. She shared that she appreciated the positive rewards she was given such as high fives, hugs, praise and encouragement, all from whom she described as “loving” therapists:

Because they were friendly, they always, like, correct you even when you're not getting it; they always correct, all with love. They will kind of tell you, ‘you can do it’ when you’re having difficulty. They are always there with love. And it seems they always know the kind of people to employ to do such jobs.

In contrast to these positive experiences, she also indicated that she “always” received consequences or punishments to stop her from getting out of her seat or moving around and that the interventions she received “sometimes” made her feel sad, angry, anxious, or depressed.

When I reminded her of her responses to the question about the consequences she received, she admitted, “Well, I can't remember saying that.” I then reviewed the survey response choices she made, including that she had selected “Aversive stimuli” such as verbal reprimands. She recalled, “Yeah, that's it. Like, maybe this ‘sit down’ all the time because I was always, like, trying to stand and move to another person’s seat just to see. I was always busy, kind of. So maybe it was annoying to the person.” Clara explained that this only occurred with a few ABA providers and admitted that when it happened, she felt “bad” but that it was also manageable for her:

... I felt bad. But I wasn't, kind of, rude to them because my mom always told me that people don't scold you for doing nothing. They scold you because you did something wrong. So that's it. So, I was able to, like, control my emotions and kind of learn. That didn't mean I was angry. I wouldn't have completed the program. I would have changed the center, so I had this all in control. I tried so it's helped.

To further understand Clara’s feelings about her experience, I asked: “if you could talk to those therapists today, would you request they do something different?” She replied: “Uh no. I think what they did was actually OK, because there was no hitting me or beating me. Just telling me with words. It's OK.” I further asked her to clarify if she meant “telling her with words” was the same as what she meant earlier when she used the word “scold”. She explained, “It was just ‘sit down’. You know, ‘You have to sit down’, which made her feel “angry-ish”:

That time I was being scold[ed] in class so, I always feel like kind of angry-ish... I always try to like control it because before I was in the room, my mom told me that I just have to be strong and learn; learn things the way other kids are doing. So, when I get scold[ed], I wouldn't want to, like, stop or quit. I just want to press on. And then when I get home, I would not want to bother my mom because she has really, like, she has really,

really been through a lot because of me. So, this kind of thing makes me feel kind of [paused] feel bad. Yeah.

Clara elaborated that she also felt she was “stress free to deal with” in comparison to other kids.

The praise she received from her teachers and therapists motivated her to keep doing well:

... because other children were always kind of not themselves. They were not, they were not cheering up. Some of them are just kind of hitting themselves. So learning was kind of hard. So, I was always ready, and they [therapists] were, like, “I am really, really learning fast.”

Clara admitted feeling that, at times, the teachers and therapists could have paid more attention to how she and her peers were feeling inside:

The staff, when they were just focusing on teaching about things that, like, they don't go into talking about people's feelings. They just want you to learn about speaking language, complex words... they don't teach us how to like, love ourselves for who you are. They only just, like, teach you on education... I didn't like those parts.

Similar to Russel, Clara shared that she was not aware that ABA was opposed by many autistic people. She emphasized how much she appreciated her programs and how she felt ABA could be helpful: “I think the program has helped me a lot and since it has helped me, I believe every other person that is ready to get along or learn, it'll be helpful to the person... Others in my situation should try it out and parents should consider it.” Finally, I asked what she felt a good program for autistic people would be like. She replied, “this is a program that will, like, teach autistic people how to increase in their behavioral activities and also decrease behavior. That's for sure.”

While Clara's experiences did not focus specifically on the intersectional experiences of being Black and autistic, it did highlight how important it was for her to not "attract people's attention". Clara's view that a good program can help autistic people to "increase in their behavioral activities and also decrease behavior" reflects her desire for autistic people to learn behavioural skills *and* to be accepted. Autistic girls are four times less likely to receive a diagnosis of autism than boys (American Psychiatric Association, 2013) and their autistic traits are more likely to be perceived as symptoms of depression, anxiety, bipolar disorder, or other misdiagnosed conditions (Kim, 2013). Without awareness of her neurodivergence, Clara spent her childhood wondering "what was wrong" with her. Intersectional stigma can lead to misinterpretations (i.e., fears) of Black and disabled people's behaviours, underestimations of their capabilities, and justifications for their segregation (Annamma et al., 2013; Erevelles, 2011). It is possible that Clara's bodily and behavioural differences marginalized her due to the historical dual stigma related to race and disability—i.e., a Black person with an "unruly" body (Erevelles, 2000).

In understanding Clara's lived experience, one can empathize with her appreciation for her ABA support. Clara experienced a world that did not accept her for who she is, which may have been compounded by her intersectional experiences of being Black, autistic, and female. The support she received from her ABA providers, which she described as mostly loving, helped to minimize the stigma she experienced. When describing her experiences of controlling her bodily movements, Clara did not use words such as "stimming" or "masking", which are common terms used by critical autism activists to destigmatize autistic traits and to describe their struggles (e.g., Bascom, 2011; Gates, 2019; Pearson & Rose, 2021; Price, 2022). In comparison

to many critical autism studies activists and scholars who are opposed to ABA, Clara's worldview is one focused on the necessity to fit into a world that would otherwise exclude her.

Similar to Russel, Clara felt that the sole focus on modifying external behaviour without going “into talking about people's feelings” was not ideal. From a critical standpoint, the “bad” and “angry-ish” feelings Clara experienced during her program provided some evidence to support the autistic allies' concerns from Chapter 5 that ABA can cause feelings of distress for autistic children who are trying to fit in while it does little to change the oppression caused by societal stigma (see Chapter 5, Concern #3). However, Clara's experience also lends evidence to Hammond's (2022a) important point that singular efforts concentrated on ABA alone will ultimately fail because:

... you are focusing your efforts on removing the strongest means by which Black bodies survive in this society, behaviorism, which will leave us more vulnerable than we already are, and are doing nothing about the systems that keep us at a disadvantage, harm us, and birthed ABA in the first place.

Clara's recommendations (to follow in the conclusion chapter) focus on the need for compassion, love and understanding of autistic children's inner feelings. Similar to Russel, her recommendations align with the advocacy efforts of autistic people who are critical of ABA, which further strengthens the important CAS tenet that stipulates all autistic people's voices matter when it comes to informing autism research (Milton, 2014).

Cross Analysis at the Intersections: Self-identified Queer Identity and Perceptions of ABA Effectiveness for Achieving Personal Goals

In a volume exploring the lived experience accounts of trans and autistic people, Adams and Liang (2020) offered a rarely explored parallel between the perspectives of queer-identified

autistic people and ABA. Through their interviews with 10 participants interviewed in the book, Adams and Liang found that,

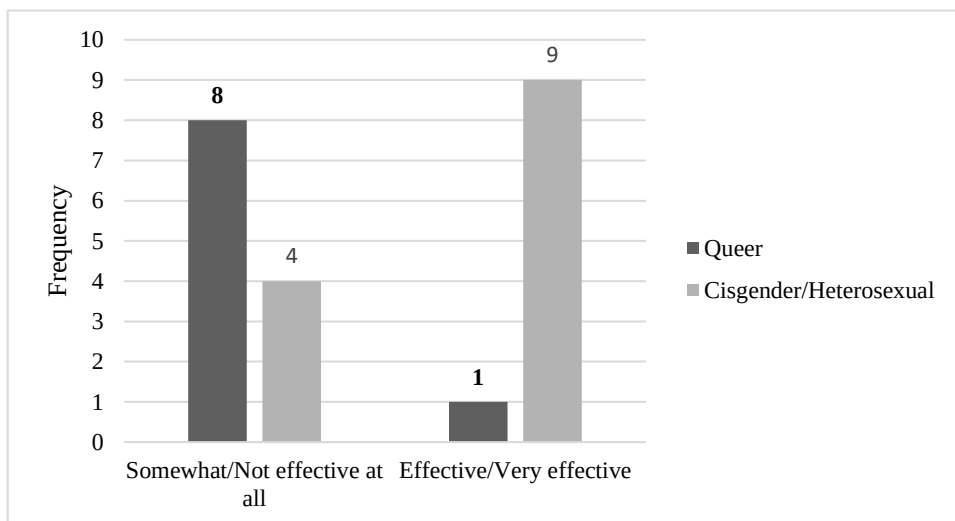
... there was wide agreement that some autism interventions, such as ABA, are ineffectual and even harmful. Participants argued that this is the case because they rely on forcing autistic children to hide or mask their autism and often use dehumanizing methods to do so. (p. 143)

The perspectives shared by these participants reflect the same concern raised by the autistic allies in Chapter 5 in regard to ABA's roots in gay conversion therapy. Given George Rekers and Ivar Lovaas's (1974) "'Sissy Boy'" experiment", which was an ABA "Therapy designed to make feminine boys more masculine" (Truth But No Logic, 2011, 1:03), coupled with concerns about ABA as an "autistic conversion therapy" (Sequenzia, 2016) designed to make autistic children appear neurotypical, I hypothesized that queer identifying autistic people would express negative feelings toward ABA.

To test this, I created binary variables that combined selections of "somewhat effective/not effective at all" and "effective/very effective" in response to the question, "*How would you rate the overall effectiveness of ABA and/or IBI methods in helping you to achieve personally valid goals that meet your own needs and desires*". I then combined gender queer (i.e., any gender identity other than female or male) and queer sexual orientation identities (i.e., any identity other than heterosexual) into one category of "Queer" (n=9) for comparison with a combined category of cisgender and heterosexual identities (n=13) (see Demographics Table 6.1 at the beginning of this chapter for detailed breakdowns). Results from a 4x4 Chi-square test of association revealed proportionately more queer-identified respondents selected responses of

“somewhat effective/not effective at all” in comparison to respondents who identified as cisgender and heterosexual, $\chi^2 (1, N = 22) = 7.246, p = .007$. See Figure 6.3.

Figure 6.3. Perspectives of ABA Effectiveness Shared by Self-Identified Queer Autistic Respondents



The one queer-identified respondent in the “effective/very effective” group selected that ABA was “very effective” and identified himself as male and “asexual” with no elaboration on his view of effectiveness in the open text box area. Four queer-identified respondents in the “somewhat effective/not effective at all” group elaborated in the open text box area with comments represented in Table 6.3 of the *Overview* section of this chapter, which reflected goals that were “incongruent” with autistic needs causing “traumatic” effects and “burdensome” feelings as a result of their ABA interventions. These comments highlight the commonly shared experiences of queer and gender non-conforming children who, as a result of stigma, were forced to suppress their genuine identities (Gibson & Douglas, 2018; Pyne, 2020). Because queer-identified autistic people may experience compounded effects of stigma in comparison to cisgender or heterosexual autistic people, the results of this analysis are not surprising. As discussed elsewhere (e.g., Gates, 2019; Price, 2022; Wilkenfeld & McCarthy, 2020), behaviour

modification cannot change a young person's core identity. At best, it seems likely that the ABA interventions these recipients received taught them to suppress their authentic (albeit divergent) human traits (see Concern #2 in Chapter 5).

Wellbeing Outcomes

Next, to test whether autistic people who received ABA interventions experienced decreased feelings of wellness as identified within CAS scholarship and activism (Autistic Self Advocacy Network [ASAN], 2022; Kupferstein, 2016, 2018; Neuroclastic, 2021; Swan, 2017; Young, 2016a), I used inferential statistics to examine three points of analysis: 1) ABA recipients' perceptions of ABA effectiveness and emotional impact; 2) current overall emotional wellness of ABA recipients compared to autistic allies who did not receive ABA; and 3) current feelings of suicide experienced by ABA recipients compared to autistic allies who did not receive ABA.

Risk-Benefit Analysis: What is The Emotional Impact of ABA?

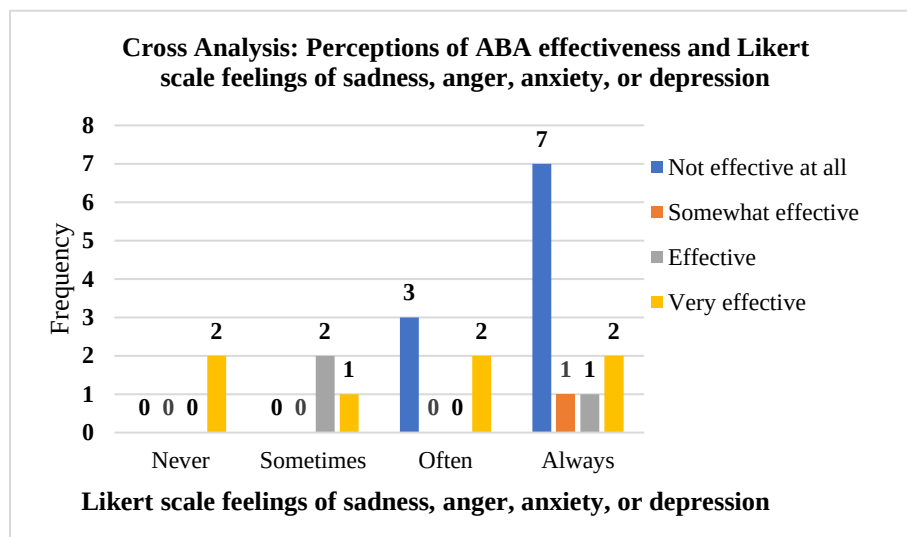
Within autistic activist and self-advocacy literature, autistic people agree that ABA interventions are an effective method of changing an autistic child's behaviours; however, they also argue that the risk versus benefit is too high due to the distress ABA interventions cause autistic people (ASAN, 2022; Swan, 2017). The following analysis examined the question of whether autistic respondents who felt ABA effectively helped them to achieve their goals also felt the interventions caused them feelings of distress. I examined Likert scale responses to the question, "*Do you feel the ABA or IBI you received has ever made you feel sad, angry, anxious, or depressed?*" Respondents could select, "never"; "sometimes"; "often"; and "always". An initial descriptive analysis revealed that over three quarters (n=16, 76.2%) of 21 respondents¹⁶

¹⁶ There was one missing case

felt that the interventions they received caused them feelings of sadness, anger, anxiety, or depression either often (n=5) or always (n=11). This included respondents who indicated that they received newer forms of ABA interventions (i.e., interventions received after the late 1990s; in my respondents' cases these were interventions received after 2004), which are argued to be less harmful and less intrusive than interventions of the past (OSETT-ASD, 2017).

Next, I conducted a 4x4 Chi-square Fisher's Exact test of association to compare responses of "never"; "sometimes"; "often"; and "always" with the four Likert scale perceptions of ABA effectiveness (i.e., "1 – not effective at all"; "2 – somewhat effective"; "3 – effective"; "4 – very effective"). Results revealed no statistically significant relationship between feelings of sadness, anger, anxiety, or depression and perceptions of ABA effectiveness across all 21 respondents, $\chi^2 (9, N = 21) = 14.504, p = .105$. In fact, 8 of the 10 respondents who found ABA interventions to be "effective" or "very effective" (including Russel and Clara interviewed earlier in this chapter) also felt that the interventions they received caused them feelings of sadness, anger, anxiety, or depression (sometimes, n=3; often, n=2; or always, n=3). This result indicates that regardless of how respondents perceived the effectiveness of the ABA they received (i.e., effective or not effective), most experienced feelings of sadness, anger, anxiety, or depression as a result of the intervention. To report this finding another way, a majority of respondents who found their ABA interventions to be either "effective" or "very effective" also found the interventions to cause them feelings of sadness, anger, anxiety, or depression (n=8, 80%). See Figure 6.4.

Figure 6.4. Cross Analysis: Perceptions of ABA Effectiveness and Likert Scale Feelings of Sadness, Anger, Anxiety, or Depression



None of the respondents who felt ABA was “effective” or “very effective” shared their experiences of sadness, anger, anxiety, or depression caused by ABA interventions in the open text box areas, making it difficult to understand the exact details of their experiences. However, the experiences shared by Clara and Russel earlier in this chapter provide insight into the ways some autistic young people find ABA interventions to be effective and distressing at the same time (e.g., focus on compliance without attention to inner feelings). Eight of the respondents who felt their interventions were somewhat effective or not effective at all, and also rated the occurrence of their feelings of sadness, anger, anxiety, or depression as “always”, “often” chose to elaborate on their experiences in the open text box area. There was an additional open text box response provided by the respondent who did not select a rating¹⁷. This was included in the open text box analysis due to the richness of their response. See Table 6.5 for qualitative results.

¹⁷ This was the one missing case noted in the Chi-square analysis

Table 6.5. “Do you feel the ABA or IBI you received has ever made you feel sad, angry, anxious, or depressed?”: Open Text Box Responses

Likert scale selection	Example Comment
3- Often	“Some of the people made my time bearable, but I also felt so betrayed, so misunderstood, and so anxious. It was hard playing along while being micromanaged for hours, doing mindless tasks which were well below my level of understanding. I have since been diagnosed with PTSD.” “It helped make me a more vulnerable target for predatory grooming.”
4- Always	“Constant flashbacks to it again. Many periods of self-loathing, I feel regret that I lost big chunks of myself to therapists acting as if they knew what was best for me.” ...contributed to nearly permanently destroying my relationship with my parents and drove me closer to suicide. They taught my parents to not look for the reasons for my behaviour: needs, struggles, feelings. They taught my parents that every move I made that wasn’t perfectly aligned with our cultural vision of a ‘good student was intentionally causing problems....’ “I have PTSD including flashbacks and nightmares from the time and disassociate often when things remind me of the time or the way they ‘helped’ me” “It’s made me feel horrible, sad, anxious, depressed, like a failure. Yes I am referring to the ‘New ABA’. It has impacted my mental health so negatively.” “I am still recovering from what I experienced and am seeing a therapist for PTSD”
No Rating Provided	“Back then, it made me actively suicidal. Now, it has left me passively depressed and dysthymic.”

Article 8 of the United Nations (2006) Convention on the Rights of Persons with Disabilities mandates that, “ States Parties undertake to adopt immediate, effective and appropriate measures... to combat stereotypes, prejudices and harmful practices relating to persons with disabilities...” (p. 8). When a majority of ABA recipients report that the interventions they received caused them distress always or often (i.e., 76.2%), it can be argued

that the interventions violate their right to receive practices that are free of harm. This finding is particularly important given that ABA is opposed by many autistic people worldwide (Ask an Autistic, 2019b; Neuroclastic, 2021; Unbound Books: Autism Acceptance Library, n.d.) and is believed to violate the bioethics of maleficence (Wilkenfeld & McCarthy, 2020). ABA is a reputed evidence-based practice, and despite flaws in its evidence-base (see Concern #4 in Chapter 5), ABA is effective at creating behaviour change in some autistic children (Swan, 2017). However, the benefits of observable outward behaviour change resulting from the compliance-based methods of many ABA practices (see Concern #3 in Chapter 5) must be weighed against the risk of harm (Wilkenfeld & McCarthy, 2020). More on feelings of sadness, anger, anxiety and depression are discussed throughout this chapter.

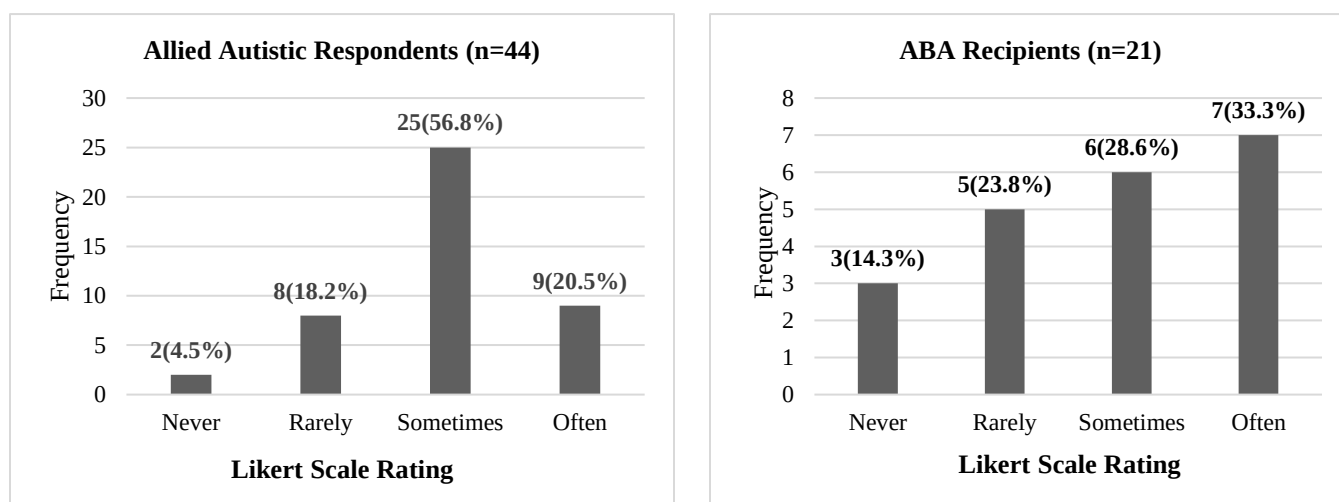
Current Overall Emotional Wellbeing

The vast number of “horror stories” exposing the ways in which ABA has deteriorated the mental health of autistic ABA recipients are well documented (Neuroclastic, 2021). These lived experiences, coupled with gaps in ABA research that examine the mental health and wellbeing outcomes of autistic ABA recipients (Koudys et al., 2018; Leaf et al., 2021), has prompted recommendations from within ABA research to examine the validity, purpose, and goals of ABA for autistic young people (Leaf et al., 2020, 2021; Mathur et al., 2024; Rajaraman et al., 2021). In order to examine the overall emotional wellbeing of the ABA recipients who responded to my study, I conducted a comparative Mann-Whitney U Test of Likert scale mean rank responses between 44 autistic allies who did not receive ABA and 21 ABA recipients¹⁸ in answer to the question, *“At this time in your life, do you feel emotionally well (e.g., satisfied with life and*

¹⁸ There were 2 missing cases in the autistic allied group and 1 missing case in the ABA recipient group

happy)?” Respondents could choose from the options of “1- never”, “2 – rarely”, “3 – sometimes”, and “4 – often”. Results revealed no significant difference of mean ranks between groups, $U = 444.50$; $z = -.263$; $p = .792$. The mean rank of the allied autistic group (33.40; $M = 2.93$) was only slightly higher than the ABA recipient group (32.17; $M = 2.81$). However, it is important to note that when selections of “often” and “sometimes” were combined, 77.3% of respondents in the autistic ally group experienced feelings of wellness compared to only 61.9% in the ABA recipient group. See Figure 6.5 for comparative results.

Figure 6.5. Allied Autistics’ and ABA Recipients’ Feelings of Emotional Wellness



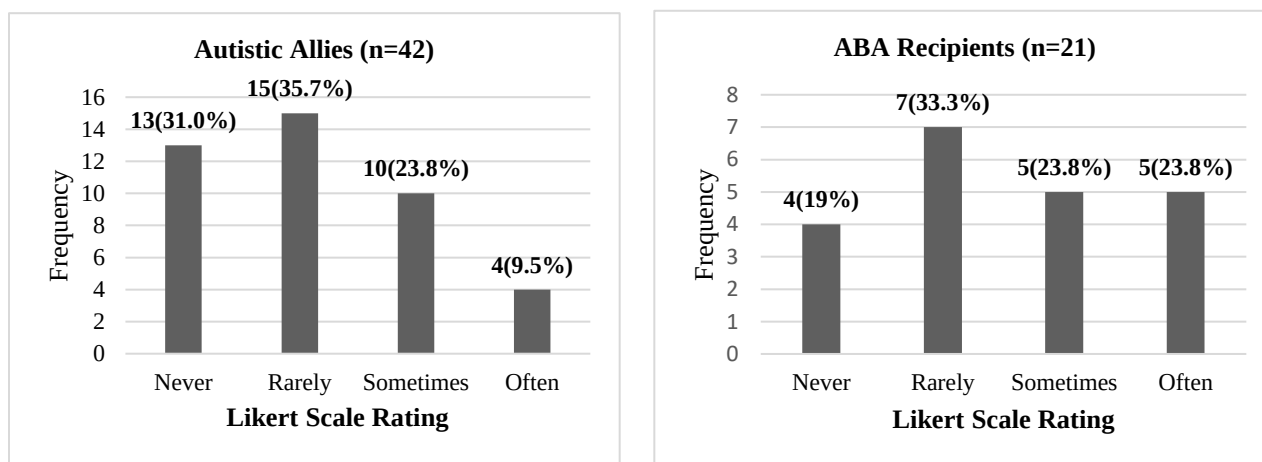
While it is encouraging that more than half of the autistic respondents in both groups experienced feelings of overall wellness at the time of the survey, it was concerning to discover the large percentage of autistic people who “never” or “rarely” experienced emotional wellness— 22.7% in the autistic ally group and 38.1% in the ABA recipient group.

Feelings of Suicide

ABA “survivor stories” abound in autism activist literature online (e.g., art twink [@art_twink], 2021; Kupferstein, 2016; Unbound Books: Autism Acceptance Library, n.d.; Young, 2016a). Several of these stories include direct reference to increased suicidal ideations as

a result of ABA interventions (e.g., Alexanderstreasuresblog, 2020; Young, 2016a). Emerging studies further suggest that ABA recipients experience post traumatic effects from ABA (Anderson, 2022; Kupferstein, 2018; McGill & Robinson, 2020). Similar to the analysis of emotional wellbeing (see above), I conducted a comparative Mann-Whitney U Test of Likert scale mean rank responses between 42 autistic allies who did not receive ABA and 21 ABA recipients¹⁹ in answer to the question, “*At this time in your life, do you feel suicidal?*” Respondents could choose from the options of “1- never”, “2 – rarely”, “3 – sometimes”, and “4 – often”. Results revealed no significant difference of rank means between groups, $U = 347.50$; $z = -1.420$; $p = .156$. However, the mean rank of the autistic ally group (29.77; $M = 2.12$) was lower than the ABA recipient group (36.45; $M = 2.52$). This indicates that proportionately more people in the ABA recipient group experienced suicidal feelings than in the autistic allies group. See Figure 6.6 (that follows) for comparative results²⁰.

Figure 6.6. Autistic Allies and ABA Recipients’ Feelings of Suicide



¹⁹ There were 4 missing cases in the autistic allied group and 1 missing case in the ABA recipient group

²⁰ Due to the sensitive nature of this question, I provided participants with the following statement in the consent form: *Should you suffer any psychological harm, please contact a mental health professional for emotional support. One recommended service for Ontarians is the Ontario branch of the Canadian Mental Health Association at <https://ontario.cmha.ca/document-category/services-and-supports/>.*

These results suggest that a staggering amount of survey respondents, close to 40% of the entire autistic sample, experienced feelings of suicide at the time of the survey. Research in the areas of autistic mental health and emotional wellness have found similar results. Rates of suicide and suicidal thoughts are disproportionately high for autistic people in comparison to the general population (Cassidy et al., 2018; Cassidy et al., 2019; Cassidy & Rodgers, 2017; Chen et al., 2017; Paquette-Smith et al., 2014).

In addition, the results indicate that over 10% more respondents who received ABA felt suicidal compared to the autistic allies group. Given that ABA is not packaged as a mental health intervention, results such as these are concerning. Similar results could be expected in studies examining suicidal feelings of a population of people receiving targeted mental health interventions for suicide and depression, such as CBT or psychotherapy. What is concerning about these findings is that ABA is an intervention promoted as medically necessary for all autistic people regardless of their mental health (Busch, 2019b). It is a behaviour modification approach with no identified aim toward improving the mental health of autistic people. ABA is expensive and often the most recommended intervention (and the only intervention until recently) available to families with autistic children (Alderson, 2011; A4A Ontario, 2018; Shyman, 2014). For this reason, many autistic children go without mental health support.

It is important to emphasize that neither correlations nor causations can be made between receiving ABA and feeling suicidal—ABA recipients had more reported support needs than respondents who did not receive ABA and therefore may experience more stigma causing feelings of depression or suicide. The scope and methods of this study make it impossible to discern whether feelings of emotional wellness (or lack thereof) and suicide were attributed to the ABA interventions they received, which was a concern raised by autistic allies in Chapter 5

(see Concern #5). This study did not include a randomized control group design nor variables which could be controlled for related to family and social supports, socioeconomic status, or experiences of discrimination and exclusion. However, the overall results of this analysis on wellbeing outcomes reveal little evidence that ABA interventions contributed to improved wellbeing for autistic people and point to an immediate need for accessible mental health and wellbeing support.

To gain further insight into the impacts of ABA on autistic people's wellbeing, I interviewed Kendra²¹ who indicated in her survey that ABA was “not effective at all” and caused her significant feelings of sadness, anger, anxiety, and depression. Kendra's story provides the experience of an autistic young person who received ABA-informed services after years of depression and a suicide attempt as a result of bullying, lack of helpful accommodations, and discrimination at school. *Content warning: mention of suicide.

Stories Behind the Statistics 3: Kendra's Experience:

Kendra (she/her) identified as a white autistic woman who was 31 at the time of the interview. She worked part-time in online design and communications at a university. She is a strong advocate for bettering autistic services in Ontario, and she runs her own consulting business for parents, educators, and therapists looking to develop neurodiversity-affirming practices. Throughout her interview, she made it clear that she knew ABA therapists were often caring individuals trying to do what they think is best for autistic people but felt that, without significant reform, the ABA industry would continue its risk of harm. Kendra had a lot she wanted to share. She began with her motivation for participating in the study, which was to advocate for change within the ableist systems ABA is a part of:

²¹ Kendra is a pseudonym selected by this participant

There needs to be many meaningful structural changes to how we treat autistic people at basically all levels of society, from public education and continuing education, careers, mental health treatment, medical treatment... ableism is entrenched in all of these institutions, as well as our personal relationships. And ABA, in many of its methods and its history, as well as the ideologies that are foundational to it, is just a big ol' microcosm of anti-autistic ableism. So yes, I want to make sure that future autistic kids do not go through what I went through when a bunch of professionals were telling me that they were helping me, and they absolutely were not.

In her survey, Kendra indicated that ABA was “not effective at all” for her personally. She received ABA-informed services via social worker and psychiatrist recommendations made to her parents and her school after she attempted suicide at the age of 14. She explained how the suicide attempt was directly tied to the chronic bullying she received from peers and the lack of accommodations and understanding from teachers at school. Later, in the edit process of this story, she added: “I dealt with constant bullying and sensory overwhelm. Even though I was ‘gifted’, I couldn’t manage the assignments. But I didn’t get real accommodations because my struggles were viewed as behaviour problems like not trying hard enough, or ‘acting out’, or not caring.” This experience led to a stay in an inpatient hospital where she was diagnosed with autism and where her parents and school received ABA-informed recommendations designed to increase school attendance.

Looking back, Kendra recalled how the social worker ignored the obvious signs that she “would have rather been dead than suffer in school for one more day”. In a follow up interview, she emphasized: “my parents were taught to force me to school ostensibly because attending school like a ‘normal kid’ would lead to my happiness and success”. She explained that, due to

the persuasive nature of the ABA recommendations for school attendance, her struggles were minimized:

I was really, really struggling with school. And school refusal was a valid thing because school was not a safe environment for me... All of the mental health treatment that I had received up until that point was aimed at forcing me to school... everything was about forcing Kendra to school and not about making school a better place... None of the recommendations involved my wellness—all of them involved how to make me go to school because the assumption was that if I would just go to school and be normal, I would somehow, like, be better.”

Kendra admitted that it was not until recently that she understood that the techniques her parents and school were trained in by the social worker were actually ABA techniques. When I asked her for some examples of the techniques and parent recommendations, she replied: “So, I would say probably the most [paused]... the one that sticks out the most in my mind is planned ignoring [began crying]”. Through tears, she went on to explain:

Planned ignoring was grossly unethical... Essentially, what they taught my parents was that the reason I was leaving school was not actually because school was bad... and I was saying that school was bad because school was *bad*. I was saying that school was dangerous because school was *dangerous*... My parents were told that that [saying school was bad] was ‘escape’²² and ‘looking for attention’. So, they were taught to ignore me if I expressed anything bad about school.

²² ‘Escape’ is a behavioural term in ABA to describe an avoidance behaviour (e.g., student escapes desk work by crying). See Concern #5 in chapter 5.

Kendra further described the distress she felt when her parents were instructed to withhold her screentime, which was necessary for her to write stories, learn about web design, and make friendships in a sensory-friendly and bully-free environment:

The computer was the source of a lot of my language learning. It was the source of a lot of my social and emotional learning because what, you know, what my mental health professionals failed to acknowledge was that my friends were on the computer, and at school, I did not have any friends [began crying]. Almost nobody was nice to me. Like, I would go to school and if somebody talked to me, it would be things like, you know, “you're a disgusting freak... Nobody wants you here.” Whereas on the computer, I had friends.

When her screentime was restricted, Kendra explained that “They would call it a reward when really it was just a punishment or less punishment... If I didn't go to school, I didn't get to use the computer... when I stopped complaining about school to my parents, I got to use the computer...” She recalled:

For some reason, even though I had been screaming all my life that school was hurting me, and I literally tried to kill myself as a 14-year-old to get out of school... the ABA goal was to send me to school. Not to make me happy, not to heal my depression, not to heal my anxiety, but to get me to school.

Throughout this experience, Kendra emphasized that she in no way blamed her parents for being trained by professionals to use rewards such as computer time to increase her target behaviour (i.e., attending school) and consequences such as planned ignoring, or restriction of screentime, to decrease target behaviour (i.e., complaining about school). She knew that her

parents were convinced that they were doing everything they could to help her succeed; they were simply taught strategies that they did not know were harmful.

My parents had good intentions. They loved me. They thought I was a good and talented person. They wanted me to be able to grow up and have a career that I loved. They wanted me to have friends, they wanted me to be happy... They just [paused here to sniffle and wipe tears] they were so misguided.

Kendra described how when her parents tried to defend her feelings in family meetings with the social worker, they were told to “listen to the experts” and not to Kendra herself. She understood now that her parents were persuaded to believe that “ABA could not possibly be harmful” because ABA is supposed to be unquestionably evidence-based. She shared that since this time, her parents have done a tremendous amount of work with her to repair the damage caused by her ABA treatment.

Kendra further emphasized how the social worker was actually quite kind, and likely did not know how harmful ABA actually was:

The weirdest thing was that the social worker wasn't some kind of villain... She did and said horrible things, but in the kindest tone of voice. I think she thought she was helping me because that's how she was taught, too. Like, ignore autistic misery because it's all part of the process.

From Kendra's perspective as a neurodiversity-affirming consultant, she shared that she often reflects on how “there haven't been enough powerful people willing to go into that [ABA method] and say, ‘are our goals ethical?’”

The impacts of reinforcement and planned ignoring strategies to reinforce Kendra's attendance at a school, a place where she was constantly bullied and had her needs ignored,

caused her further depression and rifts in her relationship with her parents. Kendra's story is one that supports the autistic allies' concerns in chapter 5 about the harms caused by ABA methods (see Concern #5, Chapter 5). This story is particularly important given the belief that positive reinforcement and planned-ignoring strategies, such as those used in Kendra's program, are considered to be non-intrusive methods of teaching autistic people new skills (OSETT-ASD, 2019). Similar to Russel's story earlier in this chapter, Kendra's parents put their trust in the professionals. The social worker instructed her parents to ignore her expressions of distress about school and to reward both her attendance and silence about the bullying and lack of accommodations at school that caused her harm. In the final edits of this story, Kendra explained:

My silence and suppressed feelings became 'the measure of ABA success' because the target behaviour of complaining about school was reduced. It didn't matter [to the social worker] that the reason I stopped complaining was that I couldn't trust my parents to listen anymore. I was devastated, but as far as she was concerned, I did a great job. I wonder, just how much autistic suffering is hidden behind studies that say ABA did a great job?

Planned ignoring is a common behavioural strategy known as "extinction" that is used to diminish or extinguish target behaviours (Lovaas, 1981). Planned ignoring is commonly used by ABA therapists both past and present to extinguish distressing behaviors in young autistic children. Lovaas (1981) defined extinction as a strategy for parents this way:

"Working through" a tantrum is a good example of extinction. Your child may scream and kick, but you go about your business as if the behavior is not occurring. Almost certainly,

the tantrum will disappear. Extinction, then, is a powerful, although time-consuming and demanding, method to get rid of a behavior. (p. 15)

Planned ignoring continues to be used as a recommended strategy for parents. In a recent podcast describing a newer form of ABA known as Acceptance and Commitment therapy (ACT), Tarbox (2018) explained how parents can use mindfulness techniques to tolerate and accept their child's signs of distress for the purpose of attaining valuable long term goals:

So, while they're hearing the kid scream, it's useful for the parent to say something like... 'I'm gonna hear you scream... and they don't have to say it to the kids out loud, but they can think it to themselves: 'I'm going to hear you scream so I can help you make friends in the future.' I'm going to hear you scream so that maybe you can live one day on your own'. I'm going to let you scream so that you can get the most out of life'.

(1:16:10)

Tarbox's example in particular was discussed in the context of a young child who might be crying and screaming when denied candy, which would tempt the parent to instinctively intervene with a verbal redirection or offer of candy to make the screaming stop. As Tarbox explained it, the parent's redirection or offer of candy would stop the behaviour in the short term but would reinforce the probability that the screaming and crying would occur again in the future as the child learns to scream to attain attention or candy from the parent. This is the reason parents are trained to tolerate the screaming without giving immediate attention. While this example is different from Kendra's situation, the basic principle remains the same. Kendra's parents were led to believe that by accepting or ignoring her distress in the short term, with the added 'reward' of computer time when she attended school without complaint, Kendra would attain the long-term goal of future success. As will be discussed later in Chapter 7, ACT can be a

helpful therapeutic modality for helping people to cope with many situations. However, when ABA modalities such as planned ignoring of distress is used in parent training without understanding the impacts of autistic trauma related to stigma, discrimination, or misinterpretation of autistic needs, there is significant risk of harm to autistic people's wellbeing.

Quality of Life (QoL) Outcomes

The following set of analyses include descriptive and inferential statistics, accompanied by a qualitative analysis of open text box responses to explore respondents' perceptions of the ways in which ABA interventions contributed to their current quality of life (QoL). I based the indicators for this analysis—education, employment and preparedness outcomes—on the ABA literature that suggests ABA interventions are designed to increase an autistic person's overall QoL (Cooper, Heron, & Heward, 2020; OSETT-ASD, 2017).

The OSETT-ASD (2017) stated that ABA interventions are designed to address behaviours of “social significance” that “have an impact on the quality of life of the individual” and “will allow that individual to engage more fully and meaningfully with the environment, and those in it” (p. 122). Similarly, Cooper et al. (2019) stated that, “applied behavior analysis research and practice have improved human performance and the quality of participants' lives across a wide range of areas” (p. 36). While neither text defined indicators of QoL specifically, both of these resources identify ABA as an effective method of supporting autistic young people to attain important life outcomes such as education, employment, and overall improved QoL.

To test these claims, I began by analysing ABA recipients' experiences of education and employment outcomes. My original plan was to conduct a similar comparative analysis as I had in the section previous (see wellbeing outcomes) between autistic respondents who had received ABA interventions with respondents who had not. In doing so, I had intended to test the

hypothesis of whether ABA recipients had improved life outcomes as a result of ABA interventions (Cooper, Heron, & Heward, 2020; OSETT-ASD, 2017). However, as mentioned prior, there was no way to do a fair comparison test between outcomes of respondents who received ABA interventions and those who did not. The differences in age ranges and support needs between these two groups meant that comparative results were skewed. Initial results from a Mann-Whitney U comparison of means revealed a higher mean rank of education level attained (i.e., postsecondary attainment) within the ally group who did not receive ABA (37.88; $M=3.3$) compared to the group who received ABA (25.50; $M=2.62$), $U=304.50$; $z=-2.589$; $p=.010$. Similarly, a Chi-square test of association revealed a statistically significant result indicating that respondents who did not receive ABA interventions were more likely to attain employment than respondents who received ABA interventions, $\chi^2(1, N=68)=7.535$, $p=.006$. On average, the ABA recipient group was much younger with more highly apparent support needs (i.e., had co-existing intellectual disabilities and were nonspeaking) compared to the autistic ally group who had not received ABA interventions. Given the differing ages and possible support needs of these two groups, attainment of postsecondary and employment outcomes cannot be correlated with receiving or not receiving ABA interventions. Rather, it is plausible that age maturity and less apparent/less stigmatized support needs within the autistic group who did not receive ABA attributed to the higher attainment of postsecondary and employment outcomes. See demographics tables in this chapter and Chapter 5 for a breakdown of age and support needs.

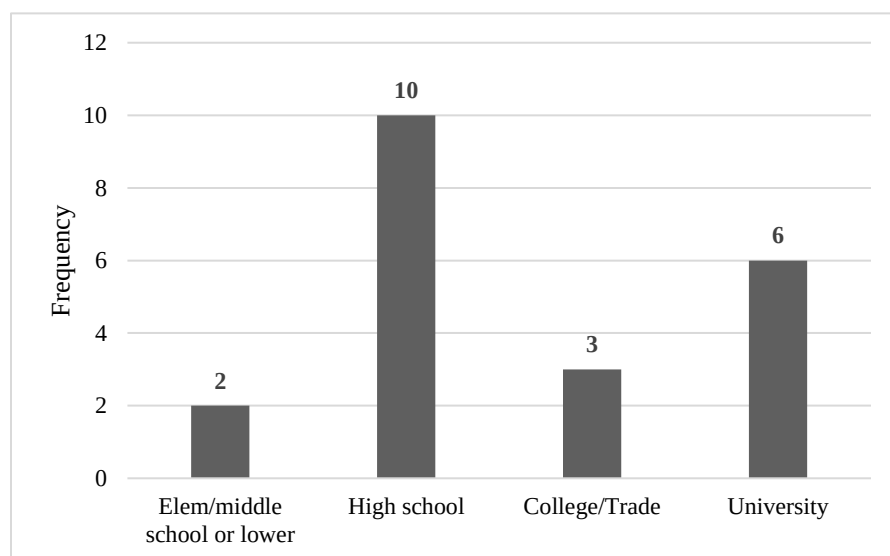
To gain a deeper understanding of the education and employment outcomes within the ABA recipient group, I conducted a parallel method of descriptive statistics and qualitative analysis of open text box responses to survey questions related to education and employment

attainment. I followed with an analysis of factors related to preparedness for independence and success.

Education outcomes

To analyse education outcomes, I examined the highest level of education received by ABA recipients. Results revealed that two respondents (who were under the age of 25) had yet to complete a high school education. 10 of the 21 recipients²³ of ABA (47.7%) had completed high school while 9 out of 21 (approximately 43%) had completed post secondary education. Seven of the 10 respondents who had only completed high school at the time of the survey were young adults between the ages of 16 to 25. This was a predictable result given that young adults may be continuing to complete their postsecondary education. Of the 9 respondents who completed postsecondary, 3 were young adults under the age of 25 (all of whom completed a university degree); 5 were between the ages of 26 to 40; and 1 was over the age of 40. See Figure 6.7.

Figure 6.7. Highest Level of Education: What is the highest level of education you have completed to date?



²³ There was one missing case

These results suggest that many autistic people who received ABA interventions went on to complete high school, and many pursued postsecondary educations. However, similar to the trend found throughout this analysis, comments were shared only by respondents who had a negative experience with ABA that they felt contributed to poorer education outcomes than they had hoped. See Table 6.6 later in this chapter for qualitative results.

The following story shared by Damon during the interview and participatory stages of the study provides further insight into the ways in which ABA “missed the mark”, as Damon put it, when attempting to meet his educational needs.

Stories Behind the Statistics 4: Damon’s Experience:

Damon (he/him) described himself as a white, cisgender, nonspeaking autistic person. He was 22 years old at the time of the interview and was completing his final high school course. After many years of “languishing in a segregated ABA classroom”, he looked forward to attending University to study disability policy or neuroscience. Damon explained that he prefers to be referred to as nonspeaking rather than non-verbal because,

This term leaves open the possibility or likelihood that I have access to another mode of communication—and that I understand despite not being able to speak. Nonverbal, on the other hand, implies one does not have words at all—and has typically been used to mean an individual has limited understanding of written or spoken words.

While people have described him as “severely” autistic, Damon would not describe himself this way. Rather, Damon described himself as an autistic person who has “extreme sensory-motor difficulties and anxiety.” He was diagnosed before the age of 2-years-old and received intensive ABA services for more than 13 years, at home and at school. Throughout his life, behaviour professionals have assessed his cognition to be at a “low level”, which he explained is far from

the truth of his lived experience: “I understand everything around me, despite my nonspeaking status. I consider myself nonspeaking because I can say many words and phrases, but usually out of context, or impulsively. I can communicate fluently using AAC [alternative and augmentative communication].”

Similar to Kendra, Damon stated that he understood that the interventions he received were meant to be helpful but felt that the BCBAs who worked with him up until age 15 misinterpreted his needs and movement difficulties, which was why he was motivated to participate in this study. Being nonspeaking meant that practitioners believed he was, as he put it, “an empty bucket, meant to be filled up with skills.” He felt his therapy was administered from the perspective that he didn't possess any thoughts of his own. He had to learn to obey menial tasks and commands “without resistance”. He found this to be humiliating and explained, “every move I made was scripted ...I was taught to maintain (all at once), ‘nice hands, nice eyes, nice shoulders, nice mouth (meaning quiet), and nice, calm body.’” Although he appreciated learning many useful skills, such as body control, printing and typing words, dressing himself, preparing food, and walking without bumping into others, he expressed frustration that no one seemed to understand that many of his bodily expressions were an integral part of the few coping mechanisms he had. These were coping mechanisms that helped him to, as he put it, “reduce my anxiety in a very overwhelming environment.”

With further respect to his movement difficulties, Damon indicated in his survey that in his ABA programs, he was often directed to physically respond immediately to requests, such as “touch your nose, point to the spoon, pick up the ball, clap your hands, etc.” Due to his challenges with initiating responses to these directions, however, Damon was often prompted too quickly, rather than being afforded the time to authentically respond, because it was believed he

did not know the answer. He further indicated that he received rewards that he neither wanted nor needed due to the misconception that he was not intrinsically motivated to learn: “My parents would not agree to food rewards, but I received them anyway. There was pressure to give me candy because I was not ‘motivated’ enough.” Damon explained, “I did not need the rewards. I am just like any other person, in that accomplishments are intrinsically motivating (or not, depending on what I am doing). One of the first things I said when I learned to communicate was that I did not want to work for candy anymore.” The presumptions about his capabilities and needs contributed to Damon’s experiences of ABA as “not effective at all” including interventions that “often” caused him feelings of sadness, anger, anxiety or depression.

Damon shared how grateful he was for the immense support he had received from his family, who have been strong advocates in helping him to receive the support and services he needs. He recalled some fond memories of elementary school and described his ABA support workers as very “sweet”. He further recalled some of the enjoyment of his early school experiences: “...participating in gym class, art class, plays, etc., without feeling as though I didn’t belong. I was very accepted—if not necessarily understood.”

Although he felt he was “integrated”, he did not always feel he was “included” because, as he explained it, “Nobody knew that I could understand, and I had no reliable means of communication.” He expressed appreciation for newer forms of ABA, such as Greg Hanley’s trauma informed and autistic-centred *Practical Functional Assessment* approach to ABA (Hanley, 2021), which is designed to increase the empowerment and autonomy of autistic people:

Greg Hanley expresses the need to listen to autistic people, and to give over control, which is a relief—he actually recommends removing all signals of dominance. He also

frames autistic people as deserving of respect and having likely being mistreated and traumatized. His framework (at least in the beginning stages) consists of allowing autistic people to lead, without judgement, without behaviourists redirecting, or acting as supervisor. This is very, very positive. Hanley seems to understand that the feeling in control of one's self is crucial in feeling safe. I agree.

However, Damon shared some concerns about these newer forms of ABA, which largely attract families, therapists, and educators of nonspeaking autistic people. Damon described one main concern with Hanley's (2021) protocol as such:

... some of the ABA support workers in charge of students in my friends' classroom do not quite "get" the aspect of thinking about autistic people with respect—or of truly giving over control, but rather, think of the protocol as a "tool" to gain cooperation. I really see this as a serious concern, because if behaviourists are simply applying a surface-level understanding of the protocol, without actually believing that autistics deserve respect (without judgement), nothing has actually changed.

If the field of ABA remains in place, Damon would like to see new methods, such as Greg Hanley's *Practical Functional Assessment* (Hanley & Cammilleri, 2021) approach, "...go further with respect to thinking of nonspeaking autistics as whole people who likely understand, and who likely have sensory and movement challenges, and anxiety." He hopes that listening to the experiences and recommendations of autistic people will improve autism services.

Damon's experience highlights the myriad challenges faced by nonspeaking autistic people. During three separate Zoom calls, I witnessed Damon patiently type his answers independently, which is an extremely arduous skill for autistic people with severe hand and bodily motor challenges to learn. While it could be argued that learning to spell to communicate

is an intervention that causes distress in ways that are similar to ABA, the risk in this case is outweighed by the benefit due to the self-determined autonomy and communication skills gained that lead to increased ability to express one's needs, desires, and hopes (Communication First, 2021; Kedar, 2012; Kirsebom, 2020). As mentioned in Chapter 5, it is not uncommon in the field of ABA for researchers and practitioners to be skeptical of nonspeaking autistic people's abilities to learn to spell to communicate (Holehan & Zane, 2020; Williams, 2020). As a result, Damon "languished" in ABA programs with well-meaning practitioners who treated him like "an empty bucket".

Damon's concern about educators' exertion of control over autistic students (whether intentional or not) is in need of careful consideration. In Pritchett and colleagues' (2021) review of ABA studies in the Journal of Applied Behavior Analysis (JABA) over five decades, they found that when Greg Hanley was guest editor in 2018 (the last decade analyzed), there were only three reports of "increased empowerment" of participants and no reports of "research goal collaboration" with participants in the 16 experimental studies selected for review. One key finding of Pritchett and colleagues' entire review was that client empowerment goals have yet to be substantially accounted for in ABA research or practice settings. This lack of attention to empowerment and goal collaboration highlights the concerns about compliance-based ABA methods that were raised by the autistic allies in Chapter 5. Time will tell as to whether empowerment goals can be attained through a reformed and more progressive ABA.

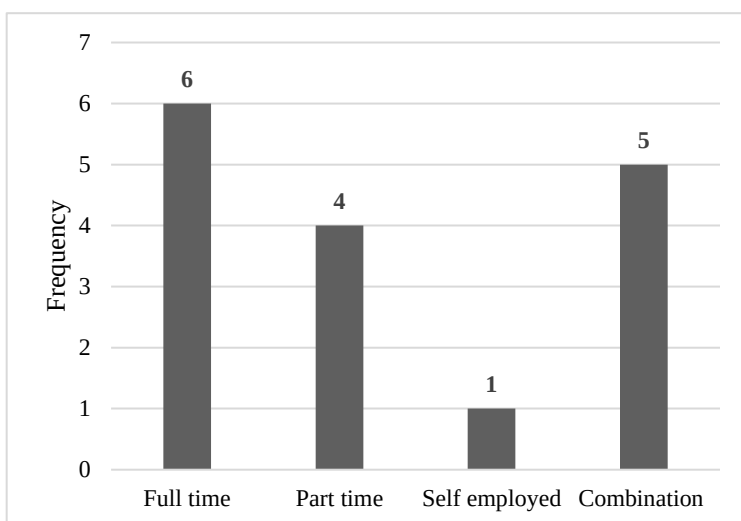
Finally, it seems clear that Damon would disagree with the assumption that "severe" autistic people are the only ones who "need" ABA (see *Overview* and *Concern #1: ABA is Based on a Faulty Premise* in Chapter 5). More focus on his rights to communication access (A4A, 2019a), without focus on menial task completion, would have led to more equitable education

outcomes for Damon.

Employment Outcomes

Next, I analysed respondents' experiences of employment. Results revealed that 16 out of 22 ABA recipients (72.8%) had attained employment in their lifetime. When broken down further, results revealed that 11 of the 16 (69.0%) respondents had attained either full time work (n=6) or a combination of part time, full time and/or self employment (n=5). Seven of these respondents were young adults under the age of 25 years old. The remaining 5 respondents had either worked part time (n=4) or were self employed (n=1). See Figure 6.8.

Figure 6.8. Employment Outcomes: Have you ever been employed?

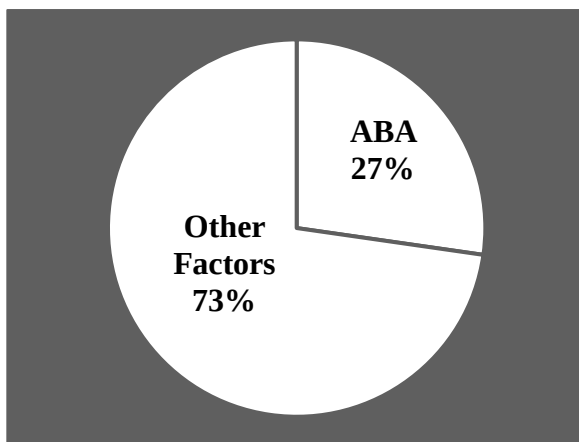


Given that over half of the ABA recipients were young adults, these results are encouraging. Close to three quarters of autistic people who received ABA went on to attain employment after high school graduation. Yet, similar to the comments shared in relation to education outcomes, respondents who chose to elaborate in the open text box areas largely expressed barriers to attaining and maintaining employment. While one positive experience of employment was shared, it was accompanied by experiences of ableism. See Table 6.6 at the end of this section for comments shared by respondents.

Feelings of Preparedness

Despite the encouraging results above, the final analysis related to QoL found that only 6 respondents (27.3%) indicated that they felt their independence and success in education and employment were attributed to the ABA interventions they received. The remaining 16 respondents (72.7%) attributed their independence and success in life to other factors that did not include ABA interventions. The survey question for this analysis posed the question, *“Throughout my life, I feel that the following factors have prepared me for independence and success in education and employment”*. Respondents could choose any and all that apply from a list of 12 options including (but not limited to): educational, family, social, and financial support, along with their own self-determination and natural maturity. See Figure 6.9.

Figure 6.9. Factors That Have Contributed to Independence and Success



Again, the respondents who chose to elaborate in the open text box were critical of ABA or felt other interventions were more helpful for them. See Table 6.6 for all open text box comments related to education, employment, and feelings of preparedness shared by respondents.

Table 6.6. Education, Employment and Feelings of Preparedness

Survey Question	Comments
Is there anything else you would like to share about your feelings of inclusion and success in school, independence, and/or employment?	“When I learned to type independently, I asked to attend academic courses. I was allowed to attend, but was not allowed to work for academic credit. I eventually tested 8 years above my age on educational testing—but still, my teacher tried to sabotage my efforts. I feel as though nonspeaking autistics are not actually human. I was always accepted by students, and they tried to include me. But, when I was finally able to prove my intellect (as if I should have to prove that!), I was still denied access to credit. I ended up having to leave the public school system.” “The public school system still segregates autistic children in segregated classrooms (i.e. ASD classrooms where Autistic children are misunderstood and traumatized daily).” “My current workplace is extremely suitable and accommodating and I do excellent work because I set my own hours, work from home, and work largely independently. I have a lot of control over my schedule and my sensory environment. Most jobs are not like this. However, my boss definitely has some ableism to unlearn. I’m almost certain she doesn’t believe me when I say I’m autistic...” “Current workplaces exclude non masking autistic people through discriminatory policies.” “I feel like I would have been more successful in life if so much of it wasn’t lost to ABA and the trauma with it.” “I was not prepared for university after high school and was unable to live independently while attending classes and dropped out. I was never able to keep a job for more than 6 months at a time before joining the military, I was not a good fit for them or some such excuse.”
Which of the following educational, vocational, and/or employment outcomes are important to you?	“I physically can’t work full time and according to capitalism that means I should spend every day of my life wondering if I’ll ever be able to retire.”
Throughout my life, I feel that the following factors have prepared me for independence and success in education and employment.	“I am not prepared for such things, I still am learning the procedure since the therapies I received were focused on making me compliant and unbothersome, and not much else.”

“Communication and physical therapies [prepared me for independence and success].”

At initial examination, the statistics related to education and employment seem to indicate that a majority of the ABA recipients of this study achieved some success in education and employment. Given the profit-oriented nature of education and work in a capitalist society that thrives on a cycle of compliance—i.e., educators are trained to be compliant and complicit toward compliant-based teaching methods that produce compliant citizens (Kohn, 2018)—perhaps this finding is not surprising. However, the gaps in open text box elaborations by respondents who had positive feelings about their successes and the ABA they received create difficulties when interpreting results from their perspectives. An even larger majority of respondents (73%) did not attribute their preparedness for this success to the ABA interventions they received. This finding indicates that many of the autistic ABA recipients of my study achieved success due to factors other than ABA, and there is no evidence in the survey results of a causal relationship between ABA and educational or employment success. Further, as the comments in Table 6.6 demonstrate, respondents of this study did not feel that education and employment outcomes (mainly in Ontario) resulted in improved life outcomes for autistic people. When both the statistics and lived experiences are examined together, there is little evidence to suggest that ABA methods have contributed to the improved QoL for the ABA recipients of this study, which is in alignment with the autistic allies’ concern that ABA is not actually evidence based in ways that matter for autistic people (see Concern #4, Chapter 5).

It is further important to note that in conventional Western capitalist societies such as Canada, that place value on each citizens’ ability to independently support themselves (Ashburn

& Edwards, 2023; Broderick, 2022; Schaber, 2021), autistic livelihoods become dependent on completion of education (usually higher education) and the ability to attain and maintain employment. Detailed responses provided by the lived experience stories of Damon and Kendra, along with the comments listed in Table 6.6, provide insight into the real impacts of discrimination and stigma that make it difficult for autistic people to succeed in education. For example, the comment, “Current workplaces exclude non masking autistic people through discriminatory policies”, highlights the lack of workplace accommodations for “non masking” autistic people (i.e., autistic people who do not suppress their autistic traits). While it may be true that ABA can help autistic people to suppress their autistic traits, it is also true that autistic masking is an exhausting experience that can lead to depression and feelings of suicide (Cassidy et al., 2019; Pearson & Rose, 2021; Price, 2022).

Experiences of Consent, Reward and Punishment Procedures

ABA approaches are premised on the effective use of reinforcement and punishment procedures to increase skill building and decrease undesired behaviours (Cooper, Heron, & Heward, 2020; Geneva Centre for Autism, 2019; OSETT-ASD, 2017). Receiving consent from autistic people for these interventions has been a contested issue raised by critical autism scholars and activists for decades (ASAN, 2022; Bascom, 2011; Dawson, 2004; Memmott, 2023; Stop ABA, Support Autistics, 2019a; Wilkenfeld & McCarthy, 2020). It is important to remember here that punishment procedures are not a form of retributive discipline as often perceived by the public (Leaf et al., 2021). However, ABA punishment procedures continue to include aversive treatments, described as “positive punishments” in ABA technical terms, such as shock therapy (Blenkush, 2017; Blenkush et al., 2023; Israel et al., 2008) and physical management or restraints (Rajaraman et al., 2021, 2022), which are intended to eliminate or

reduce challenging behaviours. In recent years, rewards-based learning, along with extensive functional behaviour assessments (FBAs) that place emphasis on changing the environment and not the child, have been recommended to replace punishment procedures as the best evidence-based approaches to support autistic children (OSETT-ASD, 2017; OSETT-CB, 2019).

To explore perspectives of consent, reward, and punishment procedures within the ABA recipient group, I conducted descriptive and inferential statistical tests to analyze survey questions that asked respondents whether they had a) consented to the ABA methods they received; and b) received rewards (i.e., positive reinforcements) and/or consequences (i.e., punishment procedures) as part of their ABA intervention programs. I further analysed survey questions that asked respondents to select what kinds of rewards and punishment procedures they received, and whether they found these approaches effective. Finally, I used a method of cross-analysis to determine whether more recent recipients of ABA interventions received punishment procedures to a lesser extent than respondents who received ABA interventions in the past. Statistical results are accompanied by a table of example open text responses.

Consent

To analyse whether ABA recipients gave consent to receive their ABA interventions, I analysed responses to the following question, “Did you consent to the ABA or IBI methods you received?” Respondents could choose from “never”, “rarely”, “sometimes”, “always”, or “not sure, can’t remember”. Results revealed that close to half (45.5%) of respondents (n=10) had consented to the interventions they received either “rarely” (n=1), “sometimes” (n=4), or “always” (n=5). See Figure 6.10. Over half, (54.6%) of the respondents (n=12) either never consented or were not sure if they consented. This means that less than 22.7% of respondents felt confident that they always consented to the interventions they received. Seven respondents in

total chose to elaborate in the open text box area with only one comment reflecting a positive response: “I always give consent”. The remaining six respondents shared experiences with consent that reflected lack of choice and autonomy. See Figure 6.10 and Table 6.7 (that follow) for detailed results.

Figure 6.10. ABA Recipients who Consented to Interventions Received

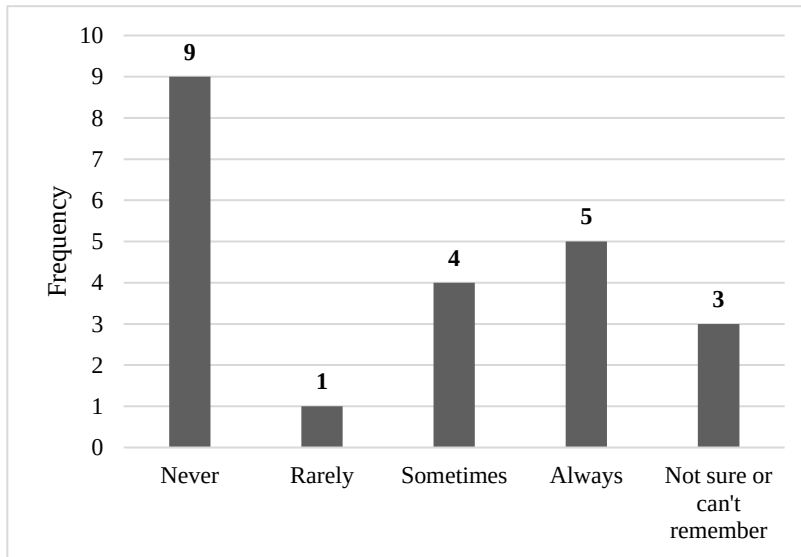


Table 6.7. Consent: Open Text Box Responses

Response Category	Comments
4- Never	“No, and I would NEVER consent to my parents doing "planned ignoring" in response to me expressing depression and anxiety (like ignoring a child who says they want to die will help them somehow??)”
4- Never	“During my adolescence when I discovered how harmful it was to my emotional state, I tried getting out only to be denied that and be stuck in that environment.” “It was mandated by courts that I receive it for my own good. No consent was sought from me because it was assumed I didn't have the ability to consent.”
4- Never	“I was too young to consent or understand the impacts of this methodology.”
4- Never	“I couldn't consent I had no choice I was a child.”

- 5- Not Sure “As a child, I was never given a choice to start receiving the services. Whether or not I consented to certain things that were done while receiving those services, I’m not sure. But the answer was at the very least usually no. There were maybe a handful of times when I allowed for certain activities, but it was almost always in a context I did not want to be in.”

The issue of children’s consent in ABA is murky, and there is no concrete way to interpret the results presented here. Several of the comments in Table 6.7 (e.g., “I couldn’t consent I had no choice I was a child”) reflect the common ethical dilemma in the behavioural and medical treatment of children that children are too young to consent to the services they receive (Hodge et al., 2023). Therefore, legal guardians (i.e., parents) are required to consent on their behalf (Behavior Analyst Certification Board [BACB], 2023). From certain vantage points, parental consent to behavioural services makes sense, particularly when ABA is marketed to parents (parents who, of course, want the best for their children) as the only evidence-based treatment for autism (Alderson, 2011; Prizant, 2009; Shyman, 2014; Wilkenfeld & McCarthy, 2020). However, the history of ableism in ABA therapy for autistic children calls the ethics of consent for behavioural treatment into question in several ways.

Michelle Dawson’s (2004) seminal essay, *The Misbehaviour of Behaviourists*, traced the history of scientists’ ableist assertions (e.g., Gresham & MacMillan, 1998) that it is “absurd” to ask for consent from autistic people because it would be, as one doctor (Dr. Frank Gresham) put it: “like consulting with the mentally-r*d” (The confounding factor of unethical dissent section, para. 6). Blatant ableism such as this, commonly left unattested (Dawson, 2004), stems from biomedical deficit-based theories of disability (e.g., will or choice theory) that valorize ableist constructions of intelligence (see discussion in Chapter 5) to justify unfounded theories that

disabled people have no say in their own treatment (Hodge et al., 2023). The ableism perpetuated by scientists such as Frank Gresham (along with Ivar Lovaas, and other behaviourists) entrenched the idea that it was nonsensical to even consider receiving consent for ABA from autistic people because autistic people have the indisputable right to “resemble non-autistics” (Dawson, 2004 Conclusion: The right to effective ethics section, para. 4). The notion that anyone would dispute an autistic person’s right to ABA interventions as a means to become ‘normal’ (and thereby human) was not up for debate in autism discourse at the time. Discriminatory attitudes about who belongs or who is ‘able’ enough to participate in the ableist systems that persist today serve to maintain the assumption that it is a therapist’s obligation to support autistic people to fit into the everyday operations of normative society (Leaf et al., 2021) rather than to support them to accept their neurodivergence with pride. Within the historical context of ableism and stigma in ABA, parental consent risks becoming unethical when the goal is to help the child develop according to neurotypical developmental norms as is the aim of many current ABA interventions (e.g., Cooper, Heron, & Heward, 2020).

Similarly, ABA consent is called into question through the consideration of conscious awareness of available services and autonomy in child development. In Ontario, ABA remains the most recommended and often mandated method of support for autistic children (Ontario Ministry of Education, 2007; OSETT-ASD, 2019). Consequently, parents and children are often unaware there are alternative person-centered and neurodiversity-affirming ways to support autistic children that do not depend on measuring behaviour against standardized developmental norms (e.g., Delahooke, 2019; Laurent & Fede, 2020a). The “banking concept of education” whereby information is deposited and accepted by students’ without resistance (Freire, 1970, p. 72) has fueled the dominant non-critical culture of accepting the education services that exist.

If parents and children are not conscious of alternatives to ABA, or worse, not offered access to alternatives, they may not be giving full informed consent to ABA.

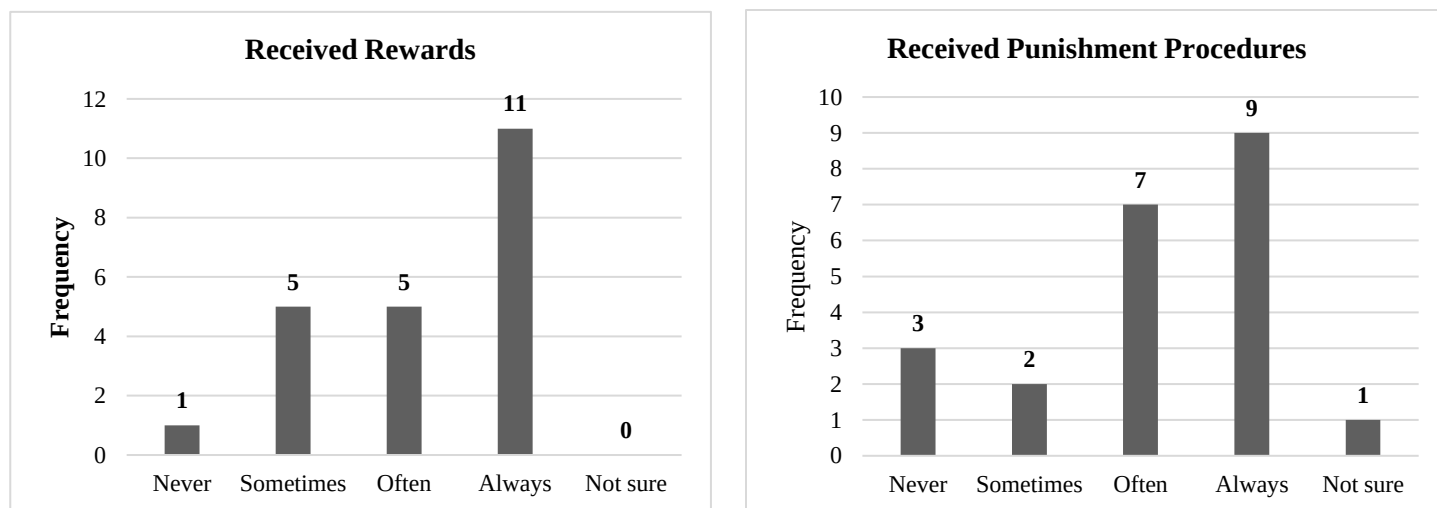
Further, Wilkenfeld and McCarthy (2020) argued that, while it is understandable for parents and professionals to have authority over decisions about young children, decisional authority should not override the “autonomy interests” of children including: “1) an interest in freedom from interference with their ability to act on their desires, and 2) an interest in freedom to develop preferences that can be cultivated into more substantive passions or pursuits” (p. 42). Wilkenfeld and McCarthy (2020) point out that because autistic children have unique ways of developing their self identity through neurodivergent interests and desires, ABA interventions risk violating autistic children’s rights to autonomy and freedom by preventing autistic children “from acting on these desires or preferences” (p. 42). Disabled children’s enshrined rights to “self-reliance” and to freely “engage in play” (among other rights) are further put at risk through decisional authority over participation in intensive behavioural interventions (United Nations, 1990, Articles 23/31). Further discussion on improvements in consent and assent practices within the field of ABA follow in Chapter 7.

Frequency of Rewards and Punishment Procedures Received

Next, to examine the frequency of rewards and punishment procedures received by respondents, I analyzed responses to two separate survey questions that asked whether respondents received rewards (i.e., positive reinforcements) and/or consequences (i.e., punishment procedures) as part of their ABA intervention programs. Responses ranged from “1 – never”, “2 – sometimes”, “3 – often”, “4 – always”, and “5- not sure/can’t remember”. In total, 21 out of 22 respondents (95.5%) indicated that they received rewards as part of their intervention programs (sometimes n=5, often n=5, always n=11). Slightly fewer than this, 18 out

of 22 (81.2%), indicated that they received consequences (sometimes $n=2$, often $n=7$, always $n=9$).

Figure 6.11. Frequency of Rewards and Punishment Procedures Received



Types of Rewards and Consequences

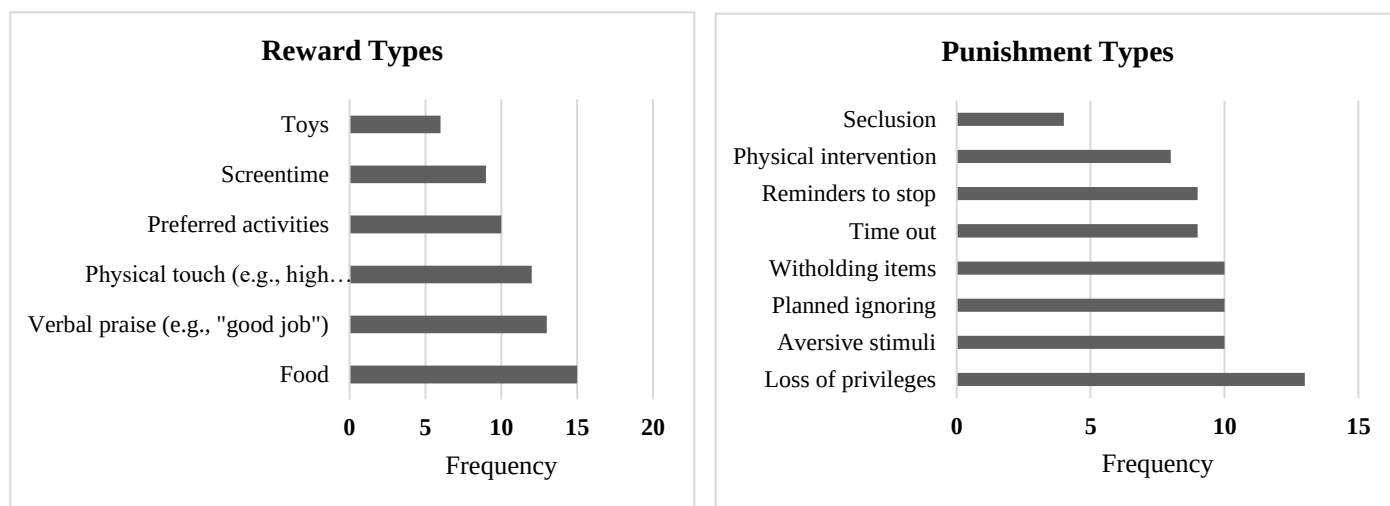
Additional survey questions asked respondents what kinds of rewards and punishment procedures they received. Respondents could choose ‘all that apply’ from a list of six common rewards used in ABA interventions (food, physical touch, preferred activities, screentime, toys, verbal praise) and eight possible punishment procedures used as a part of ABA intervention programs and/or as disciplinary measures used in schools, day care settings, etc. (aversive stimuli, loss of privileges, physical interventions, planned ignoring, seclusion room, time out, withholding items, and reminders to “stop”).

The top three rewards reported by respondents were food items such as chips or candy (selected 15 times), verbal praise such as “good job” (selected 13 times), and physical touch in the form of high fives, hugs, pats, etc. (selected 12 times). The behaviour goals respondents selected to have received these rewards for included following expectations (selected 14 times),

making eye contact (selected 12 times), and sitting still (selected 11 times), among a range of other behavioural tasks.

The most common punishment procedures selected to have been received were loss of privileges (selected 13 times), followed by aversive stimuli (that can be delivered in the form of verbal reprimands; spray bottles; etc.), planned ignoring, withholding items, and reminders to stop (each selected 10 times). Only one respondent chose to add additional procedures received in the ‘other’ option provided and wrote: “Physical abuse, hitting, shaking” and “verbal abuse”. This respondent received their ABA interventions between the years of 1976 to 1986. The following behaviours targeted for reduction through the use of these punishment procedures ranged from greatest to least: getting out of their seat (selected 14 times), noncompliance with demands (selected 13 times), meltdowns (selected 11 times), self stimulatory behaviour (selected 11 times), speaking out loud (selected 8 times), running away (selected 5 times), physically harming others (selected 3 times), self harm (selected 6 times), swearing (selected 3 times), destruction of property (selected 2 times), insults to others (selected 1 time).

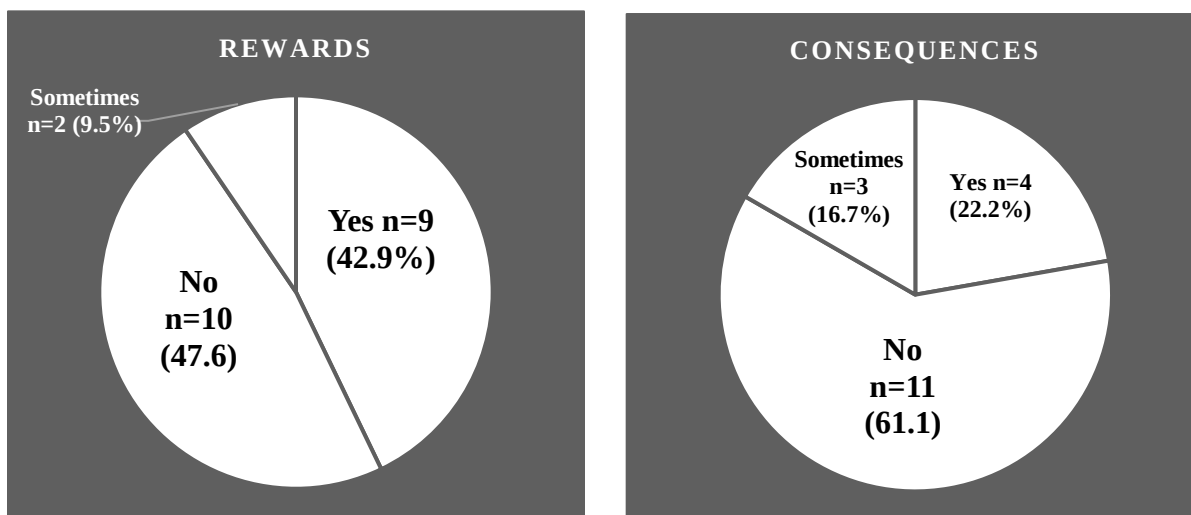
Figure 6.12. Types of Rewards and Punishments: Response Frequency



Perceptions of Effectiveness

With regard to perceptions of effectiveness, respondents were asked the following question, “Do you feel the positive reinforcements or rewards effectively helped you to learn and maintain skills that were useful to you?” and “Do you feel the consequences or punishment procedures you received were effective in helping you to reduce or eliminate behaviours that you wanted to reduce or eliminate?”. Respondents could choose from the answers “no”, “sometimes”, and “yes”. Results revealed that close to half (n=10; 47.6%) of ABA recipients who received positive reinforcements as a part of their intervention plan (n=21) did not feel the rewards were an effective means of helping them learn and maintain skills. Another 9 respondents (42.9%) felt the rewards they received were effective. When it came to punishment procedures, over half (n=11; 61.1%) of the respondents who received consequences as part of their intervention plan (n=18) did not feel the consequences were effective in helping them to reduce behaviours that they had wanted to reduce or eliminate. See Figure 6.13 for results.

Figure 6.13. Did Respondents Feel the Positive Reinforcements (rewards) or Consequences (punishment procedures) were Effective?



Perspectives on Rewards and Punishments: Open Text Box Responses

Similar to the trends found throughout my analysis, only those respondents who were critical of ABA interventions opted to share their perspectives in the open text box area provided. There was a total of 12 responses shared – 6 in each the reward and punishment procedures categories. Table 6.8 provides three example comments within each category.

Table 6.8. Perspectives on Rewards and Punishments

Category	Comment Count	Example Comment
Rewards	6	“It destroyed my sense of boundaries. I couldn’t refuse a request or think for myself, the only way to be good was to be obedient.” “It felt manipulative and I enjoyed learning for its own sake and interest. I often refused to comply with reward systems although I could perform a task well.” “I now find it very difficult to find internal motivation to do anything, even basic tasks of daily living, because I grew up expecting to be rewarded in some way beyond the intrinsic value of the task itself. And for tasks which I am rewarded, I am reminded of the trauma involved in having rewards withheld from me if I didn’t conform to the practitioner’s expectations.”
Punishment Procedures	6	“Many of the behaviours were not even necessarily problematic to begin with. Punishments added more trauma to my life and still leave me struggling to act in ways which may lead to me being punished from that time.” “All those punishments did was make the unwanted behaviours increase in frequency. Now as an adult, I have very poor emotional regulation with few effective methods to regulate.”

“I still needed my little coping mechanisms, like humming, covering my eyes, etc... and I would temporarily stop them—but I still needed them, or I would melt down. It was so frustrating, and I was so worried because I would do my little movements more when I was anxious, and could feel the tension building. It would have been better to allow me my little ways, so I could cope.”

The results of respondents’ perceptions and perspectives on the rewards and punishment procedures they received indicate that reward and/or punishment procedures, which are integral tenets of ABA, are not viewed as effective by more than half of the respondents who received them. Those who did feel the rewards and punishment procedures that they received were effective chose not to elaborate in the open text box areas, which makes it difficult to understand what it was about the rewards and punishments that they found helpful.

The experiences shared by Russel and Clara as expressed earlier in this chapter provide some insight into the positive experiences of rewards and punishment procedures. Russel was one of the few survey respondents who felt rewards and punishment procedures were “sometimes effective” (see Figure 6.13) and appreciated how they helped him to build the skills he felt he needed. Clara was a part of the respondent groups who selected “yes”, she felt both rewards and punishment procedures were effective in helping her achieve her goals. Russell appreciated the skills he learned even though he indicated that the ABA he received “always” caused him feelings of sadness and anger. Clara felt that high fives, hugs, and praise were effective, along with the verbal redirections she received, which she indicated “sometimes” caused her to feel sad or angry. Recall that her sad and “angry-ish” feelings were also tolerable for her due to the relationships she had with “loving therapists”.

It is plausible that if Russel had more loving therapists, he may have felt the positive reinforcements he received to be even more effective than they were. Likewise, if Clara had not had loving therapists, the verbal redirections she received may have been less tolerable. These experiences highlight the importance of a genuine caring relationships beyond prescriptive rapport-building (Gruson-Wood, 2016) and pairing techniques (Barnett, 2020; Special Learning, 2021) aimed at achieving compliance from autistic children (see Concern #3, Chapter 5). Their experiences also highlight Freire's (1970) position that when people are not consciously aware of the oppressive nature of their situation, they are unable to critically examine their situations in ways that lead to their liberation (i.e., better outcomes). If Russel and Clara had understood that there are other ways to learn skills without the use of rewards and punishment, would they continue to perceive ABA as an effective approach? While the answer to this question exceeds the scope of this dissertation, both Russel and Clara expressed interest in learning about the many ways educators and practitioners can better support autistic young people. My future participatory action research projects will continue this line of inquiry. For now, Russel's and Clara's stories are only two experiences. Much more research into autistic perspectives of positive reinforcements and punishment procedures in ABA are needed.

It is equally important to recognize the perspectives of Kendra and Damon who provided insight into the harmful use of rewards that are not always obvious to parents, educators, and practitioners. There is an assumption within the field of ABA that, because positive reinforcements are less intrusive than punishment procedures, they are safe for use when teaching new skills (OSETT-CB, 2019). For example, in addressing concerns about ABA from neurodiversity advocates, behaviour analysts Justin Leaf and colleagues (2021) stated:

... it is imperative that practicing behavior analysts continue to implement and advocate positive reinforcement-based contingencies when possible while designing interventions for autistics/individuals diagnosed with ASD. Which will hopefully lead to members of the neurodiversity movement and other professionals to be more accepting of ABA-based interventions. (p. 2842)

In this comment, the authors assume that if positive reinforcement procedures are used, more autistic people will be on board with ABA. However, neither Kendra nor Damon (nor many of the survey respondents who shared negative experiences with rewards) would agree that implementing “positive reinforcement-based contingencies” would lead neurodiversity activists to “be more accepting of ABA”. The rewards-based interventions Kendra and Damon received did not attend to the needs beneath the behaviours they were expected to change. Kendra needed safety and accommodations at school, not promises of screentime to force her to attend an unsafe school environment. Damon needed his therapists to presume his competence, not praise (or other rewards) for performing menial tasks. Rewards that were experienced as punishments by respondents like Kendra further reflect the concerns of education critics that rewards and punishments are one in the same (Kohn, 2018). Finally, none of the experiences expressed by respondents reflected Skinner’s argument from Chapter 2 (see Biophily2, 2016) that rewards provide feelings of freedom.

Years and Types of Punishments Received

Years received. The OSETT-ASD (2017) report claimed that, “Although in the very beginnings of the use of ABA for children with ASD, a punishment approach was included along with positive reinforcement approaches, the routine use of aversive stimuli to change problem behaviours or teach new skills is seldom used” (p. 113). In an attempt to test this claim, I created

a binary variable to represent the range of years respondents received older forms of ABA interventions (before approximately the year 2005)²⁴ and newer forms (between approximately 2005-2022)²⁵. I based the range of years selected for this analysis on two factors: 1) a literature review (see Pelios et al., 1999) and other studies (e.g., Hanley et al., 2005) that discussed trends in favour of positive reinforcement procedures over punishment procedures for the treatment of problem behaviours (e.g., self-injury and aggression) since the late 1990s; and 2) the year range that respondents of my study received their ABA interventions (most selecting years ranging between 1995 - 2005 or 2004/2005 to 2022).

My original plan was to conduct a Mann Whitney U-test to compare the mean ranks of frequency related to receiving consequence or punishment procedures (“1 – never”, “2 – sometimes”, “3 – often”, and “4 – always”) between the two groups of years (ABA received before 2005 and after 2005). However, I had to eliminate four cases of respondents who received interventions for many years that spanned across both timespans (i.e., across 2000-2022) and one respondent case of “not sure”. This left only 5 cases (n=5) in the group of respondents who received ABA before 2005, which was too uneven a comparison to the 12 cases (n=12) of respondents who received interventions after 2005. Nonetheless, a descriptive analysis revealed interesting results—the 5 respondents who received ABA interventions before 2005 selected that they received consequence or punishment procedures “sometimes” (n=2) or “often” (n=3). The 12 respondents who received ABA interventions after 2005 selected that they received consequence or punishment procedures “never” (n=3), “often” (n=2) and “always” (n=7). These results indicate no statistical evidence to show that punishment procedures are discontinued in

²⁴ Two older respondents received their ABA interventions between the years of 1974 to 1986

²⁵ One respondent indicated they received their interventions between 2004-2010; this respondent was counted in the newer forms of ABA

more recent ABA intervention programs. See Table 6.9 below for detailed breakdown with responses shared by respondents.

Type of punishments. Due to the varying degrees of intrusiveness caused by some punishment procedures compared to others (e.g., verbal reminders to “stop” are less intrusive than physical interventions), and recommendations to use the least intrusive methods as possible (OSETT-CB, 2019), I further analyzed the type of punishment procedure by the range of years the ABA interventions were received. In the past, intrusive punishment procedures such as “a swat on the rear” (Lovaas, 1981, p. 26), loud verbal reprimands, or exposure to non-preferred items/activities (e.g., forcing a child to play catch when they hate playing catch), were recommended to treat extreme problem behaviors (Lovaas, 1981, 1987). While extreme physical interventions such as contingent electric skin shock are uncommon (but still used at the Judge Rotenberg Centre, see Pierson, 2021), restrictive physical procedures such as restraint and seclusion continue to be used as a behaviour management technique for developmentally disabled young people in schools and community settings (A4A Ontario, 2019b; OSETT-CB, 2019; PACY, 2016; Snow, 2016, 2017). ABA researchers have further noted continued tendencies of ABA practitioners to rely on unnecessary physical interventions as part of their ABA programming (Rajaraman et al., 2021, 2022).

To analyze whether respondents reported intrusive punishment procedures continue to be used, I created a binary variable that divided punishment procedures into two groupings: harsher or more intrusive punishment procedures (e.g., physical intervention, seclusion room) and less harsh/intrusive procedures (loss of privileges, planned ignoring, time out, withholding items, and reminders to stop). I conducted a Chi-square test of association to compare the group who received punishment procedures before 2004/2005 and after (n=17). The three cases who

selected that they had “never” received punishment procedures were eliminated for the purpose of this test (all three cases received newer ABA interventions between 2010 and 2022). This left a sample of $n=14$. Results revealed no significant association between level of intrusiveness and years received, $X^2(1, N = 14) = 1.998, p = .158$. However, it is worth noting that 9 out of 14 respondents selected that they had received harsher/more intrusive interventions. Only two of these respondents received these interventions prior to 2004/2005. The remaining 7 respondents received these procedures between 2004 and 2022. See Table 6.9.

Table 6.9. Type of Punishment Procedure by Range of Years Received and Example Comments

	Prior to 2004/2005	Post 2005	
Category	n	n	Comments
Non-intrusive (e.g., loss of privileges, planned ignoring, time out, withholding items, and reminders to stop)	3	2	Respondent A who received ABA between 2004 -2010: "lose access to books or toys; comfort items confiscated if upset" Respondent B who received ABA between 2000-2022: "[planned ignoring] was the hardest to bear, because I was trying to convey information, and would be ignored for not doing what I should be doing. I felt so betrayed and helpless."
Intrusive (e.g., aversive stimuli; physical intervention, seclusion room)	2	7	Respondent A who received ABA between 2004-2010: "berated if uncompliant, sprayed and shocked if deemed aggressive in my refusal of something; Isolated; restraints if self-harming" Respondent C who received ABA between 1976-1986: "Physical abuse, hitting, shaking; verbal abuse"

Respondent D who received ABA between 2015-2022: "Constantly placed in an isolation room aka "calming room" that had locked doors"

Total	5	9
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These results indicate that while there is no statistical significance, proportionately more respondents who received intrusive punishment procedures received these procedures after 2004/2005, and there is no evidence to suggest that in today's ABA, "... the routine use of aversive stimuli to change problem behaviours or teach new skills is seldom used" (p. 113). Furthermore, comments shared by respondents in the open text box areas indicate that non-intrusive punishment procedures can also be experienced as harmful. The UNCRPD stipulates that, "No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment" without their "free consent to medical or scientific experimentation" and that "States Parties shall take measures to prevent persons with disabilities, on an equal basis with others, from being subjected to torture or cruel, inhuman or degrading treatment or punishment (United Nations, 2006, Article 15). Given the absence of consent and presence of punishment procedures experienced by the respondents of my study, it is evident that the field of ABA in Canada (and beyond—see Concern #5, Chapter 5) needs to critically analyse the day-to-day practices of ABA in schools and communities before it can ensure autistic children's rights to freedom from punishment are fully realised.

Conclusion

The findings discussed in this chapter explored perspectives and lived experiences of ABA in relation to concerns expressed by the autistic allies (who did not receive ABA) in Chapter 5. Overall, the findings indicated that regardless of whether ABA recipients found their

interventions to be effective or not, many agreed with at least two key concerns raised by autistic allies—that ABA can be harmful (Concern #5) and compliance-based (Concern #3). The experiences shared by Russel and Clara further provided important insights into positive experiences of ABA including the ways the interventions helped them to build confidence in their academic, speech, and life skills. Overall, the perspectives that were shared by the ABA recipients who chose to elaborate on their survey responses were deeply critical of ABA in similar ways as the ally respondents of Chapter 5. Apart from Russel and Clara, positive experiences of ABA were rarely elaborated on.

The first two analyses of this chapter examined perspectives of ABA effectiveness in relation to: a) views of autism as a disorder or difference, and b) the intersections of autism with racialized and queer identities. While close to half of the ABA recipients felt the interventions that they received were effective, these respondents may also have been impacted by stigmatized views of autism as a disorder that influenced their desires to fit in through learning neurotypical skills (e.g., sitting still, verbal communication).

With regard to the latter analyses presented in this chapter—QoL and wellness—a majority of survey respondents who found ABA interventions to be effective also felt the interventions caused them harm in the form of emotional distress. Close to half of the ABA recipients experienced overall feelings of emotional unwellness or even suicide. Only a small minority of respondents felt that the ABA interventions they received contributed to their achievement of QoL outcomes such as independence and success in education and employment. Approximately half of the ABA recipients did not provide consent to the reward and punishment procedures they received, which often caused them harm.

Throughout this chapter, the perspectives of those who had negative experiences with ABA have been made clear. Comments provided by these respondents reflect experiences of trauma, micromanagement, segregation, isolation, abuse, languishment, and being forced into compliance without choice. These experiences were (in most cases) not intentional on the part of the ABA practitioners who were often kind, loving, and nice. What is less clear are the perspectives of those who had positive experiences with ABA given the gaps in open text box responses shared by these ABA recipients. Experiences such as Russel's and Clara's shed some light on more nuanced views of how ABA is perceived as effective but also, at times, uncomfortable. They both shared perspectives that aligned with the ABA goal to help autistic children fit into a society that is "... unfortunately, less accepting than desired" (Leaf et al., 2021, p. 2845). By valuing this goal, they felt that the benefits they received from their interventions outweighed the discomfort they experienced. In this way, their experiences reflect the ongoing tension between conceptualizations of the social model (closely related to the neurodiversity perspective) and medical models of disability that value rights to treatment and rehabilitation (see Chapter 2). Their stories help us to understand autistic people's desires to work on personal impairments and/or perceived deficits through therapy, such as controlling shaky hands and learning verbal speech skills, in order to manage daily life tasks better in a neurotypically-dominated world. Their desires to improve on skills are not uncommon. As one trans autistic person explained, some behavioural interventions offered "with their full knowledge and consent, could have been helpful" (Alex's story in Adams & Liang, 2020, p. 30). The reality for many autistic people, particularly those who are multiply marginalised by race, gender, sexuality, etc., is that they need skills to adapt and thrive in a world that often does not accommodate their needs or experiences (Lewis et al., 2022).

What all of these experiences reveal is evidence to support the argument introduced in Chapter 2 that ABA employs covert methods of control (Gibson & Douglas, 2018) under a guise of humane benevolent care reminiscent of institutions of the past (Foucault, 1973). In what has been described as our neo-asylum era (Carpenter, 2007), the experiences shared by the ABA recipients of this study evidences ABA as largely biophilanthropic in that its goal is to charitably ‘help’ autistic young people contribute productively to a society that would otherwise reject them (Roscigno, 2019). The autistic participants who embraced neurodiversity experienced feelings of distress and harm as a result of ABA interventions aimed at conditioning them to behave more neurotypically. In contrast, the autistic participants who experienced their autism as a disorder appreciated the ways ABA helped them to learn skills that increased their opportunities for inclusion despite, in some cases, experiencing feelings of distress. Both Clara and Russel assessed the risk versus benefit for themselves. In their discussion of CAS discourse, Orsini and Davidson (2013) pointed out that, “Framing responses to autism in either/or terms—either it is a neurological difference to be celebrated or it is a disabling condition—can paralyze public discourses in ways that might ultimately be of little benefit to autistic people” (p. 13). This paralysation has recently been identified by justice-oriented activists as counterproductive to the aims of genuine autistic wellbeing (Ashburn & Edwards, 2023; Lewis et al., 2022). It is important in this analysis of ABA that all perspectives are listened to with authenticity (Gates, 2019) and with respect to the context of people’s experiences of stigma (Hammond, 2022a; Jaye, 2021).

The absence of elaborations from respondents who found ABA to be effective can further be interpreted in various ways. For example, it is not easy to speak about therapies and education approaches received within a culture of stigma associated with autistic experiences. Amy

Sequenzia (2015) pointed out that “Sadly, too many Autistics are not allowed to reclaim their rights. They are not allowed to say ‘no’ to forced compliance. They are the ones ‘excelling’ in ABA” (para. 11). As evidenced by Clara’s story, autistic young people may feel compelled to keep quiet and “not want to bother” their parents about their experiences at school or programs because they feel like they have put their parents “through a lot” already. Kendra shared the way her own silence about her abuse and invalidation at school became a marker of her ABA intervention’s success. Further, unlike the autistic allies in Chapter 5, or the ABA recipients like Kendra and Damon who are immersed in the neurodiversity activist movement, many autistic people are not aware of the critical advocacy that exposes the problems with ABA, nor are they fully conscious of the systems that sustain their oppression (Freire, 1970).

Finally, an analysis of power opens an understanding of the ways the formidable ABA industry, through a cultural rhetoric of scientism (see Chapter 2), may make it difficult for some autistic people and families to “reclaim their rights” and say “no” within a system wherein “many additional modes of inquiry are obscured and indeed silenced” (Broderick, 2022, p. 153). Within this context of ableist power and limited options, we can understand why Russel, Clara, or other autistic people who are unaware of skill-building alternatives to ABA (e.g., Delahooke, 2019; Desautels, 2020; Laurent & Fede, 2020a; Prizant et al., 2003), might hesitate to be overly critical of a practice that at the very least helps them to fit in.

Russel, Clara, Kendra, and Damon deserve immense respect for their bravery to speak out openly. With equal measure, the chosen silence of ABA recipients, including those who indicated positive feelings toward ABA in my survey, deserve just as much respect for participating in the ways that they could. Indeed, critical consciousness and vocal opposition to oppression may be a privilege afforded to some autistic people more than others. Further

research (including my own future research endeavors) is needed to empathetically examine all perspectives, both positive and negative, regarding the impact of behavioural therapies within systems influenced by power, ableism, racism, and stigma that impact autistic people in unique and complex ways.

Chapter 7: Parent and Provider Perspectives

Overview

This final set of findings explores the experiences of ABA as reported by parents of autistic children and ABA providers themselves. See Tables 7.1 and 7.4 of this chapter for key demographics of each respondent group. The analyses of this chapter examine perceptions of ABA effectiveness, wellbeing, and quality of life (QoL) outcomes through quantitative analyses of survey responses and qualitative examinations of open text box responses. Similar to Chapter 6, I accompany key findings with four *Stories Behind the Statistics* (two parent stories and two ABA provider stories) with follow-up discussions throughout the chapter.

To analyse responses from the parent group, I began with descriptive statistics to examine respondents' perspectives on the social validity²⁶ of their child's interventions along with their perspectives on wellbeing outcomes and reasons for enrolling their children in ABA. It is important to note that, in contrast to the autistic ABA recipients in Chapter 6, it was difficult to quantify parents' perspectives on QoL outcomes such as education and employment because in the survey, parents expressed that they could not adequately provide these perspectives due to their children's young ages. Therefore, I focused on parent perspectives related to their perceptions of social validity and wellbeing. I further used an inferential Mann Whitney U test of

²⁶ Recall that social validity is defined as the goal of increasing or decreasing behaviours that are meaningful to the individual and their family, and that will improve their overall wellbeing and quality of life (ONTABA 2020).

mean ranks to compare parent responses and autistic ABA recipient responses related to social validity from Chapter 6.

To analyse responses from the provider group, I used descriptive statistics to examine perspectives related to their clients/students QoL outcomes and wellbeing. I further examined provider experiences of whether they had ever questioned the effectiveness of their interventions. The final analyses of this chapter compare and contrast both parents' and providers' perspectives of consent, reward, and punishment procedures. See Table 7.1 for the demographic information of parent respondents.

Parent Perspectives

Table 7.1. Demographic Characteristics of Parent Respondents (n=12)

Characteristics	n	%
Gender		
Agender; Transgender; Nonbinary ¹	1	9.1%
Female	9	81.8%
Male	1	9.1%
Self-identified Race		
White	8	66.7%
Varied (e.g., East Asian, South Asian, Southeast Asian & Mixed Asian/Trinidadian)	4	33.3%
Self-identified neurodivergent identity (i.e., autistic or ADHD) ²		
Identify as neurodivergent	2	18.2%
Do not identify as neurodivergent	7	63.6%
Unsure	2	18.2%
Diagnosis of Child		
Autism level 1 support needs; or Asperger's	5	41.7%
Autism level 2 support needs	1	8.3%
Autism level 3 support needs	3	25.0%
Other (e.g., dual diagnosis with intellectual disability; PDD-NOS; ASD no level assigned)	3	25.0%
Identity Language Preference of Parent		
Identity First Language (IFL) only	7	58.3%
Person-First Language (PFL) only	3	25.0%

Either IFL and/or PFL	2	16.7%
Place of Current Residence		
Ontario	12	100.0%
Age of child when ABA was received		
0-4 years old	3	25.0%
4-12 years old	6	50.0%
12-20 years old	1	8.3%
0-20 years old (life span of child)	2	16.7%
Annual income ³		
\$50, 000 to \$100, 000	4	40.0%
\$100, 000 +	6	60.0%
Approximate Cost of ABA programs ⁴		
\$5000 or under	3	37.5%
\$5, 000 to \$10, 000	1	12.5%
\$10, 000 to \$100, 000	2	25.0%
\$100, 000+	2	25.0%

^{1 2 3 4} Note. There were missing cases

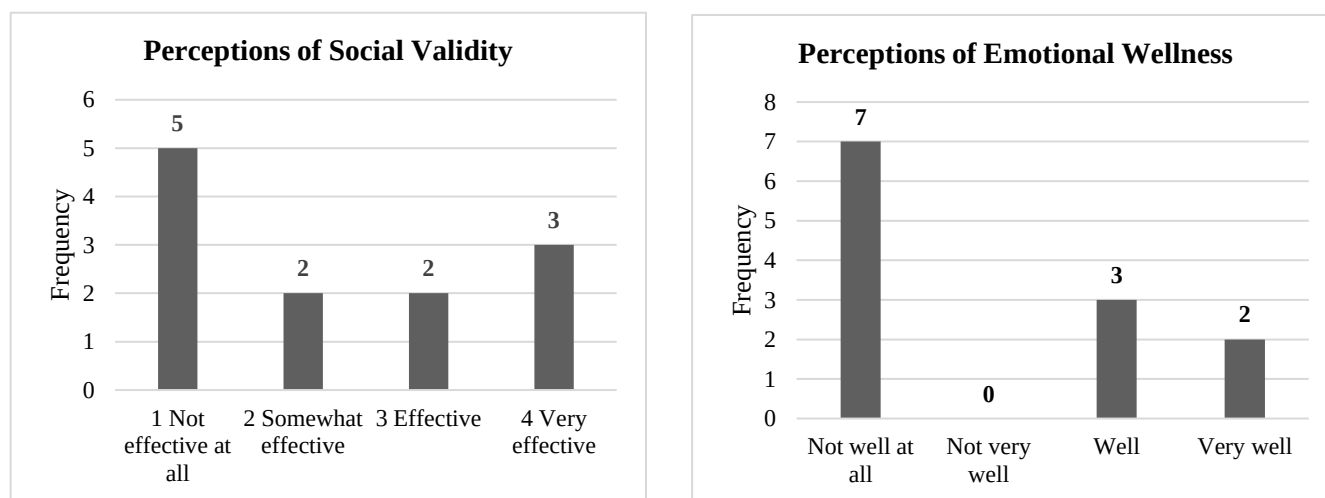
Social Validity and Wellbeing

Similar to the question posed to the autistic ABA recipient group, parents were asked the question, “*How would you rate the overall effectiveness of the ABA/IBI your child received?*” Results revealed that over half (n=7, 58.3%) of the parent respondents selected “1- not effective at all” (n=5) or “2 - somewhat effective” (n=2) (M=2.25). These results were somewhat predictable given that 5 parent respondents had selected “no” in an earlier analysis (see Chapter 4) asking whether they felt ABA interventions were an effective approach for autistic young people in general.

To gain further insight into parents’ perspectives, I analysed views related to the impacts of ABA on the wellbeing of their children by examining survey responses to the following question, “*How well do you feel ABA or IBI has prepared your child for... ?*” Respondents could choose from a list of options that included the following item selected for this point of analysis: “*Emotional/mental well-being.*” Likert scale responses ranged from, “1-not well at all”, “2-not

very well”, “3-well”, and “4-very well”. Predictably, results were similar to perceptions of social validity. Over half (n=7, 58.3%) of parents surveyed did not feel that ABA interventions prepared their child for emotional or mental wellbeing (M=2.0). Figure 7.1 provides a breakdown of results.

Figure 7.1. Parent Perceptions of Social Validity and Impact on Wellbeing



Moreso than in the autistic ABA recipient respondent group (see Chapter 6), there were several parent respondents willing to elaborate on their positive experiences of ABA. Table 7.2 provides seven respondents’ example comments related to both ABA effectiveness (i.e., social validity) and their children’s emotional wellbeing. I purposively selected detailed example comments related to perceptions of social validity and wellbeing from two parent respondents with critical views of ABA (e.g., “not effective at all”), two with positive views of ABA (e.g., “effective” and “very effective”), and one with somewhat critical views (e.g., “somewhat effective”). I further added details regarding children’s diagnoses and parental views of autism to align with the transformative paradigm’s understanding of individual versions of truth as

influenced by contextual, social, political, cultural, and personal vantage points (Mertens, 2009, 2015).

Table 7.2. Parent Perspectives on ABA Effectiveness and Wellbeing Outcomes

Respondents	View of Autism	Rating of ABA Effectiveness & Wellbeing	Comment
Parent A: Indicated child received an Autism level 1 diagnosis; has ADHD and LD	Prefers identity-first language; Autism is neurotypical, not a disorder; autistic people can be high to low functioning	1- Not effective at all 1- Not well at all	"When removed from the specific ABA classroom none of the skills lasted. He only really started to learn and grow when the ABA techniques were removed ...He liked it for the most part because he didn't have extreme behaviors or concerns but seeing the other kids upset did upset him... My son would just give up doing things he liked and go along with what he was told because it was easier than being redirected. You could see his excitement and spark dim when he was there."
Parent B: Indicated child received an Autism level 2 diagnosis; non or minimally speaking; ADHD	Prefers identity-first language; Autism is neurotypical, not a disorder; does not agree with functioning labels (i.e., high to low)	1- Not effective at all 1- Not well at all	"He did not like going to ABA but thought his therapist was "nice". I now know they use similar techniques to grooming so that the bond is later leveraged for compliance... It absolutely added to his anxiety and I am quite certain it will develop into an anxiety disorder if I do not undo this harm."
Parent C: Indicated child received an Autism level 1 diagnosis; ADHD	Prefers either Identity first or person first language; views autism as a disorder; autistic people can be high to low functioning	2- Somewhat effective 1- Not well at all	"[ABA] principals can be beneficial but so can other interventions ...cost and program did not seem to equate success ...my son disliked the program/ worker ...anxiety producing. he did not want to go."

Parent D: Indicated child received an Autism level 3 diagnosis; intellectual disability; LD	Prefers person- first language; views autism as a spectrum; autistic people can be high to low functioning	3- Effective 1- Not well at all	"ABA has given my ID [intellectually disabled] son many benefits. He's learned to read and speak. While he may never be totally independent, hopefully he will be able to enjoy life outside of an institution or a group home with limited supervision... Due to his ID, he continues to make progress but a much slower rate... He doesn't express his emotions ... "
Parent E: Indicated child received an Autism level 3 diagnosis and is "non verbal"		3- Effective 3- Well	"Slower progress than I would expect."
Parent F: Indicated child received an Autism level 3 diagnosis; global developmental delay	Prefers identity first language; autism is both a neurotype and a disorder; autistic people can be high to low functioning	4- Very effective 5- Very well	"My child is nonverbal, But we ask her [about whether she enjoys ABA] anyways. She asks for "school "which is what we call her therapy center. She's very happy to go there and play with her friends the RBTs ... [the ABA Centre] is fantastic ... Her Life experience, quality of life, health, and safety have all improved immensely since we've had access to ABA therapy"
Parent G: Indicated child received an Autism level 3 diagnosis; non or minimally speaking; intellectual disability	Prefers identity first language; views autism as a disorder; autistic people can be high to low functioning	4- Very effective 4- Very well	"[ABA] Stopped aggressive behaviours of harming others and self. [Improved] Emotional regulation/counting, alternative behaviours."

Similar to the trends found in Chapters 4 and 6, respondents who found ABA to be effective or very effective also tended to prefer person first language (PFL), believe functioning labels were accurate descriptors of autistic experiences (i.e., high to low functioning), and/or view autism as a disorder (e.g., three of the four parents in Table 7.2). The views shared in Table

7.2 indicate that parent respondents who found ABA to be effective adhered less to the neurodiversity movement (e.g., use of identity first language; view of functioning labels as harmful; view autism as a culture/identity) than those who found ABA to be ineffective. Of further note, the two parents who identified as autistic (see demographics in Table 7.1) also indicated ABA to be “not effective at all”. These results align with the observation made by Taryn Jaye (2021) who noted that those who view autism as a disorder may gravitate to ABA as a way to help them, or in this case their children, fit into a society that stigmatizes autistic ways of being (see Chapter 6).

The parents who selected “effective” or “very effective” further provided examples of the ways ABA can have positive impacts on their child’s learning and wellbeing through the learning of skills such as reading, speaking, emotional regulation, and “stopping aggressive behaviours”. These positive experiences of ABA’s focus on skill building (e.g., reading & speaking) are similar to the experiences shared by Clara and Russel in Chapter 6 who expressed gratitude for the ways their ABA providers helped them with daily life tasks and communication. While parent F did not elaborate on the details of skills their child learned, it is clear that this parent felt their child learned skills to improve their “quality of life, health, and safety”. In contrast, parent F’s report of their child being “very happy to go there” differed from the experiences of 8 out of 10 autistic ABA recipient respondents in Chapter 6, including Clara and Russel, who indicated ABA was effective but also caused them feelings of distress due to the compliance-based nature of the programming.

Parent D’s and G’s reports of their children’s experiences are further worth examination with regard to wellbeing. Parent D indicated that their child “doesn’t express his emotions”, which may be the reason this parent selected that ABA did not prepare him well at all for

emotional wellness. However, this parent saw the “many benefits” of ABA with hope that their son “will be able to enjoy life outside of an institution or a group home”, which they felt would lead to improved wellbeing for their son in the future. Parent G indicated that ABA prepared their child very well for emotional wellness due to the program’s success in supporting their child to stop aggressive behaviours, including self harm. This parent’s perspective suggests that they associate wellbeing with less aggression and self harm. What is less clear is the child’s actual feelings about participating in ABA—whether the child experienced improved wellbeing from their own perspective or whether they felt compelled to follow the adult’s expectations in order to receive rewards or avoid consequences. Unlike the child of Parent F, the children of Parents D and G did not provide indication of their children’s happiness or motivation to attend their ABA programs.

Importantly, it is difficult to be clear about the feelings of the children whose parent’s indicated ABA was “effective” or “very effective”. Parents who felt ABA was “effective” or “very effective” for their child also shared that their children had high support needs, were nonspeaking (or minimally speaking), or had an intellectual disability. When parents’ perspectives are considered as evidence of ABA effectiveness, this finding may seem to lend evidence to the claim that ABA interventions are most effective for autistic people with more significant support needs than others (see Busch, 2019a; Dawson, 2021; Kavchak, 2020). However, in light of what has become known about the abilities of nonspeaking autistic people to clearly communicate their needs and desires when accommodated with AAC access (Jaswal et al., 2024), truth claims about ABA effectiveness must be analyzed beyond parent perceptions. Parent F’s comment: “My child is nonverbal, but we ask her [about whether she enjoys ABA] anyways” reveals this parent’s efforts to communicate with their child despite the dominant

societal misconception that nonspeaking autistic people are unable to provide answers when asked (Biklen & Burke, 2006; Boskovic, 2019; Communication First, 2021; Kedar, 2012; Kirsebom, 2020; Reyes & Reyes, 2018). The parent seemed able to read their child's cues of happiness to “ask for school” in a way that indicated a genuine interest on behalf of the child to attend her ABA program. Given the limited availability of programs other than ABA in Ontario, it is understandable that a child's willingness and eagerness to engage in an ABA program is a relief for parents.

Some autistic activists have validated parent perspectives regarding their children's positive engagement and improvements in behaviour as a result of ABA programs. For example, Sparrow (2015) pointed to the variance of available ABA programs—many of which are autistic-centered and may not depend on the use of traditional methods of behaviour modification. The reputation of the ABA industry as an evidence-based practice has created a climate wherein insurance companies and provincial funding programs (i.e., the Ontario Autism Program) have, until recently, only provide funding to families for ABA programs (Broderick, 2022; Sparrow, 2015). For this reason, autism support programs may be left with little choice but to describe themselves as ABA while using autistic-centred teaching methods to promote the genuine autonomy and self-determination of autistic children without depending on methods of rewards and consequences. Indeed, it is possible that the child of Parent F (and children of other parent respondents) attended programs that genuinely attended to autistic autonomy and wellbeing. It seems important to consider whether all ABA programs can be painted with the same ‘ABA is harmful’ brush.

The existing tension between medical model advocacy for an autism cure and neurodiversity advocacy for autism acceptance can be quite confusing for parents (Ashburn &

Edwards, 2023; Carey et al., 2020). While many parents advocate alongside the aims of neurodiversity, they are often led to believe that autism will rob their child of a normal happy life unless therapy is secured quickly (Gibson & Douglas, 2018; McGuire, 2016; Runswick-Cole, 2016; Yergeau, 2018). It is important for parents to understand critical differences in program aims and goals for their children.

Additionally, it is important to recall the concerns raised in Chapter 5 in relation to how appearances of enjoyment do not necessarily equate to meaningful outcomes (see Concern #3 in Chapter 5). For example, when examining the parent respondents who indicated ABA was “not effective at all”, there is evidence to suggest that the harm caused by ABA resulted from a focus on compliance (e.g., Parent B: “they use similar techniques to grooming so that the bond is later leveraged for compliance”). Other parents noticed a decrease in their children’s autonomy and love for learning (e.g., Parent A: “You could see his excitement and spark dim when he was there”). Parents such as Parent A, who felt their child liked ABA “for the most part” but who felt he went “along with what he was told because it was easier than being redirected” raises the ethical question as to whether a child’s wellbeing and success in an ABA program can be measured by their willingness or ability to comply with a therapist who is nice (Kohn, 2018; Lynch, 2019; Wilkenfeld & McCarthy, 2020). These sentiments about ABA are shared by several parents who post their experiences online (e.g., Autistic Allies, 2018; Kupferstein, 2019; NeuroClastic, 2019). Damon’s story in Chapter 6 furthers this point by highlighting the importance of supporting nonspeaking autistic young people to communicate their motivation to attend ABA programs directly through the use of communication tools (i.e., AAC).

Finally, two parents who felt ABA was “effective” also expressed frustration at the “slower progress” than they had hoped. These parents expressed satisfaction with the ABA

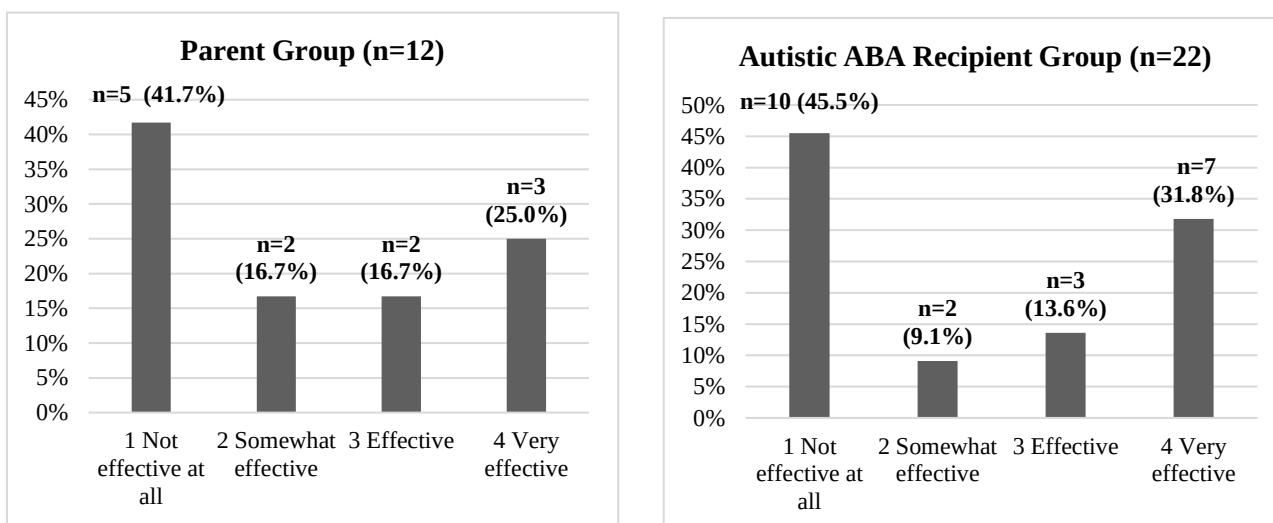
programming they received, yet they seemed disheartened by the fact that their children were not “progressing” as well as they had hoped. In fact, both Andrew Kavchak (2020) and Peter Dawson (2021), the authors of two books advocating for ABA to be considered “medically necessary” in Canada, agreed that their children (both with significant support needs) did not progress or build skills in ABA as much as they had hoped either. These comments from respondents lend some lived experience evidence in support of the many studies and meta analyses which have found ABA to be ineffective when it comes to supporting autistic children in meeting standardized developmental norms (e.g., Ackley et al., 2019; Rogers et al., 2021; Sandoval-Norton et al., 2021; U.S. Department of Defense, 2019, 2020, 2021; U.S. Department of Education, 2010; Virués-Ortega, 2010; Warren et al., 2011) (see Concern #4 in Chapter 5 for more on this discussion).

While no conclusions can be drawn about causality, Parent D’s hope that their son would “enjoy life outside of an institution or a group home with limited supervision” is similar to the hopes of parents who are led to believe that autism interventions such as ABA will ensure a life of independence for their child (Ashburn & Edwards, 2023; Broderick, 2022; Schaber, 2021). This hope harkens back to the original aims of ABA for children with developmental disabilities, which was to keep autistic children out of institutions and included in communities (Silberman, 2015). However, recall that there is no concrete evidence that ABA can fulfill the promise to parents that their children will lead an independent life (see Chapter 5, Concern #4). Further, autistic people with significant support needs have explained the ways they will always need 24 hour support regardless of how effective their interventions are, and they dream of life in caring communities wherein they can have their right to receive this support realised (Baggs, 2021). As introduced in Chapter 2, Ontario’s housing and support systems are inadequate; in fact, there is

little choice beyond institutions (e.g., hospital wings, group homes, senior homes) often in deplorable unsafe conditions (see Randle & Thurston, 2022; Slaughter, 2016; Spagnuolo, 2016; Spagnuolo & Earle, 2017; Tran, 2023). It is understandable that parents are left to hope for little else than an independent life for their child through ABA interventions.

Differences between parent and autistic perspectives. The next point of analysis in this chapter relates to the common observation that, due to the field of ABA's reputation of achieving effective results through compliance-based methods, parents appreciate ABA interventions more than autistic people themselves (Kohn, 2020; Sparrow, 2015). To explore this hypothesis, I performed a non-parametric Mann-Whitney U test to compare mean ranks of responses between parents and autistic respondents in response to the questions: "*How would you rate the overall effectiveness of the ABA/IBI your child received?*" and "*How would you rate the overall effectiveness of ABA and/or IBI methods in helping you to achieve personally valid goals that meet your own needs and desires?*" Results indicated that there was no significant difference between respondent groups, $U=129.50$ $z = [-0.96]$, $p = [.924]$. The mean rank for the parent group (17.29; $M=2.25$) and the autistic ABA recipient groups (17.61; $M=2.32$) were quite similar. See Figure 7.2 (that follows) for comparative results.

Figure 7.2. Comparative Perceptions of ABA Effectiveness Between Autistic and Parent Respondent Groups



This result reveals that contrary to what is commonly believed to be true, the parents of this study did not find ABA to be more effective than the autistic respondents who received ABA. In fact, similar to the autistic group, fewer parents found ABA to be effective or very effective than those who did not. The small sample size of this study warrants a need for more robust studies to examine whether similar trends occur amongst larger population samples. Nonetheless, the findings suggest a possibility that ABA may not be as effective as parents hope when it comes to their child's trajectories for improved quality of life and wellbeing.

Reasons for Enrolling in ABA

The third analysis of this chapter examines the reasons parents enrol their children in ABA programming. There are numerous documented accounts of parents receiving recommendations for enrolling their children in ABA programming with the message that ABA is the only evidence-based therapy for their children (e.g., Alderson, 2011; Autistic Allies, 2018; Prizant, 2009; Shyman, 2014). To examine whether the 12 parent respondents were recommended ABA therapy or whether they sought the services on their own, I analysed

responses to the question, “*What reasons did you have for enrolling your child in the ABA and/or IBI services they received?*” Respondents could choose from two options with an invitation to elaborate in the open text box areas. 1) “*ABA and/or IBI was recommended to me by a doctor, therapist, care coordinator, clinician, or other professional*” or 2) “*I chose ABA and/or IBI based on my own research (or advice from family or other personal contacts) without recommendation from a professional.*” In total, 10 out of 12 parents (83.3%) selected that their ABA programming was recommended by a professional. Four parents, including Alex, who shared their experiences in an interview to follow after this analysis, and parents A, D, and E from Table 7.2, opted to elaborate with comments in the open text box area provided. See Table 7.3.

Table 7.3. Reasons For Enrolling Child in ABA or IBI

Respondents	Years Services Received	Reason for enrolling child	Comment
Parent (Alex)	2015-2022	Recommended by Professional	“It was described as the next course of action.”
Parent A	2015-2022	Recommended by Professional	“We did ABA for a short period of time before I knew enough about it. We now push back on anyone who recommends it... they ONLY talked about supposed benefits and made it seem as if there was no down side.”
Parent D	2015-2022	Recommended by Professional	“After the diagnosis, there was little to no help from [local provider] psychologists. Ontario ASD program should create a social worker network to help parents navigate government, social and private services... Again psychologists at [Local provider] claimed only the Ontario IBI program was suitable. Not ABA.”

Parent F	2015-2022	Recommended by professional & did their own research	“It was recommended by professionals and I also went into the research behind ABA and read up about what I could do for my child. I stand firm and confident in my decision ...I was given a menu of things I could help my child ultimately I made this decision for myself. We wasted a lot of time in SLP and OT wasted a lot of developmental time and thousands of dollars before we learned that my daughter could not learn. ABA is the only scientifically proven therapy that would help her get on track so that other therapies will work.”
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The first three comments in Table 7.3 reflect the ways in which parents’ felt that their options were limited by their care providers. Alex was told in a matter-of-fact manner that ABA was simply the “next course of action”, as if to imply there were no other options. Parents A and D were told that there was no “downside” to ABA or that IBI was the only option that would work for their child. Researchers, advocates, clinicians, and therapists continue to raise the alarm on this issue, calling for more transparency regarding the ways ABA businesses profit from the advice that their services are the only options for parents (e.g., Alderson, 2011; Broderick, 2022; Fry, 2022; Prizant, 2009; Summers, 2021; Therapist Neurodiversity Collective, 2020c). Jonathan Alderson (2011) described parent experiences of being so convinced that ABA was the only evidence-based option for their children that they were made to feel that “surely it would be unwise, even foolish, to consider anything unproven” (p. 123). As discussed in Chapter 6 (see Kendra’s Story Behind the Statistics #3, Wellbeing Outcomes section), the marketing of ABA as the *only* option, without access or recommendations for alternatives, exemplifies the ways ABA

violates parents' right to autonomous and well-informed decision making "when pushed aggressively" (Wilkenfeld & McCarthy, 2020, p. 31).

The following experience shared by Alex (they/them), an autistic parent of two autistic children, reveals one parent's perspective of how ABA was harmful and ineffective for their children despite being told it was what their children needed—i.e., simply "the next course of action"²⁷.

Stories Behind the Statistics 5: Alex²⁸

Alex (they/them) described themselves and their children as a white autistic family. Alex identified as Autie-gender, which they explained is "another kind of emphasis on non-binary in that my gender expression is expressed as directly tied to my autistic experience—from a sensory perspective, from my confusion with social norms I just [paused]—to me, I'm me." They shared that everyone in the family used identity-first language and believed that "to be autistic is a state of being, culture, understanding, and processing". In the past, Alex was introduced to autism through "a medicalized lens" and admitted, "I used to think autism was something to be fixed... I thought that support and services meant giving my child the tools to be like all the other children. To neutralize his [my son's] autism." Through listening to their children and other autistic lived experiences, Alex had come to understand that "they don't have it [autism]... it's not something they carry around."

In the survey, Alex indicated that the ABA interventions their children received in a small Ontario township were "not effective at all". Alex was motivated to participate in this research because, as they explained it, "I don't think enough is known about Applied Behavioral

²⁷ Note that Alex, along with all other interviewees in this chapter, reviewed/revised the final version of this story before publication

²⁸ The name Alex, along with all other parent and ABA provider interviewee names in this chapter, are pseudonyms

Analysis and the effects that it can have on mental health and the internal experiences. I think that too often we focus on just what we see and not what's underneath the surface.”

Both of Alex’s children were diagnosed with autism spectrum disorder (ASD) and co-existing disabilities. Once the diagnosis and recommendations for services were received, Alex felt they had little choice but to enrol their children in ABA: “It was described as the only evidence-based treatment... As a parent, I just assumed the diagnosis meant the treatment. I did not realize there was a choice in the matter.” Alex remembered thinking, “I just wanted my child to be safe. I was scared because I didn't know what ‘having autism’ meant.”

Alex’s son was age 13 at the time of Alex’s interview. He was diagnosed with ASD and a label described by doctors as “high functioning”. Alex explained that he had many co-existing disabilities including, ADHD, learning disabilities, and physical disabilities (e.g., is a wheelchair user and hard of hearing). In their survey, Alex indicated that they did not feel functioning labels were a useful way of describing an autistic person’s experience because functioning abilities can change from day to day. To clarify, Alex explained in the interview that their son’s abilities and needs fluctuate due to his many challenges with social situations and the “demands placed on him”. Alex also did not think it was accurate to use speaking ability as a criterion for functioning ability. In their son’s case, they explained that “the very fact that he could speak would put him into a high functioning category.” Alex remembered being told that, “... ‘high functioning’ is actually a good thing and that when it came to ABA, he would most likely not be approved for IBI because he is doing so well...” Alex, however, disagreed that their son was “doing so well”: “... he was having a lot of difficulty and it ended up being that although he was ‘high functioning’, he was not functioning well and it didn't feel like there was anywhere to go for support other than ABA and... from the parental perspective, it set me up for failure.”

After waiting two years on a waitlist, Alex's son started receiving ABA when he was 6 years old at home, through outpatient services, and at school from three different providers in blocks of up to 30+ hours per week until he was 12 years old. Alex's daughter was 9 years old at time of the interview, and was diagnosed with ASD, Level 1 support needs and "suspected ADHD". She received ABA services in the home when she was 5 years old, and then again when she was 7 years old, for up to 10 hours per week for less than six months—a much shorter time period than her son. Alex received funding from the Ontario Autism Program (OAP) for most of their services.

Both children received functional behaviour assessments with goals addressed mainly through rewards-based interventions (e.g., candy, high fives, praise, screen time, access to toys and preferred activities) and some punishment procedures (e.g., planned-ignoring and withholding preferred items until follow through with "non-preferred tasks"). Alex explained that neither the rewards nor punishment procedures ever worked, and in many cases only made their more challenging behaviours (e.g., meltdowns, destruction of property) "worse". In the survey, Alex described their children as feeling "... sad due to low self-esteem and withholding affection/attention. Anxious due to feeling powerless... I think it has caused trauma."

In the case of their son, who received the most ABA interventions, Alex explained that what the ABA providers did not understand was that their son's behaviours were often not purposeful:

I used to say all behavior is communication, and I recently learned that that's not the case. Behavior is *indication*. So, with my son in particular, because of his co-morbidities, a lot of the things that he does and says have no purpose whatsoever. In fact, he's not even aware of it happening. He says, "I sometimes find out what's going to happen the same

time you do”, which is a wonderful way of explaining it.

Alex came to understand that the planned ignoring and other recommended interventions intended to “extinguish” his challenging behaviour were accomplishing little more than “blaming him for something he can't control”. Alex explained how difficult it was for their son to express himself, which is a skill he learned over time with patience and attention from Alex. After a particularly aggressive episode when they “were told to turn our backs on him and to not give him any attention”, Alex recalled debriefing with their son about the reasons he acted out the way he did. He responded, “Because I'm different and I'm weak, and it's the only way I can defend myself.” Now, Alex understood that planned-ignoring, which is supposed to be a non-intrusive intervention, is actually more harmful than one would expect:

... he saw what I was doing is threatening, even though I wasn't trying proactively to be threatening. I was simply ignoring his stress behavior and his stress responses, so he felt unsupported. He felt that much more upset and was not getting any kind of co-regulation or love and support.

As a result, Alex expressed strong concerns about how ABA, “... completely ignores all of the internal process... They can checkmark and often say that he's met the criteria, but in reality, all he's done is learned to repress his communication in that context and instead communicates frustration and stress elsewhere.”

Alex also expressed frustration about the claims that the “New ABA doesn't deal with punishment”. Even the rewards-based learning was experienced by their children as a kind of punishment: “... it is punishment because the only way to get an effective motivator is to take away what it is that they currently enjoy, to restrict access to it so... Ultimately, we're taking away what they enjoy.” Alex continued that the use of rewards caused a dependency on external

motivators to complete tasks: "...by getting him to do what is non-preferred and then rewarding it, it has now developed this need for him to have some kind of extrinsic motivation."

Alex expressed that "just being autistic doesn't mean that you need any kind of intervention whatsoever, other than understanding from other people..." They expressed a desire to find accessible neurodiversity-led services that "go beyond scientific evidence to the holistic person... If you go from [assuming] a purposeful behavior to [understanding] a dysregulated behavior, then you don't need to worry about all the other stuff. It just starts with your attitudes."

Alex felt that ABA has failed to help their family with the biggest struggles their children face, which are mental health and emotional regulation challenges due to ableism, discrimination, and a lack of understanding. Despite the lack of appropriate services, their children have made progress because of the family and social support they receive, along with their children's own self-determination and growth. Alex was firm in their commitment to never try anything like ABA again. They shared that they "regret all of it but I feel powerless in stopping it within educational contexts. ABA involves a lot of peer pressure."

Alex's experiences exemplify several of the key concerns about ABA described by parent respondents in Table 7.2. Alex's experiences dig deeper into some of the more "invisible" harms (see Lynch, 2019) of ABA, beginning with its focus on outward behaviour change with little regard to the inner needs of their children. For example, Alex explained their son's behaviours "were often not purposeful", therefore the reward and/or extinguishing procedures of ABA were ineffective because these were behaviours that were beyond their son's control. Vance (2021) defined non-purposeful behaviour as a type of "disinhibition" that is experienced by many neurodivergent people. Simply put, Vance explained disinhibition as: "their words and actions

are often the opposite of the message they want to send” (p. 3). When Alex’s son expressed that, “sometimes I find out what’s going to happen the same time you do”, he was explaining what Vance described as emotional and cognitive disinhibition: “Emotional disinhibition: feeling compulsive, intense emotions that are disproportionate to, or unrelated to, antecedents. Cognitive disinhibition: being unable to filter or stop intrusive, irrelevant, inappropriate, nonsensical, or overwhelming thoughts...” (p. 4). Vance further explained that perceiving disinhibited behaviours as having a “function” endangers the child’s right to autonomy and safety, especially at younger ages when they have yet to fully develop skills to cope with the stressors in their environments. This is because the rewards, consequences, or planned ignoring strategies often derived from an ABA provider’s functional behaviour analysis (FBA) (see Cooper, Heron, & Heward, 2020) may inappropriately target behaviours as ‘purposeful’ when they are in fact autonomic—i.e., an indicator of a neurological condition (e.g., Tourette’s Syndrome, apraxia/dyspraxia, etc.) (Vance, 2021) or autonomic instinctual response to stress that is out of the child’s control (Delahooke, 2019). As Alex pointed out, the reward programs and planned ignoring strategies accomplished little more than “blaming him for something he can’t control”.

Similar to Kendra and Damon in Chapter 6, Alex’s experience illuminates the more insidious harms of ABA that go unnoticed by some ABA providers and parents “because they can’t see it from an autistic point of view” (Lynch, 2019, para. 18). Lynch (2019), an autistic author and blogger, noted that when an autistic child resists direction from an adult due to the unrealistic demands put on them, they may simply accept that their “feelings don’t matter” (para. 30), and that it is much easier to comply than to be constantly redirected (as was also noted by Parent A in Table 7.2). This kind of compliance-based learning risks violating autistic children’s rights to autonomy and development into their authentic autistic selves with healthy autistic (as

opposed to neurotypical) traits (Wilkenfeld & McCarthy, 2020). It further illuminates Alex’s experiences of the ways in which children are punished by rewards (Kohn, 2018) through seemingly innocuous rewards-based learning (e.g., restricting access to their favourite things). Despite emphasis on reinforcement strategies as opposed to punishment procedures, ABA has caused much stress and harm for both Alex’s children, and Alex as a parent who deeply regretted following recommendations to enrol their children in ABA programs.

Provider Perspectives

To examine the perspectives of the provider group, I selected three survey questions for analysis related to the themes of: a) autistic QoL, b) autistic wellbeing, and c) questioning the effectiveness of their ABA practices. For a balanced analysis, I used a purposive thematic analysis method to select respondent comments that represented positive and negative experiences providing ABA interventions based on clearly articulated details related to key aspects of all three themes. See Table 7.4 for key demographics of this respondent group.

Table 7.4. Demographic Characteristics of Provider Respondents (n=20)

Characteristics	n	%
Gender		
Agender; Transgender; Nonbinary	3	15.0%
Female	17	85.0%
Self-Identified Race		
White	16	80.0%
Black	2	10.0%
Mixed Middle Eastern/Latin American/ Southeast Asian & Metis/White	2	10.0%
Self-identified neurodivergent identity (i.e., autistic or ADHD)		
Neurodivergent	8	40.0%
Neurotypical	11	55.0%
Unsure	1	5.0%
Identity Language Preference		
Identity First Language (IFL) only	10	50.0%

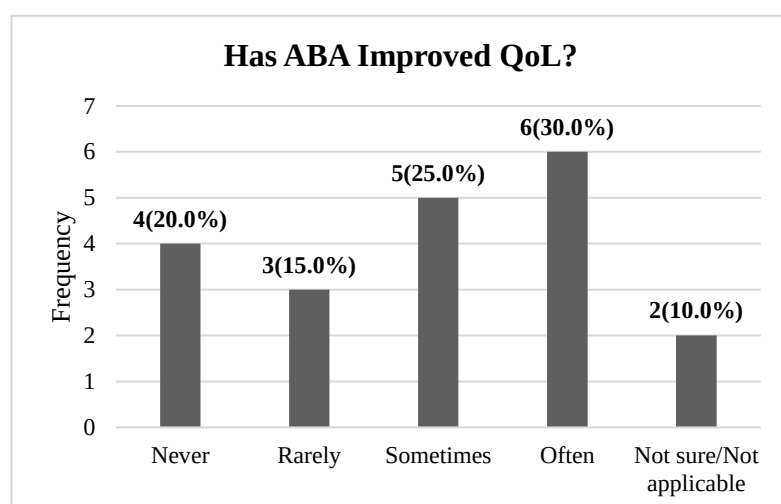
Person-First Language (PFL) only	5	25.0%
Either IFL and/or PFL	3	15.0%
Other (e.g., "on the spectrum"; neurodivergent)	2	10.0%
Province ABA was Provided		
Ontario	20	100.0%
Age of Clients/Students		
0-4 years old	9	45.0%
4 years and older	11	55.0%
ABA Setting		
Primarily school settings	11	55.0%
ABA centres, client homes, day care, community	5	25.0%
Both schools and ABA Centres	4	20.0%
Highest Level of ABA Training		
Certification with Behavior Analysis Certification Board (BACB) + Degree in related field	2	10.0%
Graduate degree in Behaviour Psychology/Health Sciences/Related Fields	3	15.0%
Undergraduate degree in Behaviour Psychology/Health Sciences/Related Fields	5	25.0%
ABA certificate training or Community College Diploma (Behaviour related field)	10	50.0%
Years of experience		
5 years or less	12	60.0%
5 years or more	8	40.0%

Quality of Life (QoL)

As explained in Chapters 5 and 6, an important aim of ABA interventions is to improve the QoL and overall wellbeing of autistic young people through goals meant to be meaningful to clients based on improved behaviour outcomes derived from developmental norms (Cooper, Heron, & Heward, 2020; OSETT-ASD, 2017). To examine provider perspectives of ABA's impact on autistic young people's QoL, I analysed responses to the question, "*Generally, in your*

experience ...”, which respondents could choose from a list of options that included, “*ABA and/or IBI has improved student(s)/client(s) quality of life*”. Likert scale responses ranged from, “1-never”, “2-rarely”, “3-sometimes”, “4-often”, and “not sure/not applicable”. Results revealed that just over half of respondents (n=11; 55.0%) felt that ABA interventions improved the QoL of the clients or students they supported “sometimes” (n=5; 25.0%) or “often” (n=6; 30.0%). See Figure 7.3.

Figure 7.3. Provider Respondents’ Perceptions of ABA for QoL



Throughout the survey, more than half of the provider respondents chose to elaborate in various open text box areas. I purposively selected nine providers’ comments based on themes identified in my literature review²⁹ regarding ABA provider perspectives (e.g., ABA effectiveness, autistic wellbeing, and questioning ABA methods). Table 7.5 (that follows) provides key example views and comments shared by four of these providers who indicated that they felt ABA methods “often”, “sometimes”, or “rarely” improved student(s)/client(s) quality of life.

²⁹ See Chapters 1 and 2

Table 7.5. Provider Perspectives and Example Comments

Respondent	View of Autism	Experience Providing ABA	Example Comments
Provider A	Prefers either identity-first language or person-first language; Autism is a neurotype, not a disorder; autistic people can be high to low functioning but has "realized... they might be "high functioning" in one or more area and "lower" in others."	"often" improves QoL; 3-5 years in practice as a camp counsellor, Instructor Therapist, volunteer	"I believe IBI/ABA practices are effective, however there are lots of other aspects involved. The relationship between child and therapist makes a huge difference ...I've worked with clients who make slow progress and may flatline on programs for months... I have also seen some clients make super fast progress. It all really depends on where they are at and what we are trying to teach. "Higher functions" [sic] clients may appear more overly to make more progress but progress looks different for everyone."
Provider B	Prefers person-first language; Autism is a spectrum; "every human functions within their own capabilities with or without a label given by society"	"often" improves QoL; over 10 years in practice as a Child and Youth Worker providing IBI in group homes, client homes, and schools	"Visual schedules, visual sensory times, First/Then, sensory based and PECS [Picture Exchange Communication System] have been incredibly effective with younger students in my experience. Not only does it provide the visual but also gives them a concrete way of knowing what is next to limit their anxiety and supporting Rhein [sic] to be proactive with tantrums. It also gives them a sense of independence and self confidence by allowing them to change their schedules independently creating that self worth"

Provider C	Prefers identity-first language or “on the spectrum”; Autism is a neurotype, not a disorder; does not agree with functioning labels	“sometimes” improves QoL; 5-10 years practice as a support worker in schools, day care setting, and Instructor Therapist in private ABA centres	“I wonder if these methods teach kids to be less autistic, which can be damaging to mental health and self-esteem.”
Provider D	Prefers identity-first language; Autism is neurotype, not a disorder; does not agree with functioning labels	"rarely" improves QoL; 3-5 years in practice as a Child and Youth Worker in group homes, ABA centres, schools and day programs	"ABA would sometimes give the appearance of skill building, but it didn't get to the root of the need. It would teach 'masking' behaviours where a child could appear 'more normal' that would make neurotypical people more comfortable, but it wouldn't teach a child how to express their needs, to be authentic or to manage anxiety... Really, this is a person expressing their needs, but a neurotypical person may see this as aggression/a tantrum. These responses are often mislabeled and not authentically responded to by a practitioner."

The comments shared by providers in Table 7.5 reflect a range of positive to more critical perspectives related to the impact of ABA interventions on autistic people’s QoL. Following the pattern observed throughout my study thus far, respondents with more critical views of ABA tended to adhere more to the social model of disability (e.g., identity-first language) and neurodiversity paradigm (autism is a neurotype and not a disorder). Interestingly, the majority of ABA providers in Table 7.5 (see also Chapter 4 - 35% of total 20 providers; n=7) did not feel that binary labels of ‘high’ and ‘low’ functioning accurately described autistic people. This was an unexpected finding given that ABA derives from a medical model of treatment that measures effectiveness by how well autistic people achieve predetermined norms of optimal (i.e., high)

behavioural and intellectual functioning (Cooper, Heron, & Heward, 2020; Perry et al., 2016). As Gruson-Wood (2016) explained it, “Intelligence, autonomy, and functioning are dominant values that undergird behavioural analysis” (p. 39). For this reason, ABA providers operate with the understanding that “to ethically care for an autistic person means working to increase their functionality” (Gruson-Wood, 2016, p. 44).

In total, 6 of the 7 ABA provider respondents who used high and low functioning labels to describe autistic people (see data reported in Chapter 4) felt that ABA interventions improved autistic people’s QoL “often” (n=5) or “sometimes” (n=1); there were 11 respondents in total who indicated that they did not agree with binary high and low functioning labels and who had more critical views of ABA (i.e., who selected ABA “never” (n=4), “rarely” (n=3), or “sometimes” (n=4) improved autistic people’s QoL. In what follows, I discuss example comments shared by providers with both binary (i.e., high or low functioning) and non-binary views of autistic functioning as they relate to QoL.

Provider A (the one respondent in Table 7.5 who adhered to the descriptors of high and low functioning labels) focused on the “progress” of autistic young people in the program. Although this respondent did not define what “progress” looked like, it can be inferred that they are referring to adaptive skills, intellectual functioning, or a reduction in autism symptoms, as these are the markers of successful ABA participants identified in the ABA literature base (Cooper, Heron, & Heward, 2020; Perry et al., 2016). The observation that autistic children make “progress” in some areas echoes the successes of ABA noted by several of the parents earlier in this chapter. Observations such as those described by Provider B regarding the “independence”, “self confidence”, and “self worth” that autistic children can experience as a result of their ABA programming cannot be overlooked. Russel, Clara, and other autistic recipients of ABA have

shared these sentiments, which provides some evidence in support of the positive outcomes of ABA on autistic people's QoL, particularly within societies fixated on ableist notions of normative skill-building wherein they are expected to fit in (Hammond, 2022a; WitandStars, 2021). However, similar to what I discussed earlier, it is difficult to discern whether these providers' clients or students felt that ABA was helpful for them without hearing from the autistic children themselves.

It is interesting to further note Provider A's perspective that "Higher functions" [sic] clients may appear more overly [sic] to make more progress". This observation is similar to that of Parents D and E in Table 7.2, and parents such as Andrew Kavchak (2020) and Peter Dawson (2021) who felt that, while ABA was "effective" for children diagnosed with significant support needs, progress occurred at slower rates than they would have expected for their own children. These provider and parent perspectives suggest that, despite having some positive impacts on autistic people's skill-building abilities, ABA does not live up to the claim that it is "medically necessary" to improve the QoL of autistic children with significant support needs (Busch, 2019a, 2019b; Dawson, 2004; Kavchak, 2020). These perspectives highlight a contradiction within the rhetoric of who benefits from ABA the most (See Chapter 5, Concern #4 for further discussion).

The perspective shared by Provider A that "The relationship between child and therapist makes a huge difference" presents yet another contradiction within the field of ABA—the idea that "progress" relies on the development of a relationship between the child and the therapist. In her ethnographic study of ABA providers' experiences, Gruson-Wood (2016) found that in practice, ABA providers are discouraged from developing relationships with autistic children (see Chapter 2). Instead, therapists are encouraged to focus on "building rapport" with their clients—a rapport that needs "to be carefully managed as to not slide into a 'relationship'" (p.

50). A participant of Gruson-Wood’s study shared that the rationale for this careful management of the provider-client relationship was explained to them this way, “... ‘if you develop a relationship with a child it will excuse your ability to make further progress because your purview of their abilities is skewed, therefore you shouldn’t do it’. It was almost like... a scare tactic” (Gruson-Wood, 2016, p. 50). Foundational ABA texts and handbooks (e.g., Cooper, Heron, & Heward, 2020; Matson, 2023) refer to provider-client relationship solely within the context of professional ethics outlined in the Ethics Code for Behavior Analysts (BACB, 2023)—e.g., do not accept gifts from clients; do not get involved in their personal lives, etc. There is little mention in the ABA literature that relationships matter outside the context of building rapport (i.e., pairing) to understand what extrinsically motivates autistic children as discussed in Chapter 5 (see Concern #3 and Special Learning, 2021).

Gruson-Woods’ (2016) findings confirmed an important distinction between the concepts of rapport and relationship in ABA interventions: “... rapport is used to advance behavioural therapists’ ability to generate replicable effective behavioural performances, while relationship contaminates this ability” (p. 50). The conclusion regarding rapport-building aligns with concerns raised by many of the autistic respondents in Chapters 5 and 6, and also parents (e.g., Parent B) in Table 7.2 of this chapter who felt that rapport-building was leveraged for the purpose of behavioral compliance (i.e., performance). It is important to consider how “relationship” differs from “rapport” within the field of ABA—if ABA providers are warned that relationships can skew a provider’s “purview” of autistic children’s abilities, thereby “contaminating” the provider’s ability to “generate replicable effective behavioural performances” (p. 50), it is possible that the goal of providers is to build rapport for the key purpose of attaining compliance. In cases where the goal of ABA is for children to comply with

predetermined developmental behavioural goals defined by adults, concerns about compliance are reasonable, particularly within the context of power-driven societies (Broderick, 2022; Dawson, 2004; Gruson-Wood, 2016; Kohn, 2018; Sandoval-Norton & Shkedy, 2019; Wilkenfeld & McCarthy, 2020; Yergeau, 2018).

It is difficult to discern whether Provider A in Table 7.5 would make that same distinction between ‘rapport’ and ‘relationship’ as others in the field of ABA. What is clear is that the providers with more critical views of ABA (e.g., Providers C and D) shared concerns with some of the parent perspectives discussed earlier in regard to the ways in which autistic children suppress (i.e., “mask”) their more genuine forms of expression to appear “less autistic” (Provider C) and “make neurotypical people more comfortable” (Provider D). Alex and other parents expressed similar concerns—when the needs beyond behaviours of autistic children are ignored, they may “sometimes give the appearance of skill building, but it didn't get to the root of the need” (see comment from Provider D, Table 7.5). Recall Alex who explained, “they can checkmark, and often say that he's met the criteria. But in reality, all he's done is learned to repress his communication in that context, and instead communicates frustration and stress elsewhere.”

The following experience shared by Cassidy, an autistic administrator in a large Ontario school board, exemplifies one ABA provider’s experiences with the ways the risk of harm resulting from ABA are best detected by autistic people and often missed by ABA providers who value neurotypical behaviours (Lynch, 2019).

Stories Behind the Statistics 7: Cassidy

Cassidy (she/her) identified as a white multiply-neurodivergent late diagnosed autistic school administrator and parent of an autistic child at the time of the interview. She described

herself as “situationally mute” but admitted she is “quite verbose” at times, which can be exhausting. She used identity-first language and felt that functioning labels and support need labels are deceiving because there is no way of understanding the experience of a person without knowing their day-to-day lives: “I think there's an assumption about low support and high support needs, and people don't know the life that you're living. If they only see you in certain roles, right?”

Cassidy has worked as a teacher and administrator in a large urban public school system in Ontario for over 25 years. Cassidy’s training in ABA interventions were received through mandatory on-the-job training legislated as a result of the Ministry of Education’s (2007) policy, PPM 140: the policy directive mandating the use of ABA approaches to support autistic students in Special Education programs. During her undergraduate teacher education program, Cassidy recalled that she didn’t learn much about autism, but what she did learn was “very much behaviour based”:

We didn't learn anything about autism. And when we did learn anything about autism, it was... teach tasks; it was first/then schedules; it was very much that dog training method, right? You got this empty vessel and now you need to fill them. So, it goes right back to Lovaas's work. It goes right back to gay conversion therapy where “You're not OK. We're going to fix you. We're going to fill you up with person”.

Throughout her undergraduate studies, teacher’s education program, and teaching career, Cassidy described the use of ABA as “pervasive”, although she admitted that she didn’t know “the term ABA until a few years into my career.” She completed all of the Additional Qualification (AQ) courses for educators in Special Education, which focused on behaviour-based strategies. Cassidy admitted that she was always “fascinated about that whole idea of behaviors and

communication... ” She recalled the fascination stemmed from her desire to figure out why and how her own behaviours seemed to differ from others: “I didn't understand autistic neurology because I hadn't yet understood my own identity. And I didn't understand that [paused] that my eye contact thing, my sensory stuff [paused]... I thought that was just something I did.”

Cassidy remembered the ABA-informed training “very clearly” and did not think there was anything wrong with it at the time. Yet, as soon as she tried to implement the strategies in practice, within what was called “a Home School Program” (HSP) for children with behavioural challenges, Cassidy intuitively knew that the approaches she learned in training were ineffective and unhelpful:

... it was kind of, you know, ‘magic one two three’, behavior reinforcers, contractual obligations... Most of my kids were autistic. At the time, I would have said ‘have autism’... I remember the progress that we made was based on attachment [paused] was based on things I, for some reason, intuitively knew. Like, why were people trying to force him to use different colors? Sammy liked green, let him use his frickin’ green all the time! If everything needed to be green, then let it be green. And that allowed him to feel safe. He felt I could feel him, right? In a different way than other staff were able to.

Cassidy described that, due to the misunderstanding of autistic distress and coping mechanisms, the planned ignoring and first/then strategies were harmful to students:

... poor Celina³⁰, who was having meltdowns every single day... people just thought she was being overly dramatic... this child was in a fetal position under a desk crying these massive [paused] like, it was horrible... I remember people laughing about the fact that like, “Oh, she's so dramatic.” It's horrendous when I think back because every time we try

³⁰ ‘Celina’ is a pseudonym

to just talk her out of it and say, “OK, come on, you're just overexaggerating” like it's not that bad. That was ABA. And that's what people don't realize. People are not realizing, you know, “use your words and then you can go to the bathroom” [or] “Oh, you have to go get your...” Seriously!?! A child's body is telling them they have to go to the bathroom, and you're going to try and force them to use their mouth words? We all do it. We all do it and it's horrendous.

Her own neurodivergent identity and awareness of autistic needs made Cassidy realise that she had a kind of empathy toward autistic students that neurotypical teachers may not have had. She found herself more capable now than ever of standing up “against the status quo”. However, even though she is autistic herself, she has undergone a journey of “unlearning” many harmful practices she thought were acceptable in the past and is grateful for the many professional allies (e.g., speech language pathologists, other educators, and therapists) who use “neuro-affirmative practices... once they see things in a different light.”

She admitted she was not always completely “neuro-affirmative” in her approaches, and used to believe positive reinforcement strategies were effective:

I used to use lots of, you know, token type reinforcers. And to me, it was like, “Yes, we want to do it in extrinsic motivation because that develops into intrinsic motivation”

[paused]... no, it doesn't work that way. And I think too often we try to make these very simplistic ways of change in quote unquote [expressed air quotes with her fingers] “behavior”.

Over the years, Cassidy has come to understand many things about autistic experiences, and continues to learn everyday—from students, from her son, and from autistic communities around the world. Similar to Alex’s parent perspective shared earlier in this chapter, Cassidy has learned

that one reason rewards fail to motivate behaviour is that not all behaviour is communication, as most educators and therapists are trained to believe:

... I was still saying ‘all behavior is communication’ until a couple of years ago. And most educators still will say that... and I'm a naysayer in a positive way where I'll say, “Well, is it really, though?” Because if you are somebody who's got a brain-body disconnect, if your mouth doesn't work the way somebody is expecting it to... If somebody is dyspraxic, is their behavior communication? If somebody is in a sensory overload situation and you are inferring their behavior to be intentional... is it their behavior or is it the fact that you are not, as a neurotypical or allistic person, understanding what it is that they're experiencing?

Without looking beyond behaviours to autistic needs, Cassidy explained that the use of ABA strategies results in a loss of autonomy and authenticity:

All you are doing is giving up your authentic self. All you're doing is having a trauma response. All you're doing is learning how to *not* be yourself. And that means that you are more prone, I mean, I don't have to preach statistics, you're more prone to sexual abuse. You're more prone to drug addiction and risk-taking behaviors because all you're trying to do is fit in.

Cassidy shared that she advocates strongly, on any platform she can get, for a more neuro-affirmative education system for autistic young people—one that does not justify behaviourist strategies under a guise of a “trauma-informed practice” that has simply changed its name for the purposes of receiving government funding to implement interventions created by a “billion-dollar industry”. Cassidy did not see any need for behaviourist strategies at all because, as she explained, “... being autistic is not a behavioral disorder. It is a neurological difference, and

every fiber of your being is autistic. So, anybody who defaults to something that's called 'behaviour anything-or-other', it's wrong." Cassidy emphasized that she wants every student to simply "get what they need." She felt that "there shouldn't be a model for it, really. It should just be what we do... we know better, we do better."

Similar to Alex's story, Cassidy's experience as an autistic person provides a perspective that is too often missed by non-autistic practitioners and parents invested in ABA. As was pointed out in earlier chapters (see, for example, Concerns #1 & 4 in Chapter 5), ABA therapists have yet to be trained to understand the unique neurological needs of autistic people (Collis, 2019; Memmott, 2023; Vivanti, 2022). Without a solid understanding of autistic sensory, emotional, physical, and neurological needs, it is unsurprising that some ABA providers view autistic children's ability to comply as a measure of successful intervention. Cassidy herself admitted that she "did not think there was anything wrong with it (ABA) at the time." Similar to Providers A and B, Cassidy witnessed observable behaviour change that she once viewed as a marker of successful intervention but has since learned that these were "very simplistic ways of change" that only created the appearance of success. In some ways, the ABA strategies likely did help students cope with the demands of school. As mentioned by Providers C and D, and several of the parents in Table 7.2, ABA interventions are effective tools for teaching autistic children to mask (i.e., suppress) their authentic expressions in order to comply and cope with the everyday norms and expectations of their environments (Gates, 2019; Pearson & Rose, 2021; Price, 2022). Recall that, from a positivists' point of view, ABA providers may feel a moral obligation to support autistic children to fit into societies that are "less accepting than desired" (e.g., Leaf et al., 2021, p. 2845). Through the lens of the critical transformative paradigm (Mertens, 2009, 2015), this obligation can be considered unethical because it means that ABA providers are

simply equipping autistic children with skills to fit into ableist and unaccommodating environments without focus on the environment itself.

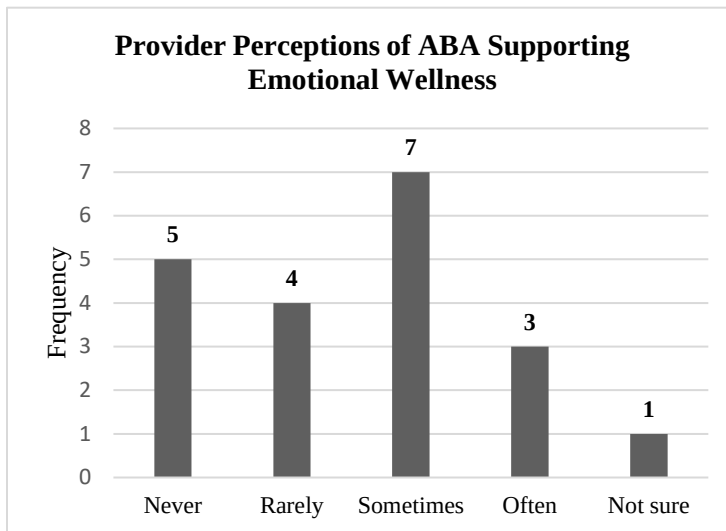
At the same time, it is important not to minimize the helpful strategies shared by Provider B, particularly “sensory based” strategies that autistic people and neurodiversity-affirming education experts have been advocating for (Laurent & Fede, 2020a; Salvesen Mindroom Research Centre, 2023). With a good understanding of autistic sensory and neurological needs, even autistic ABA critics such as Oswin Latimer (2022), an autistic consultant and president of the widely esteemed disability justice organisation Foundations for Divergent Minds (Foundations for Divergent Minds, 2024), agree that individual ABA providers can transform their methods to meet the needs of autistic students. To accomplish this, ABA providers need to attend to needs beyond behaviours, destigmatize autistic experiences, and dismantle ableism in society while supporting autistic children with useful coping skills at the same time Lewis et al., 2022; WitandStars, 2021).

Without understanding autistic needs and communication styles, Cassidy pointed out the ways “first/then strategies were harmful to students” by requiring them to first comply with expectations such as using “their mouth words” when they often cannot. It takes time to understand autistic needs and ways of being (Autistic Collaboration, 2019). From her own perspective as an autistic person, Cassidy was able to notice aspects of autistic behaviour that non-autistic educators were not, such as the ways behaviour is not always purposeful communication (as was noted by Alex in Stories Behind the Statistics #5 earlier). When “first/then”, “planned ignoring”, and positive reinforcements strategies are used to shape, expect, or force behaviour change that is not natural, autistic young people are denied opportunities to develop authentic communication styles that are safe and healthy for themselves and others

(Wilkenfeld & McCarthy, 2020). Putting pressure on autistic students to adapt to environments at the expense of their wellbeing is a neoliberal form of “inclusionism” (Mitchell & Snyder, 2015; Roscigno, 2019) that serves the needs of antiquated educational systems that have yet to dismantle environmental and attitudinal barriers to neurodivergent and disabled students’ experiences of belonging (Mitchell, 2015; OHRC, 2018; Parekh, 2022).

Wellbeing

Many ABA providers have shared that they entered the field of ABA as a vocational calling for the purpose of bettering the lives and wellbeing of autistic children (Anxiousadvocate, 2015; Ask an Autistic, 2019a; Gruson-Wood, 2016). Yet, as Cassidy and other providers have shared, providers are sometimes surprised to learn that ABA leads to the opposite of autistic wellbeing (Anxiousadvocate, 2015; Autistic Allies, 2018; Ram, 2020; Stay, 2021). To examine provider perspectives related to the impact of ABA on wellbeing, I analysed responses to a survey question that addressed emotional wellbeing: *“Do you feel ABA and/or IBI supported your students to feel... ”*. Respondents could choose from a list of options that included the following: *“Emotionally well and supported in their mental health needs?”* Likert scale responses ranged from, “1-never”, “2-rarely”, “3-sometimes”, and “4-often”. Results revealed that only half the providers (n=10; 50.0%) respondents selected “3-sometimes”, “4-often”, or “not sure”. See Figure 7.4 and Table 7.6 (that follow) for a breakdown of results, views, and comments from four different provider respondents who chose to elaborate in the open text box areas of the survey.

Figure 7.4. Provider Respondents' Perceptions of ABA for Wellbeing**Table 7.6. Provider Perspectives Regarding Wellbeing**

Respondent	View of Autism	Experiences Providing ABA	Example Comments (Emotional and Mental Health)
Dina ³¹	Prefers person-first language; views autism as a spectrum, neurodivergence, and not a disorder; autistic people can be high to low functioning	ABA "often" supported emotional & mental health; over 10 years of practice as a behaviour technician, instructor therapist, and supervisor; earned certification with the Behavior Analysis Certification Board (BACB)	"My favourite success story is with one of my very first clients. He was 5 years old and non-verbal, diagnosed as under the first percentile in development. One day, I was sitting with him at snack and he opened up a book and began to read out loud. I was astonished and immediately took this to my supervisor - clearly there was so much more to him than met the eye and really opened up my mind to the true capabilities of the individuals I supported. We ended up teaching him to label using textual prompts and slowly faded these out until he was able to label pictures/objects independently. With this we taught him how to request for things that he wanted which opened his world to communication with others, gaining access to preferred items, people, and lowered frustration and problem behaviours."

³¹ Dina's experience is shared in more detail in *Stories Behind the Statistics #7* to follow

Provider E	Prefers person-first language; views autism as a spectrum; autistic people can be high to low functioning	ABA "often" supported emotional & mental health; 1-2 years in practice as an instructor therapist & support role in Education; earned certification with the BACB	"[Emotional and mental health] May be out of scope for my role as an instructor therapist but it may improve clients' mental health... A client who always had accidents was finally able to have a bowel movement in the toilet after continuously following a specific toileting schedule. This client then received a lot of positive reinforcement and expressed a lot of happiness."
Provider F	Prefers person-first language; views autism as a spectrum; autistic people can be high to low functioning	"Not sure" if ABA supported emotional & mental health; over 10 years in practice as an Educator & support role in Education	"We looked at general well-being of students. If a strategy was not supporting the child we modified strategies ... At school we thought she [client] couldn't take care of herself. With the visual support and IBI training at the IBI site, she was very capable. We were able to replicate the visuals for school and she became a much more independent child."
Provider G	Uses identity-first language or person-first language depending on person's preference; believes autism is "defined by the individual's experience"; does not agree with functioning labels	ABA "rarely" supported emotional & mental health; over 10 years in practice as a support role in education, camp counsellor, Instructor Therapist, volunteer	"There may be characteristics of using ABA as an instructional approach that are effective (ie. telling students what to do is a "prompt"/giving praise is "positive reinforcement", teaching skills one at a time is "chaining"). However—ABA and Behaviourism is a philosophy which focusses [sic] on observable behaviour—and there is more to behaviour than what is observed in the moment."

Similar to the provider views and examples presented in Table 7.5, Table 7.6 reveals correlations between medicalised views of autism and positive perspectives of ABA—i.e., both Providers E and F use person-first language and functioning labels to describe autistic people. Both these providers acknowledge that emotional and mental health are not the focus of support they provide to their autistic clients and students. Instead, they shared that they focused on life

skills such as toileting, “general well-being”, and independence, which they suggested contributed to the wellbeing of their clients or students overall. As discussed in Chapter 6, the absence of a mental health focus in ABA is not surprising given that ABA is not intended as a mental health support for autistic people. However, because ABA remains the only accessible and recommended support for families in Ontario and Canada, it is important to consider perspectives such as that shared by Provider G—“Behaviourism is a philosophy which focusses [sic] on observable behaviour—and there is more to behaviour than what is observed in the moment.” It is dehumanizing to limit the interventions that autistic young people receive to those with a sole focus on skill-building or task-performance without regard to their inner needs. Gruson-Wood (2016) aptly described the process of intensive ABA methods as “figuratively robotic” (p. 46) in that both ABA provider and autistic client “perform” robotically for each other—the provider performs theatrics to engage the autistic child who, in turn, engages in the performance asked of them. When the child responds with compliance, the intervention is deemed a success. When the child responds with noncompliance or distress, the intervention plan is adjusted to reduce the noncompliance or distress, which risks denying the child their right to authentic expression of resistance and advocacy for their inner needs (Roscigno, 2019; Wilkenfeld & McCarthy, 2020).

It is further important to note that, similar to the trend found in the autistic ABA recipient sample, self-identified Black respondents in the provider sample (n=2) indicated more positive views of ABA than white-identified providers. While the sample is much too small to make generalizations to the wider Black community, the findings provide an important direction for further research into the critical analysis of stigma that lies at the root of the ABA problem. Black autistic people, their families, and those who care for them are doing their best to work within a

violent and discriminatory society that provides little support outside of ABA interventions to protect multiply marginalised autistic young people (Lewis et al., 2022).

Questioning Effectiveness

Similar to Cassidy and the provider respondents who shared perspectives in Tables 7.5 and 7.6, there are many ABA providers who have questioned the effectiveness and ethics of ABA due to the impacts of ABA on the QoL and wellbeing of autistic people (Anxiousadvocate, 2015; Ask an Autistic, 2019a; Gruson-Wood, 2016; Ram, 2020). To examine provider experiences of questioning the ABA methods they have used, I analysed responses to the survey question, *“Have you ever questioned the effectiveness or appropriateness of the ABA Interventions you used?”* Respondents could choose from the answers, “no”, “sometimes”, or “yes”. Three quarters (n=15) of providers selected “yes”, 15% (n=3) selected “no”, and 10% (n=2) selected “sometimes”. Only those respondents who selected “yes” or “sometimes” chose to share their perspectives in the open text box areas. See Figure 7.5 and Table 7.7 for example comments. I included comments from providers A and E (from Tables 7.5 and 7.6 above) in order to be inclusive of comments other than “yes”. I used purposive sampling to select comments from another two providers (Providers H and I) based on themes identified in my literature review (e.g., social validity and internal motivation).

Figure 7.5. Have you ever questioned the effectiveness or appropriateness of the ABA interventions you used?

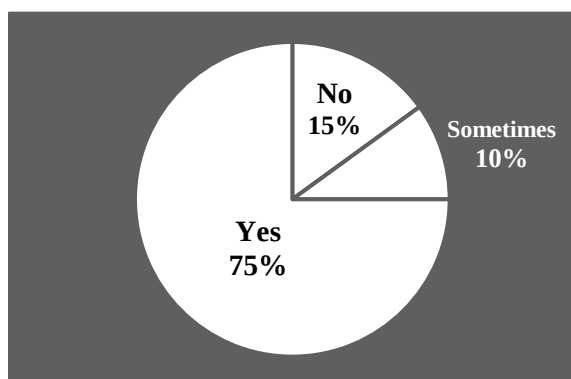


Table 7.7. Have you ever questioned the effectiveness or appropriateness of the ABA interventions you used?: Open Text Box Responses

Respondent	Response	Example Comment
Provider A	Sometimes	"I've questioned in the past as I realized once becoming more educated it was not done properly. I think when done correctly and with the right mindset and goals (ex client focused) the potential harmful impacts are minimized."
Provider E	Sometimes	"Sometimes it's hard to understand the purpose behind certain things implemented or why certain programs are run in a specific way."
Provider H	Yes	"Wasn't taking into consideration what the child wanted."
Provider I	Yes	"My scepticism grew over time but came to a head when I saw a training video where the trainer claimed that autistic students do not have internal motivation to learn and needed reinforcements. That was definitely not my experience with my autistic students at all."

The following experience shared by Dina provides insight into one ABA therapist who actively reflects on the impacts of ABA on autistic people's QoL and wellbeing and is aware of the harms caused by traditional forms of ABA. Dina is one of many emerging practitioners in her field who is working toward transformational change of ABA practices.

Stories Behind the Statistics 7: Dina

Dina (she/her) described herself as a white, third generation Canadian, Board Certified Behavior Analyst (BCBA), who was 32 years old at the time of the interview. While in her survey she indicated that she continued to use "high" and "low" functioning labels to describe the ability levels of autistic people (see Table 7.6) she stated, "This view has been conditioned as part of my history of working in the field, however... I am working to dismantle this categorization in support of the neurodivergent movement." Dina earned a master's degree in

counselling psychology along with a postgraduate certificate in ABA. She practiced ABA as a clinician in an urban health care setting in Ontario. As soon as she graduated from university in 2012, Dina started working in the field of ABA as a behaviour technician and instructor therapist providing services to autistic young people in ABA centres as well as (periodically) in family homes. She was quite dedicated to her work in the field and moved up to the role of senior therapist within two years. Since that time, she has worn “many hats” in the field, including public and private school education support, consulting, clinical supervision, and Continuing Education Unit (CEU) certification developer.

The center she was employed at during the time of the interview was affiliated with a school. As Dina explained it, a typical day for the autistic children attending the center (mainly under 10 years old with some older students online) was designed as a “hybrid” approach where “... most of the learners attend as a day program, attending between 3-35 hours per week... some are in the class, but then would come to one-on-one therapy at other times of the day, usually like a half and half split.” Additionally, she explained that some children “only access the school without individual support.” Her role was mainly to provide supervision for the ABA therapists and behaviour technicians working directly with students.

Dina stated that her motivation for participating in this study was to contribute her perspective as a passionate BCBA who recognized the harmful history of her field and who is working toward more ethical and “trauma-informed” approaches:

I think what draws me to it [this study] is that it's difficult to see something that you are [paused]... you put your goals and career focus on, presented in a negative light when you don't feel that it's negative. Obviously, there are things that are negative, and the field has come a long way. But myself personally, I don't feel like what I do on a day-to-day

basis is harmful... I do see a disparity while also wanting to understand where they [ABA critics] are coming from.

Throughout the interview, Dina expressed dedication to learning from autistic experiences. She felt it is important to listen to autistic people who have been harmed or traumatized by the ABA services they received to ensure present and future autistic people do not have the same experiences. Dina explained that most of the staff members on her team agree with her approach, and that they are beginning to open up to new ideas such as the use of identity-first language and terms other than functioning labels.

When I broached the topic of stigma and ableism, Dina shared that she understood “our society is not set up for people who have disabilities... With respect to individuals with autism, I think there's just kind of a lack of awareness of what it is.” She admitted that she did not get any training in the area of autism or the impacts of ableism within her ABA training. In response to my question as to whether she felt ABA could play a role in the reduction of autistic stigma and ableism, she responded that she was “not sure” and that this was something she felt she, and others, needed to ponder further.

However, she explained that her team had been engaged in the recent autistic-centered Practical Functional Assessment (PFA) training provided by Dr. Greg Hanley (2021), which she described as a humanistic approach aimed at understanding behaviour as having more than four basic functions:

He [Hanley] talks a lot about how this theory of four functions is... is it really accurate? Like, there are really only four functions of behaviour? And yeah, so myself, I've been kind of starting to question that a little bit more, too. ... how behaviours aren't really like a singular function, you know?... the majority of our behaviours are multifunctional.

Dina further explained she has an appreciation for the more progressive forms of ABA that consider the inner world of the person, such as Acceptance and Commitment therapy (ACT) introduced in the discussion of Kendra's story in Chapter 6 (see Dixon et al., 2020; Tarbox et al., 2020). Originally designed for use in psychotherapy and counselling contexts, ACT uses mindful “verbal interventions” aimed at altering “the functions” of “private events” first introduced by B.F Skinner (1957) in his theory of radical behaviourism “to increase the flexibility of perspective-taking... and to develop habits and patterns of overt behavior that are guided by chosen verbal establishing stimuli that establish reinforcers intrinsic to engagement in that overt behavior” (Dixon et al., 2020, p. 561). In plain language terms, ACT combines behaviourism with mindfulness techniques to support clients to understand that negative thoughts and feelings are natural and that they can be accepted and transformed into positive action through mindful awareness (Harris, 2007). Dina shared that she felt ACT was “the start of repairing that missing link... there's obviously a high prevalence of emotional challenges within our kiddos. So, to teach them how to manage those is super important for any setting that they go to.”

ACT-informed approaches being explored at her center included the Accept. Identify. Move (A.I.M) curriculum for social and emotional development (Dixon & Paliliunas, 2023) and Canvas ABA-Art, and arts-based ABA curriculum for kids (Bouchillon, 2023). Dina felt that these types of approaches were more relational and empathetic toward autistic children's needs. However, she explained that because this kind of approach “really only lends to specific learners, those who have maybe higher cognitive skills”. Dina admitted that “I kind of feel like there is a chunk of kids that are, kind of, being left behind there, and there's not a lot of research on how to support their emotional wellbeing.”

The absence of a humanistic approach in ABA for all autistic learners has always been unsettling for Dina, which is why she is working toward change from within in her field of practice:

I've kind of felt like there's something missing from ABA for a long time. And perhaps this is where my counseling background also comes to play and that, you know, the methods that we've been taught to manage behaviour seem like they're missing a humanistic approach... like they're missing an element of understanding what the other person is going through and their internal and private events.

For this reason, she explained that her team worked toward a trauma-informed and relational approach with every child, regardless of ability and skill level. For example, "... when a child is upset, rather than ignoring them and blocking them and all these strategies that we were originally taught to approach them, have them sit down on the floor with you and make them feel safe in the environment that they're in." Dina explained that using approaches such as these has ensured "learners are happy, relaxed, and engaged throughout their entire session through providing the most enriching and reinforcing environment for them full of their favourite things so that they are open to letting us in to teach them."

When I asked whether she felt autistic children could learn without positive reinforcements, Dina paused and replied,

I don't know... I mean, what I've learned and what I've observed in the past 10 years is that a lot of individuals who are on the autism spectrum might not have that intrinsic motivation... if you have a student that is extremely intrinsically motivated and wants to do well and wants to please their teachers, then yes... the lack of reinforcement is fine.

But for kids who aren't intrinsically motivated, they need to learn that motivation externally, and the goal is always to fade reinforcement.

Dina continued that the fading of reinforcement is key in order to avoid reward dependency:

We don't want them to be reliant on reinforcement because at the end of the day, nobody's going to be following them around with chips or their iPad... Whatever skills that we teach, we want to make sure that they contact reinforcement naturally in their environments because that reinforcement is going to be what establishes that as an ingrained skill in their repertoire.

In natural environments, Dina explained that she knows children are “not always going to contact that reinforcement reliably.” Therefore, she felt another way therapists can avoid reward dependency is to ensure the goals set for the child are “socially meaningful”, meaning that they learn “skills that are going to be impactful for their whole lives.” Because the clients at her center are young and often “non-verbal”, she felt that many are unable to set their own goals: “... if possible, we ask the learner what they'd like to learn or what's important to them. But we don't always have that ability to do that. So usually, we're discussing mostly with parents and caregivers, sometimes with teachers as well.” To gain consent from nonspeaking or very young children, she explained that her team established “a process to gain assent from our clients who may not be able to give us verbal consent... [we] do this by having an open-door policy—if the child is running out of the therapy room, then this is an indicator that perhaps the therapy environment isn't enriching enough.”

While she and her team observed success from using these newer forms of ABA approaches (e.g., witnessing engaged, happy learners; development of important life and

academic skills; open-door policy and enhanced choice models;³²), she admitted she has received push back from a select few staff members and psychologists at her centre. For example, she recalled how one senior staff tended “to jump to punishment procedures before considering other options... And as behavior analyst, we are trained that we should be exhausting every other option before we even consider punishment.” Dina expressed frustration about how punishments such as time outs or isolation are “being recommended more frequently than we'd like it to be... So, the BCBAs and supervisees are very frustrated right now where we are at because there's an abundance of recommendations of punishment and that's not where our field is going.” She felt fortunate she had a strong team who could advocate for better approaches, and for the most part, their trauma-informed recommendations “have always worked... those few psychologists and staff recommending punishment procedures will eventually listen.”

In stark contrast to Cassidy, Dina experienced her delivery of ABA services as contributing to the wellbeing of autistic children who are happy and engaged as they develop “socially meaningful skills” that are “impactful for their whole lives”—skills such as life skills and academic skills with particular attention to autistic needs, which Dina admitted was never a focus in her ABA training. In the ethnographic study about ABA provider experiences discussed earlier in this chapter, Gruson-Wood (2016) identified that there are ABA providers who either “reproduce or resist psychocentric aspects of their training” (p. 54). Dina, like many ABA therapists who are open to the knowledge and critique about the harmful past of ABA, are breaking free of psychocentric (i.e., pathology-driven) practices they do not agree with despite receiving push-back from more traditionalist behaviourists in their field (see Pritchett et al., 2021). This openness to practice more humanizing methods of ABA (e.g., sitting with autistic

³² See the consent section later in this chapter for further discussion and potential concerns related to the open-door/enhanced choice models of current ABA practices

children rather than “ignoring” and “blocking”; attending to mental processes, emotions, needs beyond external behaviours, etc.) can be credited to the courageous voices of autistic people who have been willing to speak out against the harms of ABA in well-researched and detailed ways (see Chapters 5 and 6). Credit is due to autistic activists calling for a ban of harmful ABA practices (Autistic Collaboration, 2022), but also to emerging neurodiversity-affirming autistic consultants (e.g., Latimer, 2022), autistic parents (e.g., Hammond, 2022a), and autistic justice-oriented ABA practitioners (e.g., Cerda, 2021) working toward transformative change by speaking to ABA practitioners who are willing to listen. Dina, along with a growing movement of dedicated ABA practitioners are listening (e.g., Allen et al., 2024; Mathur et al., 2024; Mindful Behavior, 2024; Pritchett et al., 2021).

At the same time, it is important to continually examine emerging humanistic forms of ABA as new information about autistic lived experiences becomes apparent. As Damon and numerous other nonspeaking autistic people have repeatedly explained (e.g., Communication First, 2021), the core element of any autistic support model requires the presumption of competence. New studies reveal concrete evidence that an effective method of AAC for nonspeaking autistic people is the method of spelling to communicate (see Jaswal et al., 2024). Yet, the field of ABA continues to recommend Picture Exchange Symbols (PECS) and speech generation devices (SGD) for autistic language and communication development based on studies by non-autistic researchers from within the ABA literature base (see Matson, 2023). ABA training in this area has yet to consider evidence pertaining to Spelling to Communicate (also referred to as S2C)³³ which is a preferred communication modality of many nonspeaking autistic people, particularly when just beginning to learn AAC (see I-ASC, 2019). The success story

³³ See the I-ASC website for more information on the S2C method: <https://i-asc.org/s2c-spelling-to-communicate/>

Dina shared in Table 7.6, wherein she expressed astonishment at the reading ability of a 5-year-old “nonverbal” autistic child “diagnosed as under the first percentile in development”, reflects a need for updated assessment methods to support ABA practitioners in new understandings of the literacy potential of nonspeaking autistic children (Dawson et al., 2007; Jaswal et al., 2024; Nader et al., 2016; Vance, 2020; Williams, 2020). Nonspeaking ABA recipients like Damon, who shared his perspective in Chapter 6, are grateful for practitioners like Dina who understand that there is “so much more” to nonspeaking autistic people when efforts are made to presume competence (Biklen & Burke, 2006). Without truly understanding the cognitive capabilities of nonspeaking autistic people, the potential benefit of newer forms of ABA, such as Dixon & Paliliunas’s (2023) Accept Identify and Move (A.I.M) curriculum for focusing on emotional wellbeing, will remain exclusive to autistic young people who speak to communicate. As Dina pointed out in her interview, this curriculum “only lends itself to specific learners” (i.e., learners who can speak using standard verbal language).

Further, it is important to recall Damon’s additional concern about the ways newer forms of ABA could be used “as a ‘tool’ to gain cooperation” from students without consideration for their inner needs (see Story Behind the Statistics #4, Chapter 6). A closer examination of newer ABA approaches may justify Damon’s concern. First, recall Dina’s emphasis on assuring assent through the creation of an “enriching environment... so that they [autistic children] are open to letting us in to teach them”. As discussed earlier in Chapters 2 and 5, ABA providers have power to gain compliance from autistic children through the use of rewards. In cases when the goals of the intervention violate autistic autonomy to learn and grow in neurodivergent ways (see Wilkenfeld & McCarthy, 2020), the “enriching environment” could become a tool for

compliance regardless of whether the children appear happy and engaged or not (Lynch, 2019; Real Social Skills, 2015).

To provide another example, the A.I.M curriculum Dina explained in her interview seems to be designed as “relational and empathetic” toward children. The curriculum website described A.I.M to be helpful for children “who struggle with social and emotional challenges” by supporting them to understand “... self-rules, and beliefs about the world around them” (Dixon & Paliliunas, 2023, para. 1). Indeed, there is value in supporting children to understand their inner thoughts and beliefs; the A.I.M curriculum, along with other Acceptance and Commitment therapy (ACT) tools, have potential to support the wellbeing of autistic young people (see Layle, 2022). However, implementation methods are key to the curriculum’s success and minimization of harm. For example, the A.I.M curriculum relies on a system of reward-based “token / point sheets” (Dixon & Paliliunas, 2023, para. 1). Education experts such as Alfie Kohn (2018) explained the ways reward systems such as these continue to be used as a means of controlling student behaviours for the benefit of compliance-based school systems rather than for the benefit of the students themselves (see Chapter 5, Concern #3). The following example demonstrates one way the A.I.M. curriculum risks becoming a tool for control and compliance.

In a YouTube video introducing the goals and methods of the A.I.M curriculum at one elementary school in Illinois, teachers described the ways the curriculum is implemented in action (see AIM in Action, 2020). First, the teacher expressed pride in how the whole school is involved in a brightly decorated supportive environment wherein students “can earn rewards and... points to buy opportunities to get out of the classroom and do really special things in the school” (0.26). Throughout the video, the camera reveals what are known as the six “points of the ACT Hexaflex: acceptance, defusion (i.e., separate yourself from your thoughts), present

moment attention, self-as-context, values, and committed action” (Hayes et al., 2006). These Hexaflex reminders artfully decorate the classroom walls with messages for the students such as, “Values: ‘What are you working for?’” and “Committed action: ‘Change your behavior toward values’” and “Acceptance: ‘Be OK with Good and bad things in life’” and “‘I am your thoughts, so just let me PASS BY!’” (i.e., let your thoughts pass by without judgement or reaction). There are reward bins for students who follow these Hexaflex reminders, all labelled with point values of 20, 50, 100 etc., and filled with snacks, candies, stickers, and school supplies. Colourful signs around the classroom read: “Ways to earn daily points” with lists of values including “Respect, Responsible, Positive attitude, tasks completed on time/follow directions”, etc.—each item is listed using check mark symbols to signify their importance. Another sign reads: “Ways to earn extra points... ‘Test grades: A-200 pts, B-100 points, C-50 pts’ ... Perfect attendance – 100 points” etc. In addition, students are reminded they can lose points: “Mindfulness Classroom Points Loss Matrix: Action – ‘Talking during class – cost 10 points’, ‘being disruptive – 50 points’, ‘sleeping – 50 points’, ‘Head down – 20 points’, ‘disrespect staff – 50 points’ ... ‘refusal to follow directions – 100 points’” etc. (AIM in Action, 2020).

It is not difficult to see the parallels between the classroom described in the example above and the elaborate Wizard of OZ-themed reward system discussed in Chapter 5 designed by the Judge Rotenberg Center (JRC), which is used as a means of gaining control and compliance from students under the guise of fun and enjoyment (see Concern #5 and Shields, 2019). While the A.I.M curriculum in the Illinois school was designed for all students, it is intended to support students who experienced emotional and behavioural challenges, which includes autistic students participating in mainstream school settings. Autistic students impacted daily by ableism and discrimination in schools often do not have the privilege or ability to live life by their values,

which constitutes the central goal of A.I.M and other ACT-informed ABA interventions (Dixon et al., 2020; Tarbox et al., 2020). Without consideration of the impacts of chronic invalidation trauma caused by stigma (Gates, 2019) or misinterpretations of autistic behaviour (as discussed by Alex and Cassidy earlier in this chapter), programs such as the A.I.M curriculum at the Illinois public school risk punishing autistic students for behaviours that are beyond their control. To earn their points, autistic students may need to suppress their autistic traits and behavioural reactions in order to change their “behavior toward values”. They may also be expected to “Be OK with Good and bad things in life”, including injustices imposed upon them due to stigma and ableism (Gates, 2019; Pearson & Rose, 2021; Price, 2022).

As Dina mentioned in her interview, aspects of stigma, discrimination, and autistic neurology are not yet included in the training ABA providers receive. Until ABA providers and educators are supported to truly understand the needs of autistic students, including ways to confront their own biases about behaviour, Damon is justified in his concern that newer forms of ABA can be used as a tool for behaviour management. Earlier in this chapter, Cassidy further pointed out how the newer forms of ABA are often packaged “under a guise of a ‘trauma-informed practice’ that has simply changed its name for the purposes of receiving government funding to implement interventions created by a ‘billion-dollar industry’” (see *Stories Behind the Statistics #7*). Damon, Cassidy and other autistic people who are critical of all forms of ABA understand that it takes more than a new ABA protocol to transform the everyday practices of behaviourism that have been embedded within misinformed and dehumanizing understandings of autism for decades.

Parent and Provider Experiences of Consent, Reward, and Punishment Procedures

To conclude my series of data analyses, I used a combination of descriptive and open text box analyses to examine themes related to consent, reward, and punishment procedures from the perspectives of parents and providers.

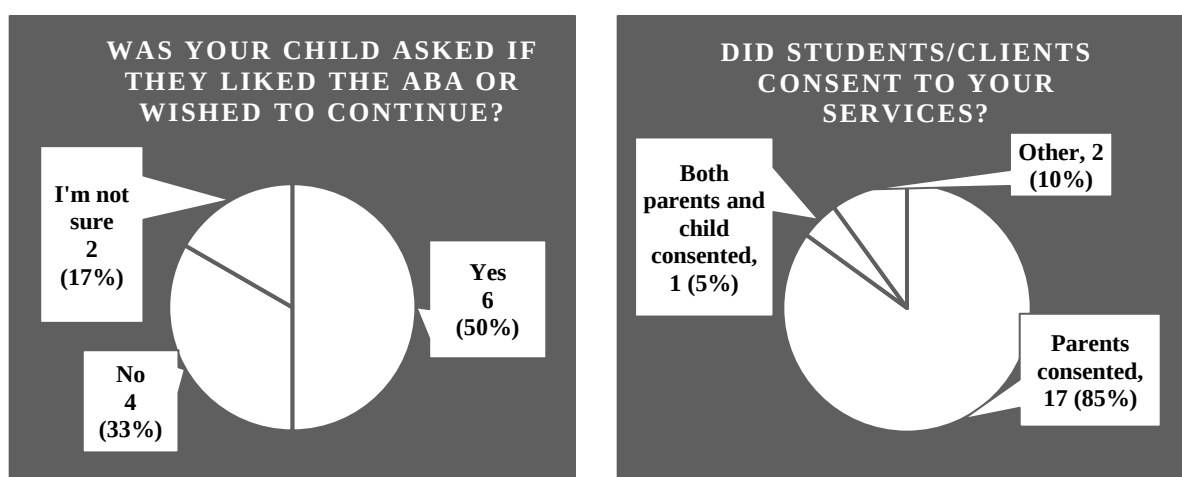
Consent

In response to concerns raised by critics of ABA regarding consent (e.g., Dawson, 2004; Wilkenfeld & McCarthy, 2020), ABA researchers have acknowledged that autistic recipients of ABA are rarely included in selection of goals—goals which are too often decided for them by parents and providers (Leaf et al., 2021). To examine whether the parent and provider respondents of my study included autistic children in ABA program goal selection, parents were asked the question, *“Was your child ever asked if they liked the ABA and/or IBI they received or whether they wished to continue?”* Answers ranged from “yes”, “no”, “sometimes” or “I’m not sure”. Providers were asked a similar but slightly different question, *“Have your student(s)/client(s) consented to receiving ABA or IBI services?”* Providers could choose from four options, 1) “The student(s)/client(s) who have directly received my ABA or IBI services have always consented”; 2) “It has generally been the parent(s)/guardian(s) of my student(s)/client(s) who have consented to my services”; 3) “Both the recipients of my ABA or IBI services and their parents or guardians have consented together”; and 4) “Other”.

Results revealed that exactly half (n=6) of the parents selected “yes”, their children were asked if they liked their ABA programming and wished to continue; one third of parents (n=4) selected “no” in response to this question, and two parents selected “unsure”. In the provider group, none of the providers selected that their students or clients consented to receiving their services, while 85% (n=17) selected that they received consent from parents alone. One provider

indicated that they received consent from both parents and providers. Two providers selected the “other” option, but only one chose to elaborate in the open text box area with the comment, “To my knowledge, there is not a formal process for consent to ABA in education”. See Figure 7.6.

Figure 7.6. Parent and Provider Responses Regarding Consent



As discussed in Chapter 6, issues of consent are murky when it comes to autistic children. Parents of nonspeaking autistic children may look to alternative ways to determine consent (e.g., expressions of happiness, etc., as was shared by Parent E in Table 7.2 and by Dina in *Stories Behind the Statistics* #7) because diagnostic tools for assessing the cognitive and communicative skills of many autistic children remain inadequate (see Dawson et al., 2007; Nader et al., 2016) and access to Augmentative and Alternative Communication (AAC) remains limited (A4A Ontario, 2019a). Similarly, as ABA providers begin to pay more attention to issues of consent, they look for expressions of “assent” as identified by Dina in her interview, which her team determined by having an “open-door policy” for clients to leave when they want to. One kind of open-door policy is referred to as the “Enhanced Choice Model” discussed earlier in Chapter 5 (Rajaraman et al., 2021). In contrast to earlier forms of ABA, the Enhanced Choice Model provides a learning environment where children are provided opportunities to: choose desired

activities; have unlimited access to reinforcers (rewards of choice); and leave the room (Rajaraman et al., 2021). The model is an application of Greg Hanley and team's (2014) practical functional assessment and treatment, which is known for its focus on creating an environment wherein "the autistic person will be happy, relaxed, and engaged, one in which they will feel safe and in control" (Hanley, 2021 para. 3).

In Chapter 6, Damon appreciated Greg Hanley and team's (2014) approach, yet worried that these newer forms of ABA may be taken up by practitioners "simply applying a surface-level understanding" (see *Stories Behind the Statistics #4*). While the Enhanced Choice Model and Practical Functional Assessment models are improvements over the restrictive ABA methods of the past (e.g., Lovaas, 1987), they are also not without need of careful examination when considered within the context of autistic stigma and autistic rights to autonomy. For example, Hanley's (2015) website provides video examples of ABA practitioners' experiences implementing the model in practice. In Max's story³⁴, an ABA therapist demonstrates how she was able to develop a rapport and successful treatment with Max, an autistic youth who exhibited severe self-injury and distress when items such as his iPad were moved out of place or when he was denied requests. In step 2 of the protocol, the therapist begins treatment by creating "contingencies" for "child-directed activities requested by Max" (1:55), by which she grants all of his requests when he shows distress. The therapist gradually teaches Max to say the phrase "My Way" to replace his habitual self-injurious behaviour or vocal distress (which in the video is defined as "whining") when she denies him requests or when she moves his iPad from one place to another. She also supports Max with toleration skills by teaching him the word "alright" when he is not allowed to have things his way. Max is immediately rewarded with access to his

³⁴ Max's story is the third link provided on the page and can be viewed here: <https://practicalfunctionalassessment.files.wordpress.com/2015/06/maxs-story.mp4>

favourite things when he uses both phrases without signs of distress. At the 3:48 minute mark, the provider is shown pausing Max's computer time as he was using it, and then going over to the shelf in front of him to move his iPad from one place to another. Max immediately says, "My way please" in a quiet but high-pitched tone. The therapist replies, "Not right now bud", by which Max follows promptly with a quick "alright". The therapist then praises Max with the words, "cool, nice job telling me alright, go ahead and play Zingo". Max reaches for the Zingo game on the desk and commences to engage with that activity.

While the video example is much too brief to understand the entirety of protocol procedures that got Max from point A (self-injurious behaviours) to point B (making requests and tolerating), it can be inferred that the therapist followed procedures described in the literature describing the model (e.g., Hanley et al., 2014; Rajaraman et al., 2021). Rajaraman et al. (2021) described the procedure to include carefully documented and programmed procedures of vocal prompting, differential reinforcement (intermittent reward schedules), and extinction (withholding of reinforcements when problem behaviours occurred). Rajaraman and his team explained that some of the key differences between this new protocol of ABA and more traditional forms of ABA are the focus on creating relaxed and happy environments, allowances for children to leave the room, and extinction procedures that "did not include any physical guidance" (p. 7). At the 4:19 mark, the text displayed on the video concludes: "Max has experienced almost 40 treatment sessions at home so far, over a period of 3 weeks. Problem behavior during structured sessions has been nearly eliminated." The video did not provide results regarding the longer-term generalisation of his new toleration skills during his everyday life.

Before concluding that these new protocols are a success, it is important to consider Damon's (among others') concern that autistic people need to be respected and genuinely empowered in the process (Lynch, 2019). The therapist in the example above is an experienced BCBA who was very gentle, friendly, and seemingly respectful of Max's space and autonomy. By teaching the phrase "my way" (which is expanded in the Enhanced Choice Model to more complex phrases such as "Excuse me . . . May I have my way please?"), therapists are seemingly equipping autistic people with the language they need to assert their own autonomy and choice. However, by immediately reinforcing toleration skills through the denial of Max's request (pausing the computer and moving the iPads anyway), it is important to consider whether the therapist is simultaneously denying his right to autonomy and respect. Even if Max enjoyed engaging in the game of Zingo he was offered as reward for saying the phrase "alright" (which he was procedurally programmed to say) his facial expression and body language indicated the possibility that he was suppressing genuine feelings of distress (i.e., masking). As Alex and other parents pointed out earlier in this chapter, it is often easier for autistic children to comply than to be constantly redirected. The stress involved in suppressing distress in one moment may result in residual expressions of stress at later times and places, which can cause more harm for autistic wellbeing in the long run (see Alex's concerns in Stories Behind the Statistics #5 and Concern #3 in Chapter 5).

Finally, it will be beneficial for the ethics of this protocol to be examined when considering autistic needs for consistency and sameness (American Psychiatric Association, 2013, p. 31). It seemed quite upsetting for Max to tolerate his iPads being moved. As Cassidy pointed out earlier in this chapter, consistency and sameness provide a sense of safety for many autistic children. It is imperative that educators, therapists, and parents stop to ask themselves

whether goals such as these are truly helpful for autistic children’s development (i.e., do the iPads really need to be moved? Does the student really need to use colours other than green? For whose benefit?). Further, it can be demeaning for autistic children to repeat short programmed phrases such as “my way” when they are too often deemed intellectually incapable of learning more complex language through access to AAC (A4A Ontario, 2019a).

Finally, it is important to remember Lynch’s (2019) concern—simply appearing to enjoy a therapy session that includes many of a child’s favourite things does not mean that the treatment setting is ethical or meaningful for an autistic child. Certainly, it is better for a child to learn how to make requests in place of self-injurious or harmful behaviour. However, reliance on reward-based, intensive, and procedural behavioural programming to achieve these aims risks diminishing autistic children’s intrinsic motivation and autonomy (Kohn, 2020; Wilkenfeld & McCarthy, 2020). Recall that there is no evidence of genuine empowerment or wellbeing outcomes for ABA participants in ABA literature (Pritchett et al., 2021). There is currently no way to determine whether these new ABA protocols meaningfully adhere to bioethics (Wilkenfeld & McCarthy, 2020).

Rewards and Punishment Procedures

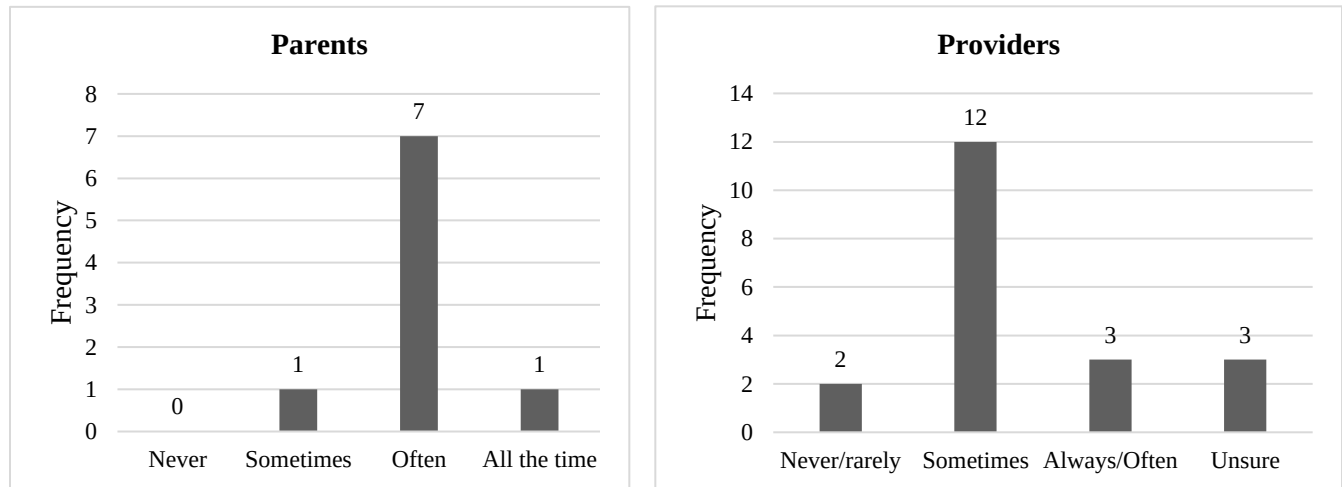
Rewards. Because ABA interventions rely on procedural data-driven implementations of positive reinforcement to support autistic young people with the development of skills (Cooper, Heron, & Heward, 2020; OSETT-ASD, 2017), both ABA providers and parents are trained in methods to assess motivating operations (recall that MOs describe the motivating power produced by rewards – see Chapter 5, Concern #1 for more on this discussion) to deliver the most effective positive reinforcement and then fade them out once the skill is learned (Geneva Centre for Autism, 2019). Researchers in the field of self-determination (Ryan & Deci, 2000) and

education (Kohn, 2018) have critiqued ABA's focus on rewards due the risk of reward dependency that diminishes natural intrinsic motivation (see Concern #3, Chapter 5). To examine parent and provider perspectives on the use of rewards, I examined the frequency and types of rewards respondents used with autistic children followed by perspectives related to reward dependency.

Close to all (91.7%; n=11) of the parent respondents indicated that they or their child's ABA therapist had used rewards "often" or "always" as part of their child's programming. The remaining parent was "unsure". The top rewards selected by parents were preferred activities and verbal praise, followed by physical gestures such as "high fives" or snacks/candy. Similarly, 85% (n=17) of providers indicated that they used rewards to support autistic children with skill building "all the time" and "often", while the remaining three providers selected "sometimes". Providers shared that they used physical touch and gestures such as high fives, preferred activities, screen time and verbal praise most often. Thirteen of the 20 providers also indicated that they used candy or snacks as reinforcers for skills.

To examine whether parents and providers felt the rewards could effectively be faded out once a skill was learned, I asked both groups of respondents the following questions' *"Can your child currently complete the tasks/skills they were taught without positive reinforcements, praise, or rewards?"* and *"Could your client(s)/student(s) maintain the skills without the continued use of the reinforcement?"* For parents, responses ranged from "never", "sometimes", "often", "all the time" or "not sure/can't remember". For providers, responses ranged from "never", "rarely", "sometimes", "often/always".³⁵ For ease of comparison, "rarely" and "never" were combined in the provider group. See Figure 7.7 for results.

³⁵ The differences in rating scales were chosen intentionally due to parents' ability to assess whether their child had developed the skill "all the time" without the use of reward.

Figure 7.7. Parent and Provider Perceptions of Reward Effectiveness for Maintaining Skills

Note. There were 3 missing cases in the parent group

Several parents and providers chose to elaborate in the open text box areas provided for this question. Of particular note were responses from parents and providers that reflected a different view than what could effectively be rated by a Likert scale method. For example, respondents who selected “sometimes” or “often”, or who did not select a response category at all, shared that they did not feel children had maintained skills as a result of reward-based learning. See Table 7.8.

Table 7.8. Can your child/client/student complete or maintain the skills without the continued use of the reinforcement?

Respondent	Response Category	Example Comment
Parent	“sometimes”	“I cannot say for sure that their successful completion of these tasks/skills can be attributed to ABA.”
Parent	No selection	“They don't use the skills that they were taught in ABA/IBI.”

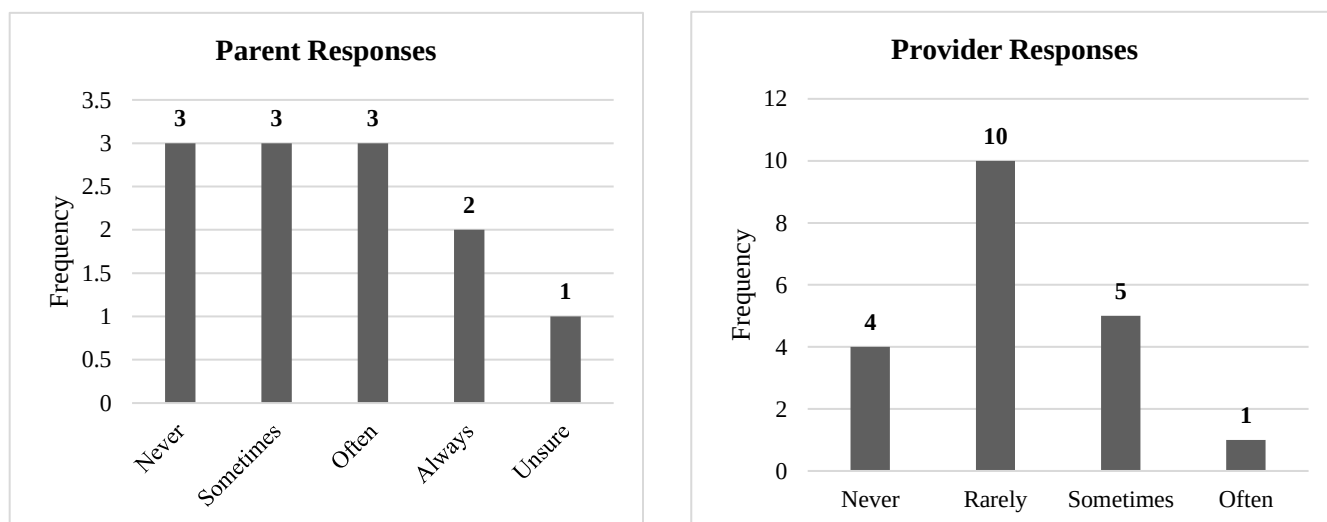
Parent	“often”	“He can, but not because of ABA but in spite of it. He made little speech progress with ABA like approaches and reward systems. Once we stopped that and took those pressures off, he developed speech on his own.”
Provider	“never”	“Panic attacks occurred when reinforcement wasn’t given immediately after skill.”
Provider	“often/always”	“I believe that children can learn skills without being bribed or reinforced. I believe their own ideas about themselves are more important than our outside reinforcement. Encouragement can be great but children should feel how they want to about their accomplishments.”

Punishment procedures. As noted in Chapter 6, contemporary ABA literature claims that punishment procedures are rarely used unless absolutely necessary to support a child in reducing challenging or dangerous behaviours (OSETT-CB, 2019). To analyse parent and provider perspectives on the use of punishment procedures, I examined the frequency and types of punishment or consequences used.

Parents were asked the question, “*Did the ABA and/or IBI approaches used with your child include consequences or punishment procedures?*” Two thirds of parents (66.7%) indicated answers ranging from “sometimes” (n=3), “often” (n=3) and “always” (n=2). Three parents selected “never” and one parent was “unsure”. The punishment procedures most often selected by parents were verbal/visual reminders to stop, planned ignoring, and withholding of desired items. When asked whether they felt these punishment procedures were effective, close to half of parents (41.7%; n=5) selected “no”. Two parents selected “sometimes” and four made no selections. See Table 7.9 for comments.

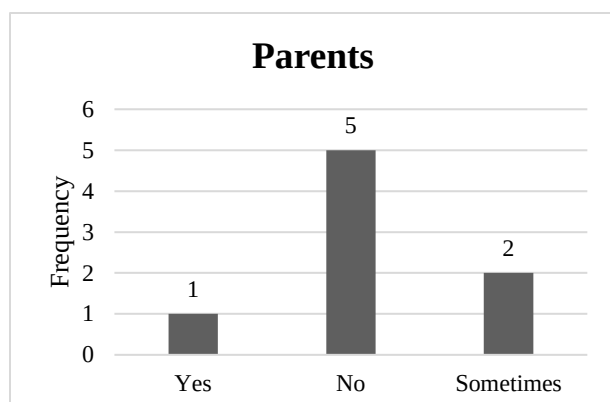
Similarly, providers were asked whether they “*used negative punishment and/or positive punishment to support the learning of student(s)/client(s)*”. Over two thirds (70%; n=14) selected “never” (n=4) or “rarely” (n=10). Five providers selected “sometimes”, and one provider selected “often”. Top punishment procedures used by providers included: loss of screen time, loss of free time, planned ignoring, and verbal reminders or gestures to “stop”. See Figure 7.8.

Figure 7.8. Frequency of Punishment Procedures Used: Parent and Provider Responses



In terms of perceptions of effectiveness, parents were asked whether they felt the punishment procedures their children received were “*effective in helping them to reduce or eliminate behaviours*” that they “*wanted them to reduce or eliminate*”. Over half of the parents who answered this question (n=5 of 8 total responses; 62.5%) selected “no”. Two parents left this question unanswered resulting in 2 missing cases. See Figure 7.9 (that follows).

Figure 7.9. Were punishment procedures effective? Parent Perspectives



Due to the philosophy of behaviourism that understands punishment procedures to have a lasting effect on the reduction of problem behaviours (OSETT-CB, 2019), providers were given Likert scale options to respond to the question, *“Were the client(s)/student(s) who you used punishment procedures with able to effectively maintain a decrease in problem behaviours without the continued use of punishment procedures?”* Only three providers selected “often”. There were 6 missing cases in this analysis due to the number of providers who indicated that they “never” or “rarely” used punishment procedures (n=14). See Figure 7.10 and Table 7.9.

Figure 7.10. Could students/clients effectively maintain a decrease in problem behaviours without the continued use of punishment procedures? Provider Perspectives

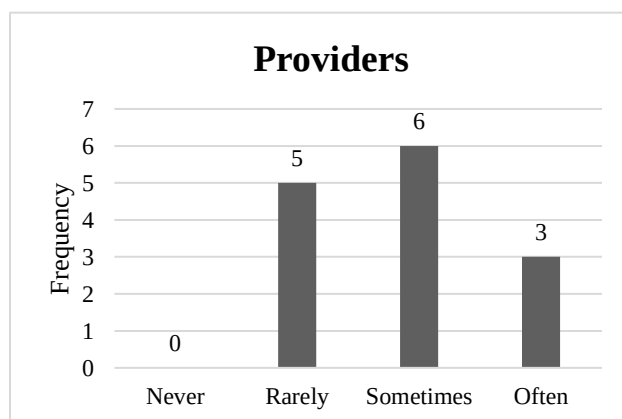


Table 7.9 provides examples of parent and provider comments made within the survey in response to questions relating to punishment procedures. Responses were selected to provide a balance of comments that reflected both positive and negative impressions of the effectiveness and or purpose of ABA punishment procedures.

Table 7.9. Parent and Provider Perspectives on Punishment Procedures

Respondent	Survey Questions	Example Comment
Parent	The consequences or punishment procedures used with my child to eliminate or reduce certain behaviours included...	“[withholding food or preferred items] worked best.”
Parent	Ibid	“This [punishment procedure] was the first thing that the therapist wanted in ABA. They had us take away all of my son's horse toys. My son did nothing that week and didn't even play with other toys! smart kid!”
Parent	Do you feel the punishment procedures your child received have been effective in helping them to reduce or eliminate behaviours that you wanted them to reduce or eliminate?	“We were told that our son was manipulative and attention seeking so of course the punishments didn't work. My son was very anxious and had sensory overload so the punishments made things worse.”
Parent	Ibid	“withholding food treats until a task was completed usually worked well when he was younger.”
Provider	In your ABA practice, have you used negative punishment and/or positive punishment to support the learning of your student(s)/client(s)	“Currently I work with a client who has dangerous attention seeking/sensory seeking behaviour (ex. Ingesting items and climbing and jumping off tables). When this happens I try my best to ignore and respect him to communicate what he wants (ex, chase, tickles, spins). Another client will often spit and attention is either removed or space is given.”

Provider	In your experience, were the client(s)/student(s) who you used punishment procedures with able to effectively maintain a decrease in problem behaviours without the continued use of punishment procedures?	“Sometimes it seemed to increase the behaviour.”
Provider	Ibid	“It seems hit or miss especially if you can't observe the behaviour for long enough.”
Provider	Ibid	“With the clients I currently work with the procedure has not been in place constantly for a long period of time. When I have previously used them they were not being used under proper supervision or with consistency, thus never really had an impact.”

The parent and provider experiences of rewards and punishments highlight important views regarding the effectiveness of operant conditioning methods (i.e., reinforcement and punishment procedures) used in ABA. The vast majority of parents and providers indicated that their children/clients/students received rewards-based learning as part of their ABA interventions, which was an expected finding given the reliance on positive reinforcements across all types of ABA interventions (OSETT-ASD, 2017). Overall, experiences of punishment procedures were infrequent with responses indicating the use of non-intrusive interventions such as reminders to stop a behaviour, planned-ignoring, or withholding of items. However, similar to the findings presented in in Chapters 5 and 6, these findings provided little evidence to suggest that rewards nor punishment procedures adequately met the needs of autistic people.

With regard to positive reinforcement strategies, the perspectives shared by autistic allies in Chapter 5 (see Concern #3) and autistic recipients of ABA in Chapter 6 (see Table 6.8 of that chapter), mirror the concerns of several parents and providers presented above who shared the common perspective that rewards were not needed for autistic children to learn because, as one

provider explained, autistic children are intrinsically motivated to learn “without being bribed or reinforced” (see Table 7.8). Recall that this perspective was similarly shared by Provider I in Table 7.7 earlier in this chapter: “My scepticism grew... when I saw a training video where the trainer claimed that autistic students do not have internal motivation to learn and needed reinforcements. That was definitely not my experience with my autistic students at all”.

Chapter 6 provided lived experience evidence of the ways both speaking and nonspeaking autistic people do not need positive reinforcements in order to learn (see Chapter 6 Table 6.8 and Damon’s story). Yet, the belief that autistic children are not intrinsically motivated is held by very experienced ABA providers, such as the therapist from the Geneva Centre for Autism (2019) mentioned in Chapter 5 who stated, “I realized that there wasn’t anything in it for them, so I started using reinforcers” (p. 9) (see Chapter 5, Concern #1) and Dina earlier in this chapter who felt, “what I’ve learned and what I’ve observed in the past 10 years is that a lot of individuals who are on the autism spectrum might not have that intrinsic motivation...” While positive reinforcements may work to gain cooperation or compliance to expectations (Kohn, 2018), and even bring pleasure to the autistic young person (Lynch, 2019), the findings above reflect the ways in which parents and providers did not find rewards effective or useful for supporting autistic children to maintain skills. In their interviews, Alex, Cassidy, and Dina all shared common concerns with reward dependency, which has been identified as a significant ethical concern of ABA interventions (Sandoval-Norton & Shkedy, 2019). Through practice and experience, Cassidy came to understand that the extrinsic motivation strategies embedded in ABA practice do not easily translate into intrinsic motivation. Dina acknowledged dependency as a common concern by advising providers to ensure goals are “socially meaningful” and that learners “contact reinforcement naturally in their environments.” It seems possible that the

parents who felt that rewards were not needed for their children to learn were able to discover truly meaningful goals for their children, which eliminated the need for reliance on extrinsic rewards. It also seems possible that the learning process in-and-of-itself was all the natural reinforcement that they needed. Considering the gaps in evidence to confirm that ABA is an effective approach to support autistic wellbeing and development (see Concern #4, Chapter 5), the findings thus far add to a growing evidence-base that suggests autistic young people can learn meaningful skills without reliance on strategic behavioural applications of positive reinforcement (Alderson, 2011; Delahooke, 2019; Laurent & Fede, 2020a; Prizant, 2009; Shkedy et al., 2019; Therapist Neurodiversity Collective, 2020b).

While punishment procedures were reported to be never, rarely, or only sometimes effective by the majority of respondents, two parents indicated that withholding of food or favourite items “worked best” or “worked well”, which was the same form of punishment Alex described as causing their son harm (see Stories Behind the Statistics #5). Roscigno (2019) examined how within the logic of ABA science, the use of punishment procedures are rationalized for the good of the autistic child’s “futuraity” (p. 405). Providers and parents are trained to use seemingly non-intrusive punishment procedures, such as planned ignoring of problem behaviours (e.g., tantrums) followed by positive reinforcement of acceptable behaviors (e.g., making requests), to efficiently reduce or eliminate targeted behaviours (Cooper, Heron, & Heward, 2020). Yet, the findings presented here and in previous chapters provide little evidence to suggest that few, if any, forms of punishment or reward procedures produce meaningful behaviour change beyond compliance with adult expectations (see Concern #3, Chapter 5 for more on this discussion). Arguably, there is great benefit for an autistic child who learns to stop engaging in harmful or self-injurious behaviour (recall parent G’s positive experience of ABA in

Table 7.2), but the long-term impacts of disregarding autistic children's inner needs through the use of punishment procedures in order to achieve this aim have yet to be adequately examined by the field of ABA (Koudys et al., 2018; Leaf et al., 2021; Sandoval-Norton & Shkedy, 2019; Shkedy et al., 2019).

The following experience shared by Brynn, a parent who indicated ABA was “somewhat effective”, provides further insight into the ways one parent found ABA to sometimes be “beneficial” but, as Brynn explained, “so can other interventions”, which is a comment she made on her survey in Table 7.2 (see Parent C).

Stories Behind the Statistics 8: Brynn

Brynn (she/her) described herself as a white single mother in her late thirties who worked as an educational assistant in an intensive support program (ISP) classroom for students with developmental disabilities. At the time of the interview, she was working toward her BA in Child and Youth Care part time, and her son was eight years old. When I asked her what motivated her to participate in this study, she replied, “... as someone whose kind of got both roles [parent and ABA provider in schools], I thought that maybe I'd have something interesting to contribute being on both sides.”

Brynn shared that her son preferred to be identified as a person with autism and she was “going with that” because, until he says otherwise, that is what he uses. In addition to a diagnosis of autism, he has ADHD and a learning disability. She shared that he is described as high functioning by his teachers and other support workers due to his verbal, academic, and life skill abilities. However, similar to Alex's experience (earlier in this chapter) with the inadequate functioning labels placed on their son, Brynn admitted that she gets frustrated when the teachers at his school often underestimated his needs: “[they] expect him to be presenting like everyone

else. And for the most part, he can mask and do those things, but when it's overwhelming, he can't.” Due to the inconsistent education about neurodiversity and the wide spectrum of autistic differences, Brynn felt that her son struggled to find a sense of belonging and identity. On one day after school, Brynn recalled him saying, “Mommy, I don't really think I have autism because the video we watched at school said that they can't make friends and I'm really good at that.”³⁶

Brynn was quite familiar with ABA through receiving it for her son and also through online training in ABA methods as a special education worker through the mandate of PPM 140 (Ontario Ministry of Education, 2007). Brynn shared that her reasons for enrolling her son in ABA were not to change his behaviour as she does not want to change anything about him: “He's a fascinating young boy who is very thoughtful and has lots of questions, and I have learned so much just from what he says, and asks, and ponders. It's powerful.” Her reasons for enrolling him in ABA programming were to help him learn new skills such as collaboration, cooperation, and emotional regulation. Brynn described her son's challenges as significant, but less apparent than some of his other autistic peers:

... his difficulties don't necessarily stand out until he finds the situation more challenging... and then you start seeing him shutting down or acting out or the fight flight freeze really shows up. And I find if people aren't necessarily aware that they won't know how to support him in those challenges.

Brynn described her son's more recent experiences with ABA in school and at summer camp as more effective than other ABA programs in the past. For example, she described her son's early experiences with the “tabletop kind of method” of ABA as ineffective. She first enrolled him in the program for support with behaviour challenges when he was about 4 or 5 years old: “He was

³⁶ The video Brynn referenced can be viewed on YouTube: Amazing Things Happen - by Alexander Amelines (National Autistic Society, 2017). <https://www.youtube.com/watch?v=RbwRrVw-CRo&t=133s>

a massive runner. He's just gone. Fight or flight—boom, he's out. Or he would start hitting, kicking and be aggressive towards people, like, he would push them out of the way because he couldn't communicate his needs or his fears or his struggles.” Brynn recalled how much her son disliked the experience: “He ended up hating it, and he was very resistant to wanting to go... I know that she said he was just very resistant to working with her, so their rapport wasn't the greatest. He didn't like her [Brynn chuckled slightly at this].” Again, similar to Alex's experience, Brynn shared that the professionals felt her son didn't need one-to-one or intensive forms of ABA:

... I remember when we sat down with her, and we were kind of identifying some of the areas that we wanted to work on. She said that he doesn't really need ABA. He doesn't fit into the ABA category... she said he needed to work with others, so he couldn't really practice social skills with others when it was just another adult.

After 4 or 5 months of the program, she discontinued it because, as she put it, “I just I didn't think it was worth it”.

Since that time, her son has received ABA-informed interventions at his school, which she felt are going really well despite the lack of neurodiversity awareness. Additionally, every summer, Brynn enrolled her son in an ABA summer camp that, in her words, he absolutely “loves”. Brynn described it as “... a two-week program to work on behavior, social skills in outdoor settings... [it's] goal-oriented for him”. She also described it as a program heavily focused on rewards. The provider of the program informed Brynn that “they do it all, including focus on emotions and handling anxiety, so not necessarily a focus on behaviour only.” Brynn explained: “... they use token economy big time there, so good behavior meant that he got some kind of money that he then got to trade in at the tuck shop at the end of the day and came home

with a fistful of candy. So, he's very motivated to work for rewards.” She also felt he could have learned those skills without rewards, and that reward-based learning is often not needed when a good rapport is established and learning is fun, much like it was at this Summer camp: “It kind of gives him a buy in to begin with, like, ‘Oh, if I do that then....’ But then he develops relationships with the people he's working with, and they get to know each other and kind of work in sync.”

For Brynn, it is the rapport and relationship that counted most, along with an accurate understanding of her son’s needs: “It's that relational piece—how you relate to the individual and how they relate back to you. And I think it's just that calm, kind, caring person who can assist and support him through something”. Brynn felt that it is a good therapeutic relationship, along with an understanding of physiological responses to stress that is key to effective support. Overall, Brynn felt ABA can be a good support for autistic young people. She also shared that she did not “... necessarily think that everyone needs to have an ABA therapist if they're autistic to make it through their day. They really don't.”

Because Brynn’s experience reveals the ways ABA can be both harmful and helpful, it serves as a fitting conclusion to the overall findings discussed throughout this dissertation. Brynn shared that her first experience with ABA was frustrating because providers underestimated her son’s needs due to his skillful ability to suppress (i.e., mask) his anxiety until he was overwhelmed to the point of “fight flight freeze”. This experience lends more evidence to the concern that ABA interventions inadequately attend to the underlying needs of autistic children’s behaviors (Delahooke, 2019; Kohn, 2020; Kupferstein, 2018; Sandoval-Norton & Shkedy, 2019). However, Brynn’s son’s positive experiences at a rewards-based ABA Summer camp, one that focused on building relationships and understanding needs beyond behaviours within an

intrinsically motivating learning environment, exemplifies the ways ABA interventions can also be helpful even when external rewards are used to motivate children. In Brynn's son's case, the token economy was an added bonus that Brynn felt he would not necessarily need if they were eliminated from the program. The difference between Alex and Brynn's experiences with ABA lie in the key elements identified by Brynn and others who advocate for improved autism services in Ontario—a) genuine understanding of autistic children's needs beyond behaviours (which requires relationship-building) and b) intrinsically fun and engaging learning environments that do not *rely* on the need for external rewards but implement them as a part of their program. Emerging ABA providers like Dina earlier in this chapter have begun to understand these important elements as integral to a more nuanced and ethical ABA practice.

Conclusion

Neither the parent nor provider findings revealed compelling evidence that ABA is an approach that genuinely improves the quality of life or wellbeing of autistic people. What the findings do reveal are similar to the findings discussed in Chapter 6—there are complex and nuanced issues related to raising autistic children in ableist societies that stigmatize autistic people. Within these societies, all parents want the best for their children—they desire their children to develop skills that will help them survive in an unjust world. Some parents continue to turn to ABA providers for their promise of supporting the normative development of autistic children so that they can better fit in. In Chapter 6, these desires were shared and appreciated by both Clara and Russel. Other parents and providers witnessed children experience harm as a result of ABA, which was similar to the experiences of both Damon and Kendra. With the emergence of newer forms of ABA provided by therapists such as Dina, parents like Brynn are witnessing the benefits of more relational and person-centred ABA. Yet, newer forms of ABA are

also not without need of scrutiny within the context of ableist capitalist societies that value productive and ‘high’ functioning citizens through a lens of conventional normalcy (Schaber, 2021). Given the evidence presented thus far concerning the lack of adequate supports (e.g., 24-hour care or safe housing), along with the entrenched ableism in ABA-based institutions (e.g., schools, health care, etc., as discussed alongside the stories of Kedra, Damon, and Alex), there is risk that the ‘help’ provided by the ABA industry will continue to operate as institutions of the past “albeit without walls” (Carpenter, 2007, p. 16).

Roscigno (2019) observed that “A successful application of the science of behaviorism allows for the recipient to be made includable in liberal capitalist society” and that some autistic people are viewed as more includable than others (p. 408). Providers such as Provider A noted that ‘higher functioning’ autistic people show more progress, while parents expressed disappointment in the slower progress of their “nonverbal” or “intellectually disabled” children. This focus on normative functioning reflects the reasons that parents are marketed “hope” by the ABA industry (Broderick, 2022) and the reasons some providers are “seduced” into the “biopolitical project” of an industry that promises to improve the functioning levels of autistic children (Roscigno, 2019, p. 405). Until all autistic people are truly valued as citizens in their own right, without pressure to conform to the production-oriented norms of our settler colonialist society, simply replacing ABA with something else will not suffice either. Gentler forms of ABA or alternatives to ABA are just as capable of reproducing oppression when the roots of the problem, namely power, stigma, and constructions of normalcy, are left untouched (Hammond, 2022a). Targeted collective efforts toward resisting the hegemony of developmentalism (Davies et al., 2022) that stifles the development of healthy autistic ways of being in the world (Autistic Collaboration, 2019) are necessary for support programs to truly benefit autistic people.

Chapter 8: Final Thoughts and Future Directions

Through a focus on various perspectives and lived experiences of ABA interventions in Canada, this dissertation study explored key issues related to a) the impacts of ABA services on autistic people's well-being and quality of life (QoL); b) whether ABA services meet the needs of autistic people; c) the ways ableist processes of power and stigma influence experiences with ABA interventions; and d) how diverse autistic expertise can transform autism intervention practices and policy. In regard to the first three items, the analysis revealed that over three quarters (76.5%) of autistic survey respondents did not feel ABA was an effective support model for autistic young people. Parent and ABA provider respondents indicated varied perspectives with proportionately more parents and providers finding ABA to be effective than autistic people themselves. However, less than half of the parent and provider respondents (41.7% and 40.0% respectively) felt ABA was an effective approach and only 20.0% (n=4) of providers felt ABA was an effective method of teaching in schools (see Chapter 4). Chi-square test analyses revealed correlations between various respondent viewpoints (e.g., whether autism is a disorder or neurotype) and perspectives about ABA. Based on this evidence, it is reasonable to conclude that ABA does not meet the needs of many of the autistic people it aims to support, and in some case, it causes harm. Eight in-depth lived experiences revealed nuanced outcomes and perspectives analyzed within the context of ableism in society and the understanding that all respondents want what is best for autistic people.

ABA has become a cog in the wheel of a lucrative autism industry fueled by profit from the tragedy narrative of autism (Broderick & Roscigno, 2021; Dawson, 2004; McGuire, 2013; Milton & Moon, 2012), and it remains the top educational recommendation for autistic children in Ontario. Conventional ABA intervention and education programs follow a one-size-fits all

model that relies on observable behaviour change recorded by non-autistic practitioners and parents. Behavioural approaches such as these do not have a reputation for listening authentically to autistic people (Dawson, 2004; Gates, 2019), nor do they have a reputation for being flexible to the needs of differing autistic experiences (Alderson, 2011; Prizant, 2009; Shyman, 2014). Without evidence of autistic people being included in the goal selection of their ABA interventions, the logical conclusion is that the ABA industry remains the main beneficiary of ABA for autism.

Emancipation from intervention harm for autistic people can only be achieved through educational and therapeutic strategies that are endorsed by autistic people themselves. To do this, it is important to recognize that autistic experiences are not monolithic and it takes many autistic voices to contribute meaning to the varied lived experiences of autism (Autistic Collaboration, 2019). Emancipation from harm further requires collaboration with autistic people in ways that truly transform ableist attitudes, practices and policies and that value autistic expertise regarding matters that affect autistic well-being (Chown et al., 2017; Milton, 2014; Rosqvist et al., 2019).

Co-authored Recommendations for Policy and Practice

Damon, Clara, Russel, and Kendra all shared important recommendations for future practice and policy considerations. The process for creating these recommendations began with discussing them in individual interviews and in follow-up Zoom meetings when creating the audio-visual materials for knowledge dissemination³⁷. The first four recommendations emerged in response to my question, *what recommendations do you have for teachers, ABA practitioners, or autism services?* In February of 2024, I met with each participant a final time to review, edit, and add to the recommendations. During this final meeting, I posed one additional question

³⁷ These materials can be made available for workshop and guest speaking requests. To make a request, send a message to Nancy Marshall on LinkedIn: www.linkedin.com/in/nancy-marshall-ma-cyc-rsw

based on my own recommendation for educators and ABA practitioners, *do you have any other recommendations that may foster feelings of belonging for autistic students?*³⁸

All participants added thoughtful comments based on their own lived experiences and hopes for autistic futures. Each participant worked on these recommendations individually with online support from me via Zoom meetings and email exchanges (e.g., to review/edit their word choices). I thematically organized the recommendations based on key themes expressed by each participant. I then divided each recommendation into five subheadings authored by each participant(s) respectively and labelled by each of their names: 1) Damon: involve autistic people in policy and practice decisions; 2) Clara: be a loving therapist; 3) Russel: create safety in the environment; 4) Kendra: understand what's behind the behaviour; and 5) Everyone: foster feelings of belonging. Proceeding with each recommendation, I added relevant discussion points that I extracted from CAS and inclusive practice literature. Each participant reviewed the final recommendations to edit or add what they felt was necessary once the draft was complete.

Damon: Involve Autistic People in Policy and Practice Decisions

Listen to the reports of autistic people. Listen to people like me. Unfortunately, autistic people, particularly nonspeakers, have not been considered competent enough to participate in government decisions. Access to inclusive education and sensory-friendly communication must be prioritized. Develop social programs in which autistic and non-autistic people learn about each other's ways of thinking and being. For nonspeakers, augmentative and alternative communication (AAC) access is key (Autistic AAC Underground, 2019; see Autistics for Autistics [A4A] Ontario, 2019a; Therapist Neurodiversity Collective, 2020a) with the knowledge that sensory and movement differences are typically the greatest of barriers—not motivation or

³⁸ Grammar errors that do not impede the clarity of the participants' recommendations have been left uncorrected so as to keep the authenticity of voice and writing style.

cognitive function. Any means of communication should take into consideration: movement differences, visual scanning difficulties, initiation difficulties, sensory differences, and anxiety. Being able to fully communicate one's thoughts is the most crucial element of doing well, and in having true autonomy. For example, when my sensory-motor challenges are considered, people around me are more likely to give me time to reason through and respond to age-level academic material, rather than presenting the same (low-level) materials until I am able to answer “correctly” and repetitively within a short response time. When people are aware of my sensory and movement challenges, they're more likely to employ appropriate support strategies for communication, and for accomplishing general motor tasks.

Relying on people who “know and love” the autistic person might not be an accurate measure of what needs to be taught/learned. I believe this is particularly true of nonspeaking autistics who are most likely to be the subjects of Greg Hanley's *Practical Functional Assessment* protocol (see Hanley & Cammilleri, 2021). I believe this protocol will be helpful in mitigating “challenging behaviour” but might not lead to greater feelings of accomplishment for the autistic person if the educator or therapist is still offering low-level academic materials, or asking the autistic individual to participate in programs in which they are standing up, clapping, touching their nose, etc. It is important to remember that low academic expectations and menial tasks can be humiliating for the autistic person.

The following three questions can help teachers and therapists guide their practice:

- Do you understand that sensory and movement challenges often create stress, and lack of body control in nonspeaking individuals?

- Do you assume difficulty with spoken communication automatically reflects a lack of understanding? (I assure you this is rarely the case). Movement difficulties affect communication output.
- Does the autistic individual have a reliable way to communicate what they are thinking? Communication access must take into consideration sensory and motor challenges – including visual scanning.

Discussion. Scholarship and activism from within the field of CAS places emphasis on involving autistic people in the policy, research, and practice decisions that impact their lives. This first recommendation from Damon emphasises the need for ABA practitioners and policy makers to listen to autistic people and presume their competence when it comes to informing the therapy and education practices that involve them. Damon’s recommendations are shared by nonspeaking autistic people around the world who remain misrepresented in autism related media and research due to their divergent and nonnormative communication styles. This misrepresentation of nonspeaking autistic people prompted the creation of the short film, *Listen*, which Damon himself was featured in (see Communication First, 2021). The message of the film and advocacy from nonspeaking autistic people is simple: it is time for society to realize that nonspeaking autistic people “have a contribution to make” (Communication First, 2021, 1:35). Organizations such as the *International Association for Spelling as Communication* (I-ASC) (2023) and *Communication for Education* (2024) offer training in AAC, including multi-modal text-based modes of communication to individuals, to families, educators, and therapists in Canada and all over the world. Recall from Chapter 5 that lived experience stories reveal the ways access to AAC has proven to relieve the distress experienced by many nonspeaking autistic people, making it more effective than ABA for mitigating behaviour that is experienced as

challenging by parents and educators (Chang, 2019; Dixit, 2019; Kedar, 2012). Stories collected in volume such as *Leaders around me: Autobiographies of Autistics Who Type, Point, and Spell to Communicate*, in which nonspeakers such as Nathan Chang (2019), Rohit Dixit (2019), Ido Kedar (2012), and Damon himself share their experiences of the ways AAC has helped them overcome the multitude of barriers in their life, are integral to understanding the ways AAC can enhance wellbeing and QoL. Further information and resources about the importance of AAC are readily available online (e.g., A4A Ontario, 2019a; Therapist Neurodiversity Collective, 2020a).

Presuming competence involves letting go of preconceived notions of intelligence, setting high standards for skill building, and trusting disabled people to understand their own areas of need (Biklen & Burke, 2006; Khumalo, 2019; Kirsebom, 2020; PACY, 2016). Damon's recommendations emphasize the need to trust that nonspeaking autistic people have the ability to formulate and communicate their own thoughts, which, due to stigma and misrepresentations of nonspeaking autistic people, has had to be proven time and again in media and in the literature (e.g., Communication First, 2021; Jaswal et al., 2024; Ngeow et al., 2017; Sedgwick, 2019; Srinivasan, 2018).

Finally, presuming competence means understanding that autistic young people can be intrinsically motivated and self-determined in the same ways neurotypical children can (Everett, 2019; Gardiner, 2019; Kim, 2019; Kohn, 2020). Presuming competence further involves understanding the value of *interdependence* (Baggs, 2021; Schaber, 2021) while nurturing autistic children to become independent in ways that reflect their authentic and self-determined ways of being in the world (Wilkenfeld & McCarthy, 2020).

Clara: Practice with Love and Care

Be a loving therapist because children should be corrected with love. Some children hate to be shouted at, even the rebellious ones who you feel will not listen if you don't shout. You just have to observe the child because people are different and there are other ways to correct a child other than scolding. For example, correcting a child with a smile on your face and making them see the reason why they should not do what they are doing will really help. There was a lady at the centre who was always very nice to me. She liked the point that I was always trying to speak my mind regardless. She liked me for that, and she was telling me that if I continued like this, it would be very helpful. She was the person that was always showering me with love. Whenever I saw her, I just felt relaxed and comfortable. I could talk to her when I was bothered.

There was also a therapist who didn't seem dedicated to her job. So, I perceived that maybe it was not really what she wanted to do, or maybe she had personal issues or things bothering her. I needed her to be more available. She was not always ready to listen to our needs and was always very harsh. She didn't correct with love. It was as if she was forced to do the job and teachers and therapists should love their job. Therapists and teachers should be dedicated because if you love what you do, you are going to give it your all and make the best out of it.

Discussion. The second recommendation from Clara focused on love and caring support and highlights the need for instructional approaches that show genuine care for autistic children without reliance on discipline and control. Clara also highlighted the importance of being dedicated and passionate about supporting autistic young people. As Clara pointed out, ABA practitioners and teachers may experience stress, which can impede their ability to be present and loving toward the autistic people they support. Often, in school settings in particular, training in alternatives to disciplinary approaches “is varied and ineffective” (Alliance Against Seclusion and Restraint, 2022, para. 6). Organizations such as the Alliance Against Seclusion and Restraint

(AASR) offer practical resources (see the Toolkit at Alliance Against Seclusion and Restraint, 2022) to support educators and therapists to unlearn existing biases or misinformation about autism as a result of stigma while learning compassionate approaches to support the distressed students Clara remembered witnessing in her own ABA programs (see Chapter 6). Other resources, such as the new manual *Body and Brain Brilliance* (Desautels, 2024), offer easily digestible infographics that support teachers and therapists to co-create behaviour plans *with* young people by noticing and attending to emotional triggers experienced by both adult and child. Combined with training in sensory and behavioural differences that are unique to autistic children, these approaches can complement advancements in newer forms of autistic-centred ABA (e.g., Hanley, 2021; Mindful Behavior, 2024; Rajaraman et al., 2021) and mitigate the risk of harm that has been caused by traditional behavioural practices.

Russel: Create Safety and Acceptance in the Environment

Create a safe space in the environment—somewhere where these kids can feel love and feel accepted. Sometimes autistic young people like me, like a lot of my friends, get scared of the environment because there are places where, as a kid with such a condition, you don't want to be. You feel mocked. This is when people don't understand you. Some kids get beaten up or attacked by other kids because of their condition—their disability. They feel bad. They really don't want that fear of being laughed at. For autistic kids there is this fear of mixing up with normal kids. It is also very important if teachers could teach autistic kids to face the fear because not everyone is going to get the opportunity to always be with a teacher or someone to protect them.

Encourage autistic kids to reduce their negative behaviours like self-harm. At my younger age, there were times where I felt sad to some point, where I felt like nobody was communicating with me. So sometimes, I always switched to harming myself. It was like I was

being different from every other person. It is important to encourage autistic children so that they can get out of the situation and know that there is more to life. Sometimes you get situations where autistic kids have thoughts about being rejected, which could lead to depression. Depression could get these kids into a situation where they could never be fine again or feel they could never be accepted in society.

Discussion. This third recommendation from Russel extended Clara's important points by highlighting the need for safety and acceptance. Russel emphasized the need for teachers and therapists to focus on what autistic young people are thinking and inform important recommendations to support the confidence and mental health of autistic young people. ABA modalities such as Acceptance and Commitment Therapy (ACT) that include a focus on inner thoughts and emotions are a good start (Dixon et al., 2020; Tarbox et al., 2020). However, as evidenced in Chapters 6 (see Kendra's story) and 7 (see Dina's story), some ACT-based curriculums (e.g., AIM in Action, 2020) risk becoming unintentionally harmful when the focus remains on behaviour change or rewards-based strategies without a deep understanding of needs specific to each student.

Fortunately, mental health support for autistic young people is becoming more available in Canada, although it remains scarce. Researchers such as Jonathan Weiss (2022) in Ontario have developed educational trainings that promote mental health in autistic people with a focus on relevant support that acknowledges the impact of stigma (see Weiss, 2022)³⁹. Weiss's resource offers ways to combine the benefits of ABA mindfulness approaches such as ACT (among several other non-ABA based approaches) with practical strategies (e.g., counselling therapy; autistic peer-mentorship; destigmatization; etc.) to ameliorate autistic distress and mental

³⁹ The webinar pdf can be downloaded here: https://www.autismontario.com/sites/default/files/2020-08/Jonathan%20Weiss_%20Promoting%20Mental%20Health%20in%20Autistic%20People_PPT_EN.pdf

unwellness caused by societal stressors and oppression. New initiatives, such as the collaboration between AASR and the Crisis Prevention Institute (Stephens, 2022), which includes training in the tools and strategies provided by Lori Desautel (2021), further facilitate atmospheres of safety through knowledge of the neuroscience involved in young people's emotional regulation.

Kendra: Understand What Underlies Behaviours

Start by operating under the assumption that the autistic person's feelings make sense. This is a recommendation I make with every parent, every teacher, every therapist, everyone. Even if they don't make sense to you just yet. If we believe their feelings make sense, we enable ourselves to get curious about autistic individuals' internal experiences, and we therefore allow ourselves to a) locate barriers instead of personal flaws and b) embrace autistic interests as helpful, not harmful, to learning. When we validate and get curious about autistic individuals' internal experiences, we enable ourselves to be curious about autistic individuals' internal experiences, and we therefore allow ourselves to depathologize how we view and speak to those experiences (e.g., if we would use neutral or empowering terms like “hobby,” “talent,” or “future career” when we talk about non-autistic students, we shouldn't reduce those to “preferred activities” when we talk about autistic ones). It is important to:

- Locate barriers instead of personal flaws. Is the student having a “temper tantrum”, or is the sensory environment in need of changing? and
- Embrace autistic interests as helpful, not harmful, to learning—and necessary to their well-being as a whole.

Ask yourself:

- a) Is behaviour always “intended?” When we default to rewarding and punishing behaviours, we therefore default to locating issues in intent and motivation (or lack

thereof) to “be good” – *but behaviours and skills are so much more complex than that.*

In taking this approach, we block ourselves from identifying learning disabilities, trauma, hunger, relationships, alternative priorities, stages of development, bad days and plenty more as roots of “bad behaviour” or low marks. In seeking to correct behaviour without first understanding its many complex, layered, dynamic causes, we are distracted from necessary ethical questions about education: who decides what’s “good?” Who benefits from what’s “good?” Is being “good” realistic in this moment for this child? Is it even safe? Is what we call being “good” actually good for the child?

- b) Is being “good” really good? Is “making good eye contact” good for the child who experiences deep sensory overwhelm from eye contact? Is “staying good and still” good for the child whose sensory system requires hand flapping to cope with their environment? Is “good attendance” good for the child who is violently bullied upon attendance? Very importantly, can we expect students to feel safe sharing these experiences if they feel adults only view them through the lens of “being good?”

Discussion. This fourth recommendation from Kendra further builds on what Damon, Clara, and Russel recommended thus far. One barrier to truly understanding what underlies behaviour is the reality that not all self-determined behaviour looks nice, or even safe. Autistic young people experiencing micro-traumas due to chronic invalidation and/or other forms of trauma due to myriad other life experiences, often become overwhelmed within their own nervous systems in ways that lead them to act out and resist ableism in conventionally non-compliant and challenging ways (Gates, 2019). In contrast to this, as Kendra and other participants of this study have pointed out, not all behaviours are intentional. Autistic people

often experience sensory processing differences that are actively more “bottom up” (i.e., from within the body or “body up”) than non-autistic people, which can cause behaviours that are beyond their control (Delahooke, 2019, p. 30). Pete Wharmby (2022), autistic educator and activist, has argued that the challenging behaviour of autistic students should not be viewed as challenging to educators, but rather should be viewed as “...challenging to the structures of the school” (35:35). Wharmby explained that rather than punish autistic students, or force compliance through rewarding conventionally appropriate behaviours, we should first be grateful for their signalling of our systemic failures to provide them with the environmental and relational safety they need to thrive.

Through this fundamental shift in viewing behaviour as a form of resistance versus defiance, it is possible that some behavioural practices, such as rewards and consequences that are already a natural component of childrearing when not performed within rigid behaviour management plan models, can provide safe, restorative, and relationship-building opportunities. For example, Ross Greene’s *Lives in the Balance* approach offers comprehensive evidence-based strategies for educators and parents to support neurodiverse young people through collaborative, proactive, and compassionate alternatives to traditional discipline intended for compliance and control (Greene, 2024). Other resources, such as Mona Delahooke’s (2019) *Beyond Behaviours* and Barry Prizant et al’s (2003) *SCERTS Model*, are grounded in neuroscientific and autistic-centered knowledge that enhance adult-child relationships while remaining focused on the emotional regulation needs that underly behaviours. These models of care work in partnership with the practical tools and strategies that enhance the need for safety and acceptance for autistic young people recommended by Russel.

Most importantly, there are a plethora of neuro-affirming support services, consultations, tools, and strategies provided by organizations led by the experts—autistic people themselves.

These include (but are not limited to):

- *A4A Ontario* (Autistics for Autistics [A4A] Ontario, 2024);
- *AUsome Training* (AUsome Training, 2024);
- *Autism Level UP!* (Laurent & Fede, 2020b);
- *AWN* (Autistic Women & Nonbinary Network, 2024)
- *Freely Divergent* (*Freely Divergent*, 2021)
- *NeuroClastic* (NeuroClastic, 2020)
- *NINE* (Neurodivergent Infinity Network of Educators [NINE], 2023)
- *The FDM Model* (Foundations for Divergent Minds, 2024);

Everyone: Foster Feelings of Belonging

This fifth recommendation consolidates the expert ideas and advice from all four participants. Additionally, in conversations with Russel and Damon I was able to ask their thoughts on including young adult novels, children's books, and literature representing autistic lived experiences and identity in classroom curriculum and school libraries, which are added as additional recommendations at the end of the list.⁴⁰

Damon: Ideally, best practice approaches (for belonging) are ones that take into account the importance of relationships; an understanding of how one's unique neurology relates to feeling safe or unsafe within the worldview that nonspeaking autistic individuals can learn and grow just like anyone else. I believe a helpful example of this approach is Mona Delahooke's

⁴⁰ See Dr. Aaron Richmond's (2024) doctoral thesis titled, *In Their Own Words: The Voices of Disabled First-person Protagonists in Children's and Young Adult Literature*, which inspired this question. Due to several circumstances, I was not able to ask Clara or Kendra their thoughts on autistic representation in literature but hope to follow up with their thoughts in future publications.

book, *Beyond Behaviors* (see Delahooke, 2019). I appreciate the way Dr. Delahooke looks beyond surface behaviors in order to understand strengths and challenges of each individual.

It is through reading, watching, and listening to the lived experiences of many nonspeaking individuals that non-autistic people can learn how to foster feelings of belonging in nonspeaking autistic students. Personally, I am most likely to feel a sense of belonging when the people around me think of me and speak to me as though I am my age, even when I can't communicate in the moment. When the environment is calm, and not too loud or bright, the layers of sensory stress are less overwhelming. Overall, when people are welcoming, with the understanding that I am always doing my best, through challenging sensory environments, and movement difficulties, I am able to participate with the trust that I belong—just like every other student. It is important that I am included in activities because I *do* understand and am interested in what is going on. A book I recommend for educators is Dr. Edlyn Vallejo Pena's (2019) *Communication Alternatives in Autism*.

Clara: I believe therapists and teachers should learn to love their students. Show autistic children kindness and have empathy because if you don't have empathy, you will likely treat people the way they shouldn't be treated. Allow autistic young people to feel safe in the environment and let them be comfortable talking to you. If it is an environment where we have mixed race, I feel there should be an awareness that, irrespective of one's skin colour or race, people should be treated equally. It is very common to prefer a white child over a Black child and it is important to make everyone in the room feel comfortable irrespective of their race and colour. It is important to always learn to love yourself for all you are because if you don't love yourself and value yourself, no one will. That's just the truth.

Russel: One way teachers and ABA practitioners can make autistic young people feel accepted is by creating a more supportive and inclusive environment. This includes the aspect of understanding, respecting autistic children's individual needs, providing a clear means of communication, including their interests into learning activities, and promoting social skills in an inclusive community. I also think it is important that the relationship that is created is created based on them, not on pity. No one wants to be pitied. When relationships are based on pity, I think it makes autistic young people feel that the love isn't genuine; that teachers are just helping because of their condition. No one really loves that.

Kendra: Depathologize different brains openly in the classroom in ways that are normalizing. For example, everyone stims—neurotypical and neurodivergent people. We tap toes, listen to music, take a bath to calm ourselves, etc. Because everyone has different sensory systems, teach *all* kids to meet their sensory needs with music, with fidget toys or items, or by taking a bath (etc.). It is further important to understand autistic brains first—we are bottom-up sensory processors, meaning our brains may involuntarily, and without our consent, try to take in a large amount of sensory information around us and process that information at the same time. This can be overwhelming for autistic people and speaks to the reasons it is so important to have sensory accommodations in the classroom. Without understanding autistic sensory needs in this way, it is difficult to foster genuine atmospheres of belonging.

Nancy: What are your thoughts on including children's books or young adult literature with autistic representation (autistic characters and protagonists) in school curricula?

Russel: Books could be powerful tools for promoting acceptance and understanding among young people. Teachers and ABA practitioners could incorporate books that could feature

autistic characters and incorporate them into the curriculum. I feel these books could help foster empathy, promote good relationships, and facilitate learning and growth in the whole classroom.

Damon: I believe it is crucial that autistic students and their classmates are exposed to books which accurately represent the lived experiences of autistic individuals. As a nonspeaking student, I felt as though I was reading about my own life when I was exposed to (nonspeaking author) Ido Kedar's book, *Ido in Autismland* (see Kedar, 2012). If interested classmates had read about experiences similar to mine, they would have been more likely to think of me and interact with me as though I understood them. Further, if school staff were exposed to such literature, they would have been more likely to grasp that my movement and sensory difficulties were preventing me from reliably communicating and demonstrating my understanding academically. An excellent picture book for younger nonspeaking students and their classmates is, *A Day with No Words*, by Tiffany Hammond (who is a Black, Autistic mother of a nonspeaking, autistic AAC user.)

Future directions

In reference to the autism industry that has profited from the metaphor of autism as a puzzling disorder (McGuire, 2016) that is in need of treatment, Hodge, Douglas and Byrne (2023) observed that:

Strategies such as making a person feel safe and secure in their learning environment, building up an understanding of how and when they learn and developing lessons around what interests and motivates them just do not feel magical enough to be the puzzle solvers that unlock the mysteries of autism (p. 121).

Supporting autistic young people to feel safe, secure, and self-regulated with the confidence to be proudly neurodivergent, with autonomy, is a decolonizing approach that involves removing the

compliance-based focus on disciplining children (Michaelson & Durrant, 2020)—in the form of *both* punishments and rewards (Kohn, 2018)—from our education systems. The patience and time required for this kind of intervention is difficult to practice and measure within fast-paced achievement-focused school environments that view autism (rather than the environment) as the puzzle to be solved. Perhaps the inefficiency of outcomes produced through less compliant-based methods is the reason newer ABA-based interventions (e.g., AIM in Action, 2020; Hanley & Cammilleri, 2021) may continue to reproduce some of the harm caused by operant conditioning methods of the past (see Chapter 6 and 7 for these examples of newer ABA approaches). To quote Alfie Kohn (2018), “Let us be honest when we reward or punish by asking ourselves for whom we are doing it (them or us?) and for what (the development of good values or mere obedience?) (p. 162).

Within Ontario’s sustained “neo-asylum era” (Carpenter, 2007), it is necessary to consider the ways autism education and intervention services can genuinely support autistic and neurodivergent young people to attain their human rights to inclusion and belonging (Hodge et al., 2023). While considering this, it is important to examine whether the field of ABA can actualize its participatory justice-oriented research aims to partner with marginalised communities (Pritchett et al., 2021) or whether it will continue to serve the same discipline and control aims of the past. Autistic researchers have made it clear that they can no longer accept misinformed knowledge production produced through the exclusion of autistic voices (Chown et al., 2017; Milton, 2014; Nicolaidis et al., 2019, 2019; Raymaker & Nicolaidis, 2013; Rosqvist et al., 2019; Shields et al., 2022). Policies such as PPM 140 in Ontario (Ontario Ministry of Education, 2007) which mandate the use of ABA interventions in schools without the inclusion of autistic input on program development or delivery need to be repealed and revised in

collaboration with autistic students themselves. As noted by Freire (1970) pathways to emancipation are paved through efforts to empower those who are oppressed through collective critical reflections that make conscious the impacts of oppression. Thus, providing autistic people with opportunities for critical reflection about the intent of their education program and its relationship to power is integral to autistic wellbeing.

In her chapter, *Toward a Politics of Wonder*, disability scholar, Tanya Titchkosky (2011), called for “recasting problems in new and interesting ways” (p. 130), which involves a collective process of wondering, reflecting, and assessing the ways in which people make meaning of existing problems. By recasting “scientific knowledge as the question of how we make the meaning of people, and how we develop our interrelatedness in social space” (p. 131), Titchkosky argued that a “poetic knowledge” can emerge to disrupt the scientific goal of absolute certainty and move toward transformative access to liberation.

Given the evidence reviewed in this study, it seems that any possible transformation of the field of ABA will need to involve an intentional moving away from the positivist view of behaviour management for the benefit of capitalist and hegemonic societies (Shyman, 2014). Further, for neurodiversity-affirming support to be successful, advocacy efforts must move beyond specific critiques of any one intervention (e.g., ABA) toward a collaborative dismantling of ableist, racist, and compliant based systems as a whole (Hammond, 2022a). Without dismantling of stigma, ableism, and the social relations and ideals embedded within colonial-capitalist structures, any intervention has the potential of harming autistic and neurodivergent young people. As Tiffany Hammond (2022) reminds us, ABA is the leaf of a much bigger problem, and simply taking away ABA does not solve this problem. Calls for a ban on ABA (e.g., Autistic Collaboration, 2022) must include the root of the problem; working together toward

dismantling racism and ableism within autism services, practices, and education is a good place to start.

The overarching conclusion of this study remains steadfast—autistic liberation from harmful behavioural practices relies on patient and authentic engagement with diverse autistic lived-expertise to inform autism research, policy, and practice. Justice-oriented disability and neurodiversity theories, along with an openness to learning from diverse worldviews that place emphasis on accepting the child for who they are regardless of their desire or ability to fully comply with the antiquated industrial and capitalist aims of our school systems (e.g., the more relational worldview of Indigenous cultures), can further support action toward these aims.

Limitations

There are several limitations in need of highlighting. First, the 10 autistic recipients who responded that they felt the ABA interventions they received were effective for them personally but did not choose to elaborate on the reasons why, created a significant gap in analysis. As a result, this study did not produce enough data from positive experiences of ABA to gain insight into the benefits of behavioural interventions for autistic people in Canada. Deeper analysis into the reasons why these respondents decided to complete the survey may have provided more information regarding respondent motivation. Second, the explanatory methods of this study (Teddle & Tashakkori, 2009) did not provide proof nor confirmation of positive or negative impacts of ABA that can be generalized to the wider population of people interacting with ABA services in Canada. Overall, the population sample was small and further research is needed to understand the varied impacts of ABA on autistic wellbeing and QoL. Third, contrary to some mixed methods designs (see study examples in Mertens, 2015), the qualitative results cannot be deemed reflective of each subgroup who answered the surveys because I only chose two

participants for interviews from each group of participants in stage one (autistic people, parents/guardians, and ABA providers). However, given the limited resources available to me as a novice mixed methods researcher, I feel the results from stage two provided a necessary in-depth analysis that would not have been possible had I only completed a single quantitative or qualitative stage of research. The inclusion of therapists and educators in particular fills a gap in the lived experiences of ABA practitioners in research (Gruson-Wood, 2016).

Additionally, due to the constraints of my timeline as a PhD student, the recruitment of interviewees commenced before survey recruitment was closed, which limited the potential to optimize my inclusion criteria. While I remain confident in my purposive sampling decisions, the potential of important missing data, particularly from queer and racialized participants, must be noted. Finally, the parent participants of this study both had similar experiences with white male identifying children who were deemed ‘high functioning’ through diagnoses in the DSM-5 (American Psychiatric Association, 2013), which limited the potential of understanding the experiences of parents with diverse children who have more visible or apparent support needs. Overall, results should be interpreted with an understanding that everyone who interacts with ABA has unique lived experiences.

References

- ABA PBS Controversy Autism Discussion UK. (2020, December 26). *This is how the disgraceful field of ABA uses scaremongering and emotional manipulation to sell ABA* [Online post]. Facebook.
<https://www.facebook.com/ABAUKAutismDiscussion/posts/this-is-how-the-disgraceful-field-of-aba-uses-scaremongering-and-emotional-manip/2927765777501109/>
- Ackley, M., Subramanian, J. W., Moore, J. W., Litten, S., Lundy, M. P., & Bishop, S. K. (2019). A review of language development protocols for individuals with autism. *Journal of Behavioral Education*, 28(3), 362–388. <https://doi.org/10.1007/s10864-019-09327-8>
- Adams, N., & Liang, B. (2020). *Trans and autistic: Stories from life at the intersection*. Jessica Kingsley Publishers.
- Agresti, A. (2018). *Statistical methods for the social sciences*. Pearson Prentice Hall.
- AIM in Action. (2020, September 25). *AIM: Accept-Identify-Move* [Video recording]. Youtube.
<https://www.youtube.com/watch?v=IzqT1NO4DYg>
- Akers, J. S., Davis, T. N., Gerow, S., & Avery, S. (2020). Decreasing motor stereotypy in individuals with autism spectrum disorder: A systematic review. *Research in Autism Spectrum Disorders*, 77, 101611. <https://doi.org/10.1016/j.rasd.2020.101611>
- Alabood, L., Krul, E., Shahidi, A., Jaswal, V. K., Krishnamurthy, D., & Wang, M. (2022). *HoloType-CR: Cross reality communication training for minimally verbal autistic persons*. [Paper presentation]. IEEE International Symposium on Mixed and Augmented Reality Workshops (ISMARW), Singapore. <https://doi.org/10.1109/ISMAR-Adjunct57072.2022.00042>
- Ala'i-Rosales, S., Cihon, J. H., Currier, T. D. R., Ferguson, J. L., Leaf, J. B., Leaf, R., McEachin, J., & Weinkauff, S. M. (2018). The big four: Functional assessment research informs preventative behavior analysis. *Behavior Analysis in Practice*, 12(1), 222–234.
<https://doi.org/10.1007/s40617-018-00291-9>

- Alderson, J. (2011). *Challenging the myths of autism: Unlock new possibilities and hope*. Harper Collins.
- Alexanderstreasuresblog. (2020, January 27). On hurling myself into traffic to get out of ABA therapy. *NeuroClastic*. <https://neuroclastic.com/on-hurling-myself-into-traffic-to-get-out-of-aba-therapy/>
- Allen, L. L., Mellon, L. S., Syed, N., Johnson, J. F., & Bernal, A. J. (2024). Neurodiversity-affirming Applied Behavior Analysis. *Behavior Analysis in Practice*. <https://doi.org/10.1007/s40617-024-00918-0>
- Alliance Against Seclusion and Restraint. (2022, January 19). *Toolkit: The issues*. <https://endseclusion.org/resources/model-legislation-advocacy-toolkit/toolkit-the-issues/>
- Allport, G. W. (1954). *The nature of prejudice*. Addison-Wesley Publishing Company.
- Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., Pillar, S., Uljarević, M., Varcin, K., Wray, J., & Whitehouse, A. J. (2020). The misnomer of “high functioning autism”: Intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism: The International Journal of Research and Practice*, 24(1), 221–232. <https://doi.org/10.1177/1362361319852831>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders [DSM-5-TR]* (5th ed.). American Psychiatric Publishing.
- American Psychological Association [APA]. (2015). *Choosing words for talking about disability*. <https://www.apa.org/pi/disability/resources/choosing-words>
- Anderson, L. K. (2022). Autistic experiences of applied behavior analysis. *Autism*, 27(3), 737–750. <https://doi.org/10.1177/13623613221118216>
- Annamma, S. A., Connor, D., & Ferri, B. (2013). Dis/ability critical race studies (DisCrit): Theorizing at the intersections of race and dis/ability. *Race Ethnicity and Education*, 16(1), 1–31. <https://doi.org/10.1080/13613324.2012.730511>

- Anxiousadvocate. (2015, May 22). Why I left ABA. *Socially Anxious Advocate*.
<https://sociallyanxiousadvocate.wordpress.com/2015/05/22/why-i-left-aba/>
- Arnold, L. (2012). Introduction. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(1).
<http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/ED1>
- art twink [@art_twink]. (2021, April 4). *As an ABA survivor I obviously don't support ABA*. [Tweet]. X. https://twitter.com/art_twink/status/1378765095107497986
- Ashburn, M., & Edwards, J. (2023). *I will die on this hill: Autistic adults, autism parents, and the children who deserve a better world*. Jessica Kingsley Publishers.
- Ask an Autistic. (2019a, July 25). Why professional behavior analysts are leaving the field. *Stop ABA, Support Autistics*. <https://stopabasupportautistics.home.blog/2019/07/25/why-professional-behavior-analysts-are-leaving-the-field/>
- Ask an Autistic. (2019b, August 11). The great big ABA opposition resource list. *Stop ABA, Support Autistics*. <https://stopabasupportautistics.home.blog/2019/08/11/the-great-big-aba-opposition-resource-list/>
- Asperger, H. (1991). 'Autistic psychopathy' in childhood. In U. Frith (Ed.), *Autism and Asperger Syndrome* (pp. 37–92). Cambridge University Press.
<https://doi.org/10.1017/CBO9780511526770.002>
- Association for Behavior Analysis International. (2022). *Contingent electric skin shock (CESS) task force*. <https://www.abainternational.org/about-us/organizational-chart/cess-task-force.aspx?s=03>
- AUsome Training. (2024). *Neuro-affirming resources*. <https://ausometraining.com/resources/>
- Autism Alliance of Canada. (2020). *2020_evidence-based interventions policy compendium*. <https://docs.google.com/document/d/1IMiEZ6GJiAuqPnTKbrlgVGPg1or7OynRVlAKD4teFuI/edit#heading=h.aiki2kspqp4s>

Autism Alliance of Canada. (2022, June 14). *Announcing our new name: Autism Alliance of Canada*. <https://autismalliance.ca/new-name/>

Autism Ontario. (2022, September). *An overview of intervention programs for young autistic children resource list*. <https://www.autismontario.com/sites/default/files/2022-09/Additional%20Resources%20Overview%20of%20Treatments.pdf>

Autistic AAC Underground. (2019, November 1). *There is more to speaking than vocal oral speech*. <https://autisticaacunderground.blogspot.com/2019/11/there-is-more-to-speaking-than-vocal.html>

Autistic Allies. (2018). Testimonials from parents who tried and then rejected ABA for their child. *Autistic Allies*. <http://autisticallies.blogspot.com/2018/05/testimonials-from-parents-who-rejected.html>

Autistic Collaboration. (2019, March 2). *A communal definition of autistic ways of being*. <https://autcollab.org/projects/a-communal-definition-of-autism/>

Autistic Collaboration. (2022, February 16). *Ban of all forms of applied behaviour analysis*. <https://autcollab.org/aba/>

Autistic Self Advocacy Network [ASAN]. (2022). *For whose benefit? Evidence, ethics, and effectiveness of autism interventions*. <https://autisticadvocacy.org/wp-content/uploads/2021/12/ACES-Ethics-of-Intervention.pdf>

Autistic Strategies Network. (2022, April 14). *Nonspeaking autists' experiences of ABA*. <https://autisticstrategies.net/nonspeaking-autistics-against-aba/>

Autistic Women & Nonbinary Network. (2024). *Resource library*. <https://awnnetwork.org/resource-library/>

Autistics for Autistics [A4A] Ontario. (2018, May 24). *Why we oppose ABA in any form*. <https://a4aontario.com/2018/05/24/why-we-oppose-aba-in-any-form/>

- Autistics for Autistics [A4A] Ontario. (2019a, June 23). *From our report and recommendations to the Ontario government: AAC in the early years and school age*.
<https://a4aontario.com/2019/06/23/from-our-report-and-recommendations-to-the-ontario-government-aac-in-the-early-years-and-at-school/>
- Autistics for Autistics [A4A] Ontario. (2019b, December 9). *Bill 160, calling for a ban on seclusion in schools, introduced in Ontario Legislature*.
<https://a4aontario.com/2019/12/09/ontario-legislature-debating-restraint-and-seclusion-in-schools-about-the-new-bill-and-how-you-can-help/>
- Autistics for Autistics [A4A] Ontario. (2023, April 8). *Ban seclusion rooms in Canadian schools*. <https://a4aontario.com/ban-seclusion-rooms-in-canadian-schools/>
- Autistics for Autistics [A4A] Ontario. (2024). *A4A Ontario*. <https://a4aontario.com/>
- AutSciPerson [@AutSciPerson@mstdn.social]. (2021, July 7). *#StopTheShock A primary source, someone who literally went to JRC*. [Tweet]. X.
<https://twitter.com/AutSciPerson/status/1412851439496466438>
- Axe, J. B. (2020, October 13). *Antecedent interventions for challenging behavior* [Presentation]. Lake Ridge Community Support Services, Stone Soup Series, online.
https://www.youtube.com/watch?v=SLdkUn_SYA4
- Baer, D. M., Wolf, M. M., & Risley, T. R. (1968). Some current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis*, 1(1), 91–97.
<https://doi.org/10.1901/jaba.1968.1-91>
- Baer, D. M., Wolf, M. M., & Risley, T. R. (1987). Some still-current dimensions of applied behavior analysis. *Journal of Applied Behavior Analysis*, 20(4), 313–327.
<https://doi.org/10.1901/jaba.1987.20-313>
- Baggs, M. (2021). Ten things I wish my parents had known when I was growing up (S. J. Mounce, Narr.). In E. P. Ballou, S. daVanport, & M. Giwa Onaiwu (Eds.), *Sincerely your autistic child* (Audiobook edition). Beacon Press.

- Barnett, E. (2020, February 6). Pairing: The foundation of ABA therapy. *Attentive Behavior Care*. <https://www.attentivebehavior.com/pairing/>
- Bartlett, N., & Ellis, T. (2021, January 4). Restraining and secluding students with disabilities is an urgent human rights issue. *The Conversation*. <http://theconversation.com/restraining-and-secluding-students-with-disabilities-is-an-urgent-human-rights-issue-141929>
- Bascom, J. (2011, October 5). Quiet Hands. *Just Stimming...*
<https://juststimming.wordpress.com/2011/10/05/quiet-hands/>
- Bascom, J., & Perry, D. M. (2022, January 31). Dividing up the autism spectrum will not end the way you think. *The Nation*. <https://www.thenation.com/article/society/autism-division/>
- Behavior Analyst Certification Board [BACB]. (2023). *Ethics code for Behavior Analysts*.
<https://www.bacb.com/wp-content/uploads/2022/01/Ethics-Code-for-Behavior-Analysts-230119-a.pdf>
- Bell, C. (2006). Introducing white disability studies: A modest proposal. In L. J. Davis (Ed.), *Disability Studies Reader* (2nd ed., pp. 275–283). Routledge.
- Berger, P., & Luckmann, T. (1966). *The social construction of reality a treatise in the sociology of knowledge*. Anchor Books.
- Berne, P. (2015, June 9). Disability justice—A working draft by Patty Berne. *Sins Invalid*.
<https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne>
- Bettin, J., Melnychuk, T., Dexter, Q., Benjamin, S., & Crawley, K. (2021, December 17). *Panel discussion towards a ban of all forms of autistic conversion therapies including ABA: Sixth panel discussion* [Video recording]. Youtube.
https://www.youtube.com/watch?v=P6Jg_W7Q-uM
- Biklen, D. (1990). Communication unbound: Autism and praxis. *Harvard Educational Review*, 60(3), 291–315. <https://doi.org/10.17763/haer.60.3.013h5022862vu732>

- Biklen, D., & Burke, J. (2006). Presuming competence. *Equity & Excellence in Education*, 39(2), 166–175. <https://doi.org/10.1080/10665680500540376>
- Biophily2. (2016, September 20). *B. F. Skinner - Skinner on behaviorism (1977)* [Video recording]. Youtube. <https://www.youtube.com/watch?v=rDi9VdEzpeI>
- Blaxill, M., Rogers, T., & Nevison, C. (2023). Retraction note: Autism tsunami: The impact of rising prevalence on the societal cost of autism in the United States. *Journal of Autism and Developmental Disorders*, 53(8), 3315–3315. <https://doi.org/10.1007/s10803-023-06016-4>
- Blenkush, N. (2017). A risk-benefit analysis of antipsychotic medication and contingent skin shock for the treatment of destructive behaviors. *International Journal of Psychology & Behavior Analysis*, 3(121), 1–14. <https://doi.org/10.15344/2455-3867/2017/121>
- Blenkush, N., O'Neill, D. A., & O'Neill, J. (2023). Contingent electric skin shock: An empirical or ideological issue? *Perspectives on Behavior Science*. <https://doi.org/10.1007/s40614-023-00380-3>
- Bleuler, E. (1950). *Dementia praecox or the group of schizophrenias* (J. Zinkin, Trans.). International Universities Press. <https://philpapers.org/archive/BLEDPO-2.pdf>
- Bonello, C. (2022, March 23). The autistic not weird autism survey. *Autistic Not Weird: Insights from an Autistic Teacher, Author, and Speaker*. <https://autisticnotweird.com/autismsurvey/>
- Boskovic, N. (2018, March 19). Re: Autism Therapy and Treatment. *Niko Boskovic*. <https://nikoboskovic.wordpress.com/2018/03/19/re-autism-therapy-and-treatment/>
- Boskovic, N. (2019). Niko Boskovic. In E. V. Peña (Ed.), *Leaders around me: Autobiographies of autistics who type, point, and spell to communicate*. Independently published.
- Botha, M., Chapman, R., Giwa Onaiwu, M., Kapp, S. K., Stannard Ashley, A., & Walker, N. (2024). The neurodiversity concept was developed collectively: An overdue correction on

- the origins of neurodiversity theory. *Autism*, 28(6), 1591–1594.
<https://doi.org/10.1177/13623613241237871>
- Bottema-Beutel, K., & Crowley, S. (2021). Pervasive undisclosed conflicts of interest in applied behavior analysis autism literature. *Frontiers in Psychology*, 12, 1–7.
<https://doi.org/10.3389/fpsyg.2021.676303>
- Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2020). Adverse event reporting in intervention research for young autistic children. *Autism*, 25(2), 322–335.
<https://doi.org/10.1177/1362361320965331>
- Bottema-Beutel, K., Crowley, S., Sandbank, M., & Woynaroski, T. G. (2021). Research review: Conflicts of Interest (COIs) in autism early intervention research: A meta-analysis of COI influences on intervention effects. *Journal of Child Psychology and Psychiatry*, 62(1), 5–15. <https://doi.org/10.1111/jcpp.13249>
- Bouchillon, N. (2023). *Cavas ABA-art*. <https://www.artbehaviortherapy.com/about>
- Brantlinger, E. A. (2006). Conclusion: Whose labels? Whose norms? Whose needs? Whose benefits? In E. A. Brantlinger (Ed.), *Who benefits from special education? Remediating (fixing) other people's children* (pp. 233–247). Lawrence Erlbaum Associates.
- Brock University Academic Programs. (2024). *Applied Behaviour Analysis (PhD)*. Brock University. <https://brocku.ca/programs/graduate/applied-behaviour-analysis-phd/>
- Broderick, A. A. (2022). *The autism industrial complex: How branding, marketing, and capital investment turned autism into big business* (eBook edition). Myers Education Press.
- Broderick, A. A., & Roscigno, R. (2021). Autism, Inc.: The autism industrial complex. *Journal of Disability Studies in Education*, 2(1), 77–101. <https://doi.org/10.1163/25888803-bja10008>
- Brown, D. (2018, August 27). Self-Reg and DIR/Floortime with Dr. Stuart Shanker. *We Chose Play*. <https://affectautism.com/2018/08/27/self-reg-and-dir/>

- Brown, I., & Radford, J. P. (2015). The growth and decline of institutions for people with developmental disabilities in Ontario: 1876–2009. *Journal on Developmental Disabilities*, 21(2), 7–27. https://oadd.org/wp-content/uploads/2015/01/41021_JoDD_21-2_v23f_7-27_Brown_and_Radford.pdf
- Brown, L. X. Z. (2014, May 14). *Bearing witness, demanding freedom: Judge Rotenberg Center living archive*. <https://autistichoya.net/judge-rotenberg-center/>
- Brown, L. X. Z. (2016). *Disability justice intersection with racial justice and queer/trans liberation*. [Presentation]. Disability Intersectionality Summit. <https://www.disabilityintersectionalitysummit.com/lydia-brown-disability-justice-intersection-with-racial-justice-and-queer-trans-liberation/>
- Brown, L. X. Z. (2017). Introduction: Notes from the field (not the ivory tower). In *All the weight of our dreams: On living racialized autism* (eBook edition, pp. 1–10). DragonBee Press.
- Bucholtz, M. (2000). The politics of transcription. *Journal of Pragmatics*, 32(10), 1439–1465. [https://doi.org/10.1016/S0378-2166\(99\)00094-6](https://doi.org/10.1016/S0378-2166(99)00094-6)
- Burgess, R. (2016, April 4). Understanding the spectrum. *Theorah*. <https://theoraah.tumblr.com/post/148230505212/understanding-the-spectrum>
- Burns, A. (2019, January 14). “High/low-functioning” labels are harmful to autistics. *Learning Disability Today*. <https://www.learningdisabilitytoday.co.uk/why-highlow-functioning-labels-are-hurtful-to-autistic-people>
- Busch, L. (2019a, April 26). Autism is a spectrum. Ignoring this will harm children, adults and families. *Medium*. <https://medium.com/@louisbusch/autism-is-a-spectrum-ignoring-this-will-harm-children-adults-and-families-c34f632349e>
- Busch, L. (2019b, May 30). Evidence-based behavioural treatments for autism as medical necessity. *Medium*. <https://medium.com/@louisbusch/evidence-based-behavioural-treatments-for-autism-as-medical-necessity-d1c736b77171>

- California Association for Behavior Analysis. (2011). *Report of the task force of the California Association for Behavior Analysis: Guidelines for applied behavior analysis (ABA) services*. <https://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/CalABA-TaskForceReport-ABAServiceGuidelines-Mar2011.pdf>
- Callahan, A. E., Sidener, T. M., DeBar, R. M., Deshais, M. A., Pane, H. M., & Patil, P. (2023). Multiple schedules with response interruption and redirection to reduce stereotypy in children with autism spectrum disorder: Generalization and social validity. *Behavioral Interventions*, 38(2), 329–346. <https://doi.org/10.1002/bin.1935>
- Canadian Academy of Health Sciences [CAHS]. (2022). *Autism in Canada: Considerations for future public policy development: Weaving together evidence and lived experience*. <https://cahs-acss.ca/wp-content/uploads/2022/04/CAHS-Autism-in-Canada-Considerations-for-future-public-policy-development.pdf>
- Carey, A. C., Block, P., & Scotch, R. (2020). *Allies and obstacles: Disability activism and parents of children with disabilities*. Temple University Press.
- Carpenter, S. (2007, January 10). Neo-asylum era: Institutions without walls. *Centre for Independent Living Toronto*. <https://www.cilt.ca/wp-content/uploads/2015/12/Neo-Asylum-Era-Institutions-Without-Walls.pdf>
- Cassidy, S. A., Gould, K., Townsend, E., Pelton, M., Robertson, A. E., & Rodgers, J. (2019). Is camouflaging autistic traits associated with suicidal thoughts and behaviours? Expanding the interpersonal psychological theory of suicide in an undergraduate student sample. *Journal of Autism and Developmental Disorders*, 50(10), 3638–3648. <https://doi.org/10.1007/s10803-019-04323-3>
- Cassidy, S., Bradley, L., Shaw, R., & Baron-Cohen, S. (2018). Risk markers for suicidality in autistic adults. *Molecular Autism*, 9. <https://doi.org/10.1186/s13229-018-0226-4>
- Cassidy, S., & Rodgers, J. (2017). Understanding and prevention of suicide in autism. *The Lancet Psychiatry*, 4(6). [https://doi.org/10.1016/S2215-0366\(17\)30162-1](https://doi.org/10.1016/S2215-0366(17)30162-1)

- Cerda, M. (2021, August 10). *Mari Cerda, BCBA....Advocate....Autist – Behavior Science Dissemination* (P. Wright, Interviewer) [Association for Behavior Analysis International]. <https://science.abainternational.org/2021/08/10/mari-cerda-bcba-advocate-autist/>
- Chang, N. (2019). Nathan Chang. In E. V. Peña (Ed.), *Leaders around me: Autobiographies of autistics who type, point, and spell to communicate* (pp. 152–155). Independently published.
- Chapman, R. (2023). *Empire of normality* (eBook edition). Pluto Press.
- Chasson, G. S., Harris, G., & Neely, W. (2007). Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies*, 16(3), 401–413.
http://resolver.scholarsportal.info/resolve/10621024/v16i0003/401_ccoeibsefcwa.xml
- Chen, M. H., Pan, T. L., Lan, W. H., Hsu, J. W., Huang, K. L., Su, T. P., Li, C. T., Lin, W. C., Wei, H. T., Chen, T. J., & Bai, Y. M. (2017). Risk of suicide attempts among adolescents and young adults with Autism Spectrum Disorder: A nationwide longitudinal follow-up study. *The Journal of Clinical Psychiatry*, 78(9), e1174–e1179.
<https://doi.org/10.4088/JCP.16m11100>
- Chomsky, N. (1967). Review of B. F. Skinner's Verbal Behavior. In L. A. Jakobovits & M. S. Miron (Eds.), *Readings in the Psychology of Language* (Vol. 1, pp. 142–143). Prentice-Hall. https://chomsky.info/1967____/
- Chown, N. (2017). *Understanding and evaluating autism theory* (eBook edition). Jessica Kingsley Publishers.
- Chown, N., Hughes, E., Leatherland, J., & Davison, S. (2019). Response to Leaf et al.'s critique of Kupferstein's finding of a possible link between applied behaviour analysis and post-traumatic stress disorder. *Advances in Autism*, 5(4), 318–318.
<https://doi.org/10.1108/AIA-01-2019-0002>

- Chown, N., & Murphy, S. (2022). Social validity in relation to applied behaviour analysis. *Academia Letters*, 4751. <https://doi.org/10.20935/AL4751>
- Chown, N., Murphy, S., & Suckle, E. (2023). The autism worldview dilemma: To normalise or not to normalise, that is the question. *Good Autism Practice*, 24(2), 5–12. <https://doi.org/10.31235/osf.io/musf5>
- Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: A draft framework for inclusive autism research. *Disability & Society*, 32(5), 720–734. <https://doi.org/10.1080/09687599.2017.1320273>
- Clinton, K. (2019). Kaylie Clinton. In E. V. Peña (Ed.), *Leaders around me: Autobiographies of autistics who type, point, and spell to communicate*. Independently published.
- Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics*, 27(2), 145–155.
- Čolić, M., Araiba, S., Lovelace, T. S., & Dababnah, S. (2021). Black caregivers' perspectives on racism in ASD services: Toward culturally responsive ABA practice. *Behavior Analysis in Practice*. <https://doi.org/10.1007/s40617-021-00577-5>
- College of Psychologists of Ontario. (2023, July 25). *Regulations for applied behaviour analysis receive approval, proclamation date announced*. <https://cpo.on.ca/regulations-for-applied-behaviour-analysis-receive-approval-proclamation-date-announced/>
- Collins, H., & Evans, R. (2007). *Rethinking expertise*. University of Chicago Press. <https://press.uchicago.edu/ucp/books/book/chicago/R/bo5485769.html>
- Collis, R. (2019). *Negotiating the meaning of 'evidence based' autistic programming* [Undergraduate Thesis, York University]. <https://drive.google.com/file/d/1RXmdon7eIe5MQBVuu7CUxARiIsxmUk1W/view>

- Collis, R. (2022, May 16). *Learning from violent pasts and presents. A future where we don't hate children*. [Paper presentation]. Canadian Society for the Study of Education, online. <https://drive.google.com/file/d/136zv27jBqpqIKZ54r67i0LZVkjjbpb9X/view>
- Collis, R. (2023). A response to Singer, Lutz, Escher, and Halladay's "a full semantic toolbox is essential for autism research and practice to thrive" in autism research. *Autism Research*, 16(4), 679–680. <https://doi.org/10.1002/aur.2902>
- Communication First. (2021, February 12). *LISTEN Movie* [Film]. Youtube. <https://communicationfirst.org/listen/>
- Communication For Education. (2024). <https://www.communicationforeducation.com>
- Cooper, J., Heron, T., & Heward, W. (2020). *Applied behavior analysis* (3rd edition). Pearson Education.
- Cooper, J., Heron, T., & William, H. (2020). Motivating operations. In *Applied Behavior Analysis* (3rd edition, pp. 412–436). Pearson Education Limited.
- Courchesne, V., Meilleur, A.-A. S., Poulin-Lord, M.-P., Dawson, M., & Soulières, I. (2015). Autistic children at risk of being underestimated: School-based pilot study of a strength-informed assessment. *Molecular Autism*, 6(1), 12. <https://doi.org/10.1186/s13229-015-0006-3>
- Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and conducting mixed methods research* (3rd ed). SAGE.
- Crossley, R., & Remington-Gurney, J. (1992). Getting the words out: Facilitated communication training. *Topics in Language Disorders*, 12(4), 29–45.
- Davies, A., Karmiris, M., & Berman, R. (2022). Contesting the hegemony of developmentalism in pre-service early childhood education and care: Critical discourses and new directions. *Contemporary Issues in Early Childhood*, 23(4), 371–375. <https://doi.org/10.1177/14639491221139065>

- Dawson, M. (2004, January 18). The misbehaviour of behaviourists: Ethical challenges to the autism-ABA industry. *No Autistics Allowed: Explorations in Discrimination Against Autistics*. http://www.sentex.net/~nexus23/naa_aba.html
- Dawson, M., & Fletcher-Watson, S. (2021). When autism researchers disregard harms: A commentary. *Autism*, 1–3. <https://doi.org/10.1177/13623613211031403>
- Dawson, M., Soulières, I., Ann Gernsbacher, M., & Mottron, L. (2007). The level and nature of autistic intelligence. *Psychological Science*, 18(8), 657–662. <https://doi.org/10.1111/j.1467-9280.2007.01954.x>
- Dawson, P. (2021). *On parenting a non-verbal child with autism*. Independently published.
- Decarvalho, R. (1990). A history of the “third force” in psychology. *Journal of Humanistic Psychology*, 30(4), 22–44. <https://doi.org/10.1177/002216789003000403>
- Deci, E. (1971). Effects of externally mediated rewards on intrinsic motivation. *Journal of Personality and Social Psychology*, 18(1), 105–115. <http://dx.doi.org.ezproxy.library.yorku.ca/10.1037/h0030644>
- Delahooke, M. (2019). *Beyond behaviors: Using brain science and compassion to solve children’s behavioral challenges*. PESI Publishers.
- Desautels, L. (2021, January 14). *Templates and lessons*. <https://revelationsineducation.com/free-lesson-plans/>
- Desautels, L. (2024, March 1). *As part of the new manual , “Body and Brain Brilliance”, we have created “Consequence Wheels” addressing administrator, teacher and student* [Online post]. Facebook. <https://www.facebook.com/lori.l.desautels/posts/pfbid0HswWQjd6yDyNy7ngaPQeuftJvJDsCk86bSgd2bJiY9LJwZWWrG8WgHL5RmM7ZNcTl>
- Desautels, L. L. (2020). *Connections over compliance: Rewiring our perceptions of discipline*. Wyatt-MacKenzie Publishing.

- Dike, J. E., DeLucia, E. A., Semones, O., Andrzejewski, T., & McDonnell, C. G. (2022). A systematic review of sexual violence among autistic individuals. *Review Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s40489-022-00310-0>
- Dillenburger, K., & Keenan, M. (2023). No Irish, no behavior analysts, no dogs! *International Electronic Journal of Elementary Education*, 15(3), 199–208.
<https://www.iejee.com/index.php/IEJEE/article/view/2054>
- Dixit, R. (2019). Rohit Dixit: Breaking the barriers. In E. V. Peña (Ed.), *Leaders around me: Autobiographies of autistics who type, point, and spell to communicate* (pp. 6–10). Independently published.
- Dixon, M., Hayes, S. C., Stanley, C., Law, S., & al-Nasser, T. (2020). Is acceptance and commitment training or therapy (ACT) a method that applied behavior analysts can and should use? *The Psychological Record*, 70(4), 559–579. <https://doi.org/10.1007/s40732-020-00436-9>
- Dixon, M., & Paliliunas, D. (2023). *AIM: A behavior analytic curriculum for social-emotional development in children*. Emergent Learning Press.
<https://emergentlearningpress.com/products/aim-a-behavior-analytic-curriculum-for-social-emotional-development-in-children>
- D’Mello, A. M., Frosch, I. R., Li, C. E., Cardinaux, A. L., & Gabrieli, J. D. E. (2022). Exclusion of females in autism research: Empirical evidence for a “leaky” recruitment-to-research pipeline. *Autism Research*, n/a(n/a), 1–12. <https://doi.org/10.1002/aur.2795>
- Do Better Collective. (2023). *Home*. <https://Collective.Dobettermovement.Us/>.
<https://collective.dobettermovement.us/>
- Dolmage, J. (2017). *Academic ableism*. University of Michigan Press.
- Dolmage, J. (2018). *Disabled upon arrival: Eugenics, immigration, and the construction of race and disability*. The Ohio State University Press.

- Durling, J. (2022, June 18). ABA: Inside the controversy surrounding the most popular therapy on autistic children in Ontario. *The Pointer*. <https://thepointer.com/article/2022-06-18/aba-inside-the-controversy-surrounding-the-most-popular-therapy-on-autistic-children-in-ontario>
- Edwards, J. (2021a, April 18). Applied behavior analysis is abusive to native children. *Indian Country Today*. <https://indiancountrytoday.com/opinion/applied-behavior-analysis-is-abusive-to-native-children>
- Edwards, J. (2021b, October 19). *Integrating Indigenous knowledge with modern supports* [Video]. Penn State Educational Equity, Trio Training Academy. <https://www.watch.psu.edu/actuallyautistic/day-one/integrating-indigenous-knowledge.html>
- Ellis, J. (2013). “Inequalities of children in original endowment”: How intelligence testing transformed early special education in a north american city school system. *History of Education Quarterly*, 53(4), 401–429. <https://doi.org/10.1111/hoeq.12035>
- Engelbrecht, N. (2024). Autism assessments. *Embrace Autism*. <https://embrace-autism.com/autism-assessments/>
- Epstein, R. (2019, September 4). How to enroll more ABA clients by overcoming parent objections... without being pushy or salesy. *Internet Archive: Unpack Machine*. <https://web.archive.org/web/20190904141632/http://www.reputationelevation.net/how-to-enroll-more-aba-clients-by-overcoming-parent-objections-without-being-pushy-or-salesy/>
- Erevelles, N. (2000). Educating unruly bodies: Critical pedagogy, disability studies, and the politics of schooling. *Educational Theory*, 50(1), 25–47. <https://doi.org/10.1111/j.1741-5446.2000.00025.x>
- Erevelles, N. (2011). *Disability and difference in global contexts: Enabling a transformative body politic*. Palgrave Macmillan.

- Erevelles, N., Kanga, A., & Middleton, R. (2006). How does it feel to be a problem? Race, disability, and exclusion in educational policy. In E. A. Brantlinger (Ed.), *Who benefits from special education? Remediating (fixing) other people's children* (pp. 77–99). Routledge.
- Everett, R. (2019, July 21). On ABA therapy, self-determination, & healthy psychological development. *NeuroClastic*. <https://neuroclastic.com/2019/07/21/aba-and-self-determination/>
- Falligant, J. M., Chin, M. D., & Kurtz, P. F. (2022). Renewal and resurgence of severe problem behavior in an intensive outpatient setting: Prevalence, magnitude, and implications for practice. *Behavioral Interventions*, 37(3), 909–924. <https://doi.org/10.1002/bin.1878>
- Ferguson, J. L., Cihon, J. H., Leaf, J. B., Van Meter, S. M., McEachin, J., & Leaf, R. (2019). Assessment of social validity trends in the journal of applied behavior analysis. *European Journal of Behavior Analysis*, 20(1), 146–157. <https://doi.org/10.1080/15021149.2018.1534771>
- Flanagan, H. E., Perry, A., & Freeman, N. L. (2012). Effectiveness of large-scale community-based intensive behavioral intervention: A waitlist comparison study exploring outcomes and predictors. *Research in Autism Spectrum Disorders*, 6(2), 673–682. <https://doi.org/10.1016/j.rasd.2011.09.011>
- Flynn, J. (2018, July 22). Why autism functioning labels are harmful—And what to say instead. *The Mighty*. <https://themighty.com/2018/07/autism-functioning-labels-low-functioning-high-functioning/>
- Forsythe, A., Pick, C., Tremblay, G., Malaviya, S., Green, A., & Sandman, K. (2022). Humanistic and economic burden of conversion therapy among LGBTQ youths in the united states. *JAMA Pediatrics*, 176(5), 493–501. <https://doi.org/10.1001/jamapediatrics.2022.0042>
- Foucault, M. (1973). *The birth of the clinic: An archaeology of medical perception*. Routledge. <http://site.ebrary.com/id/10639215>

- Foucault, M. (1980). *The history of sexuality: An introduction*. Vintage.
- Foucault, M. (1995). *Discipline and punish: The birth of the prison*. Vintage.
- Foucault, M. (2007). *Security, territory, population: Lectures at the College de France, 1977-78*. Springer.
- Foundations for Divergent Minds. (2024). *About us*. <https://divergentminds.org/about>
- Freely Divergent*. (2021, August 19). <https://www.freelydivergent.com/>
- Freeman, M. (1999). Children are unbeatable. *Children & Society*, 13(2), 130–141.
[https://doi.org/10.1002/\(SICI\)1099-0860\(199904\)13:2<130::AID-CHI542>3.0.CO;2-Z](https://doi.org/10.1002/(SICI)1099-0860(199904)13:2<130::AID-CHI542>3.0.CO;2-Z)
- Freeman, N., & Perry, A. (2010). Outcomes of intensive behavioural intervention in the Toronto preschool autism service. *Journal on Developmental Disabilities; Toronto*, 16(2), 17–32.
<https://search.proquest.com/docview/817394664/citation/4F1E6E7EA4564CC1PQ/1>
- Freire, P. (with Macedo, D., & Shor, I.). (1970). *Pedagogy of the oppressed: 50th anniversary edition* (M. B. Ramos, Trans.; eBook edition). Bloomsbury Publishing.
- French, L., & Kennedy, E. M. M. (2018). Annual research review: Early intervention for infants and young children with, or at-risk of, autism spectrum disorder: A systematic review. *Journal of Child Psychology and Psychiatry*, 59(4), 444–456.
<https://doi.org/10.1111/jcpp.12828>
- Fry, E. (2022, July 29). How a private equity “money grab” has reshaped autism therapy. *Fortune*. <https://fortune.com/2022/07/29/autism-therapy-care-centers-private-equity-hopebridge/>
- Gardiner, F. (2019). *First-Hand perspectives on behavioral interventions for autistic people and people with other developmental disabilities*. Office of Developmental Primary Care Department of Family and Community Medicine University of California and Autistic Self Advocacy Network. <https://autisticadvocacy.org/wp-content/uploads/2017/07/First->

Hand-Perspectives-on-Behavioral-Interventions-for-Autistic-People-and-People-with-other-Developmental-Disabilities.pdf

Gardiner, F. (2023, March 27). “A catalyst for activism”: Talking with Finn Gardiner from the autistic people of color fund (A. Borden King, Interviewer) [Audio podcast episode]. In *Noncompliant Podcast*. <https://noncompliantpodcast.com/2023/03/27/a-catalyst-for-activism-talking-with-finn-gardiner-from-the-autistic-people-of-color-fund/>

Gates, G. (2019). *Trauma, stigma, and autism: Developing resilience and loosening the grip of shame*. [eBook edition]. Jessica Kingsley Publishers.

Geneva Centre for Autism. (2019). *ABA for educators level II: Practical applications of reinforcement and prompting in the classroom*.
https://courses.sonderly.io/course_/t22110/s22298-aba-for-educators-level-ii--reinforcing-and-prompting

Gibson, M. F., & Douglas, P. (2018). Disturbing behaviours: Ole Ivar Lovaas and the queer history of autism science. *Catalyst: Feminism, Theory, Technoscience*, 4(2), 1–28.
<https://doi.org/10.28968/cftt.v4i2.29579>

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose expertise is it? Evidence for autistic adults as critical autism experts. *Frontiers in Psychology*, 8. <https://doi.org/10.3389/fpsyg.2017.00438>

Giwa Onaiwu, M. (2017). Preface: Autistics of color: We exist... We matter. In *All the weight of our dreams: On living racialized autism* (eBook edition). DragonBee Press.

Giwa Onaiwu, M. (2020). “They don’t know, don’t show, or don’t care”: Autism’s white privilege problem. *Autism in Adulthood*, 2(4), 270–272.
<https://doi.org/10.1089/aut.2020.0077>

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Penguin.

Gould, S. J. (1996). *The mismeasure of man*. Norton & Co.

- Government of Canada. (2021, November 29). *Proposed changes to Canada's Criminal Code relating to conversion therapy*. <https://www.justice.gc.ca/eng/csj-sjc/pl/ct-tc/index.html>
- Greene, R. W. (2018). Transforming school discipline: Shifting from power and control to collaboration and problem solving. *Childhood Education*, 94(4), 22–27.
<https://doi.org/10.1080/00094056.2018.1494430>
- Greene, R. W. (2024). *Helping your most difficult students starts here*. Lives in the Balance.
<https://livesinthebalance.org/educators-schools/>
- Gresham, F. M., & MacMillan, D. L. (1998). Early intervention project: Can its claims be substantiated and its effects replicated? *Journal of Autism and Developmental Disorders*, 28(1), 5–13. <https://doi.org/10.1023/A:1026002717402>
- Grinker, R. R. (2018). Who owns autism? Economics, fetishism, and stakeholders. In E. Fein & C. Rios (Eds.), *Autism in translation: An intercultural conversation on autism spectrum conditions*. Palgrave Macmillan.
- Grinker, R. R. (2020). Autism, “stigma,” disability: A shifting historical terrain. *Current Anthropology*, 61(S21), S55–S67. <https://doi.org/10.1086/705748>
- Gruson-Wood, J. F. (2016). Autism, expert discourses, and subjectification: A critical examination of applied behavioural therapies. *Studies in Social Justice*, 10(1), 38–58.
<https://doi.org/10.26522/ssj.v10i1.1331>
- Gubrium, J. F., & Holstein, J. A. (2002). *Handbook of interview research: Context & method*. Sage Publications.
- Habib, D. (2018, August 7). *Intelligent lives* [Film]. Like Right Now Films.
<https://intelligentlives.org/trailer>
- Hammond, T. (2022a, January 19). Autistic voices: This was never about ABA [Facebook]. *The Kisha Project*. <https://thekishaproject.com/aba/>

- Hammond, T. (2022b, September 9). Episode 45—Autistic advocacy with Tiffany Hammond of Fidgets & Fries (B. Reiman, Interviewer) [Audio podcast episode]. In *The Behaviour Speak Podcast*. <https://www.behaviourspeak.com/e/episode-45-advocating-for-systemic-change-with-tiffany-hammond-of-fidgets-fries/>
- Hanley, G. (2015, November 23). *Experiences of BCBA practitioners* [Video recording]. Practical Functional Assessment. <https://practicalfunctionalassessment.com/2015/11/23/experiences-of-bcba-practitioners/>
- Hanley, G. (2021, September 9). A perspective on today's ABA from Dr. Hanley. *Practical Functional Assessment: Understanding Problem Behavior Prior to Its Treatment*. <https://practicalfunctionalassessment.com/2021/09/09/a-perspective-on-todays-aba-by-dr-greg-hanley/>
- Hanley, G., & Cammilleri, A. (2021). *Practical functional assessment*. Practical Functional Assessment. <https://practicalfunctionalassessment.com/>
- Hanley, G., Jin, C. S., Vanselow, N. R., & Hanratty, L. A. (2014). Producing meaningful improvements in problem behavior of children with autism via synthesized analyses and treatments. *Journal of Applied Behavior Analysis*, 47(1), 16–36. <https://doi.org/10.1002/jaba.106>
- Hanley, G., Piazza, C. C., Fisher, W. W., & Maglieri, K. A. (2005). On the effectiveness of and preference for punishment and extinction components of function-based interventions. *Journal of Applied Behavior Analysis*, 38(1), 51–65. <https://doi.org/10.1901/jaba.2005.6-04>
- Harris, R. (2007). *The happiness trap: How to stop struggling and start living* (eBook edition). Exisle Publishing.
- Hayes, N. (1995). The influence of behaviourism. In N. Hayes (Ed.), *Psychology in perspective* (pp. 19–33). Macmillan Education UK. https://doi.org/10.1007/978-1-349-23862-0_2

- Hayes, S. C., Bond, F. W., Barnes-Holmes, D., & Austin, J. (Eds.). (2006). *Acceptance and mindfulness at work: Applying acceptance and commitment therapy and relational frame theory to organizational behavior management*. Routledge.
- Higashida, N. (2016). *The reason I jump: The inner voice of a thirteen-year-old boy with autism*. Random House.
- Hodge, N., Douglas, P., & Byrne, B. (2023). Developing the right(s) approach for autism. In A. E. Beckett & A.-M. Callus (Eds.), *Routledge international handbook of children's rights and disability* (pp. 113–128). Routledge.
- Holehan, K., & Zane, T. (2020). Is there science behind that? Facilitated communication. *Association for Science in Autism Treatment*. <https://asatonline.org/for-parents/becoming-a-savvy-consumer/is-there-science-behind-that-facilitated-communication/>
- Howard, J. S., Stanislaw, H., Green, G., Sparkman, C. R., & Cohen, H. G. (2014). Comparison of behavior analytic and eclectic early interventions for young children with autism after three years. *Research in Developmental Disabilities*, 35(12), 3326–3344. <https://doi.org/10.1016/j.ridd.2014.08.021>
- Hume, K., Steinbrenner, J. R., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yücesoy-Özkan, S., & Savage, M. N. (2021). Evidence-based practices for children, youth, and young adults with autism: Third generation review. *Journal of Autism and Developmental Disorders*, 51(11), 4013–4032. <https://doi.org/10.1007/s10803-020-04844-2>
- Husserl, E. (1970). *The idea of phenomenology*. Martinus Nijhoff.
- International Association for Spelling as Communication (I-ASC). (2019). *Nonspeakers and spellers stories*. <https://I-Asc.Org/>. <https://i-asc.org/about-us/speller-stories/>
- International Association for Spelling as Communication (I-ASC). (2023). *Who we are*. <https://i-asc.org/>

- Israel, M. L., Blenkush, N. A., von Heyn, R. E., & Rivera, P. M. (2008). Treatment of aggression with behavioral programming that includes supplementary contingent skin-shock. *The Journal of Behavior Analysis of Offender and Victim Treatment and Prevention*, 1(4), 119–166. <https://doi.org/10.1037/h0100460>
- Jacobson, J., Mulick, J., & Green, G. (1998). Cost–benefit estimates for early intensive behavioral intervention for young children with autism—General model and single state case. *Behavioral Interventions*, 13, 201–226.
- Jaswal, V. K., Lampi, A. J., & Stockwell, K. M. (2024). Literacy in nonspeaking autistic people. *Autism*, 1–12. <https://doi.org/10.1177/13623613241230709>
- Jaswal, V. K., Wayne, A., & Golino, H. (2020). Eye-tracking reveals agency in assisted autistic communication | Scientific Reports. *Scientific Reports*, 10(7882). <https://www.nature.com/articles/s41598-020-64553-9>
- Jaye, T. (2021, June 12). “But what about the autistic people who support ABA?” *Taryn Is Autistic*. <https://tarynisautistic.ca/2021/06/12/but-what-about-the-autistic-people-who-support-aba/>
- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250. <https://doi.org/TBD>
- Kapp, S. K. (Ed.). (2020). *Autistic community and the neurodiversity movement: Stories from the frontline*. Palgrave Macmillan.
- Kapp, S. K., Steward, R., Crane, L., Elliott, D., Elphick, C., Pellicano, E., & Russell, G. (2019). ‘People should be allowed to do what they like’: Autistic adults’ views and experiences of stimming. *Autism*, 23(7), 1782–1792. <https://doi.org/10.1177/1362361319829628>
- Kavchak, A. (2020). *The fight for autism treatment in Canada—Reflections of a parent activist*. Independently published.
- Kayleen. (2019, May 28). 5 important reasons even “new ABA” is problematic & hurts autistics. *Autistic Mama*. <https://autisticmama.com/even-new-aba-is-problematic/>

- Keating, C. T., Hickman, L., Geelhand, P., Takahashi, T., Schuster, B., Rybicki, A., Girolamo, T., Clin, E., Papastamou, F., Belenger, M., Eigsti, I.-M., Cook, J., & Sowden, S. (2024). Cross-cultural variation in experiences of acceptance, camouflaging and mental health difficulties in autism: A registered report. *PsyArXiv Preprints*.
<https://doi.org/10.31234/osf.io/gmdxu>
- Kedar, I. (2012). *Ido in autismland: Climbing out of autism's silent prison*. Independently published.
- Khumalo, A. (2019, September 29). Presumption of competence. *Akha Khumalo: In My Own Words*. <https://akhaswords.home.blog/2019/09/29/presumption-of-competence/>
- Kim, C. (2013). Autistic women: Misdiagnosis and the importance of getting it right. *Autistic Women & Nonbinary Network (AWN)*. <https://awnnetwork.org/autistic-women-misdiagnosis-and-the-importance-of-getting-it-right/>
- Kim, S. Y. (2019). The experiences of adults with autism spectrum disorder: Self-determination and quality of life. *Research in Autism Spectrum Disorders*, 60, 1–15.
<https://doi.org/10.1016/j.rasd.2018.12.002>
- King, A. B. (2020). *2020 has not been a good year for ABA: A research review*.
<https://a4aontario.com/wp-content/uploads/2020/12/ABA-Research-Review-2020.pdf>
- Kirsebom, D., (2020, November 15). *Reframing "Severe" Autism* [Video recording]. Youtube.
<https://www.youtube.com/watch?v=CtK9paFGUjc>
- Klass, P. (2020, January 6). Early treatment for autism is critical, new report says. *The New York Times*. <https://www.nytimes.com/2020/01/06/well/family/early-treatment-for-autism-is-critical-new-report-says.html>
- Kohn, A. (2018). *Punished by rewards*. Mariner Books.
- Kohn, A. (2020, January 21). *Autism and behaviorism*. <https://www.alfiekohn.org/blogs/autism/>

- Kolu, C. (2021a, August 26). 25 things I want you to know: Ways I use trauma to inform my practice of behavior analysis. *Cusp Emergence*.
<https://cuspemergence.com/2021/08/26/25-things-i-want-you-to-know-ways-i-use-trauma-to-inform-my-practice-of-behavior-analysis/>
- Kolu, C. (2021b, October 11). Get ready to learn about ASD and trauma. *Cusp Emergence*.
<https://cuspemergence.com/2021/10/11/get-ready-to-learn-about-asd-and-trauma/>
- Koudys, J., Perry, A., Ho, H., & Charles, M. (2018). Psychosocial outcomes in adolescents with autism who received intensive behavioural intervention as young children. *Journal on Developmental Disabilities*, 23(2), 85.
- Krishnamurthy, D., Jaswal, V., Nazari, A., Shahidi, A., Subbaraman, P., & Wang, M. (2022). *Holotype: Lived experience based communication training for nonspeaking autistic people*. [Paper presentation]. CHI Conference on Human Factors in Computing Systems Extended Abstracts, New Orleans. <https://doi.org/10.1145/3491101.3519869>
- Kubina, R. & Kostewicz, D. (2021, April 29). *ABA on call: Season 3 episode 20 - What does the science of behavior say about free will?* [Youtube episode]. In *ABA On Call*.
<https://www.youtube.com/watch?v=fJ2QBw9CXyQ>
- Kupferstein, H. (2016, July 25). *Autistic aba survivors grow into soul-crushed teenagers: Tracing the roots of the damage*. <https://henryk.com/2016/07/25/autistic-aba-survivors-grow-into-soul-crushed-teenagers-tracing-the-roots-of-the-damage/>
- Kupferstein, H. (2018). Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis. *Advances in Autism*, 4(1), 19–29. <https://doi.org/10.1108/AIA-08-2017-0016>
- Kupferstein, H. (2019). Why caregivers discontinue applied behavior analysis (ABA) and choose communication-based autism interventions. *Advances in Autism*, 6(1), 72–80.
<https://doi.org/10.1108/AIA-02-2019-0004>
- Kupferstein, H. (2023, December 9). Critique of compassion as a “dimension” of applied behavior analysis (ABA) [Online newsletter]. LinkedIn.

- <https://www.linkedin.com/pulse/critique-compassion-dimension-applied-behavior-aba-henny-cdvqc/>
- Lamb, E. (2019, January 6). A balanced view on ABA therapy, by an autistic adult. *The Autism Cafe*. <https://theautismcafe.com/a-balanced-view-on-aba-therapy-by-an-autistic-adult/>
- Langthorne, P., & McGill, P. (2009). A tutorial on the concept of the motivating operation and its importance to application. *Behavior Analysis in Practice*, 2(2), 22–31.
<https://doi.org/10.1007/BF03391745>
- Larsson, E. (2012, March 20). *The cost of autism and the cost-effectiveness of ABA and EIBI - early intensive behavioral intervention*.
<https://www.whatdotheyknow.com/request/210877/response/525530/attach/9/Annex%20A%20Larsson%202012%20The%20Costs%20of%20Autism.pdf>
- Larsson, E. [@evlarsson]. (2014, February 15). *The Lovaas study—A 2002 followup report by BBC Newsnight* [Video recording]. Youtube.
<https://www.youtube.com/watch?v=8RFvY8Un0vM>
- Latif, S. (2016). The ethics and consequences of making autism spectrum diagnoses. In K. Runswick-Cole, R. Mallett, & S. Timimi (Eds.), *Rethinking autism: Diagnosis, identity and equality* (eBook edition, pp. 288–298). Jessica Kingsley Publishers.
- Latimer, O. (2022, August 30). *I am 100% against ABA* [Online post]. Facebook.
<https://www.facebook.com/OGLatimer/posts/pfbid02srt2YkrYMPtNFEHNwdfAxbjw48Bm245pTALLr4Fa2yuWF4CFeyYQ3nXswL8xG5Jl>
- Laurent, A. C., & Fede, J. (2020a). Leveling up regulatory support through community collaboration. *Perspectives of the ASHA Special Interest Groups*, 6(2), 288–305.
https://doi.org/10.1044/2020_PERSP-20-00197
- Laurent, A. C., & Fede, J. (2020b). *Autism level up!* <https://www.autismlevelup.com/#tools>
- Layle, P. (2022, April 2). *Paige learned this in therapy: ACT for depression* [Video recording]. Youtube. <https://www.youtube.com/watch?v=31bA4HTKcgI>

- Leaf, J. B., Cihon, J. H., Ferguson, J. L., Milne, C. M., Leaf, R., & McEachin, J. (2020). Advances in our understanding of behavioral intervention: 1980 to 2020 for individuals diagnosed with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-020-04481-9>
- Leaf, J. B., Cihon, J. H., Javed, A., Klick, S., Ferguson, J. L., Milne, C., Creem, A., Arthur, S., Saunders, M., S., Olive, M. L., Ross, R. K., Leaf, R., & McEachin, J. (2022). A call for discussion on stereotypic behavior. *European Journal of Behavior Analysis*, 1–25. <https://doi.org/10.1080/15021149.2022.2112810>
- Leaf, J. B., Cihon, J. H., Leaf, R., McEachin, J., Liu, N., Russell, N., Unumb, L., Shapiro, S., & Khosrowshahi, D. (2021). Concerns about ABA-based intervention: An evaluation and recommendations. *Journal of Autism and Developmental Disorders*, 52(6), 2838–2853. <https://doi.org/10.1007/s10803-021-05137-y>
- Leaf, J. B., Leaf, R., McEachin, J., Taubman, M., Ala'i-Rosales, S., Ross, R. K., Smith, T., & Weiss, M. J. (2016). Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders*, 46(2), 720–731. <http://link.gale.com/apps/doc/A442892508/AONE?sid=bookmark-AONE&xid=1f4916cd>
- Leaf, J. B., Ross, R. K., Cihon, J. H., & Weiss, M. J. (2018). Evaluating Kupferstein's claims of the relationship of behavioral intervention to PTSS for individuals with autism. *Advances in Autism*, 4(3), 122–129. <https://doi.org/10.1108/AIA-02-2018-0007>
- Lepper, M. R., & Greene, D. (2015). *The hidden costs of reward: New perspectives on the psychology of human motivation*. Psychology Press.
- Lewis, C., Joseph, T., Hammond, T. (2022, April 7). *ABA, advocacy, and intersections*. [Presentation]. NJ Autism Center of Excellence, online. <https://www.youtube.com/watch?v=eZSq1vj4O5Q>
- LIFE Magazine. (1965, May 7). Screams, slaps, and love. *LIFE Magazine*. <https://bpb-us-e1.wpmucdn.com/blogs.uoregon.edu/dist/d/16656/files/2018/11/Screams-Slaps-and-Love-Life-Magazine-13javg3.pdf>

- Lovaas, I. (1974). *Ivar Lovaas interview with Paul Chance* (P. Chance, Interviewer). *Psychology Today*. http://neurodiversity.com/library_chance_1974.html
- Lovaas, I. (1981). *Teaching developmentally disabled children: The me book*. Pro-Ed.
- Lovaas, I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Counselling and Clinical Psychology*, 55(1), 3–9.
- Lovaas, I., & Smith, T. (1989). A comprehensive behavioral theory of autistic children: Paradigm for research and treatment. *Journal of Behavior Therapy and Experimental Psychiatry*, 20(1), 17–29. [https://doi.org/10.1016/0005-7916\(89\)90004-9](https://doi.org/10.1016/0005-7916(89)90004-9)
- Lynch, C. L. (2019, March 28). Invisible abuse: ABA and the things only autistic people can see. *NeuroClastic*. <https://neuroclastic.com/2019/03/28/invisible-abuse-aba-and-the-things-only-autistic-people-can-see/>
- Mallett, R., & Runswick-Cole, K. (2016). The commodification of autism: What's at stake? In K. Runswick-Cole, R. Mallett, & S. Timimi (Eds.), *Re-thinking autism: Diagnosis, identity and equality* (eBook edition, pp. 110–131). Jessica Kingsly Publishers.
- Mantzoros, T., Lee, D. L., Ajemigbitse, A. R., & Stover, L. J. (2023). Implementing a differential reinforcement of low rates schedule to alter vocal stereotypy and task engagement in two adolescents with autism spectrum disorder. *Behavioral Interventions*, 38(3), 689–705. <https://doi.org/10.1002/bin.1948>
- Marshall, N., Wilton, F., & Weinroth, S. (2018). It's our turn! Autistic young people inform praxis and policy. *Relational Child and Youth Care Practice*, 31(2), 36–51.
- Mathur, S. K., Renz, E., & Tarbox, J. (2024). Affirming neurodiversity within applied behavior analysis. *Behavior Analysis in Practice*, 17, 471–485. <https://doi.org/10.1007/s40617-024-00907-3>
- Matson, J. L. (Ed.). (2023). *Handbook of applied behavior analysis: Integrating research into practice*. Springer.

- McDonald, M. (2020). A prophetic call to churches in Canada. In V. E. Michaelson & J. E. Durrant (Eds.), *Decolonizing discipline: Children, corpora punishment, Christian theologies, and reconciliation* (pp. 17–22). University of Manitoba Press.
- McFadden, C., Monahan, K., & Kaplan, A. (2021, April 28). The FDA banned a form of shock treatment. But it's still in use. *NBC News*. <https://www.nbcnews.com/health/health-care/decades-long-fight-over-electric-shock-treatment-led-fda-ban-n1265546>
- McGill, O., & Robinson, A. (2020). “Recalling hidden harms”: Autistic experiences of childhood applied behavioural analysis (ABA). *Advances in Autism*, 7(4), 269–282. <https://doi.org/10.1108/AIA-04-2020-0025>
- McGlade, A., Whittingham, K., Barfoot, J., Taylor, L., & Boyd, R. N. (2023). Efficacy of very early interventions on neurodevelopmental outcomes for infants and toddlers at increased likelihood of or diagnosed with autism: A systematic review and meta-analysis. *Autism Research*, 16(6), 1145–1160. <https://doi.org/10.1002/aur.2924>
- McGuire, A. (2013). Buying time: The space of advocacy and the cultural production of autism. *Canadian Journal of Disability Studies*, 2(3), Article 3. <https://doi.org/10.15353/cjds.v2i3.102>
- McGuire, A. (2016). *War on Autism: On the Cultural Logic of Normative Violence*. University of Michigan Press.
- McHugh, C. L. (2019). *A comparison of modified food chaining and simultaneous presentation plus nonremoval of the spoon to treat food selectivity in children with autism spectrum disorder* [Master of Arts Major Research Paper, Brock University]. <https://dr.library.brocku.ca/handle/10464/14085>
- Mead Jasperse, S. C., Iwata, B. A., & Topham, K. H. (2023). Problem behavior maintained by a precurrent relation. *Behavioral Interventions*, 38(1), 283–289. <https://doi.org/10.1002/bin.1908>
- Melnyczuk, T. (2019, April 11). *Non-speaking autists' thoughts on ABA* · Tania Melnyczuk. <https://tania.co.za/non-speaking-autistics-thoughts-on-aba/>

- Memmott, A. (2023, January 22). Ethics and autism: Rights and responsibilities within Applied Behaviour Analysis. *Ann's Autism Blog*. <http://annsautism.blogspot.com/2023/01/ethics-and-autism-rights-and.html>
- Mertens, D. M. (2009). *Transformative research and evaluation*. The Guilford Press.
- Mertens, D. M. (2015). *Research and evaluation in education and psychology: Integrating diversity with quantitative, qualitative, and mixed methods* (4th edition). SAGE Publications, Inc.
- Mertens, D. M., Bledsoe, K. L., Sullivan, M., & Wilson, A. (2015). Utilization of mixed methods for transformative purposes. In A. Tashakkori & C. Teddlie (Eds.), *SAGE Handbook of Mixed Methods in Social & Behavioral Research* (pp. 193–214). SAGE Publications. <https://doi.org/10.4135/9781506335193.n8>
- Michaelson, V. E., & Durrant, J. E. (2020). Introduction. In V. E. Michaelson & J. E. Durrant (Eds.), *Decolonizing discipline: Children, corporal punishment, Christian theologies, and reconciliation*. University of Manitoba Press.
- Millman, C. (2019, March 27). Is ABA really “dog training for children”? A professional dog trainer weighs in. *NeuroClastic*. <https://neuroclastic.com/is-aba-really-dog-training-for-children-a-professional-dog-trainer-weighs-in/>
- Milne, C., Leaf, J. A., Leaf, J. B., Cihon, J. H., Torres, N., Townley-Cochran, D., Taubman, M., Leaf, R., McEachin, J., & Oppeheim-Leaf, M. (2017). Teaching joint attention and peer to peer communication using the cool versus not cool procedure in a large group setting. *Journal of Developmental and Physical Disabilities*, 29(5), 777–796. <https://doi.org/10.1007/s10882-017-9556-y>
- Milton, D. (2012). On the ontological status of autism: The ‘double empathy problem.’ *Disability & Society*, 27(6), 883–887. <https://doi.org/10.1080/09687599.2012.710008>
- Milton, D. (2014). Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, 18(7), 794–802. <https://doi.org/10.1177/1362361314525281>

- Milton, D., & Moon, L. (2012). The normalisation agenda and the psycho-emotional disablement of autistic people. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(1). <http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR3>
- Milton, D., Waldock, K. E., & Keates, N. (2023). Autism and the ‘double empathy problem.’ In F. Mezzenzana & D. Peluso (Eds.), *Conversations on empathy: Interdisciplinary perspectives on imagination and radical othering* (pp. 78–97). Routledge.
- Mindful Behavior. (2022). *Meet our service providers*. <https://mindfulbehaviorllc.org/our-team/>
- Mindful Behavior. (2024). *Who we are*. <https://mindfulbehaviorllc.org/about-us/>
- Mitchell, D. (2015). *Education that Fits: Review of international trends in the education of students with special education needs: Second edition*. University Of Canterbury. https://www.education.vic.gov.au/Documents/about/department/psdlitreview_Educationthatfits.pdf
- Mitchell, D. T., & Snyder, S. L. (2015). *The biopolitics of disability: Neoliberalism, ablenationalism, and peripheral embodiment*. University of Michigan Press.
- Mitteer, D. R., Greer, B. D., Randall, K. R., & Haney, S. D. (2022). On the scope and characteristics of relapse when treating severe destructive behavior. *Journal of Applied Behavior Analysis*, 55(2), 688–703. <https://doi.org/10.1002/jaba.912>
- Morris, D. (2018, November 19). The ABA business boom. *Relias*. <https://www.relias.com/blog/the-aba-business-boom>
- Motiwalla, S., Gupta, S., Lilly, M., Ungar, W., & Coyte, P. (2006). The cost-effectiveness of expanding intensive behavioural intervention to all autistic children in Ontario. *Healthcare Policy*, 1(2), 135–151. <https://doi.org/10.12927/hcpol.2006.17884>
- Mottron, L. (2017). Should we change targets and methods of early intervention in autism, in favor of a strengths-based education? *European Child & Adolescent Psychiatry*, 26(7), 815–825. <https://doi.org/10.1007/s00787-017-0955-5>

- Msumba, J. (2018, February 15). *Escaping the Judge Rotenberg Center* [Video recording]. Youtube. <https://www.youtube.com/watch?v=A7hklHN-qqY>
- Mukhopadhyay, T. R. (2011). *The mind tree: A miraculous child breaks the silence of autism*. Arcade Publishing.
- Nader, A.-M., Courchesne, V., Dawson, M., & Soulières, I. (2016). Does WISC-IV Underestimate the intelligence of autistic children? *Journal of Autism and Developmental Disorders*, 46(5), 1582–1589. <https://doi.org/10.1007/s10803-014-2270-z>
- National Autism Center. (2015). *Findings and conclusions: National standards project phase 2*. May Institute. <https://nationalautismcenter.org/national-standards/phase-2-2015/>
- National Autistic Society. (2017, July 18). *Amazing things happen—By Alexander Amelines* [Video recording]. Youtube. <https://www.youtube.com/watch?v=RbwRrVw-CRo>
- Neumeier, S. M., & Brown, L. X. Z. (2020). Torture in the name of treatment: The mission to stop the shocks in the age of deinstitutionalization. In S. K. Kapp (Ed.), *Autistic community and the neurodiversity movement: Stories from the frontline* (pp. 195–210). Palgrave Macmillan. https://doi.org/10.1007/978-981-13-8437-0_14
- NeuroClastic. (2019, July 4). *A mother's fight against court-ordered ABA*. <https://neuroclastic.com/2019/07/03/mothers-aba-experience/>
- NeuroClastic. (2020, December 30). *Resources*. <https://neuroclastic.com/resources/>
- Neuroclastic. (2021, August 17). *ABA horror stories are far too common*. <https://neuroclastic.com/aba-horror-stories-are-far-too-common/>
- Neurodivergent Infinity Network of Educators [NINE]. (2023). *Resources*. <https://sites.google.com/ddsb.ca/nine/home/resources>
- Newman, B. (2020). *B.F. Skinner and his involvement in humanism: An underappreciated aspect of ABA history* [Workshop]. <https://abatechnologies.com/continuing-education/bf-skinner-and-his-involvement-in-humanism-an-underappreciated-aspect-of-aba>

- Ngeow, J., Peschka, G., & Zurcher-Long, E. (2017, October 12). *Unspoken* [Documentary]. Disruptor Productions. <https://www.unspokendoc.com/>
- Nicolaidis, C., Raymaker, D., Kapp, S. K., Baggs, A., Ashkenazy, E., McDonald, K., Weiner, M., Maslak, J., Hunter, M., & Joyce, A. (2019). The AASPIRE practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants. *Autism*, 23(8), 2007–2019. <https://doi.org/10.1177/1362361319830523>
- Nicolaidis, C., Raymaker, D. M., McDonald, K. E., Lund, E. M., Leotti, S., Kapp, S. K., Katz, M., Beers, L. M., Kripke, C., Maslak, J., Hunter, M., & Zhen, K. Y. (2020). Creating accessible survey instruments for use with autistic adults and people with intellectual disability: Lessons learned and recommendations. *Autism in Adulthood*, 2(1), 61–76. <https://doi.org/10.1089/aut.2019.0074>
- Odom, S. L., Collet-Klingenberg, L., Rogers, S. J., & Hatton, D. D. (2010). Evidence-based practices in interventions for children and youth with autism spectrum disorders. *Preventing School Failure: Alternative Education for Children and Youth*, 54(4), 275–282. <https://doi.org/10.1080/10459881003785506>
- Oliver, M. (2013). The social model of disability: Thirty years on. *Disability & Society*, 28(7), 1024–1026. <https://doi.org/10.1080/09687599.2013.818773>
- Ontario Association for Behaviour Analysis [ONTABA]. (2020). *ABA primer*. <https://ontaba.org/wp-content/uploads/2021/07/ABA-Primer.pdf>
- Ontario Human Rights Commission [OHRC]. (2018). *Policy accessible education for students with disabilities*. <https://www.ohrc.on.ca/en/policy-accessible-education-students-disabilities>
- Ontario Ministry of Education. (2007). *Policy/program memorandum no. 140*. <http://www.edu.gov.on.ca/extra/eng/ppm/140.html>
- Ontario Scientific Expert Task Force for the Treatment of Autism Spectrum Disorder [OSETT-ASD]. (2017). *Evidence-based practices for individuals with autism spectrum disorder: Recommendations for Caregivers, Practitioners, and Policy Makers*. The Ontario

Association for Behavioural Analysis.

<https://www.behaviourinnovations.com/app/uploads/2019/03/ONTABA-OSETT-ASD-Report.pdf>

Ontario Scientific Expert Task Force for the Treatment of Challenging Behaviour [OSETT-CB].

(2019). *Evidence-based practices for the treatment of challenging behaviour in intellectual and developmental disabilities: Recommendations for caregivers, practitioners, and policy-makers*. The Ontario Association for Behavioural Analysis. https://ontaba.org/wp-content/uploads/2021/11/ONTABA_OSETT-CB_Final_Report_Jan_2019.pdf

Orsini, M., & Davidson, J. (2013). Introduction. Critical autism studies: Notes on an emerging field. In J. Davidson & M. Orsini (Eds.), *Worlds of autism: Across the spectrum of neurological difference* (eBook edition). University of Minnesota Press.

Owen, T. M., & Rodriguez, N. M. (2023). Toward establishing a qualifying autoclitic repertoire in children with autism spectrum disorder. *Journal of Applied Behavior Analysis*, 1–21. <https://doi.org/10.1002/jaba.1026>

Paquette-Smith, M., Weiss, J., & Lunsy, Y. (2014). History of suicide attempts in adults with Asperger Syndrome. *Crisis*, 35(4), 273–277. <https://doi.org/10.1027/0227-5910/a000263>

Parekh, G. (2022). *Ableism in education: Rethinking school practices and policies*. W. W. Norton & Company.

Pearson, A., & Rose, K. (2021). A conceptual analysis of autistic masking: Understanding the narrative of stigma and the illusion of choice. *Autism in Adulthood*, 3(1), 52–60. <https://doi.org/10.1089/aut.2020.0043>

Pecora, L. A., Hooley, M., Sperry, L., Mesibov, G. B., & Stokes, M. A. (2021). Sexuality and gender issues in individuals with autism spectrum disorder. *Psychiatric Clinics of North America*, 44(1), 111–124. <https://doi.org/10.1016/j.psc.2020.11.009>

- Pelios, L., Morren, J., Tesch, D., & Axelrod, S. (1999). The impact of functional analysis methodology on the treatment choice for self-injurious and aggressive behavior. *Journal of Applied Behavior Analysis*, 32(2), 185–195. <https://doi.org/10.1901/jaba.1999.32-185>
- Peña, E. V. (Ed.). (2019). *Leaders around me: Autobiographies of autistics who type, point, and spell to communicate*. Independently published.
- Penner, M., Rayar, M., Bashir, N., Roberts, S. W., Hancock-Howard, R. L., & Coyte, P. C. (2015). Cost-effectiveness analysis comparing pre-diagnosis autism spectrum disorder (ASD)-targeted intervention with Ontario's autism intervention program. *Journal of Autism and Developmental Disorders*, 45(9), 2833–2847. <https://doi.org/10.1007/s10803-015-2447-0>
- Perry, A., Cummings, A., Dunn Geier, J., Freeman, N. L., Hughes, S., LaRose, L., Managhan, T., Reitzel, J.-A., & Williams, J. (2008). Effectiveness of intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, 2(4), 621–642. <https://doi.org/10.1016/j.rasd.2008.01.002>
- Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., Managhan, T., Reitzel, J.-A., & Williams, J. (2011). Predictors of outcome for children receiving intensive behavioral intervention in a large, community-based program. *Research in Autism Spectrum Disorders*, 5(1), 592–603. <https://doi.org/10.1016/j.rasd.2010.07.003>
- Perry, A., Koudys, J., & Blacklock, K. (2016). Early intensive behavioral intervention. In N. N. Singh (Ed.), *Handbook of evidence-based practices in intellectual and developmental disabilities* (pp. 511–535). Springer International Publishing. https://doi.org/10.1007/978-3-319-26583-4_19
- Perry, A., Koudys, J., Prichard, A., & Ho, H. (2019). Follow-up study of youth who received EIBI as young children. *Behavior Modification*, 43(2), 181–201. <https://doi.org/10.1177/0145445517746916>
- Peterson, K. M., Piazza, C. C., & Volkert, V. M. (2016). A comparison of a modified sequential oral sensory approach to an applied behavior-analytic approach in the treatment of food

- selectivity in children with autism spectrum disorder. *Journal of Applied Behavior Analysis*, 49(3), 485–511. <https://doi.org/10.1002/jaba.332>
- Piccininni, C., Bisnaire, L., & Penner, M. (2017). Cost-effectiveness of wait time reduction for intensive behavioral intervention services in Ontario, Canada. *JAMA Pediatrics*, 171(1), 23–30. <https://doi.org/10.1001/jamapediatrics.2016.2695>
- Pierson, B. (2021, July 6). D.C. Circuit overturns FDA ban on shock device for disabled students. *Reuters*. <https://www.reuters.com/legal/litigation/dc-circuit-overturns-fda-ban-shock-device-disabled-students-2021-07-06/>
- Pothier, D., & Devlin, R. F. (2006). Introduction: Toward a critical theory of dis-citizenship. In R. F. Devlin & D. Pothier (Eds.), *Critical disability theory: Essays in philosophy, politics, policy, and law* (pp. 1–22). UBC Press.
- Price, D. (2022). *Unmasking autism: Discovering the new faces of neurodiversity* (eBook edition). Harmony Books.
- Pritchett, M., Ala'i-Rosales, S., Cruz, A. R., & Cihon, T. M. (2021). Social justice is the spirit and aim of an applied science of human behavior: Moving from colonial to participatory research practices. *Behavior Analysis in Practice*, 15(4), 1074–1092. <https://doi.org/10.1007/s40617-021-00591-7>
- Prizant, B. (2009). Treatment options and parent choice is ABA the only way? *Autism Spectrum Quarterly*, 28–32.
- Prizant, B., Wetherby, A. M., Rubin, E., & Laurent, A. C. (2003). The SCERTS Model: A transactional, family-centered approach to enhancing communication and socioemotional abilities of children with autism spectrum disorder. *Infants & Young Children*, 16(4), 296–316. <https://doi.org/10.1097/00001163-200310000-00004>
- Provincial Advocate for Children and Youth [PACY]. (2016). *We have something to say: Young people and their families speak out about special needs and change*. <https://ocaarchives.files.wordpress.com/2019/01/we-have-something-to-say-report-en.pdf>

- Public Health Agency of Canada [PHAC]. (2023, April 2). *Message from the Minister of Health – World autism awareness day* [Statement]. <https://www.canada.ca/en/public-health/news/2023/03/message-from-the-minister-of-health--world-autism-awareness-day.html>
- Pyne, J. (2020). “Building a person”: Legal and clinical personhood for autistic and trans children in Ontario. *Canadian Journal of Law and Society*, 35(2), 341–365. <https://doi.org/10.1017/cls.2020.8>
- Rajaraman, A., Austin, J. L., Gover, H. C., Cammilleri, A. P., Donnelly, D. R., & Hanley, G. P. (2022). Toward trauma-informed applications of behavior analysis. *Journal of Applied Behavior Analysis*, 55(1), 40–61. <https://doi.org/10.1002/jaba.881>
- Rajaraman, A., Hanley, G. P., Gover, H. C., Staubitz, J. L., Staubitz, J. E., Simcoe, K. M., & Metras, R. (2021). Minimizing escalation by treating dangerous problem behavior within an enhanced choice model. *Behavior Analysis in Practice*. <https://doi.org/10.1007/s40617-020-00548-2>
- Ram, J. (2020, June 2). I am a disillusioned BCBA: Autistics are right about ABA. *NeuroClastic*. <https://neuroclastic.com/2020/06/02/i-am-a-disillusioned-bcba-autistics-are-right-about-aba/>
- Randle, J., & Thurston, Z. (2022). *Housing experiences in Canada: Persons with disabilities*. <https://www150.statcan.gc.ca/n1/pub/46-28-0001/2021001/article/00011-eng.htm>
- Raymaker, D., & Nicolaidis, C. (2013). Participatory research with autistic communities. In J. Davidson & M. Orsini (Eds.), *Worlds of autism: Across the spectrum of neurological difference* (eBook edition, pp. 196–221). University of Minnesota Press.
- Real Social Skills. (2015, July 17). *Appearing to enjoy behavior modification is not meaningful*. <https://www.realsocialskills.org/blog/appearing-to-enjoy-behavior-modification-is-not>
- Reaume, G. (2002). Lunatic to patient to person: Nomenclature in psychiatric history and the influence of patients’ activism in North America. *International Journal of Law and Psychiatry*, 25, 405–426.

- Reaume, G. (2017). From the perspectives of mad people. In G. Eghigian (Ed.), *The Routledge history of madness and mental health* (pp. 277–296). Routledge.
- Reed, A. (2023, September 7). Use of electric shocks on disabled people upheld by court (2). *Bloomberg Law*. <https://news.bloomberglaw.com/litigation/shock-therapy-for-disabled-people-upheld-by-massachusetts-court>
- Reichow, B., Barton, E. E., Boyd, B. A., & Hume, K. (2012). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD009260.pub2>
- Reichow, B., Hume, K., Barton, E. E., & Boyd, B. A. (2018). Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database of Systematic Reviews*. <https://doi.org/10.1002/14651858.CD009260.pub3>
- Rekers, G. A., & Lovaas, O. I. (1974). Behavioral treatment of deviant sex-role behaviors in a male child. *Journal of Applied Behavior Analysis*, 7(2), 173–190. <https://doi.org/10.1901/jaba.1974.7-173>
- Re•Storying Autism Collective. (2023). Re•Storying autism in education. <https://www.restoryingautism.com/collective>
- Reyes, P., & Reyes, L. (2018, January 3). I have nonverbal autism. Here’s what I want you to know. *Organization for Autism Research*. <https://researchautism.org/i-have-nonverbal-autism-heres-what-i-want-you-to-know/>
- Richmond, A. (2024). *In their own words: The voices of disabled first-person protagonists in children’s and young adult literature* [Doctoral Thesis, York University]. <https://yorkspace.library.yorku.ca/items/bd4d3246-5f0d-481a-8454-8ea0e915c954>
- Rogers, S. J., Yoder, P., Estes, A., Warren, Z., McEachin, J., Munson, J., Rocha, M., Greenson, J., Wallace, L., Gardner, E., Dawson, G., Sugar, C. A., Hellemann, G., & Whelan, F. (2021). A multisite randomized controlled trial comparing the effects of intervention intensity and intervention style on outcomes for young children with autism. *Journal of*

- the American Academy of Child & Adolescent Psychiatry*, 60(6), 710–722.
<https://doi.org/10.1016/j.jaac.2020.06.013>
- Rosa, S. D. R. (2020, October 21). Why no autistic child should be in ABA therapy. *Thinking Person's Guide to Autism*. <http://www.thinkingautismguide.com/2020/10/why-no-autistic-child-should-be-in-aba.html>
- Roscigno, R. (2019). Neuroqueerness as fugitive practice: Reading against the grain of applied behavioral analysis scholarship. *Educational Studies*, 55(4), 405–419.
<https://doi.org/10.1080/00131946.2019.1629929>
- Rosqvist, H. B., Kourti, M., Jackson-Perry, D., Brownlow, C., Fletcher, K., Bendelman, D., & O'Dell, L. (2019). Doing it differently: Emancipatory autism studies within a neurodiverse academic space. *Disability & Society*, 34(7–8), 1082–1101.
<https://doi.org/10.1080/09687599.2019.1603102>
- Rothwell, J. (2020). *The reason I jump* [Film]. Vulcan Productions.
<https://www.vulcanproductions.com/our-work/the-reason-i-jump>
- Rubey, R. (2017). *Privileging autistics of color: A human rights approach to applied behavior analysis (ABA) therapy* [Master's Projects and Capstones, The University of San Francisco]. <https://repository.usfca.edu/capstone/680/>
- Runswick-Cole, K. (2016). Understanding this thing called autism. In K. Runswick-Cole, R. Mallett, & S. Timmi (Eds.), *Re-thinking autism: Diagnosis, identity, and equality* (eBook edition, pp. 19–30). Jessica Kingsley Publishers.
- Runswick-Cole, K., Mallett, R., & Timimi, S. (2016). Introduction. In K. Runswick-Cole, R. Mallett, & S. Timimi (Eds.), *Re-Thinking Autism: Diagnosis, Identity and Equality* (eBook edition, pp. 7–16). Jessica Kingsley Publishers.
- Ryan, R., & Deci, E. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68–78.
<https://doi.org/10.1037/0003-066X.55.1.68>

- Ryan, S., & Milton, D. (2023). Critical autism studies: An introduction. In D. Milton & S. Ryan (Eds.), *The Routledge International Handbook of Critical Autism Studies* (eBook edition, pp. 13–22). Routledge.
- Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation*, 110(6), 417–438. [https://doi.org/10.1352/0895-8017\(2005\)110\[417:IBTFCW\]2.0.CO;2](https://doi.org/10.1352/0895-8017(2005)110[417:IBTFCW]2.0.CO;2)
- Salvesen Mindroom Research Centre. (2023). *Learning about neurodiversity at school (LEANS)*. The University of Edinburgh. <https://salvesen-research.ed.ac.uk/leans>
- Sandbank, M., Bottema-Beutel, K., Crowley, S., Cassidy, M., Dunham, K., Feldman, J. I., Crank, J., Albarran, S. A., Raj, S., Mahbub, P., & Woynaroski, T. G. (2020). Project AIM: Autism intervention meta-analysis for studies of young children. *Psychological Bulletin*, 146(1), 1–29. <http://dx.doi.org.ezproxy.library.yorku.ca/10.1037/bul0000215>
- Sandoval-Norton, A. H., & Shkedy, G. (2019). How much compliance is too much compliance: Is long-term ABA therapy abuse? *Cogent Psychology*, 6(1), 1–8. <https://www.tandfonline.com/doi/full/10.1080/23311908.2019.1641258>
- Sandoval-Norton, A. H., Shkedy, G., & Shkedy, D. (2021). Long-term aba therapy is abusive: A response to gorycki, ruppel, and zane. *Advances in Neurodevelopmental Disorders*. <https://doi.org/10.1007/s41252-021-00201-1>
- Schaber, A. (2021). Unconventional. In *Sincerely, your autistic child: What people on the autism spectrum wish their parents knew about growing up, acceptance, and identity* (Audio Book). Beacon Press. https://books.google.ca/books/about/Sincerely_Your_Autistic_Child.html?id=3Y7wDwAAQBAJ&redir_esc=y
- Schopler, E., Short, A., & Mesibov, G. (1989). Relation of behavioral treatment to “normal functioning”: Comment on Lovaas. *Journal of Consulting and Clinical Psychology*, 57(1), 162–164. <http://dx.doi.org.ezproxy.library.yorku.ca/10.1037/0022-006X.57.1.162>

- Schopler, E., Van Bourgondien, M., Wellman, G., & Love, S. (2010). *Childhood autism rating scale, second edition (CARS2)*. Western Psychological Services.
<https://www.wpspublish.com/cars-2-childhood-autism-rating-scale-second-edition.html>
- Schuller, K. (2017). *The biopolitics of feeling: Race, sex, and science in the nineteenth century*. Duke University Press.
- Scotchie, M., & Borrero, C. S. W. (2023). Evaluation of empirical pretreatment assessments for developing treatments for expulsion in pediatric feeding disorders. *Behavioral Interventions*, 38(2), 356–375. <https://doi.org/10.1002/bin.1925>
- Sedgwick, M. (2019, June 2). *People Like Me (2019)* [Film]. <https://vimeo.com/339903359>
- Sequenzia, A. (2015). My thoughts on ABA. *Autistic Women & Nonbinary Network (AWN)*.
<https://awnnetwork.org/my-thoughts-on-aba/>
- Sequenzia, A. (2016, April 27). Autistic conversion therapy. *Autistic Women & Nonbinary Network (AWN)*. <https://awnnetwork.org/autistic-conversion-therapy/>
- Shanker, D. S. (2017). *Self-reg: How to help your child (and you) break the stress cycle and successfully engage with life*. Penguin Canada.
- Shepherd, C. A., & Waddell, C. (2015). A qualitative study of autism policy in Canada: Seeking consensus on children's services. *Journal of Autism and Developmental Disorders*, 45(11), 3550–3564. <https://doi.org/10.1007/s10803-015-2502-x>
- Shields, R. (2019). *The carpet felt five inches thick!: A socio-spacial analysis of the Judge Rotenberg Center* [Master of Arts Major Research Paper, York University].
<https://yorkspace.library.yorku.ca/items/04a60399-296b-48ed-82a7-782af31dc5c0>
- Shields, R., Easton, S., Gruson-Wood, J., Gibson, M. F., Douglas, P. N., & Rice, C. M. (2022). Storytelling methods on the move. *International Journal of Qualitative Studies in Education*, 1–20. <https://www.tandfonline.com/doi/full/10.1080/09518398.2022.2061625>

- Shkedy, G., Shkedy, D., & Sandoval-Norton, A. H. (2019). Treating self-injurious behaviors in autism spectrum disorder. *Cogent Psychology*, 6, 1–9.
<https://doi.org/10.1080/23311908.2019.1682766>
- Shyman, E. (2014). *Besieged by behavior analysis for autism spectrum disorder: A treatise for comprehensive educational approaches*. Lexington Books.
<https://rowman.com/ISBN/9780739193198/Besieged-by-Behavior-Analysis-for-Autism-Spectrum-Disorder-A-Treatise-for-Comprehensive-Educational-Approaches>
- Sibley, K. (2015). The cost of indistinguishability is unreasonable. In M. Sutton (Ed.), *The real experts: Readings for parents of autistic children* (pp. 44–47). Autonomous Press.
- Silberman, S. (2015). *Neurotribes: The legacy of autism and the future of neurodiversity*. Penguin.
- Simmonds, M. (2023). Through the lens of (Black) critical race theory. In D. Milton & S. Ryan (Eds.), *The Routledge international handbook of critical autism studies* (eBook edition, pp. 100–107). Routledge.
- Sinclair, J. (1993). Don't mourn for us. *Our Voice*, 1(3).
https://www.autreat.com/dont_mourn.html
- Singh Chawla, D. (2019, July 3). Large study supports discarding the term 'high-functioning autism.' *Spectrum*. <https://www.spectrumnews.org/news/large-study-supports-discarding-term-high-functioning-autism/>
- Sins Invalid. (2019). *Skin, tooth, and bone: The basis of movement is our people: A disability justice primer* (2nd edition). Sins Invalid. <https://www.sinsinvalid.org/disability-justice-primer>
- Skinner, B. F. (1948). "Superstition" in the pigeon. *Journal of Experimental Psychology*, 38(2), 168–172. <https://doi.org/10.1037/h0055873>
- Skinner, B. F. (1957). *Verbal Behavior*. Prentice-Hall.

- Skinner, B. F. (1971). *Beyond freedom and dignity*. Penguin Books.
http://archive.org/details/Beyond_Freedom_and_Dignity
- Skinner, B. F. (1974). *About behaviorism*. Vintage.
- Skjott Linneberg, M., & Korsgaard, S. (2019). Coding qualitative data: A synthesis guiding the novice. *Qualitative Research Journal*, 19(3), 259–270. <https://doi.org/10.1108/QRJ-12-2018-0012>
- Slaughter, G. (2016, June 8). Group homes for adults with autism unaffordable and inaccessible, parents say. *CTV News*. <https://www.ctvnews.ca/health/group-homes-for-adults-with-autism-unaffordable-and-inaccessible-parents-say-1.2937838?cache=>
- Slocum, S. K., Donaldson, J. M., Vollmer, T. R., & Miller, M. (2022). Aggression and crying as side effects of time-out. *Behavior Analysis: Research and Practice*, 23(1), 15–23.
<https://doi.org/10.1037/bar0000256>
- Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal of Mental Retardation*, 105(4), 269–285.
- Snow, K. (2016). *Serious occurrences report*. Provincial Advocate for Children and Youth.
https://ocaarchives.files.wordpress.com/2019/01/sor_preliminary_report_022016_en.pdf
- Snow, K. (2017). *In Harm's Way 2017*. Provincial Advocate for Children and Youth.
<https://cwrp.ca/sites/default/files/publications/en/in-harms-way-serious-occurrences-report-vol-2.pdf>
- Songbird. (2022, December 2). *What are motivating operations (MOs)?*
<https://www.songbirdcare.com/articles/what-are-motivating-operations-mos>
- Spagnuolo, N. (2016). Building back wards in a “post” institutional era: Hospital confinement, group home eviction, and Ontario’s treatment of people labelled with intellectual disabilities. *Disability Studies Quarterly*, 36(4), Article 4.
<https://doi.org/10.18061/dsq.v36i4.5279>

- Spagnuolo, N., & Earle, K. (2017, July 4). Freeing our people: Updates from the long road to deinstitutionalization. *Canadian Centre for Policy Alternatives*.
<https://www.policyalternatives.ca/publications/monitor/freeing-our-people-updates-long-road-deinstitutionalization>
- Sparrow, M. (2015). ABA- applied behavior analysis. In M. Sutton (Ed.), *The real experts: Readings for parents of autistic children* (pp. 50–59). Autonomous Press.
- Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2016). *Vineland 3 adaptive behavior scales*. Pearson. <https://www.pearsonclinical.com.au/files/640251470974563.pdf>
- Special Learning. (2021, November 21). What is pairing? *Special Learning, Inc.* https://special-learning.com/article__trashed/how-can-i-pair/
- Srinivasan, H. (2018, October 17). *Familiar library spaces, peace of mind* (UC Berkeley Library, Interviewer) [Video recording]. Youtube.
<https://www.youtube.com/watch?v=MRQSad-IxjY>
- Stack, A. (2021, January 22). Trauma-informed supports for autism with Alexia Stack, M.Ed., BCBA (B. Reiman, Interviewer) [Audio podcast episode]. In *The Behaviour Speak Podcast*. <https://www.behaviourspeak.com/e/episode-2-trauma-informed-supports-for-autism/>
- Stack, A., & Lucyshyn, J. (2019). Autism spectrum disorder and the experience of traumatic events: Review of the current literature to inform modifications to a treatment model for children with autism. *Journal of Autism and Developmental Disorders*, 49(4), 1613–1625. <https://doi.org/10.1007/s10803-018-3854-9>
- Stay, L. (2021, August 27). I was part of the “good ABA.” *NeuroClastic*.
<https://neuroclastic.com/i-was-part-of-the-good-aba/>
- Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. S., Yücesoy-Özkan, Ş., & Savage, M. N. (2020). *Children, youth, and young adults with autism* [The University of North Carolina at Chapel Hill]. The University of North Carolina at Chapel Hill, Frank Porter Graham Child

Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team.

Stephens, G. (2022, December 14). *Crisis prevention institute and the alliance against seclusion and restraint announce collaborative initiatives*. Alliance Against Seclusion and Restraint. <https://endseclusion.org/2022/12/14/crisis-prevention-institute-and-the-alliance-against-seclusion-and-restraint-announce-collaborative-initiatives/>

Sterne, J., Hernán, M. A., McAleenan, A., Reeves, B. C., & Higgins, J. P. (2022). Chapter 25: Assessing risk of bias in a non-randomized study. In J. P. Higgins, J. Thomas, J. Chandler, M. Cumpston, T. Li, M. Page, & V. Welch (Eds.), *Cochrane handbook for systematic reviews of interventions version 6.3* (6.3). Cochrane. <https://training.cochrane.org/handbook/current/chapter-25>

Sterne, J., Savović, J., Page, M. J., Elbers, R. G., Blencowe, N. S., Boutron, I., Cates, C. J., Cheng, H.-Y., Corbett, M. S., Eldridge, S. M., Emberson, J. R., Hernán, M. A., Hopewell, S., Hróbjartsson, A., Junqueira, D. R., Jüni, P., Kirkham, J. J., Lasserson, T., Li, T., ... Higgins, J. P. T. (2019). RoB 2: A revised tool for assessing risk of bias in randomised trials. *BMJ*, 366, l4898. <https://doi.org/10.1136/bmj.l4898>

Stone, E., & Priestley, M. (1996). Parasites, pawns and partners: Disability research and the role of non-disabled researchers. *The British Journal of Sociology*, 47(4), 699–716. <https://doi.org/10.2307/591081>

Stop ABA, Support Autistics. (2019a, July 23). *ABA and the refusal to teach children about consent*. <https://stopabasupportautistics.home.blog/2019/07/23/aba-and-the-refusal-to-teach-children-about-consent/>

Stop ABA, Support Autistics. (2019b, August 11). *The great big ABA opposition resource list*. <https://stopabasupportautistics.home.blog/2019/08/11/the-great-big-aba-opposition-resource-list/>

Strydom, A., Bosco, A., Vickerstaff, V., Hunter, R., Poppe, M., Ratti, V., Hall, I., Crabtree, J., Omar, R. Z., Biswas, A., Blickwedel, J., Cooper, V., Crawford, M., Hassiotis, A., & the

- PBS study group. (2020). Clinical and cost effectiveness of staff training in the delivery of positive behaviour support (PBS) for adults with intellectual disabilities, autism spectrum disorder and challenging behaviour. *BMC Psychiatry*, 20(1), 161.
<https://doi.org/10.1186/s12888-020-02577-1>
- Sullivan, P. M., & Knutson, J. F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse and Neglect*, 24(10), 1257–1273.
[https://doi.org/10.1016/S0145-2134\(00\)00190-3](https://doi.org/10.1016/S0145-2134(00)00190-3)
- Summers, J. (2021, April 2). As private equity comes to dominate autism services.... *The Nation*.
<https://www.thenation.com/article/society/private-equity-autism-aba/>
- Summers, J. (2022, November 21). The mismeasure of Misha. *The Boston Globe*.
<https://www.bostonglobe.com/2022/11/21/opinion/mismeasure-misha/>
- Sutton, M. (Ed.). (2015). *The real experts: Readings for parents of autistic children*. Autonomous Press.
- Swan, M. (2017, April 7). Behaviour modification therapy does work. *Hello Michelle Swan*.
<https://hellomichelleswan.com/behaviour-modification-therapy-does-work/>
- Tachibana, Y., Miyazaki, C., Ota, E., Mori, R., Hwang, Y., Kobayashi, E., Terasaka, A., Tang, J., & Kamio, Y. (2017). A systematic review and meta-analysis of comprehensive interventions for pre-school children with autism spectrum disorder (ASD). *PLOS ONE*, 12(12), 1–28. <https://doi.org/10.1371/journal.pone.0186502>
- Tarbox, J. (2018, April 22). Session 50: Get your ACT together with Jonathan Tarbox (M. Cicoria, Interviewer) [Audio podcast episode]. In *Behavioral Observations*.
<https://behavioralobservations.com/session-50-get-your-act-together-with-jonathan-tarbox/>
- Tarbox, J., Szabo, T. G., & Aclan, M. (2020). Acceptance and commitment training within the scope of practice of applied behavior analysis. *Behavior Analysis in Practice*, 15(1), 11–32. <https://doi.org/10.1007/s40617-020-00466-3>

- Tashakkori, A., & Teddlie, C. (2010). *SAGE handbook of mixed methods in social & behavioral research*. SAGE Publications. <https://doi.org/10.4135/9781506335193>
- Teddlie, C., & Tashakkori, A. (2009). *Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioral sciences*. SAGE Publications.
- The Black Autist. (2022, January 21). *A lot of the current discussions on autism and neurodivergent masking only focus on the experiences of it for those whom [Images attached]* [Online post]. Facebook. <https://www.facebook.com/blackautist/posts/4714299638654637>
- The European Council of Autistic People [EUCAP]. (2022). *Autistic people's opinions on Applied Behavior Analysis in Europe EUCAP survey results 2022*. <https://eucap.eu/projects/aba/>
- Therapist Neurodiversity Collective. (2020a). *Augmentative and alternative communication (AAC)*. <https://therapistndc.org/therapy/aac/>
- Therapist Neurodiversity Collective. (2020b). *Non-ABA evidence based practice*. <https://therapistndc.org/therapy/non-aba-evidence-based-practice/>
- Therapist Neurodiversity Collective. (2020c, February 22). *ABA: Modern-day brainwashing*. <https://therapistndc.org/aba-modern-day-brainwashing/>
- Thomas, C. (2004). How is disability understood? An examination of sociological approaches. *Disability & Society*, 19(6), 569–583. <https://doi.org/10.1080/0968759042000252506>
- Thornton, C. (2021, April 18). ABA for creating masking black autistics. *NeuroClastic*. <https://neuroclastic.com/aba-for-creating-masking-black-autistics/>
- Titchkosky, T. (2011). *The question of access: Disability, space, meaning*. University of Toronto Press.

- Tolley, B. (2021, January 6). *Moving beyond behaviorism and into the twenty-first century to meet the needs of today's students* [Presentation]. NJ Autism Center of Excellence, online. <https://www.youtube.com/watch?v=ioDQ6NDolto&t=1s>
- Torrey, E. F. (1997). Psychiatric survivors and non-survivors. *Psychiatric Services*, 48(2), 143.
- Tran, C. (2023, March 14). Why parents of some Ontario adults with severe autism say they're "terrified" for their futures. *CBC News*. <https://www.cbc.ca/news/canada/toronto/parents-children-severe-autism-future-1.6778630>
- Truth But No Logic. (2011, June 8). "‘Sissy’" *boy experiment part 1* [Video recording]. Youtube. https://www.youtube.com/watch?v=CJ7VigOWm_M
- Tuck, E., & Yang, K. W. (2012). Decolonization is not a metaphor. *Decolonization: Indigeneity, Education & Society*, 1(1), 1–40.
- Unbound Books: Autism Acceptance Library. (n.d.). *Autistic people and ABA survivors on ABA*. Retrieved July 14, 2021, from <https://lanathomas209.wixsite.com/unboundbooks/aba>
- United Nations. (1990). *Convention on the rights of children*. Office of the High Commissioner. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>
- United Nations. (2006). *Convention on the rights of persons with disabilities*. Office of the High Commissioner. <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>
- United Nations. (2019). Strengthen inclusion, participation of people with autism to ‘achieve their full potential’ says UN chief. *United Nations*. <https://www.un.org/fr/desa/strengthen-inclusion-participation-people-autism-%E2%80%99achieve-their-full-potential%E2%80%99>
- U.S. Department of Defense. (2019). *The Department of Defense comprehensive autism care demonstration annual report*. <https://www.altteaching.org/wp-content/uploads/2019/11/TRICARE-Autism-Report.pdf>

- U.S. Department of Defense. (2020). *The Department of Defense comprehensive autism care demonstration annual report*. <https://health.mil/Reference-Center/Congressional-Testimonies/2020/06/25/Annual-Report-on-Autism-Care-Demonstration-Program>
- U.S. Department of Defense. (2021). *The Department of Defense comprehensive autism care demonstration annual report*. <https://health.mil/Reference-Center/Reports/2021/12/03/Annual-Report-on-Autism-Care-Demonstration-Program-for-FY-21>
- U.S. Department of Education. (2010). *What Works Clearinghouse (WWC) intervention report. Early childhood education interventions for children with disabilities: Lovaas model of Applied Behavior Analysis*. Institute of Education Sciences. <https://files.eric.ed.gov/fulltext/ED511483.pdf>
- Vallejo, P. E. (2019). *Communication alternatives in autism: Perspectives on typing and spelling approaches for the nonspeaking*. McFarland and Company, Inc.
- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. State University of New York Press.
- Vance, T. (2020, April 12). On autism and intelligence: Language and advocacy. *NeuroClastic*. <https://neuroclastic.com/2020/04/12/on-autism-and-intelligence-language-and-advocacy/>
- Vance, T. (2021). Not all behavior is communication: Disinhibition part 1 overview. *NeuroClastic*. <https://neuroclastic.com/wp-content/uploads/2022/02/Disinhibition-Part-1.pdf>
- Verriden, A. L., & Roscoe, E. M. (2019). An evaluation of a punisher assessment for decreasing automatically reinforced problem behavior. *Journal of Applied Behavior Analysis*, 52(1), 205–226. <https://doi.org/10.1002/jaba.509>
- Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, meta-regression and dose–response meta-analysis of multiple outcomes. *Clinical Psychology Review*, 30(4), 387–399. <https://doi.org/10.1016/j.cpr.2010.01.008>

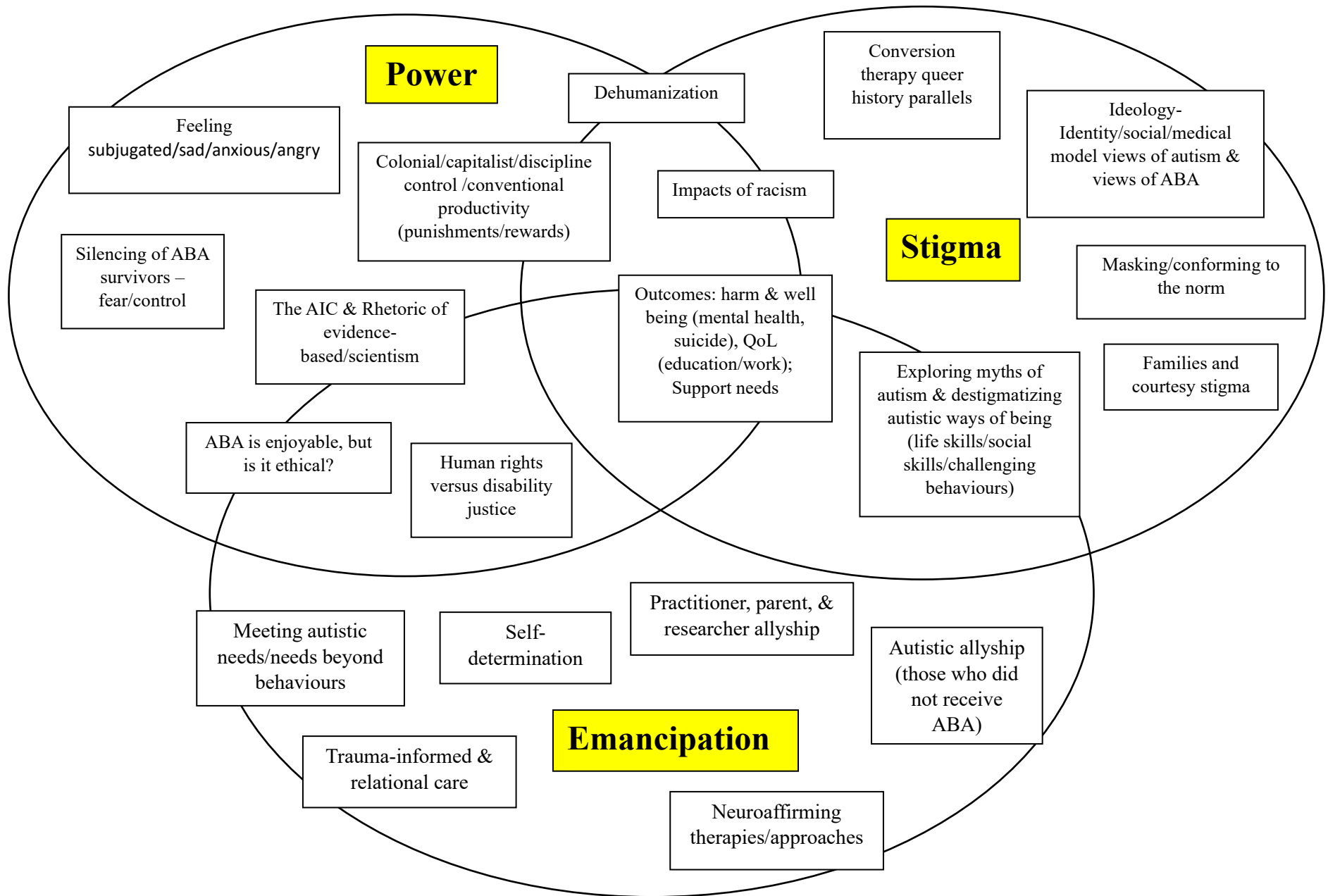
- Vivanti, G. (2022). What does it mean for an autism intervention to be evidence-based? *Autism Research*, 15(10), 1787–1793. <https://doi.org/10.1002/aur.2792>
- Vivian, A. F., Des Roches Rosa, S., Logsdon-Breakstone, S., Liebowitz, C., Ford, S., Kapp, S., Carey, M., & Julia, B. (2019). Neurodiversity FAQ. *Thinking Person's Guide to Autism*. <http://www.thinkingautismguide.com/p/so-youre-doing-story-about.html>
- Walker, N. (2016, June 23). Autism and the pathology paradigm. *Neuroqueer: The Writing of Dr. Nick Walker*. <https://neuroqueer.com/autism-and-the-pathology-paradigm/>
- Walker, N. (2021). *Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Autonomous Press.
- Warren, Z., Veenstra-VanderWeele, J., Stone, W., Bruzek, J. L., Nahmias, A. S., Foss-Feig, J. H., Jerome, R. N., Krishnaswami, S., Sathe, N. A., Glasser, A. M., Surawicz, T., & McPheeters, M. L. (2011). *Therapies for children with Autism Spectrum Disorders comparative effectiveness review no. 26*. Agency for Healthcare Research and Quality U.S., Department of Health and Human Services. https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/autism_research.pdf
- Watkins, T. (2021, February 8). What is “pairing” in applied behavior analysis? *Just 1 Voice*. <https://just1voice.com/neurodiversity/autism/pairing-in-applied-behavior-analysis/>
- Watson, J. B. (1913). Psychology as the behaviorist views it. *Psychological Review*, 20, 158–177. <https://psychclassics.yorku.ca/Watson/views.htm>
- Watson, J. B. (1994). Psychology as the behaviorist views it. *Psychological Review*, 101(2), 248–253. <http://dx.doi.org.ezproxy.library.yorku.ca/10.1037/0033-295X.101.2.248>
- Wechsler, D. (2014). *Wechsler Intelligence Scale for children fifth edition: Canadian*. <https://www.pearsonclinical.ca/store/caassessments/en/Store/Professional-Assessments/Cognition-%26-Neuro/Comprehensive-Ability/Wechsler-Intelligence-Scale-for-Children-%7C-Fifth-Edition%3A-Canadian/p/P100008008.html>

- Weiss, J. (2022). *Webinar: Promoting mental health in autistic people: The importance of context and support*. Autism Ontario. <https://www.autismontario.com/node/591>
- Weitlauf, A. S., McPheeters, M. L., Peters, B., Sathe, N., Travis, R. T., Aiello, R., Williamson, E., Veenstra-VanderWeele, J., Krishnaswami, S., Jerome, R., & Warren, Z. (2014). *Therapies for children with Autism Spectrum Disorder: Behavioural interventions update: Comparative effectiveness review no. 137*. Agency for Healthcare Research and Quality U.S., Department of Health and Human Services. https://effectivehealthcare.ahrq.gov/sites/default/files/pdf/autism-update_research.pdf
- Wergeland, G. J. H., Posserud, M.-B., Fjermestad, K., Njardvik, U., & Öst, L.-G. (2022). Early behavioral interventions for children and adolescents with autism spectrum disorder in routine clinical care: A systematic review and meta-analysis. *Clinical Psychology: Science and Practice*, Advance online publication. <https://doi.org/10.1037/cps0000106>
- Wharmby, P. (2022, October 28). *Keynote presentation—Supporting an autistic child's education*. Au-Some Conference, Autism Canada. <https://www.youtube.com/watch?v=cnzEYthkh-0>
- Wilkenfeld, D. A., & McCarthy, A. M. (2020). Ethical concerns with applied behavior analysis for autism spectrum “disorder.” *Kennedy Institute of Ethics Journal*, 30(1), 31–69. <https://doi.org/10.1353/ken.2020.0000>
- Williams, K. (2019, April 4). The fallacy of functioning labels. *National Centre for Mental Health*. <https://www.ncmh.info/2019/04/04/fallacy-functioning-labels/>
- Williams, R. M. (2020). Falsified incompetence and other lies the positivists told me. *Canadian Journal of Disability Studies*, 9(5), Article 5. <https://doi.org/10.15353/cjds.v9i5.696>
- Wing, L. (1997). A history of ideas on autism: Legends, myths and reality. *Autism*, 1(1), 13–23.
- WitandStars. (2021, December 31). *Edit: The fact that I have both people angry about me still saying ABA is wrong in the end and* [Online post]. Facebook. https://m.facebook.com/story.php?story_fbid=326864749442259&id=100063562089688

- Wójcik, M., Eikeseth, S., Eikeseth, F. F., Budzinska, E., & Budzinska, A. (2023). A comparison controlled study examining outcome for children with autism receiving intensive behavioral intervention (IBI). *Behavior Modification*, 1–23.
<https://doi.org/10.1177/01454455231165934>
- Wolf, M. (1978). Social validity: The case for subjective measurement or how applied behavior analysis is finding its heart. *Journal of Applied Behavior Analysis*, 11(2), 203–214.
<https://doi.org/10.1901/jaba.1978.11-203>
- Wolf, M., Risley, T., & Mees, H. (1963). Application of operant conditioning procedures to the behaviour problems of an autistic child. *Behaviour Research and Therapy*, 1(2), 305–312. [https://doi.org/10.1016/0005-7967\(63\)90045-7](https://doi.org/10.1016/0005-7967(63)90045-7)
- Wong, C., Odom, S. L., Hume, K. A., Cox, A. W., Fettig, A., Kucharczyk, S., Brock, M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2015). Evidence-based practices for children, youth, and young adults with autism spectrum disorder: A comprehensive review. *Journal of Autism and Developmental Disorders*, 45(7), 1951–1966.
<https://doi.org/10.1007/s10803-014-2351-z>
- Woods, R., Milton, D., Arnold, L., & Graby, S. (2018). Redefining critical autism studies: A more inclusive interpretation. *Disability & Society*, 33(6), 974–979.
<https://doi.org/10.1080/09687599.2018.1454380>
- Worth, P. (n.d.). Dare to dream. *Inclusion Press*. Retrieved December 11, 2019, from <https://inclusion.com/inclusion-stories-news/life-stories/patrick-worth-says/>
- Yergeau, M. (2018). *Authoring autism: On rhetoric and neurological queerness* (eBook edition). Duke University Press.
- Young, K. (2016a, December 29). Autistic Christian misfit: The dangers of ABA: A survivor's story, pt. 1. *Autistic Christian Misfit*. <http://autistic-christian-misfit.blogspot.com/2016/12/the-dangers-of-aba-survivors-story-pt-1.html>

- Young, K. (2016b, December 30). Autistic Christian misfit: The dangers of ABA: A survivor's story, pt. 2. *Autistic Christian Misfit*. <http://autistic-christian-misfit.blogspot.com/2016/12/the-dangers-of-aba-survivors-story-pt-2.html>
- Young, K. (2017, March 29). Autistic Christian misfit: ABA's harmful message to children: You can't say "no." *Autistic Christian Misfit*. <http://autistic-christian-misfit.blogspot.com/2017/03/abas-harmful-message-to-children-you.html>
- Zamzow, R. (2022, April 14). Why autism therapies have an evidence problem. *Spectrum*. <https://www.spectrumnews.org/news/why-autism-therapies-have-an-evidence-problem/>

Appendix A: Ven Diagram



Appendix B: Inclusion and Exclusion Criteria for Interviews

Inclusion Criteria:

- Respondents who provided responses that reflected enthusiasm and motivation to participate in interviews (e.g., “I would be happy to be selected for an interview”)
- Respondents who represented either positive or negative experiences with ABA and that provided insight into the influences of stigma, power, and emancipatory aims of the study (e.g., indicated autism is a disorder and found ABA to be effective; indicated autism was a neurotype and were critical of ABA; etc.)
- Respondents who represented a wide range of ABA experiences (recent forms of ABA; ABA-informed approaches in schools, community settings, etc.; formal ABA and IBI in private therapy centres, government funded medical centers; etc.)
- Respondents who represented diversity in identity (e.g., nonspeaking autistic people; racialized identities; etc.)
- Respondents who were unknown to me, if possible (*due to the small sample pool of eligible respondents, I selected two respondents out of eight who were previously known to me but who expressed great enthusiasm to participate in the interview)
- Autistic respondents who had overall positive experiences of ABA had to also have indicated at least one or two ways that ABA could improve (e.g., the rewards/consequences were not “always” effective); this was necessary so that if autistic people interviewed wished to participate in the dissemination stage of the study, they would be able to provide recommendations for further improving ABA to meet the needs of all autistic people
- Conversely to the above, respondents who were critical of ABA had to also have indicated one or two positive aspects of ABA (e.g., the ABA practitioners were kind, well-meaning, or helpful; there may be possibilities for ABA reform; etc.)

Exclusion Criteria:

- Respondents who did not provide an email address
- Respondents with experiences of ABA outside of the province of Ontario (*with the exception of one autistic participant from British Columbia who was selected based on his nonspeaking identity and enthusiasm to participate in the interview); Ethics protocol was adjusted to include this participant

Appendix C: Example Interview Questions

- How is person-first (“I have autism”) or identity-first language (“I am autistic”) important to you?
- Describe what a typical ABA session was like for you/your child?
- In what ways did ABA help you/your child? In what ways was ABA unhelpful?
- What have been your goals in your ABA program?
- How do you define optimal wellbeing and mental health for yourself/your child/your client?
- How has ABA helped or not helped to attain wellbeing and quality of life?
- In what ways would you like to see ABA services in Ontario to improve?
- In your opinion, has ABA improved over the years? In what ways?