Substantially Silent: Exploring the Variability of “Voice” at the Intersection of Race and Dis/Ability in a Restrictive Special Education Placement

Christopher N. Hall
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SUBSTANTIALLY SILENT: EXPLORING THE VARIABILITY OF “VOICE” AT THE INTERSECTION OF RACE AND DIS/ABILITY IN A RESTRICTIVE SPECIAL EDUCATION PLACEMENT

A Dissertation Presented

by

CHRISTOPHER N. HALL

Submitted to the Office of Graduate Studies,
University of Massachusetts Boston
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2022

Urban Education, Leadership, and Policy Studies Program
SUBSTANTIALLY SILENT: EXPLORING THE VARIABILITY OF “VOICE” AT THE INTERSECTION OF RACE AND DIS/ABILITY IN A RESTRICTIVE SPECIAL EDUCATION PLACEMENT

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ABSTRACT

SUBSTANTIALLY SILENT: EXPLORING THE VARIABILITY OF “VOICE” AT THE INTERSECTION OF RACE AND DIS/ABILITY IN A RESTRICTIVE SPECIAL EDUCATION PLACEMENT

May 2022

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M. Ed., Bridgewater State University
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Directed by Professor Patricia Krueger-Henney

The overrepresentation of Black students in special education, particularly in the most restrictive educational placements, is well documented in the literature. In addition, Black students are disproportionately placed into far more segregated educational spaces than their same-aged White peers with similar dis/ability labels. With limited qualitative studies that center the voices of students of color labelled as severely disabled in restrictive educational settings, informed by the tenets of Disability Studies in Education (DSE), this study adds to the growing body of research foregrounding the voices of individuals with dis/abilities in telling their own story from their perspective through narrative portraiture.

This inquiry uses a Disability Studies and Critical Race Theory in Education (DisCrit) framework to analyze the lived educational experiences of a Black high school student
labeled as severely disabled, his mother, and his former teacher to explore how race, dis/ability, and ableism work in-tandem to segregate and exclude students with intersecting identities from equitable access to a free and appropriate public education (FAPE). Using the metaphor of a siege, narrative portraits of both the student and his mother illuminate the ways that the exclusionary practices of a large urban school district are used to besiege students and families by creating three distinct walls of exclusion: the administrative wall, the academic wall, and environmental wall.

The implications of this study include the importance of valuing the voices of culturally and linguistically diverse students and family members in educational decision making, especially when educational programming and special education classroom placement is being proposed.

*Keywords:* Student voice, special education, exclusion, ableism, racism, restrictive educational placements, Disability Studies in Education (DSE), bricolage, Disability Studies and Critical Race Theory in Education (DisCrit), metaphor, Hip-Hop Based Education (HHBE).
ACKNOWLEDGEMENTS

This past eight years has been a transformative experience to say the least and I am truly grateful to all of my friends, family, students, and colleagues that have supported me along this long and meaningful journey. Some have helped me through their encouragement and unwavering support and others helped by reminding me daily how important this research is the students that need us the most. I thank you all for listening with me, laughing with me, shedding tears with me, and most importantly bringing a positive perspective to this research endeavor.

First, I would like to thank my committee chair and mentor Dr. Krueger-Henney. Your passion and dedication to social justice and uplifting the voices of young people marginalized by the same educational structures that we must maneuver through on a daily basis has inspired me in all aspects of my life, from being a father, husband, student, researcher, and special education teacher. Your mentorship has completely transformed my life in ways I never thought possible, and I have you to thank for opening my eyes and illuminate the educational injustices faced by individuals at the intersection of race and dis/ability in my research.

Dr. Menashy, thank you for giving me the tools to critically examine special education policy that so closely affects our most marginalized students that find themselves, unjustly, in the most restrictive and segregated educational spaces. Your guidance helped me conceptualize and make visible power hierarchies that exist in education, particularly between those that are perceived as “normal” and those that do not live up to these unrealistic and rigid White, middle-class, and Eurocentric notions of normality.
Dr. Connor, I will never forget your kindness that day I sent you an email after reading an article you wrote talking about this thing called Disability Studies in Education that I had never heard of. Your dedication and passion for inclusive education has transformed my conception of disability and helped me put a name on so many things that I recognized were wrong with special education, particularly the over-representation of students of color in the most restrictive educational spaces.

The Real Patrick and Beverly words cannot express how much your friendship, sacrifice, and dedication to this work means to me. You have always believed in me and always been there when I needed you the most. Eleven years ago, the stars aligned to place us on the same educational path, and I am so grateful that we continue doing this work together a decade later. My Cohort, arguably the best cohort ever, and everyone in our incredible Urban Education, Leadership and Policy Studies Program that made this possible. Paraeducators, the undervalued, often forgotten, and the most dedicated and hardest workers in the school, I see you and appreciate you all so much. Dr. Kress and Dr. Zakharia thank you for encouraging me to embrace my creativity in the design and implementation of this not-so-traditional research project and sticking by my side through every crazy idea. Thank you to my Specialist team and Dr. Gellerstein for always being there for me.

Lastly and most importantly, my family for being my rock and foundation for this long and transformative journey. I know how much you sacrificed to get us to this milestone, I love you all so much. I hope that you will find something that you are passionate about and follow that dream no matter what stands in your way! But remember, if you ever travel back in time, don’t step on anything because even the tiniest change can alter the future in ways you can’t imagine.
# TABLE OF CONTENTS

ABSTRACT ................................................................................................................................. iv

ACKNOWLEDGEMENTS ........................................................................................................... vi

LIST OF TABLES ......................................................................................................................... xii

LIST OF FIGURES ...................................................................................................................... xiii

CHAPTER

<table>
<thead>
<tr>
<th>CHAPTER</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. SUBSTANTIALLY SILENT: A NEED FOR A DIVERSITY OF VOICE</td>
<td>1</td>
</tr>
<tr>
<td>Introduction</td>
<td>1</td>
</tr>
<tr>
<td>Goals and Significance of Study</td>
<td>5</td>
</tr>
<tr>
<td>Definition of Terms</td>
<td>8</td>
</tr>
<tr>
<td>Identity First Language</td>
<td>8</td>
</tr>
<tr>
<td>Individuals with Disabilities Education Act</td>
<td>10</td>
</tr>
<tr>
<td>Students Labeled as Severely Disabled</td>
<td>11</td>
</tr>
<tr>
<td>Substantially Separate Classroom</td>
<td>11</td>
</tr>
<tr>
<td>Voice</td>
<td>12</td>
</tr>
<tr>
<td>Participants</td>
<td>12</td>
</tr>
<tr>
<td>School Profile</td>
<td>14</td>
</tr>
<tr>
<td>The Frederick Douglass K-8 School</td>
<td>14</td>
</tr>
<tr>
<td>Urban Collegiate Academy Charter School</td>
<td>14</td>
</tr>
<tr>
<td>Leading Theories in the Field</td>
<td>15</td>
</tr>
<tr>
<td>Medical Model of Disability</td>
<td>15</td>
</tr>
<tr>
<td>Social Model of Disability</td>
<td>16</td>
</tr>
<tr>
<td>Theoretical Framework</td>
<td>18</td>
</tr>
<tr>
<td>Disability Studies in Education</td>
<td>18</td>
</tr>
<tr>
<td>DisCrit</td>
<td>20</td>
</tr>
</tbody>
</table>

2. A REVIEW OF THE LITERATURE ......................................................................................... 23
|Introduction| 23|
|Federal Education Policy| 24|
|Free and Appropriate Public Education (FAPE)| 26|
|The Impact of Standards-based Reform| 29|
|Student Voice| 34|
|Pedagogy| 40|
|Curriculum| 41|
|Home-school Partnership| 42|
|Hip-Hop Based Education| 43|


3. TOWARD A PLURALITY OF METHODOLOGIES: RESEARCH DESIGN AND METHODOLOGICAL APPROACHES .......................................................... 48
   Introduction .................................................................................................. 48
   Refusing to Document Damage ................................................................. 50
   Bricolage ...................................................................................................... 51
   Portraiture ..................................................................................................... 53
   Metaphor ....................................................................................................... 54
   Autoethnography .......................................................................................... 57
   Data Collection ............................................................................................. 58
   Art Journaling ............................................................................................... 59
   Free-draw ....................................................................................................... 62
   Interviews ....................................................................................................... 63
   Improvisational Lyrical Remiking ............................................................... 65
   Three-way Discussions Over Dinner .......................................................... 69
   Data Collection Timeline ............................................................................ 70
   Phases of the Research Process ................................................................. 71
   Data Analysis ............................................................................................... 76
   Research Quality .......................................................................................... 77
   Conclusion .................................................................................................... 79

4. KING PATRICK IN THE CASTLE AT WALT DISNEY ............................................. 80
   Introduction .................................................................................................. 80
   The Big Yellow School Bus: A Tale of Two Transitions ......................... 82
   The Artist: Creative and Resourceful ......................................................... 90
   The Choreographer: Musings of Music and Movement ......................... 100
   The Composer: A Creative Mash-up ......................................................... 103
   The Conductor: Making Connections Through Location .................... 108
   A Week in the Life of Patrick at Urban Collegian Academy .................. 116
   Conclusion: Creating the Walls of Exclusion ........................................ 134

5. AN EDUCATION UNDER SIEGE: INVESTIGATING THE EXCLUSIONARY PRACTICES OF A HIGH SCHOOL SPECIAL EDUCATION CLASSROOM IN A LARGE URBAN SCHOOL ................. 139
   Introduction .................................................................................................. 139
   The Use of a Metaphor ................................................................................ 140
   The Siege as a Metaphor ............................................................................. 141
   The Siege, Phase One: The Fortification .................................................... 142
   Administrative Exclusion ............................................................................ 143
   Forming of the individualized education plan team and the special education process ................................................................. 143
   Funding ......................................................................................................... 148
   Academic Exclusion .................................................................................... 154
CHAPTER

Patrick’s Desire to Become a Math Teacher ........................................ 154
Exclusion From His Environment; Physical Exclusion ........ 164
The breakfast room of isolation ........................................ 164
The Siege, Phase Two: Lessening the Resistance .................... 174
The Blockade: Starvation Through Educational Attrition ...... 174
Non-educational video watching .................................. 174
The Siege, Phase Three: Surrender .................................. 184
The Capture: Surrounded and Isolated .............................. 184
Isolation over time .............................................. 185
Emotional cover up ........................................... 196
Conclusion: The Forced Paralysis of Exclusion .................. 212

6. I DIDN’T PICK AUTISM, AUTISM PICKED ME: A MOTHER’S BATTLE AGAINST SYSTEMIC BESIEGEMENT ........................................ 215
Introduction: Autism as a Mother’s Battle Ground ................ 215
Origin Story: “Autism Found Me” ................................ 217
The Administrative Battlefield: The “Autism Bitch” .............. 223
The Day the Home School Relationship Deteriorated .......... 226
Empty Bag: Empty Dreams: Academic Desires in Black and White .......................................................... 233
Environmental Battlefield: Autism is a Life Sentence ...... 240
Black, Autistic, and in the System .................................. 242
Fighting for Inclusion in Society .................................. 244
Caught in the Cultural Crossfire of Autism ...................... 248
Losing Hope: Autism Becomes Your World ...................... 254
Conclusion: “Why Bother?” ...................................... 259

7. “HE LOVES SCHOOL BECAUSE HE DOESN’T KNOW WHAT HE IS MISSING OUT ON” ........................................ 264
Introduction ...................................................................... 264
Guiding Research Questions ........................................ 267
Answering Sub Questions Through the Multiplicity of Perspectives .................................................. 273
Patrick Talbot ................................................................. 274
Beverly Mendes .............................................................. 277
Christopher Hall ............................................................. 279
Analysis of Finding Through the Tenets of Disability Studies and Critical Race Theory in Education (DisCrit) .......... 282
The Siege: Suggesting a Thirdspace in Special Education? .... 301
Implications of the Study .................................................. 305
Administrative Implications ............................................ 305
Valuing families and family member voices ................. 305
## CHAPTER

<table>
<thead>
<tr>
<th>Educational policy</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academic Implications</td>
<td>307</td>
</tr>
<tr>
<td>Pedagogy and curriculum in k-12 education</td>
<td>309</td>
</tr>
<tr>
<td>Teacher education</td>
<td>310</td>
</tr>
<tr>
<td>Environmental Implication</td>
<td>312</td>
</tr>
<tr>
<td>Building a truly inclusive community</td>
<td>312</td>
</tr>
<tr>
<td>Limitations of Study</td>
<td>315</td>
</tr>
<tr>
<td>Recommendations for Future Research</td>
<td>318</td>
</tr>
<tr>
<td>Concluding Thoughts</td>
<td>322</td>
</tr>
</tbody>
</table>

## APPENDIX

<table>
<thead>
<tr>
<th>APPENDIX</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. RECRUITMENT FLYER</td>
<td>325</td>
</tr>
<tr>
<td>B. PARENTAL PERMISSION CONSENT FORM</td>
<td>326</td>
</tr>
<tr>
<td>C. CHILD ASSENT FORM AND VERBAL SCRIPT</td>
<td>331</td>
</tr>
<tr>
<td>D. FAMILY MEMBER INFORMED CONSENT FORM</td>
<td>344</td>
</tr>
<tr>
<td>E. AUDIO OR VIDEOTAPING PARENT CONSENT FORM</td>
<td>348</td>
</tr>
<tr>
<td>F. CHILD ASSENT SCRIPT FOR AUDIO OR VIDEOTAPING</td>
<td>350</td>
</tr>
<tr>
<td>G. AUDIO OR VIDEOTAPING PARTICIPANT CONSENT FORM</td>
<td>353</td>
</tr>
</tbody>
</table>

REFERENCES ................................................................................................. 355
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 The Five Elements of Hip-Hop</td>
<td>45</td>
</tr>
<tr>
<td>3.1 Data Collection Types and Sample Size</td>
<td>59</td>
</tr>
<tr>
<td>3.2 Data Collection Timeline</td>
<td>71</td>
</tr>
<tr>
<td>3.3 Phase 1: Getting to know the family</td>
<td>72</td>
</tr>
<tr>
<td>3.4 Phase 2: Coming together</td>
<td>74</td>
</tr>
<tr>
<td>3.5 Phase 3: Data Analysis</td>
<td>75</td>
</tr>
<tr>
<td>3.6 Phase 4: Creation of narratives</td>
<td>76</td>
</tr>
</tbody>
</table>
## LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1</td>
<td>Front cover of Patrick’s book “Jarren Get in a Fight”</td>
<td>61</td>
</tr>
<tr>
<td>4.1</td>
<td>Example of a communication board with picture symbols</td>
<td>95</td>
</tr>
<tr>
<td>4.2</td>
<td>Construction paper mosaic from 2013</td>
<td>98</td>
</tr>
<tr>
<td>4.3</td>
<td>Foam tile mosaic from 2015</td>
<td>98</td>
</tr>
<tr>
<td>4.4</td>
<td>Patrick’s weekly ninth-grade schedule</td>
<td>118</td>
</tr>
<tr>
<td>4.5</td>
<td>One of Patrick’s multiple art journal entries where he draws himself</td>
<td></td>
</tr>
<tr>
<td></td>
<td>swimming in the pool</td>
<td></td>
</tr>
<tr>
<td>4.6</td>
<td>Patrick’s art journal entry depicting himself taking the bus to work</td>
<td>121</td>
</tr>
<tr>
<td>4.7</td>
<td>Patrick’s art journal depicting him performing his job duties</td>
<td>122</td>
</tr>
<tr>
<td>4.8</td>
<td>Patrick’s art journal entry depicting his class watching “The Magic School Bus”</td>
<td>125</td>
</tr>
<tr>
<td>4.9</td>
<td>Patrick’s art journal entry depicting himself and his friends playing</td>
<td></td>
</tr>
<tr>
<td></td>
<td>“Duck Duck Goose”</td>
<td>126</td>
</tr>
<tr>
<td>4.10</td>
<td>Patrick’s art journal entry depicting himself taking the school van to the</td>
<td></td>
</tr>
<tr>
<td></td>
<td>local boathouse</td>
<td></td>
</tr>
<tr>
<td>4.11</td>
<td>Patrick’s art journal entry depicting himself and a friend watching videos</td>
<td></td>
</tr>
<tr>
<td></td>
<td>on his phone in the gym</td>
<td>129</td>
</tr>
<tr>
<td>4.12</td>
<td>Patrick’s art journal entry depicting himself and a friend watching a video</td>
<td></td>
</tr>
<tr>
<td></td>
<td>on his phone in the gym</td>
<td>130</td>
</tr>
<tr>
<td>4.13</td>
<td>Patrick’s art journal depicting his class participating in Access Sports</td>
<td>132</td>
</tr>
<tr>
<td>5.1</td>
<td>Patrick’s self-regulatory IEP goals from Frederick Douglass School compared with Urban Collegian Academy</td>
<td>145</td>
</tr>
<tr>
<td>5.2</td>
<td>Patrick’s self portrait of himself as a math teacher</td>
<td>156</td>
</tr>
<tr>
<td>5.3</td>
<td>Patrick’s student work sample of color-by-number math worksheet</td>
<td>158</td>
</tr>
<tr>
<td>5.4</td>
<td>An art journal entry of Patrick’s recounting math work he did in school</td>
<td>158</td>
</tr>
<tr>
<td>Figure</td>
<td>Description</td>
<td>Page</td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------------------------------------------------------------</td>
<td>------</td>
</tr>
<tr>
<td>5.5</td>
<td>An art journal entry of Patrick recounting what he ate at lunch</td>
<td>165</td>
</tr>
<tr>
<td>5.6</td>
<td>An art journal entry of Patrick recounting spending time with friends at</td>
<td>166</td>
</tr>
<tr>
<td></td>
<td>lunch</td>
<td></td>
</tr>
<tr>
<td>5.7</td>
<td>An art journal entry of Patrick’s recounting watching videos at lunch</td>
<td>167</td>
</tr>
<tr>
<td>5.8</td>
<td>Conceptual framework of the three walls of exclusion surrounding Patrick,</td>
<td>173</td>
</tr>
<tr>
<td></td>
<td>administrative, academic, and environmental walls</td>
<td></td>
</tr>
<tr>
<td>5.9</td>
<td>An art journal entry of Patrick recounting a conversation he had with</td>
<td>177</td>
</tr>
<tr>
<td></td>
<td>Ms. Harris when she wouldn’t allow him to watch YouTube videos during class</td>
<td></td>
</tr>
<tr>
<td></td>
<td>time</td>
<td></td>
</tr>
<tr>
<td>5.10</td>
<td>Patrick’s school day makeup gathered from art journal entries</td>
<td>178</td>
</tr>
<tr>
<td>5.11</td>
<td>Patrick’s non-academic video watching accounts in his art journal from</td>
<td>180</td>
</tr>
<tr>
<td></td>
<td>January 8, 2019 through June 7, 2019</td>
<td></td>
</tr>
<tr>
<td>5.12</td>
<td>Welcome letter from UCA that was sent home with Patrick</td>
<td>182</td>
</tr>
<tr>
<td>5.13</td>
<td>Patrick’s art journal entries from the first week of January and the first</td>
<td>186</td>
</tr>
<tr>
<td></td>
<td>Week of June</td>
<td></td>
</tr>
<tr>
<td>5.14</td>
<td>How are you feeling? Visual emotions chart</td>
<td>197</td>
</tr>
<tr>
<td>5.15</td>
<td>An art journal entry of Patrick’s, recounting doing math work in school</td>
<td>198</td>
</tr>
<tr>
<td>5.16</td>
<td>An art journal entry of Patrick’s, depicting him doing math work in</td>
<td>199</td>
</tr>
<tr>
<td></td>
<td>Mr. Marcus’ class</td>
<td></td>
</tr>
<tr>
<td>5.17</td>
<td>An art journal entry of Patrick’s, depicting him cleaning the elevator</td>
<td>200</td>
</tr>
<tr>
<td></td>
<td>doors at the Central Offices</td>
<td></td>
</tr>
<tr>
<td>5.18</td>
<td>An art journal entry of Patrick’s, depicting him washing the windows</td>
<td>201</td>
</tr>
<tr>
<td></td>
<td>at the Central Offices</td>
<td></td>
</tr>
<tr>
<td>5.19</td>
<td>An art journal entry of Patrick’s, depicting him cleaning the doors and</td>
<td>202</td>
</tr>
<tr>
<td></td>
<td>windows at the Central Offices</td>
<td></td>
</tr>
<tr>
<td>5.20</td>
<td>An art journal entry of Patrick’s, depicting him cleaning the doors and</td>
<td>203</td>
</tr>
<tr>
<td></td>
<td>windows at the Central Offices with his tongue sticking out</td>
<td></td>
</tr>
<tr>
<td>Figure</td>
<td>Page</td>
<td></td>
</tr>
<tr>
<td>--------</td>
<td>------</td>
<td></td>
</tr>
<tr>
<td>5.21</td>
<td>An art journal entry of Patrick’s, depicting him in a bad mood at school ................................. 204</td>
<td></td>
</tr>
<tr>
<td>5.22</td>
<td>An art journal entry of Patrick’s, depicting him expressing that he doesn’t like getting hit by a ball ................................................................. 205</td>
<td></td>
</tr>
<tr>
<td>5.23</td>
<td>An art journal entry of Patrick’s, expressing that he gets sad when he doesn’t go rowing ................................................................. 206</td>
<td></td>
</tr>
<tr>
<td>5.24</td>
<td>An art journal entry of Patrick’s, depicting him drinking water in the bathroom ................................................................. 207</td>
<td></td>
</tr>
<tr>
<td>5.25</td>
<td>An art journal entry of Patrick’s, depicting him refusing to eat salad .......... 208</td>
<td></td>
</tr>
<tr>
<td>5.26</td>
<td>An art journal entry of Patrick’s, depicting his friend being mad and grumpy ................................................................. 209</td>
<td></td>
</tr>
<tr>
<td>5.27</td>
<td>An art journal entry of Patrick’s, depicting him doing recycling .......... 210</td>
<td></td>
</tr>
<tr>
<td>6.1</td>
<td>A Photograph of Patrick’s Backpack After Returning Home from ......................................................... 236</td>
<td></td>
</tr>
<tr>
<td>6.2</td>
<td>Patrick’s Report Card from November 15, 2018 .............................................................................. 245</td>
<td></td>
</tr>
<tr>
<td>7.1</td>
<td>Photograph of a construction paper mosaic celebrating Black History Month ................................................................. 266</td>
<td></td>
</tr>
</tbody>
</table>
CHAPTER 1

SUBSTANTIALLY SILENT: A NEED FOR A DIVERSITY OF VOICE

Aligned with [Disability Studies in Education], we embark on our research in ways that question, challenge, and reframe conceptions of ‘voice’ in qualitative research in an effort to continually resist privileging spoken voice as the primary and preferred means of communication.

— (Woodfield & Ashby, 2016, p.438)

Introduction

At the beginning of the era of educational accountability and high-stakes testing, it was unclear whether including students with dis/abilities\(^1\) in the general accountability system would lead to “best educational practices” and higher expectations, or simply maintain the status quo (Manset & Washburn, 2000, p. 165). Almost two decades after the passage of the No Child Left Behind Act (NCLB) in 2001, research by Tefera (2019) suggests that “test scores have remained largely unchanged” (p.460). Pazey et al. (2014) suggests that instead of raising scores and improving outcomes for students with dis/abilities, this legislation might go as far as to “devalue, demoralize and alienate the very students it intended to help” (p.386). This holds especially true for students labeled as having severe

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\(^1\) Informed by the work of Connor (2005) and Tefera and colleagues (2019), following the social model of disability, by ‘dis/ability’ or ‘dis/abilities’ this study seeks to separate “dis” from “ability” to acknowledge that the “dis” is dependent on the environment in which a student learns rather than an innate deficit in the individual. The dash in ‘dis/ability’ is used to disrupt the constructions of “disability” while at the same time highlighting “the social construction of both ability and disability as emotionally, socially, culturally historically, economically and politically constructed” (Tefera, Hernández-Saca, & Lester, 2019, p. 3)
disabilities (SD)\textsuperscript{2} who may not communicate through the traditional means of spoken and written word. Because of the complexity of their perceived communication impairments, standardized assessments may not provide these students with an opportunity to accurately demonstrate their true academic knowledge (McLaughlin, & Thurlow, 2004; Thurlow & Johnson, 2000; Biklen & Burke, 2006). What is clear is that the simultaneous implementation of both the Individuals with Disabilities Education Improvement Act (IDEIA) of 2004, and the NCLB, has had a significant impact on the educational programming for students labeled as SD, especially those students who are educated in substantially separate classrooms\textsuperscript{3}.

Historically, educational programming for students labeled as SD in a substantially separate classroom consisted of an educational curriculum focused on building both functional and academic skills and creating meaningful and attainable goals that were individualized to each student (Cohen, Safran, & Polloway, 1980). Students labeled as SD were traditionally excluded from district wide assessments, and eventually without a system of accountability monitoring their progress they suffered from lowered expectations, and limited access to the general education curriculum and grade-level standards (Lowrey, Drasgow, Renzaglia, & Chezan, 2007; Thurlow & Johnson, 2000). In order to address this issue, the NCLB added a requirement that all students must participate in high-stakes testing, without exception (Christenson, Decker, Triezenberg, Ysseldyke, & Reschly, 2007; Lowrey et al., 2007).

\textsuperscript{2} Students labeled as having severe disabilities (SD) is a term that is used to describe students that are educated in substantially separate classrooms composed of only special education students. A more detailed description is provided in the definition of terms.

\textsuperscript{3} Substantially separate classrooms are self-contained classrooms composed solely of students with dis/abilities where students have limited or no access to their neurotypical peers.
Since standardized tests are designed to measure performance on academic content standards, curriculum and instructional strategies must align with the content contained in the assessment (Thurlow & Johnson, 2000). One possible consequence of this practice could potentially be a curricular shift in special education. Research suggests that special education curriculum that once focused on building both functional and academic skills based on individualized student-centered goals has shifted to an academic curriculum that prioritizes the learning of state content standards (Ayres, Lowrey, Douglas, & Sievers, 2011). Lowrey et al. (2007), warned that standards-based reform efforts may create a practice of aligning Individualized Education Plan (IEP)\(^4\) goals with grade-level learning standards, conflicting with the IDEIA’s requirement of providing students with IEPs that create meaningful and individualized goals to meet their unique needs. What is well documented in the literature is that one of the intended consequences of the NCLB was to raise expectations for students labeled as SD and provide them with educational programming that was more academically rigorous (Christenson et al., 2007; Thurlow & Johnson, 2000); however, there is limited evidence that increasing academic rigor has improved the quality of education for students with disabilities (Ayres et al., 2011; McLaughlin & Thurlow, 2003), and the policy assumptions behind the NCLB remain largely unchallenged in the scholarship (Pazey, Heilig, Cole, & Sumbera, 2014).

Missing from the literature is an examination of the unintended consequences of ostensibly raising academic rigor, particularly from the perspective of the students themselves, their families, and their teachers. As Gonzalez, Hernández-Saca, and Artilles

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\(^4\) Individualized Education Plan is an educational plan developed by a team of individuals that work directly with a student with dis/abilities. The team includes the student, family, special education teacher, general education teacher, occupational and speech therapists, special education coordinators, school administrators, and other educators that work with the student.
(2017) suggest, this lack of student voice calls for more research that centers the voices of students with dis/abilities. With limited qualitative studies that provide students with the most complex perceived\(^5\) dis/abilities an opportunity to share their “voice”\(^6\), it is unknown what these students desire from their educational programing, how they feel about their current educational programming, and whether or not the educational programing they are receiving provides them access to a free and appropriate public education (FAPE), which is guaranteed under the IDEIA.

A review of the Massachusetts Comprehensive Assessment System Alternative Portfolio Assessment\(^7\) (MCAS-ALT) results from 2001 through 2014 for tenth-grade students labeled as SD reveals that 0.0019% of portfolios satisfied high school graduation requirements (Mass. DESE, 2014). Given that assessment results should measure the effectiveness of instruction, then these statistics would seem to suggest that the educational programing provided to students labeled as SD may not be providing them with access to a FAPE. If they are devoting a majority of their educational time striving towards meeting academic grade-level learning targets that seem to be unobtainable, then what are they missing out on? In addition, what type of education, if any, are they receiving?

\(^5\) The use of the term perceived here, and throughout this inquiry, is informed by the work of Biklen and Burke (2006) and is used here to acknowledge that although an individual may present as having “deficits” in academic performance, it may be a result of the measurement tool used to determine the extent of these deficiencies. Using what Biklen and Burke (2006) describe as “presuming competence”, this study is guided by the belief that one must assume that an individual with perceived deficits is capable of comprehension, and it is incumbent on the researcher and/or educator to present information in a way that the individual can understand.

\(^6\) Voice is placed in parenthesis to signify that this inquiry privileges voice in forms other than spoken or written word to include art renderings, alternative forms of communication, visual picture symbols, sign language, and any other method that individuals express their experiences, feelings, thoughts, and desires.

\(^7\) The MCAS-ALT is a portfolio-based state-wide assessment taken by special education students when the IEP team determines that they cannot participate in the traditional MCAS test taken by general education students. Students can still meet the requirements to earn a high school diploma by participating in the MCAS-ALT test; however, it is statistically unlikely that this is possible.
Goals and Significance of the Study

In their article entitled “I Can Identify Saturn But I Can’t Brush My Teeth,” Ayres et al. (2011) argue that academic learning standards themselves are not harmful, it is what they take the place of that warrants our attention. Tefera et al. (2019) suggest that although a significant number of studies exist that highlight the negative effects of “high-stakes” testing, limited in the scholarship are studies that “centralize and examine the experiences and perspectives of students themselves, particularly Black and Latinx students labeled with dis/abilities” (p.4). Addressing this gap in the scholarship, this study foregrounded the voice of a Black high school student labeled with SD in a restrictive educational placement,8 and took an in-depth look at his educational experiences from his perspective during the current standards-based reform movement. In their systematic review of empirical research on student voice during a twenty-year period (1990-2010), Gonzalez et al. (2017) found that out of the forty-nine studies that met their study criteria, only one study included the voice of students with dis/abilities, none of which included students with intellectual dis/abilities. Given the limited number of studies foregrounding the voices of historically marginalized youth with dis/abilities, Hernádez-Saca et al. (2018) call for school reform efforts to include the voices of students at the intersection of both race and dis/ability that have been historically marginalized in the scholarship.

Following this call, this study looked beyond the quantitative achievement statistics that locate academic deficiencies within the individual, rather than illuminating the systematic deficiencies within the special education system itself. The goal of this inquiry was to create a narrative of the lived experiences of a student labeled as SD and began by

8 Restrictive educational placements is used to refer to a segregated educational placement where students with dis/abilities receive educational programing solely with other students with dis/ability labels.
shining a positive light on this student, providing an opportunity for him to share his unique perspective and express his thoughts, feelings, and desires as they related to his educational experiences. In response to critiques of student voice research by Robinson and Taylor (2017) that suggest many investigators primarily focus on student spoken language as their analytic focus, this study created opportunities for the participant to share his voice in a multitude of ways, including visual representations, lyrical expressions, and spoken and written word.

Using my expertise as a special education art teacher, I adapted and modified traditional research methodologies to meet the individual needs of a student labeled as SD, as needed, in order to privilege his knowledge base, honor his diverse methods of communication, and create a variety of opportunities for him to share his voice. For students labeled as SD, many of which are also labeled with intellectual dis/abilities, this inquiry represents a shift in the current research paradigm that excludes individuals that use non-traditional methods of communication and provided an opportunity for a fifteen-year-old high school freshman to share his voice using his preferred method of communication as naturally and uninhibitedly as possible. Valente and Danforth (2016) describe a main goal of research conducted through a Disability Studies in Education (DSE) framework as using storytelling to, “give life to stories of exclusion as well as to stories of successful inclusion” (p.5). With this in mind, this study centered the educational experiences of a student labeled with dis/abilities, following in the footsteps of a growing body of research foregrounding the voices of individuals with dis/abilities in telling their own story from their perspective (Peters, Klein, & Shadwick, 1998; Biklen & Burke, 2006; Connor, 2008; Naraian, 2008; Sauer, 2012; Hernández-Saca, 2016; Coié-Peña, 2018; Tefera, 2019).
This study followed the DSE approach to research by providing a vehicle for a student labeled as SD to share his voice and express his goals and desires as they related to his educational experiences (Baglieri, Valle, Connor, & Gallagher, 2011). In addition to providing a firsthand account of how a student labeled as SD experiences teaching and learning in a substantially separate classroom, this inquiry also looked at how the student’s mother, and his teacher made meaning of these same experiences. This grounded theory study was guided by one overarching research question:

What do the educational experiences and desires of a student in a substantially separate classroom, their family, and their teacher reveal about access to a free and appropriate public education (FAPE)?

In order to answer this overarching question, this study was guided by two additional questions, each with three sub questions:

1. How does a student from a substantially separate classroom, their family, and their teacher describe their educational experiences?
   a. How do they describe pedagogy in a substantially separate classroom?
   b. How do they describe the curriculum in a substantially separate classroom?
   c. How do they describe the home school partnership and the roles of the student, the family, and the teacher in educating a student in a substantially separate classroom?

2. What are the educational desires of a student from a substantially separate classroom, their family, and their teacher?
   a. What do they desire for pedagogy in a substantially separate classroom?
b. What do they desire from the curriculum in a substantially separate classroom?

c. What do they desire from a home school partnership and what roles do they feel that the student, the family, and the teacher must play in order to educate a student from a substantially separate classroom?

**Definition of Terms**

In this study there are a few key terms that are presented here alphabetically that need to be defined in detail in order to provide a contextual foundation for their usage throughout this inquiry. These terms are central to this inquiry and will be described here in detail. Other terms are defined throughout this study, as needed, in footnotes to provide a clear definition of their usage.

**Identity First Language**

This study acknowledges that autism discourse is non-static and constantly changing, especially as educators and researchers make concerted efforts to foreground and privilege the perspectives of autistic individuals in the scholarship. As such, as researchers and educators it is imperative to reflect on the ways that we use language when addressing individuals that are members of selected populations in which we do not identify as being members of, in this case, members of the autism community. To this end, in answering the question posed to Vivanti (2020) “What is the most appropriate way to talk about individuals with a diagnosis of Autism? Should we stop saying “person with autism”, and use “autistic

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9 I purposely, respectively, and cautiously use the term “autistic” here to describe individuals diagnosed with autism spectrum disorders (ASD), choosing to use identity first language, supported by the Autistic Self-Advocacy Network, rather than person first language commonly used in educational settings that supports the medical model of disability (Brown, 2011).
person” instead?”, this study choses to use what is known as identity-first language (p.691). With identity-first language, the autism community, including self-advocates and their allies, identity-first language (“autistic”, “autistic individual”, “autism spectrum disorders (ASD) person”, etc.) is preferred by many because it recognizes autism as something that is an inherent part of an individual’s identity (Brown, 2012). Whereas with person-first language (“students with autism”, “people with autism”, “individual with ASD”, etc.”), although historically well intended (Dunn & Andrews, 2015), by placing the person before the condition, suggests that a person can be separated from autism and if not for autism, they would be typical (Brown, 2012). Some argue that separating autistic people from their autism, as seen in person-first language, is an act of “violence” and has serious implications for the autism community (Botha, Hanlon, & Williams, 2021, p.1).

Brown (2012) urges members of the autism community, as well as their allies to use identity-first language “everywhere possible, whenever discussing autism and issues that affect Autistic people, and to develop coherent, rational explanations for why you prefer this terminology” (p.2). Answering this call can be difficult when working in special educational spaces that have long used person-first language when referring to autistic students. Before this study I was trained to use person-first language as a means of highlighting the humanity of a student by seeing the person first rather than the perceived dis/ability or condition of the student; however, in my scholarly journey my perspective has evolved and continues evolving. I have come to believe that the use of person-first language in educational spaces serves as merely a “euphemism” used to justify the exclusion of autistic students from general education or inclusive classrooms (Dunn & Andrews, 2015, p. 257). By saying “student with autism” educators are essentially sending the message that if not for autism the
student could be included in less restrictive placements. Furthermore, by isolating the perceived dis/ability from the individual, an educational placement in a more restrictive setting is justifiable because following the medical model of disability, autism is something that should be cured through interventions and specialized services (Campbell, 2009). Both of which are thought to be most efficiently provided in a substantially separate educational placement composed of students with similar dis/ability labels.

Botha and colleagues (2021) acknowledge that there is no current consensus in the scholarship regarding the preferred terminology from autistic people; however, their research suggests that person-first language is “the most offensive” (p.2). They argue that identity-first language is essential in highlighting the autonomy and rights of autistic people, but also support the use of the less offensive term “person on the autism spectrum” if a “middle ground” is needed when talking about autism (Botha, Hanlon, & Williams, 2021, p.2). In this study no compromise or middle ground was needed. To highlight the humanity of the participants in this study we chose to use their first names\(^\text{10}\), and when it was necessary to talk about autism in this inquiry, I used the terminology preferred by the individuals in this study, identity-first language.

**Individuals with Disabilities Education Act**

Throughout this study the term Individuals with Disabilities Education Act (IDEA) is used to refer to federal education legislation that provides individuals with dis/abilities access to a free and appropriate public education, among other entitlements. The original legislation, the Education of All Handicapped Children Act (EAHCA) of 1975, was reauthorized as the IDEA in 1990, and is now known as the Individuals with Disabilities

\(^{10}\text{Pseudonyms were used for the names of the participants and all places I mentioned throughout this dissertation.}\)
Education Improvement Act (IDEIA) after another reauthorization in 2004. Throughout this study the terms IDEA and IDEIA are sometimes used interchangeably to refer to the federal legislation that provides an entitlement to students with dis/abilities access to a free and appropriate public education, among other entitlements, which paved the way for special education.

**Student Labeled as Severely Disabled**

In this study I use the term “student labeled as severely disabled” to refer to a student that receives more than sixty percent of their educational programming in a substantially separate or self-contained classroom consisting solely of students with similar disability labels. In the urban school district where this study takes place, autistic students that are not educated in a general education classroom and/or an inclusion classroom are generally considered to be severely disabled. Notably, the data suggests that in this urban school district the difference between a label of moderate disabled and severely disabled often comes down to “judgment call” that occurs at the intersection of race and dis/ability (Baglieri et al., 2011). Educators that teach students in restrictive settings, like the one that the main participant in this study is educated in, typically need a “severe special needs” special education license. Throughout this study the term student labeled as severely disabled, students in a substantially separate classroom, and autistic student are sometimes used interchangeably.

**Substantially Separate Classroom**

For the purposes of this inquiry, the term substantially separate classroom will be used to refer to a restrictive educational placement where students receive a large majority (sixty percent or more) of their educational programming in a self-contained classroom
consisting of only special education students. These students have minimal access to their neurotypical peers that are educated in general education and/or inclusion classrooms. The terms substantially separate classroom and self-contained classroom are synonymous and are sometimes used interchangeably in this study. This study also assumes that an IEP team has determined that this educational placement represents the least restrictive environment (LRE) for the students discussed in this study and has provided justification for such placement.

**Voice**

In the context of this inquiry the term voice will be used as a term to describe the individualized method of communication that the student in this study will use to share his feelings and his desires. Or using the work of Gonzalez and colleagues (2017) to succinctly define voice in this study, “a domain of inquiry that aims to document the ideas, perceptions, opinions, or perspectives of students with situated schooling contexts and for specific purposes” (p. 453). “Voice” will not be limited to the traditional forms of communication that include written and spoken word, instead, the term will be used as a broad definition that may include but is not limited to: Picture Exchange Communication (PECs), visual communication boards, augmentative alternative communication devices (AAC), drawings, photographs, utterances, and any other alternative form of communication used to supplement or replace speech or writing in the production or comprehension of spoken or written language. Chapter three of this study will take a closer look at voice through scholarship.

**Participants**

This inquiry was conducted with a total of three participants, n = 3. The first participant in this study included a fifteen-year-old autistic student of Cape Verdean descent
that began his freshman year at Urban Collegian Academy (UCA) at the beginning of this study. Patrick Talbot (a pseudonym) spends more than sixty percent of his school day in a substantially separate classroom. The second participant, representing the family voice in this investigation, included Patrick’s mother Beverly Mendes (a pseudonym), a single mother also of Cape Verdean descent that identifies as having a dis/ability. The last participant, providing the teacher perspective in this inquiry was myself, a special education art teacher that has built a trusting relationship with both Patrick and Beverly during the seven years that Patrick was in my art class, and we continue this relationship today. Patrick, Beverly, and myself, all experienced teaching and learning in Dagobah Public Schools (DPS), a pseudonym. This large urban school district is located in the Northeastern United States.

I made the conscious decision to choose one of my former students as a participant for several reasons. First, through my own experiences I have found that it may sometimes take a great deal of time to understand the nuances of the unique communication style of a student labeled as SD without developing trust, mutual respect, and working with the student through prolonged engagement. Understanding how the student communicates is a critical step in designing research methods that best support a student in sharing their voice. Second, the personal insight that I have gained over the years working with Patrick and Beverly allowed me to specifically tailor my research methods to answer the research questions of this study. This is important because knowing the right questions to ask allowed me to be as thorough as possible in the data collection process and provided me with the most detailed representation of the lived experiences of both Patrick and his mother. Lastly, the trust and mutual respect already established within this seven-year relationship, created a research environment where all participants felt comfortable sharing their lived experiences during
interviews and three-way discussions. This was important because I not only wanted to ask both participants personal questions during this investigation, but I also want them to be comfortable and feel safe asking me questions as well.

School Profile

In addition to documenting Patrick’s lived educational experiences as a freshman in UCA, this study also looks back retrospectively at his educational experiences from kindergarten through eighth grade where he attended the Frederick Douglass School\textsuperscript{11} (FDS). Below are the school profiles taken from the Department of Education School and District profile website.

The Frederick Douglass K-8 School

The FDS is a Title 1\textsuperscript{12} school that serves students in preschool through grade eight in an urban school district in the Northeast United States. The FDS is Patrick’s former school where he attended from kindergarten through grade eight. There are approximately 550 students enrolled in the school, approximately 53% of the student body is African American, approximately 33% is Hispanic, 5% Asian, 4% White, and 5% Multi-race or Native American. Approximately 95% of students are designated as high need, 85% are low income, 44% are students with dis/abilities, and 26% are English Language Learners.

Urban Collegiate Academy Charter School

The Urban Collegiate Academy Charter School (UCA) is a Title 1 school that serves students in grades six through twelve in an urban school district in the Northeast United States. The UCA is where Patrick attended school during his freshman year of high school.

\textsuperscript{11} A pseudonym is used to protect the confidentiality of the participants

\textsuperscript{12} A Title 1 school is a school that receives supplemental federal funding to assist schools with large concentrations of low-income students to help meet their educational goals.
when this study was conducted. He currently still attends school here. There are approximately 475 students enrolled in the school, approximately 44% of the student body is African American, approximately 44% is Hispanic, 6% White, 2% Asian, and 4% Multi-race or Native American. Approximately 89% of students are designated as high need, 79% are low income, and 17% are English Language Learners.

**Leading Theories in the Field**

Disability Studies in Education (DSE) was the anchoring philosophy and rationale for doing this research; however, I conducted this inquiry using grounded theory. According to Charmaz (2014), “grounded theory methods consist of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories from the data themselves” (p.1). With this inquiry it was important for me to construct theories based on the data I collected and using DSE as a framework allowed me to design this research study to privilege the knowledge of an individual with dis/abilities. Since student voice from students labeled as SD is limited in the scholarship (Gonzalez, Hernández-Saca, & Artiles, 2017), using grounded theory allowed me to collect data in the field and construct my theory based on the emerging themes that were revealed through analyzing my data (Charmaz, 2014). In order to lay the contextual foundation of this issue of investigation, I first turned to the two leading theories in the field of special education, the medical model of disability and the social model of disability.

**Medical Model of Disability**

With the medical model, dis/ability is located within the individual, something that is missing or deficient, which in turn, is in need of remediation (Connor, 2013). The medical model is a deficit centered model grounded in positivist science and serves as a foundation
for special education legislation and practice (Reid & Knight, 2006). In order to receive special education services under the IDEIA, a student must have one of thirteen eligible disabilities that must be shown to adversely affect educational performance, as determined by norm-referenced testing (Individuals with Disabilities Education Improvement Act, 2007). Once perceived educational deficiencies\textsuperscript{13} are identified, students are given interventional services aimed at ameliorating these deficits, with the hopes of curing the student of these impairments and making them whole again (Campbell, 2009). This practice is predicated on the belief that individuals that do not live up to unobtainable measures of normalcy must be fixed and refuses to recognize neurodiverse ways of being as natural. Creating what Davis (2013) calls, “a dominating, hegemonic vision of what the human body should be” (p. 5). In this light, dis/ability is then cast as a “diminished state of being human” (Campbell, 2009, p. 5).

**Social Model of Disability**

With the social model, dis/ability is believed to be a phenomenon produced by social, cultural, political, economic, and historical forces (Baglieri, et al., 2011; Connor, 2013). This model does not conceptualize dis/ability as being housed within the individual; it locates dis/ability within society’s response to their real or presumed impairments (Gallagher, Connor, & Ferri, 2014). As opposed to the medical model of disabilities, the social model is not concerned with how individuals differ from a standardized norm; rather, they are concerned with the meanings that society attaches to these differences (Baglieri, et al., 2011). Scholars working within the social model of disability believe that special education is less

\textsuperscript{13} The author holds that these perceived educational deficiencies may not reflect their true educational performance, rather, in the case of Patrick, these perceived deficiencies may reflect not living up to the unobtainable measures of normalcy that are often compare students like Patrick to cisgender, white, and middle-class norms.
about changing the individual through interventions, and more about removing environmental obstacles that are impeding their success (Baglieri, et al., 2011).

These two conflicting philosophies on dis/ability have two entirely different theories of action. Take for example the puzzle piece\textsuperscript{14}, which is commonly used as the well-known albeit controversial symbol of autism that for some represents the “missing piece”. Scholars working in the medical model of disability assume that something is missing in the individual, and therefore, the “missing piece” must be adjusted to make the piece fit into the puzzle. Whereas scholars working in the social model of disability hold the assumption that something is missing from the puzzle rather than the individual piece; therefore, to make the “missing piece” fit, adjustments must be made to the puzzle as a whole rather than the individual piece.

The conflict between these two diametrically opposed theories of dis/ability presents some significant challenges when it comes to providing a FAPE to students labeled as SD. The IDEA was developed using the medical model of disability, with the assumption that the individual needs to be provided with the supports to make them “normal” again (Reid & Knight, 2006). Limited in the literature are qualitative studies that use student voice to investigate to what extent this medical model of special education is providing students labeled as SD with a FAPE. Hearing the firsthand accounts of individuals marginalized by traditional research methodologies will provide an opportunity to see the perspectives of a student, the student’s family, and the student’s teacher in relation to FAPE, and to what extent these two theories of dis/abilities inform their educational decision-making.

\textsuperscript{14} Although the puzzle piece is used to signify autism, in recent years there has been a movement to change the symbol of autism to a more inclusive image that embraces neurodiversity, rather than symbolizing “something that is missing” from an individual.
Theoretical Framework

In this inquiry I drew on two complementary theories in the methodological design of this study and in the analysis of the findings, Disability Studies in Education (DSE) and Disability Studies and Critical Race Theory in Education (DisCrit). The research methods used in this study were designed and conducted using a DSE framework; however, during the data collection process, emerging themes suggested that the intersection of race and dis/ability impacted the exclusionary educational experiences of the participant in this study. To clearly explore these emerging themes, during the data analysis process I chose to use a framework informed by DSE and Critical Race Theory (CRT) known as DisCrit. Through the application of these two theories, I was able to design and conduct this study in an inclusive way that centered the voice of an individual with dis/abilities and made visible the ways that race and dis/ability affected the educational experiences of this student. In the next section I will provide an overview of each of these theories highlighting the specific foundational tenets of each that guided the design and analysis of this inquiry.

Disability Studies in Education

The American Educational Research Association (AERA) is a national research organization that promotes the use of scholarly inquiry in practice to improve education and shape educational policy across the United States and around the globe. Among the over twenty-five thousand members, AERA is composed of one hundred and fifty-five Special Interest Groups (SIG) that specialize and focus on conducting research following a particular area of inquiry. When the Disability Studies in Education (DSE) SIG was formed in 2000, it consisted of a group of multidisciplinary scholars that worked together to create the following mission statement for this newly formed and evolving group:
The mission of the Disability Studies in Education SIG is to promote understandings of disability from a social model perspective drawing on social, cultural, historical, discursive, philosophical, literary, aesthetic, artistic, and other traditions to challenge medical, scientific, and psychological models of disability as they relate to education (Connor, Gabel, Gallagher, & Morton, 2008, p. 447).

Although not a complete list, in addition to this mission statement, scholars in the DSE SIG created foundational tenets to guide research conducted using a DSE framework. Connor and colleagues (2008) presented the following tenets for conducting research using this framework, DSE scholarship:

1. Welcomes scholars with disabilities and non-disabled scholars working together.

2. Recognizes and privileges the knowledge derived from the lived experience of people with disabilities.

3. Whenever possible adheres to an emancipatory stance (for example, working with people with disabilities as informed participants or co-researchers, not ‘subjects’).

4. Welcomes interdisciplinary approaches to understanding the phenomenon of disability, e.g., with educational foundations, special education, etc.

5. Cultivates interdisciplinary approaches to understanding the phenomenon of disability, e.g., interfacing with multicultural education, the humanities, social sciences, philosophy, cultural studies, etc.

6. Challenges research methodology that objectifies, marginalizes, and oppresses people with disabilities. (Connor et al., 2008, p.449)

Following the founding tenets of DSE, the methodological design of this study foregrounded the voices of individuals with dis/abilities by conducting research with these individuals, which privileged their perspective in the telling of their own stories (Connor & Cavendish, 2020). In addition, a DSE standpoint privileges the social model of disability, that looks to situate dis/ability within the social, political, historical, and economical environment (Tefera, Hernández-Saca, & Lester, 2019). DSE scholars are less concerned
about differences in perceived ability of individuals and focus on what value is placed on these differences by society (Baglieri et al., 2011). Linton (1998) writes:

A disability studies perspective adds a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection—issues that pervade every aspect of the civic and pedagogic culture.

Valente and Danforth (2016) suggest that the personal and collaborative narratives informed by DSE highlight the “realities and complexities of the lives of children, parents, and teachers” in the world of special education (p.6). These collaborative narratives “give life to stories of exclusion as well as to stories of successful inclusive classrooms” (Valente & Danforth, 2016, p.6). This emancipatory stance acknowledges that dis/ability is an “unstable and shifting” category and focuses on the inequitable educational structures that exist because of the social construction of dis/ability (Hernández-Saca, Kahn, & Cannon, p.289). An important goal of research conducted in the DSE tradition is to improve the lives of individuals with dis/abilities based on their “self-expressed needs and desires" rather than having researchers speak for them (Reid & Knight, 2006, p. 18). This study was conducted with the belief that the use of traditional one-size-fits-all research methods create the conditions that inhibit some individuals with dis/abilities from telling their own stories. By using a DSE framework, I was able to design and conduct this study to adapt to the participant, rather than having the participant adapt to the researcher, creating the optimal research environment for the participant to tell his own story.

**DisCrit**

During the data collection stage of this study, it quickly became apparent that the educational experiences of Patrick were not only being affected by his dis/ability label, but also by the color of his skin. To analyze the data in this study I turned to DisCrit to reveal
ways in which the intersection of race and dis/ability impacted the educational experiences of both Patrick and his mother. In particular, I used the following seven tenets of DisCrit, outlined by Connor and colleagues (2016), to provide an intersectional lens to analyze Patrick and his mother’s experiences and revel the interconnected ways in which racism and ableism impacted their educational experiences:

1. DisCrit focuses on ways that the forces of racism and ableism circulate interdependently, often in neutralized and invisible ways, to uphold notions of normalcy.

2. DisCrit values multidimensional identities and troubles singular notions of identity such as race or dis/ability or class or gender or sexuality, and so on.

3. DisCrit emphasizes the social constructions of race and ability and yet recognizes the material and psychological impacts of being labeled as raced or dis/abled, which sets one outside of the western cultural norms.

4. DisCrit privileges voices of marginalized populations, traditionally not acknowledged within research.

5. DisCrit considers legal and historical aspects of dis/ability and race and how both have been used separately and together to deny the rights of some citizens.

6. DisCrit recognizes Whiteness and Ability as Property and that gains for people labeled with dis/abilities have largely been made as the result of interest convergence of White, middle-class citizens.

7. DisCrit requires activism and supports all forms of resistance. (p.19)

In chapter seven I analyze the data presented in this study through each of these seven tenets, providing a detailed look at how racism and ableism have impacted the educational experiences of Patrick and his mother. In an attempt to create an academic bridge between DSE and CRT, DisCrit explores the socially constructed and interrelated nature of both race and dis/ability (Annamma, 2013). In doing so, DisCrit seeks to reveal how racism and ableism work in tandem, operating in powerful institutional and societal structures (including schools) to exclude marginalized students from access to equitable educational opportunity
(Miller, 2019). This framework is particularly useful in analyzing Patrick’s educational experiences as an autistic Cape Verdean student being educated in a restrictive educational placement. DisCrit examines these educational experiences and provides a framework for examining these experiences revealing how racism and ableism have impacted Patrick’s equitable access to education. Chapter two will outline the methodological considerations of this study and provide a detailed look at the research design that was influenced by the tenets of DSE.
CHAPTER 2

A REVIEW OF THE LITERATURE

Do not try and bend the spoon, that’s impossible. Instead, only try to realize the truth… There is no spoon… Then you’ll see that it is not the spoon that bends, it is only yourself.

—Spoon Boy, The Matrix

Introduction

This study is investigating a problem of practice, specifically the glaring gap in the scholarship that foregrounds the voice of culturally and linguistically diverse students labeled as severely disabled (SD) in sharing their educational experiences in restrictive educational settings during the era of high stakes testing and accountability. The review of the literature is informed by a cross-section of several themes including: the segregation and isolation of students of color into restrictive educational placements; the educational track of functional life skills forced on students that are racialized and labeled as dis/abled; the importance of student and family member voice in educational decision making for students with dis/abilities; the rigor-less educational programing provided to students in restrictive placements because of the labels they are given; the exclusionary practices used by educational structures on the administrative, academic, and environment level used to
exclude students with dis/abilities from a FAPE; and the pathologizing of Black mothers that advocate for their Black children by these same educational structures. Since this inquiry was conducted using a grounded theory methodology, I will provide an overview of the relevant literature that helped me to gain a basic understanding of the complexities involved in this issue of investigation and identify key gaps in the scholarship.

This literature review is organized and discussed in the following sections, federal education policy, student voice, pedagogy, curriculum, home-school partnership, and Hip-Hop Based Education. Through this literature, the gaps in the literature reveal that the voice of culturally and linguistically diverse students labeled as SD is faintly heard, suggesting that in order to make visible how these students experience restrictive educational spaces, research must be designed to foreground their voices, as well as value their knowledge base as it relates to their lived educational experiences.

**Federal Education Policy**

The groundbreaking *Brown v. Board of Education* decision in 1954 not only served as a catalyst to the civil rights movement, but also offered significant support to the disability rights movement of the sixties and seventies (Hyatt & Filler, 2011). Following the decision of *Brown v. Board of Education*, advocates for special education argued that students with dis/abilities were a protected class of people, and that they should not be denied access to an equal opportunity to an education because of their dis/ability (Morse, 2000). A Congressional study in 1974 discovered that more than 1.75 million students with dis/abilities were being excluded from schools nationwide, and more than three million were not receiving a quality education that was appropriate to their needs (*Hendrick Hudson Dist. Bd. Ed. V. Rowley*, 1982). The *Brown* decision provided the framework for providing access
to a public education for millions of students with dis/abilities (Chinn, 2004), and the passage of the Education of All Handicapped Children Act (EAHCA) of 1975, now known as the Individuals with Disabilities Education Improvement Act (IDEIA), provided them with an entitlement to such access.

The Individuals with Disabilities Education Act (IDEA) is a federal education policy that was written by the United States government in 1990, and the reauthorization of this bill was enacted in 2004 and called the IDEIA of 2004. With this reauthorization, the IDEIA was modified to align more closely with the goals set forth in the No Child Left Behind (NCLB) Act of 2001. The IDEA was strongly influenced by three previous federal policies, the Civil Rights Act of 1964, the Rehabilitation Act of 1973, and the EAHCA of 1975. In addition to being influenced by these policies, the EAHCA was a congressional response to case law centered around segregation and the inclusion of students with dis/abilities in the public school system, as seen in The Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania case of 1972. Among other provisions, the EAHCA provided students with dis/abilities from age four years and seven months to twenty-one years with procedural safeguards, a right to a due process hearing, a free appropriate public education (FAPE), and access to a program of education and training appropriate to the child’s capacity in the least restrictive environment (LRE) (P.A.R.C. v. Comm. Of Pa., 1972). All of these provisions were included in a student’s individualized education program (IEP), a legal document which includes the student’s current academic performance levels, annual goals that the student will be working to achieve during the school year, and the specific educational services that will be provided in order for the student to accomplish these goals. An IEP team that is typically composed of teachers, the student’s parent or guardian, a school
administrator, support staff, itinerant service providers, and other educational professionals work together to create a student’s IEP. These are the individuals that know this student the best, and therefore the most qualified to make educational decisions on their behalf (until the student is old enough to join the team).

**Free and Appropriate Public Education (FAPE)**

One of the most contentious components of the EAHCA, and the IDEIA which preceded this legislation, is the entitlement of a free “appropriate” public education or FAPE. Many legal scholars have speculated that no substantive definition of what constitutes an appropriate education was included in the EAHCA because what is considered appropriate varies from student to student based on their individual needs (Yell, Katsiyannis, Drasgow, & Herbst, 2003). Osborne (1992) argues that given the significant variation of disabling conditions and the range of severity within each category, to create a broad definition of appropriate would have been an impossible task for congress. These ambiguities in the law created much discussion, controversy, and debate as to not only what constituted an appropriate education, but also what level of services were required to provide students with dis/abilities an educational opportunity commensurate with that experienced by children without dis/abilities (Yell, Katsiyannis, & Hazelkorn, 2007). In *Board of Education v. Rowley*, 1982, the Supreme Court attempted to further interpret the Congressional intent of the concept of FAPE and clarify what constituted a quality FAPE.

Amy Rowley, a high achieving deaf child with an IQ about 120, had the ability to comprehend approximately fifty percent of what was said without the use of a sign language interpreter (Broadwell & Walden, 1988). Amy was performing at or above grade level without an interpreter, and as a result, the district’s multidisciplinary team created an IEP for
Amy that did not include the services of a sign language interpreter (Rowley, 1982). Given that she had only comprehended fifty percent of communication in her classroom, Amy’s family felt that in order to reach her maximum potential and be provided with a FAPE that met her individual needs, she needed the services of the interpreter (Zirkel, 2013). After a due process hearing, the District Court found that because of the disparity between Amy’s achievement and her potential, she was not given the supports necessary for her to achieve her full potential, and therefore was not provided with an equal educational opportunity (Rowley, 1982, p.186).

In granting this case certiorari to review the lower court’s interpretation of FAPE, the Supreme Court stated that the statutory definitions of FAPE did not clearly explain what is meant by “appropriate”, and absent from the statute was a substantive standard prescribing the level of education to be provided to students with disabilities (Rowley, 1982).

In Rowley (1982) the Supreme Court concluded that the original intent of the EAHCA was to provide students with dis/abilities access to education on appropriate terms, provide them with an education that conferred “some educational benefit”, and in doing so, it did not guarantee any particular level of education for these students (Rowley, 1982, p.192). Since Amy Rowley was performing better than the average child in her class, the Court ruled that Amy was receiving an adequate education and added that the intent of the Act was never to provide students with dis/abilities an education that would help them reach their maximum potential (Yell et al., 2007). In addition, the Court stated that the court lacked the specialized knowledge for answering questions of educational policy, and once the court determined whether the requirements of the Act had been met, questions of methodology used in the classroom are to be resolved by the States (Rowley, 1982).
In the dissenting opinion, Justice White argued that the original intent of the Act was to provide more than simply access to education; it was to provide equal access to education by minimizing the effects of a given dis/ability (Rowley, 1982). Justice White argued that although Amy was receiving passing grades, without a sign language interpreter, she could only comprehend less than half of what was said in the classroom, which was hardly an equal opportunity to learn (Rowley, 1982, p.215). In this ruling the Court prioritized access over substance, and as Justice White argued, the majority rejected the belief that a FAPE should provide equal educational opportunity to students with dis/abilities (Rowley, 1982). Legal researchers speculated that Congress purposely created a vague definition of FAPE because what constituted an appropriate education varied from student to student (Yell et al., 2003), which would allow school districts to determine what was “appropriate” based on the individual needs of each student.

The Supreme Court has attempted to provide guidelines for determining if a student is being provided a FAPE, most notably in Board of Education v. Rowley in 1982, and most recently in Endrew v. Douglas County School District in 2017; however, ambiguities in the law still leave FAPE open for interpretation. In Rowley, the Court found that “the intent of the Act [IDEIA] was more to open the door of public education to handicapped children…than to guarantee any particular level of education” and a FAPE needed to provide students with “some educational benefit” (Rowley, 1982, p.192). In Endrew, as a response to the Rowley decision, the Court stated that “a student offered an educational program providing ‘merely more than de minimis’ progress from year to year can hardly be said to have been offered an education at all”, and receiving instruction that aims so low would be
“tantamount to sitting idly….awaiting the time when they were old enough to drop out” (Endrew, 2017, p.14).

It is clear that with these two Supreme Court cases that specifically address the FAPE principle of the IDEIA, the Court has avoided answering the call for a substantive definition of FAPE, leaving the interpretation of this mandate in the hands of school districts to be determined on a case-by-case basis. Looking at the educational experiences of the student, the family, and the student’s teacher in this study provided insight into what the educational experience of an autistic freshman student of Cape Verdean descent revealed about FAPE for this particular student, and to what extent this educational mandate was being fulfilled in practice.

The Impact of Standards-based Reform

The implications of the Rowley decision have significantly impacted students with dis/abilities during the current standards-based reform movement resulting from the NCLB. As states continue including students with dis/abilities in district-wide assessments and holding school districts accountable for their performance on high-stakes standardized tests, the question of what constitutes an “appropriate” education for these students has created much controversy in the field of special education (Lowrey et al., 2007; Zatta & Pullin, 2004; McLaughlin & Thurlow, 2003; Turnbull, Turnbull, Wehmeyer, & Park, 2003).

Until the passage of the NCLB, there was generally a dual assessment system for accountability, one for general education and one for special education (Zatta & Pullin, 2004). Some would argue that for students with dis/abilities, accountability is a new phenomenon (Zatta & Pullin, 2004), and this population of students has been historically excluded from accountability measures. Eventually, without a system of accountability...
monitoring their progress, students with dis/abilities suffered from lowered expectations, and limited access to the general education curriculum and grade-level standards (Thurlow & Johnson, 2000).

Accountability in special education traditionally focused on the school system’s compliance with legal procedural standards, and individual student performance based on the IEP review process, rather than compared to grade-level standards (McLaughlin & Thurlow, 2003). The IEP serves as the instrument for measuring individual progress and is used for both system, and student accountability (McLaughlin & Thurlow, 2003). Special education has operated under a federally mandated accountability system since the passage of the EAHCA, and because of the Act’s emphasis on compliance with legal procedures rather than student performance, students with dis/abilities have been omitted from general education accountability systems (Turnbull et al., 2003). Due to the variability in state accountability systems for students with dis/abilities, as well as growing concerns about poor educational performance, many stakeholders demanded a major shift in special education accountability from compliance with procedures to evidence that these students were learning (McLaughlin & Thurlow, 2003). Soon the National Council on Disability suggested that it was time to shift the focus in special education from access to education to the quality of the education provided (McLaughlin & Thurlow, 2003).

The amendments to the IDEA in 1997 created mandates to provide students with dis/abilities not only access to the general education curriculum, but it also improved the quality of instruction they were provided. The IDEA of 1997 required that children with dis/abilities be included in general state and district-wide assessments, it made each state responsible for developing participation guidelines for students with dis/abilities and gave the IEP team the
The IDEA, in creating the mandate for the participation of students with dis/abilities in state and district-wide assessments, included safeguards to ensure the appropriate participation of each individual student; however, with the passage of the NCLB and the implementation of high-stakes testing and accountability, these ambiguities in the law quickly became open for interpretation. High-stakes testing refers to any assessment that significantly impacts a student’s educational path, and in the case of students with dis/abilities, high-stakes testing directly affects their chances for high school graduation (Christenson, Decker, Triezenberg, Ysseldyke, & Reschly, 2007).

The NCLB is a federal educational policy that targets the academic achievement of all students by holding school districts accountable for their success. For students with dis/abilities, curriculum under the NCLB focuses on building academic skills that are aligned with grade-level content standards. In a three-year longitudinal study, Russell and Bray (2013) found that the major difference between the IDEIA and the NCLB were their respective theories of action; the NCLB promotes standardization through common content standards, whereas the IDEIA promotes an individualized education program based on the student’s needs.

The essential components of the NCLB include the use of content standards, performance assessments, and accountability (Zatta & Pullin, 2004). The passage of this federal legislation has added a new layer of accountability to local school districts, and as a result, states are now
required to implement high stakes testing to all students, without exception. Where the IDEA serves students with dis/abilities by providing individualized supports and instruction, the NCLB serves all students by holding schools accountable for student performance (Schifter, 2011). One of the intended consequences of this legislation was to create high-expectations for students with dis/abilities by holding districts accountable for their performance on standards-based assessments; however, the unintended consequence for students with dis/abilities in creating these challenging expectations, is the accountability piece that places legislative pressure on school districts, compelling them to change from a curriculum focused on specially designed individualized instruction to a uniform curriculum aligned with learning standards. With the simultaneous implementation of two federal educational policies affecting students with dis/abilities, we turn to the scholarship to examine which policy takes preference in the legal discourse.

As a result of the standards-based reform movement in education through the NCLB, McLaughlin (2010) found that there was a trend towards creating standards-based IEPs for SWSDs. Caruana (2015) suggests that since the reauthorization of the IDEA in 2004, standards-based IEPs have been an expectation for SWSDs. Russel and Bray (2013) found that when educators and administrators were left to interpret these educational initiatives and determine how to implement special education policies in the context of standards-based accountability reforms, meeting grade-level content standards took preference over meeting goals in a student’s IEP. In addition, they found that when teachers were required to interpret the mandates of both educational policies, the NCLB took preference because of the clear consequences for schools (Russel & Bray, 2013). Bacon and Ferri (2013) found that when compared to the IDEIA, because of the accountability and tougher sanctions attached to the mandates of the NCLB, the
NCLB often takes precedence in the classroom. What is absent from the literature is a comprehensive look at how the accountability mandates of each federal policy influences the decision-making process of school districts as they are left to simultaneously interpret these two educational policies.

As this review has indicated, greater understanding has been obtained about how federal education policy has affected the educational experiences of students with dis/abilities; however, there remain some significant gaps in the scholarship, as well as, under research areas in this body of literature. One major under researched area of this body of literature pertains to educator interpretations of federal educational policy, which would provide a better understanding of how policy is transformed into classroom practice. The limited studies of educator interpretations did reveal that because of the clear consequences for schools, the NCLB takes preference over the IDEA in classroom practice; however, the two studies discussed did not provide a clear look at the decision-making process’ of educators and school systems in their implementation of federal education policy. Missing from the literature were quantitative studies of academic achievement of students with dis/abilities. All of the quantitative studies of the achievement of students with dis/abilities only addressed students that participated in traditional high stakes testing and did not include students with dis/abilities that participated in alternative assessments. Lastly, missing from the literature was a look at the lived experiences of students with dis/abilities affected by these judicial and legislative acts. The literature did reveal disparities in achievement between students with dis/abilities and students without dis/abilities; however, the literature did not provide a look at how these disparities have impacted the lived experiences of students with dis/abilities.
As these laws and the scholarly commentary on them reveal, the simultaneous implementation of two federal educational policies, with distinctly different theories of action, affect the educational experiences of students with dis/abilities. Although the theories of action of the IDEIA and the NCLB may be distinctly different, the scholarly research suggests that the intended consequences of both policies are raising the expectations for a population of students that has been historically marginalized by the education system. Regardless of which federal educational policy takes preference in the legal discourse, it reveals that the assumptions held by each policy are quite similar. For students with dis/abilities both policies center on the premise that this population of students lack the ability to demonstrate the academic proficiency to meet the statistical threshold of normalcy. Therefore, both policies are used as a way to mitigate their deficiencies and attempt to fix their dis/ability (Campbell, 2009). The implications of the Rowley case suggest that although both policies were designed to mitigate a student’s perceived dis/ability, it appears as though the congressional intent was never for students with dis/abilities to reach their maximum potential, it was only designed to maintain the status quo.

**Student Voice**

The voice of students labeled as SD is very limited in the scholarship, and studies involving individuals that communicate in alternative ways other than spoken or written word are even more limited (Woodfield & Ashby, 2015). I contend that this is not due to the limited number of students labeled as SD with the desire to share their voice as it relates to their educational experiences; rather, it is a reflection of traditional qualitative research that does not acknowledge or value the alternative ways that some students communicate and therefore are unable to provide the research environment designed to support students in sharing the variability of their voice (Maes et al., 2019). Most of the studies that do provide student voice
have been conducted with individuals labeled as learning disabled (LD) (Peters, Klein, & Shadwick, 1998; Connor, 2009); individuals labeled as having Autism Spectrum Disorders (ASD) that communicate by speaking (Biklen, 2005; Saggers, Hwang, & Mercer, 2011); or students labeled as having ASD that type to communicate (Biklen, 1990; Biklen et al., 1992; Ashby & Causton-Theoharis, 2009; Woodfield & Ashby, 2016). Studies that do provide student voice for students labeled as SD are typically qualitative in nature and are on a smaller scale than inquiries involving students with disabilities that communicate through traditional means (Sauer, 2012). Notably, Sauer (2012) found success in capturing voice from students with the complex dis/abilities using the qualitative methodology of portraiture. In the context of working with students labeled as SD, portraiture allows the researcher the flexibility to create a robust narrative using traditional, as well as non-traditional data sources such as, journals, drawings, pictures, and videos in order to share participant voice (Lawrence-Lightfoot & Davis, 1997).

Following the traditions of Disability Studies in Education (DSE), this study was designed to allow students labeled as SD the opportunity to share, “their voices so that they can tell their own stories and share their own goals, aspirations, and needs” (Baglieri et al., 2011, p.273). Given that the voice of students labeled as SD is faintly heard in the literature, this inquiry privileged the knowledge of the participants and resisted replicating the research traditions of speaking for these individuals. In the same respects, the goal of this study was not for the researcher to discover voice, rather, the goal was creating a research environment that acknowledged and welcomed the variability of student voice, supporting the participant in telling their own story through their voice in whatever form they chose. In the process of reaching this goal, this study seeks to problematize traditional understanding of “voice” as

15 The word “voice” in the traditional application typically includes an assumption that voice is a means of an individual expressing themselves through spoken or written word. The parenthesis around “voice” here is used
merely spoken and written expression, highlighting the “heterodoxy” and variability of voice in traditional and non-traditional ways (Peters, 2010, p.599). Building on the work of Woodfield and Ashby (2016), this study seeks to “question, challenge, and reframe conceptions of ‘voice’ in qualitative research in an effort to continually resist privileging spoken voice as the primary and preferred means of communication” (p.438-439). Research that seeks to gain insight into the lived experiences of individuals labeled as SD that privileges “voice” in whatever form it may take is not without controversy.

At the center of the often-contentious debate in the literature surrounding the use of non-traditional forms of communication for students labeled as SD raise such questions as “what is author?” (Foucault, 1977 as cited by Erevelles, 2002, p.25); “how do we know who is speaking?” (Gonzalez, Hernández-Saca, & Artiles, 2017, p.451); and who is speaking, the facilitator or the client? (Mostert, 2010; Ganz, Katsiyannis, & Morin, 2018). All of which have significant implications for qualitative research that seeks to foreground the voices of students labeled as SD that may or may not prefer to communicate through traditional means. Since the scholarship tends to privilege spoken voice, research conducted with participants that do not choose to communicate in this manner often face tougher scrutiny in the literature (Mostert, 2001; Mostert, 2010; Lilienfeld et al., 2014; Ganz, Katsiyannis, & Morin, 2018).

One such method of communication that has drawn criticism by proponents is known as Facilitated Communication. Erevelles (2002) describes Facilitated Communication as “a technique where a facilitator holds the hand, wrist, elbow, or shoulder of a person with a disability as she/he constructs messages by typing on a keyboard or by pointing to letters on an alphabet display” (p.24). Rosemary Crossley and her colleagues at the Dignity through

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to signify that in this study, voice was communicated through not only spoken and written word, but also through the arts, valuing each form of communication equally.
Education and Language (DEAL) Communication Center in Melbourne, Australia used Facilitated Communication as a means for individuals labeled severely autistic to communicate with the support of a facilitator (Biklen, 1990). The facilitator will typically physically support an individual as they press buttons on an augmentative alternative communication (AAC) device to express their feelings, wants, or answer specific questions, with the goal of eventually fading out the support so the individual can use the device independently. Scholars that are skeptical of this technique have branded it as “pseudoscientific” (Lilienfeld et al., 2014); accused proponents of this technique as “exploit[ing] people’s desires to help individuals with disabilities (Ganz, Katsiyannis, & Morin, 2018); and even compared this method to the Ouija Board (Biklen, 1990).

Proponents of Facilitated Communication suggest that this method challenges the widely held assumptions of the communicative abilities of individuals labeled as autistic (Biklen, 1990; Biklen et al., 1992). Erevelles (2002) argues that this debate over the efficacy of Facilitated Communication is brought to light because it challenges conventional knowledge that individuals labeled with SD are unable to live up to positivist notions of normality. In other words, Facilitated Communication challenges the long-held belief by the scientific community that autistic individuals have communication impairments making it impossible for them to be “rational, coherent, and above all autonomous” (Erevelles, 2002, p.27). As Biklen (1990) explains “my initial difficulty in understanding and accepting the claim that children with autism who were mute or highly echolalic could be literate was undoubtedly influenced by what I knew about autism” (p. 301). As an educator that works primarily with autistic students, my beliefs about Facilitated Communication have also been influenced by what I know about autism; however, I have seen non-speaking students
communicate through the use of an AAC device\textsuperscript{16}, as well as through the use of a communication board\textsuperscript{17} in ways that I would have never imagined they could if I had relied solely on their ability to express their feelings through spoken word.

Critics of Facilitated Communication as a scientifically sound method of communication for autistic individuals suggest that this method is “devoid of scientific plausibility” (Lilienfeld et al., 2014), suggest that proponents favor anecdotal over scientific evidence (Mostert, 2001), foster unrealistic hopes for individuals with severe dis/abilities (Danforth, 1997), “exploit people’s desire to help individuals with dis/abilities” (Ganz, Katsiyannis, & Morin, 2018, p. 54), and may potentially be a violation of a child’s right to a free and appropriate education (Ganz, Katsiyannis, & Morin, 2018). In addition, Mostert (2001) argues that Facilitated Communication “emanates from the facilitator and not the client” (p. 31). The problem with these assertions is that many of the critics of Facilitated Communication fail to take into consideration the relationship between the facilitator and the autistic individual, and the individualized nature of the communication between the two. In other words, the critics fail to acknowledge the ability of the facilitator to support the student in sharing their voice because they are focused on the generalizability of the method rather than the individualized nature of communication. In addition, outsiders conducting research on individuals that they haven’t worked with and have no relationship with could potentially create the conditions where students will be unable to perform (Biklen, 1996, as cited by Ganz, Katsiyannis, & Morin, 2018). Through my experiences working with autistic students

\textsuperscript{16} Including such devices as a digital tablet and digital audio output devices

\textsuperscript{17} A communication board is a set of pre-selected visuals that aid in communication. For example, a communication board could feature visual picture symbols that would allow students to point to the visuals to express their needs including “I” “want” “lunch”. It is a method for students to communicate their basic wants and needs using visuals.
for prolonged periods of time, I have learned the nuances of many of my student’s communication styles, and therefore bring knowledge that may or may not be valued and/or measurable by the positivist scientific community. The critics of Facilitated Communication may not be wrong in their assertion that this methodology is not empirically sound, or that it isn’t generalizable, but what the critics fail to take into consideration is the relationship between the autistic individual and the facilitator that may or not be measurable through quantitative means. I would argue that since many autistic individuals prefer to communicate through methods other than spoken expressions, different measures of validity need to be used for research conducted through non-traditional methods of communication such as Facilitated Communication.

Although the methodologies used in this study would not be considered Facilitated Communication as discussed previously, they still raise the question “who is speaking, the researcher or the participant?” given that many of the methods used have been individualized based on the participants' unique needs (Mostert, 2010; Ganz, Katsiyannis, & Morin, 2018). In this context student “voice” was in many ways facilitated by the researcher using an individualized research environment that honored the unique communication needs of the participant, making it less generalizable to the greater population of individuals that find themselves similarly situated. Viewed through the same positivist scientific research standards criticizing Facilitated Communication, the findings of this study may be considered less empirical; however, although less quantitative in nature, I argue that they are equally as valid. From the humanist perspective, we must extend our understanding of communication beyond the “transparent medium of language” and value student voice in both traditional and non-traditional ways (Erevelles, 2002, p. 19). This study attempts to do just that and fill the
gap in the literature by foregrounding student voice in non-traditional ways, responding to the wonderings of Gonzalez and others (2017), that call into question how student voice is conceptualized.

**Pedagogy**

Research on pedagogy for students labeled as SD falls into two major categories, inclusive18 and substantially separate classroom pedagogies. Most studies looking at pedagogy for students labeled with SD are specific to inclusive settings where they are included with their same-aged peers and the general education curriculum is adapted and modified based on their needs. According to Loreman (2017), inclusive education for students labeled as SD is about “removing barriers to participation” (p.2). Expanding on the architectural principle of Universal Design, Universal Design for Learning (UDL) is a common philosophy in inclusive education that is designed to provide access to learning and success for all students (Sokal & Katz, 2015). Rose, Gravel, and Gordon (2014) describe a UDL model that provides students with multiple means of engaging students in learning by designing instruction to incorporate the needs of all learners, multiple means of representation to help all learners communicate, and multiple means of action and expression to demonstrate their learning. Overall, inclusive practices follow the social model of disability with the goal of adapting the environment to suit the learner.

A review of literature on pedagogy for self-contained, or substantially separate classrooms suggested that best practices for instruction included the use of intense interventions to build skill sets. The major instructional techniques found in the scholarship are Applied Behavior Analysis (ABA) and Discrete Trial Training (DTT) (Lovaas, 1987); systematic instruction (Spooner, Browder, & Mims, 2011); least intrusive prompts (Doyle, Wolery, Ault, &

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18 In this context inclusive refers to an educational placement that includes students with dis/abilities learning alongside their neurotypical peers.
Gast, 1988); Direct Instruction (DI) (Adams & Engelmann, 1996); and Picture Exchange Communication System (PECS) (Bondy & Frost, 2011). Most of these instructional techniques follow the medical model of disability and consist of scientific evidence-based practices designed to target specific learning deficiencies with the goal of making measurable progress.

With such a stark difference between the two philosophies of classroom pedagogies, it is imperative that students labeled as SD receive the “appropriate” educational programming based on their needs. The wrong placement could significantly impact a student’s educational trajectory and have serious implications on adult outcomes. By hearing the firsthand accounts of the pedagogical desires of a student labeled as SD, his mother, and his teacher, this study closely examined the extent to which the pedagogy used in a substantially separate classroom is providing Patrick access to a FAPE.

**Curriculum**

A review of the relevant literature pertaining to curriculum for students labeled as SD revealed two major categories of curriculum, functional and academic curriculum. In a systematic review of the top 10 special education journals over a 15-year period from 1996 – 2013, Shurr and Bouck (2013) found that 43% of curriculum articles focused on functional life skills, and 19% focused on cognitive academics. This is an important statistic because studies suggest that with the implementation of the No Child Left Behind Act (NCLB) came a curricular shift in special education from building individualized functional and academic skills to an academic curriculum focused on learning state content standards (Ayres, Lowrey, Douglas, & Sievers, 2011). The classroom implications suggest that if high-stakes testing is aligned with academic content standards, then so too should the curriculum. For students with the most severe dis/abilities, Ayres et al. (2011) argue that the standards themselves are not harmful, it is
what they take the place of that warrants our attention. By narrowing the curriculum and prioritizing academic skills over functional living skills, some scholars believe that students labeled as SD may not develop the tools they need to become independent and productive members of society (Lowrey, Drasgow, Renzaglia, & Chezan, 2007).

Although the literature did not reveal any qualitative studies directly addressing how this curricular shift has impacted students labeled as SD, a look at quantitative achievement statistics reveal that these students are not meeting minimal levels of proficiency based on academic learning standards (Mass. DESE, 2014). By prioritizing academic standards, the scholarship suggests that these standards are unobtainable for students with the most complex dis/abilities. In addition, missing from the literature are qualitative studies that look at the educational desires of these students and their families, and whether or not these desires are being met in the current standards-based reform movement. For some students labeled as SD, it may make more sense to follow a more academically rigorous educational track, and for others, prioritizing functional living skills may be more meaningful. This is the reason why special education services are designed to provide an individualized course of study for each child, as determined by an IEP team consisting of teachers, parents, and other educational professionals. This study provided a firsthand account of the educational experience of a student labeled as SD, his mother, and their teacher offering valuable insight into what access to a FAPE looks like in the context of teaching and learning in a substantially separate classroom in a large urban school district.

**Home-School Partnership**

The benefits of a home-school partnership for students are well documented in the literature, and include improved academic outcomes, positive attitudes, better behavior, and enhanced family well-being (West & Pirtle, 2014; Trainor, 2010; Houser, Fontenant, & Spoede,
These studies suggest that these benefits are not limited to students in general education, but they do not discuss these benefits in relation to the home-school partnership for students labeled as SD. Through my experiences as a special educator, I have seen firsthand how a positive home-school partnership can benefit students labeled as SD in similar ways; however, there can be some significant barriers to collaboration. These barriers include the teacher’s deficit views of the child; caregiver knowledge not being valued; lack of trust or respect; overuse of special education jargon; intimidation; English Language proficiency of family members; and disparity in power between the school and families (Blue-Banning et al., 2004; Brantlinger, 1991; Buchner et al., 2015; Houser, Fontenant, & Spoede, 2015; LaBarbera, 2017; Trainor, 2010; West & Pirtle, 2014).

Missing from the literature is a look at the roles that both the teacher and the family play within the special relationship that exists between the families of students with the most complex dis/abilities and their teacher. Through my experiences I have seen that the most successful home-school partnerships occur when there is a clear line of communication, and both the teacher and the family play the role of advocate for the student. Trainor (2010) suggests that the teacher as both advocate for the student and the service provider may be a conflict of interest. For the teacher, playing the role of advocate and fighting for services can be a dangerous undertaking and put their professional career in jeopardy. This study looked at how the student, the teacher and the family defined their roles in the home-school partnership and implications of this partnership on the teaching and learning in a substantially separate classroom.

**Hip-Hop Based Education**

Informed by the work of Marc Lamont Hill, Love (2014) uses the term Hip-Hop based education (HHBE) to describe educational research that uses the elements of Hip-Hop
culture to “inform pedagogy in formal and non-formal school spaces” (p.108). Irby and Hall (2011) suggest that this emerging field of scholarship is “unsettled in its exact theoretical tenets” (p.219). As scholars continue to engage in debate about the effectiveness of HHBE, teachers, researchers, and community organizers are using HHBE in a myriad of ways (Hall, 2009). Most of the literature pertaining to HHBE investigates the use of HHBE in urban educational spaces that focus on youth perceived as “at-risk” (Irby & Hall, 2011, p.217). In these spaces, Emdin (2011) argues “students begin to perceive that the expected behavior in the classroom is to not question, to be quiet, and to be passive” (p.8). These types of practices are embedded within systems that “privilege Eurocentric knowledge and experience while marginalizing, or even pathologizing, communities of color” (Kim & Pulido, 2015, p.19). Love (2014) argues that Hip Hop is “hardwired” not only to the culture of urban youth, but also “to the learning potential and [their] identities” (p.109). This supports the notion that at its core, Hip Hop can be a vehicle for promoting “civic education and engagement, critical dialogue, and social consciousness among young people” (Love, 2014, p.53). In addition, HHBE provides a space to “critically interrogate and question” Whiteness and its normalcy (Kruse, 2020, p.497). Missing from the literature are detailed ways in which HHBE education can be used as a way of critically examining Eurocentric notions of normalcy in relation to students of color labeled with dis/abilities.

In the literature there is a common misconception that HHBE refers solely to the use of rap lyrics during academic instruction (Love, 2014), undermining the potential of HHBE to address the complexities of “both pedagogy and urban youth culture” (Emdin, 2011, p.2). To address these common misconceptions, Love (2014) outlines five key elements of Hip-Hop, as seen in Table 2.1 (p.54):
### Table 2.1

**The Five Elements of Hip-Hop**

<table>
<thead>
<tr>
<th>Element</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rapping</td>
<td>The verbal art of expression through rhyming lyrics or spoken word</td>
</tr>
<tr>
<td>Breakdancing</td>
<td>An athletic, high-energy dance style set to the break, or the beat patterns, of hip-hop music</td>
</tr>
<tr>
<td>Graffiti</td>
<td>Writings, drawings, or personalized signatures (tags) inscribed on walls or public buildings.</td>
</tr>
<tr>
<td>Deejaying</td>
<td>The use of music to set the tone, educate, and excite partygoers</td>
</tr>
<tr>
<td>Knowledge of Self and Community</td>
<td>The study of hip-hop culture, music, and elements, alongside the examination of issues within one’s surroundings to create positive change in one’s community</td>
</tr>
</tbody>
</table>

Using these five tenets, through HHBE education, young people have the potential to comprehend and analyze how systemic racism has impacted their lived educational experiences (Love, 2016), and “counter the effects of racism by developing empowering identities” (Kim & Pulido, 2015, p.21). Although HHBE education has shown some significant potential as a pedagogical tool for engaging young people in critical dialogue about systemic racism deeply rooted in the educational structures where they are situated, it is not without its criticisms (Love, 2014; Irby & Hall, 2011).

Love (2014) cautions that Hip Hop “can be a space that reinscribes and oftentimes celebrates sexism and violence” (p.125). This is one reason why it is imperative for educators to look beyond commercialized Hip Hop that values this genre for its monetary success rather than its emancipatory possibilities actively fighting against “hegemonic ideas and oppression” (Love, 2014, p.125). In addition, Irby (2014) argues that HHBE scholarship
“has done little more than bolster the tenets of culturally relevant pedagogy, critical pedagogy, social justice education, critical multicultural education, and place-based education perspectives” (p. 26). Kruse (2020) suggests that HHBE also has the potential “to contribute to perpetuating stereotypes and facilitating cultural appropriation” (p.498). This is particularly significant for educators that are navigating urban educational spaces that may not be familiar with Hip Hop culture and/or the culture of their students. Despite these critiques and warnings, HHBE education shows some promising potential for making a positive impact on the lives of youth that “engage in the complex and multi-modal culture of Hip Hop” (Emdin, 2011, p.2).

Based on the work of Ladson-Billings (1995), Love (2014) argues that for HHBE to make an impact on research and classroom contexts, it must be explicitly positioned under the framework of culturally relevant pedagogy (CRP). CRP not only addresses student achievement in urban settings, but also can be used as a method to “accept and affirm their cultural identity while developing critical perspectives that challenge inequities that schools (and other institutions) perpetuate” (Ladson-Billings, 1995, p. 469). Kruse (2020) argues that Hip Hop alone does not constitute CRP; however, it can be used to gain insight into students’ realities and promote social justice. This asset-based pedagogy asserts that all children have “linguistic, literate, and cultural practices that derive from their homes and communities to inform their identities” (Love, 2014, p.114). Love (2014) argues that the “lynchpin” for using HHBE as a pedagogical approach is to understand, recognize, and affirm that students engage in cultural practices that influence their ways of navigating their life spaces (p.115). Hip Hop is where these students find their voice, which provides them with the ability to actively challenge and fight the injustices that they face on a daily basis.
Love (2014) suggests that “improvisation is an indispensable part of Hip Hop and the engine for its creativity” (p.124). As Kim and Pulido (2015) argue, “we can gain insight into teaching and learning first by framing hip-hop as collaborative and democratic, dialogic, improvisational and experimental, critical, and evolving” (p.21). With this in mind, the use of HHBE as a research tool shows some promise, especially with youth of marginalized groups of students in urban settings (Adjapong & Emdin, 2015). Given that improvisation is a key component in Hip Hop, opportunities for eliciting student voice, both inside and outside of the classroom that focus on improvisation, could potentially increase student engagement (Kim & Pulido, 2015). In addition, Adjapong and Emdin (2015) call for an approach to research and education that values the “complex nuances of communication” of students in urban settings through the use of HHBE (p.67). The benefits of improvisation are particularly useful in conceptualizing the methodology that I have termed Improvisational Lyrical Remixing that will be discussed in detail in chapter three.

Conclusion

This review of the literature that was informed by a cross-section of themes that revealed significant gaps in the literature that will be addressed during this study; namely, scholarship that foregrounds the voice of culturally and linguistically diverse students labeled as SD in sharing their educational experiences in restrictive educational settings during the era of high stakes testing and accountability. Chapter three will provide a comprehensive look at the research methodologies that will make visible ways of how race and dis/ability collide in special education practices in urban educational settings.
CHAPTER THREE

TOWARD A PLURALITY OF METHODOLOGIES: RESEARCH DESIGN AND METHODOLOGICAL APPROACHES

Our theoretical framework of [Disability Studies in Education] seeks to centre the people who are researched, and work with them to ensure their perspectives are heard, and lest we do not lose sight of a mantra from the disability rights movement, “Nothing about us without us” (Charlton, 2000, p.1)

—Connor & Cavendish, 2020, p.305)

Introduction

The perspective that I bring to this study is of a cisgender, middle-class, heterosexual white male that does not identify as having a dis/ability. Patrick and his mother Beverly are both of Cape Verdean descent and identify as individuals with dis/abilities. Although I am well versed in dis/ability discourse, no article, book, or documentary could begin to help me see the world from their perspectives, specifically the implicit and explicit ways in which racism and ableism work in tandem to create the exclusionary experiences that impact their life spaces. This study foregrounded their experiences with racism and ableism within the education structures of an urban school district, and privileged their cultural ways of knowing, revealing what it means to be excluded and marginalized by these same structures that purport to value diversity, but refuse to listen to the voices of culturally and linguistically
diverse families. Without coming from the same culture as my participants, I could never fully see things from their perspective or completely understand the gravity of being an individual of color that has a dis/ability whose wants and needs as they relate to educational decision making are ignored. This study required me to look beyond, question, and reconceptualize my shallow understanding of dis/ability that was implicitly informed by white, middle-class educational priorities deeply rooted in the medical model of disability. In doing so, I used a variety of inclusive research methodologies designed to support Patrick and Beverly in telling their stories in their preferred way, which will be discussed in this chapter.

Patrick’s educational journey is not unlike many autistic students trying to navigate the complexities of special education in a large urban school district, only the telling of his story is truly unique. Using the tenets of Disability Studies in Education (DSE), and the foundational special education principles of differentiation and individualization, the research methods used to foreground his story were adapted and modified to meet the needs of the participant and provide the optimal environment for Patrick to share his story as natural and uninhibited as possible. Patrick shares his lived experiences through spoken and written word, illustrations, and visual representations, musically and lyrically, and through movement and rhythm. The data types used to create this story included 17 interviews with Patrick, 17 interviews with his mother Beverly, 14 improvisational lyrical remixing musical interview sessions with Patrick, 10 three-way group discussions, 863 art journal entries including story boarding, 37 original storybooks created by Patrick, school correspondence, and researcher memos. This chapter will describe in detail the research methodologies used in this study providing a rationale for each method.
Refusing to Document Damage

Tuck and Yang (2014) argue that social science researchers who conduct research on students with dis/abilities, as well as, other marginalized populations of students, have primarily been concerned with “documenting damage” within these communities, or with reproducing stories of oppression in their own voices (p.226). This damage-centered research is conducted with the false assumption that to make change within these disenfranchised communities, the researcher must investigate pathology and disease to portray these communities as defective and justify outside help (Lawrence-Lightfoot & Davis, 1997). The flaw in this logic is that pain narratives are incomplete, and never tell the whole side of the story (Tuck & Yang, 2014). By focusing on damage and failure, the researcher leaves out the health and resilience that is the lifeblood of these communities on the fringe. Consequently, the educational experiences of students labeled as SD are rarely examined from a humanistic perspective in the scholarship (Sauer, 2012). Tuck and Yang (2014) suggest that an antidote to the tradition-laden practice of documenting failure is using a desire-centered framework which does not deny the experiences of trauma and pain but sees the present as being enriched by both the past and the future.

In order to avoid replicating stories of damage and pathology, with this inquiry I turned to DSE, which aims to provide individuals labeled as having a dis/ability with an opportunity to tell their own story (Baglieri et al., 2011). Expanding on this goal, this study not only provided a student labeled as SD the opportunity to tell his own story, but it also helped him tell it in his preferred way. This work was not without limitations. Although special education is based on individualization, traditional research in this field uses a “one size fits all” framework (Connor, 2013, p. 495). The use of these traditional research
methodologies rooted in the medical model of disability can be extremely limiting when working with individuals who may or may not communicate through what would be considered traditional means. To provide a vehicle for a student labeled as SD to share their voice this inquiry moved past the hegemony of written and spoken word, and constructed research methodologies that honored both traditional, as well as alternative forms of communication. This study followed the long-held slogan of the dis/ability rights movement, “nothing about us without us”, to privilege the knowledge of individuals who remain unheard, unseen, and underrepresented in the scholarship (Charlton, 1998, 1).

Before conducting this study, I anticipated using several different qualitative research methodologies, but made the determination of which ones to use during the data collection process. This investigation employed many of the research methodologies that were proposed, but in addition, a few of these methodologies were adapted and modified to meet the needs of the research participant. The blending of these methodologies allowed me to create a rich narrative account of the experiences of a student, his mother, and his teacher in a substantially separate classroom that is both thorough and accessible. In this next section I will discuss the research methodologies used during this mixed-methods inquiry.

**Bricolage**

With this inquiry I used the bricolage methodology which included the use of multiple methods during the data collection process. All of which allowed me to provide a student labeled as SD the opportunity to contribute his own story to a growing body of educational research foregrounding the voices of individuals with dis/abilities (Peters, Klein, & Shadwick, 1998; Biklen & Burke, 2006; Connor, 2008; Naraian, 2008; Sauer, 2012; Hernández-Saca, 2016; Coié-Peña, 2018; Tefera, 2019; Woodfield & Ashby, 2016). In
designing this study, paramount to the success of the methodologies used in this investigation was acknowledging the potential differences in communication style that the participant may have and providing access to alternate ways for them to share their lived experiences if needed. As a result, I thoroughly planned for the “complexity and unpredictability of this cultural domain” knowing that this study would evolve during the data collection process (Kincheloe, 2005, p.327). Kincheloe and McLaren (2005) describes the bricolage as a research methodology that actively constructs research methods, as needed, from the tools at hand rather than using predetermined guidelines developed out of context.

In addition to using the bricolage methodology, I relied on my special education expertise of providing differentiated levels of accessibility in the classroom, as well as, a variety of methods that were used, as needed, given the situation at hand. The flexibility of the bricolage allowed me to investigate this issue from a variety of different angles, and given the unique communication style of the participant, it allowed me to tailor my methods to meet the individual needs of the student. As discussed previously, limited in the literature is the voice of students from substantially separate classrooms. Using bricolage with this investigation will allow me to deviate from using universally applicable methodologies that reproduce the traditional voiceless narratives, and instead use methodological flexibility to provide an accurate representation of student voice (Kincheloe, 2005).

Entering this investigation knowing that the research methods would evolve during the data collection process and given the imitations in predicting which methods I would use ahead of time, it was difficult to know the specific ways that this research project would unfold. In preparation, I explored a variety of qualitative methodologies that I believed would help me to create a robust description of the lived experiences of the student, many of
which I used, some I adapted and modified, and others I left in my toolbox. In this next section I will discuss in detail the qualitative methodologies that I used in this inquiry.

**Portraiture**

The portraiture method allowed me to privilege both traditional forms of voice, through spoken and written expression, and alternative forms of voice through visual picture symbols, artistic renderings and lyrical expressions from a student labeled as having dis/abilities (Woodfield & Ashby, 2015). This methodology is framed by the phenomenological paradigm and uses the tenets of ethnography to capture the essence of lived experiences through context (Lawrence-Lightfoot & Davis, 1997). With portraiture, the artistic process is used in the development, data collection, and analysis of the study, and may include such artifacts as photographs, drawings, poems, and other works of art (Marshall & Rossman, 2016). Portraiture resists the positivist view of context as a source of distortion and embraces the perspective that human experience is framed and shaped by context. Context becomes the frame of this inquiry that anchors the individuals and their actions in time and space where the realities of context problematize earlier held assumptions (Lawrence-Lightfoot & Davis, 1997).

Sauer (2012) describes portraiture as a transformative methodology offering emancipatory possibilities for students with dis/abilities by challenging the social construction of dis/ability through positive stories of resilience. According to Lawrence-Lightfoot and Davis (1997) the goal of portraiture is “to combine systematic, empirical description with aesthetic expression, blending art and science, humanistic sensibilities and scientific rigor” (p.3). Portraiture is both a narrative research methodology and a participatory method of analysis between the researcher and participant that is
simultaneously product and praxis (Eddleton, 2012). The underlying “co-constructive structure” of portraiture assumes a shared responsibility of scrutinizing and reviewing the data, where the participant plays an active role in negotiating meaning (Sauer, 2012, p.4). Through this co-constructing of meaning, portraiture offers transformative opportunities not only through the knowledge production of researcher and participant, but also by the reader of the final narrative text (Sauer, 2012). Using the portraiture method, I co-constructed three data chapters that provided narrative accounts of Patrick’s educational experiences, his mother’s educational experiences, and used the metaphor of a siege to portray the exclusionary practices experienced by Patrick and his mother in the Dagobah Public Schools (DPS). The result was a product that is accessible to scholars and practitioners, as well as the participants themselves.

**Metaphor**

The use of metaphors to describe autistic people and the experiences of their families is not without controversy. A historical review of the use of metaphor in autism discourse reveals that the use of metaphor in autism is heavily rooted in the medical model of disability, oftentimes using dominant cultural notions of normalcy to paint a deficit view of a “normal child” taken prisoner by a debilitating disease. In their comprehensive review of the use of metaphor in autism discourse, Broderick and Ne’eman (2008) argue for the use of counter-narrative, “in the process of cultural critique and resistance to ideological hegemony” (p.474). Following this call to action, in this inquiry I presented the exclusionary practices used by the DPS with a familiar metaphor used in autism discourse, the siege.

The siege has been used by authors to create metaphoric notions of an outside force trapping a “normal child” within a seemingly impenetrable exterior, suggesting that the
autistic child needs to be rescued from within because there are no other means of escape (Park, 1967). Botha and colleagues (2021) warn that when autism is seen through this perspective, “then metaphors around the destruction of [autism] may be used without consideration for the life attached-- autism becomes an opponent, a disembodied force” (p.3). Following the social model of disability and the notion that dis/ability in education is a function of the learning environment, rather than a specific flaw or deficit in the individual, to create this “counter-narrative” I used the siege metaphor to illuminate how the actions of Patrick’s school and the school district in many ways limit Patrick’s educational opportunities “trapping” him within an exclusionary “one-size-fits-all” educational environment for which any attempt of escape seems futile. By applying this metaphor to describe and interpret Patrick and his mother’s experiences and their relations with his school and his educators, this allowed me to examine the educational practices of the school and the school district, how these practices impacted both teaching and learning and ultimately the educational experiences of both students and families navigating the complexities of this environment. Viewing Patrick and his mother’s experience through the siege metaphor created the vantage point to see clearly that although these accounts seem to be in direct conflict, the forces of exclusion work to isolate, surround, and paralyze both Patrick and his mother in similar ways. Most importantly, the use of this metaphor allowed me to shift the ableist and deficit-centered gaze from the individual to the system, presenting any perceived deficit or deficiency as a reflection of Patrick’s learning environment rather than an intrinsic flaw that must be overcome in order for him to become “normal.”

A review of literature related to the battlefield tactic of the siege found that the siege typically followed a predictable progression that occurred in several intentional stages
(Levithan, 2013) and typically involved either surrounding the enemy, the enemy retreating to a fortified place, or a combination of the two (Egan, 2016). A less nuanced definition from Dictionary.com defines a siege as, “the act or process of surrounding and attacking a fortified place in such a way as to isolate it from help and supplies, for the purpose of lessening the resistance of the defenders and thereby making capture possible.” Using this definition with the historic and ableist application of the siege metaphor, autism would be considered the outside force “surrounding and attacking” the autistic individual, or “fortified place”, causing isolation from “help”, and thereby placed in a state of “capt[ivity].” With this application of the metaphor suggesting that a “normal child” has been besieged and taken captive by autism, with no viable method of escape. This would follow the medical model of disability suggesting that there is something intrinsically flawed in the autistic individual and therefore mitigation strategies need to be used in order to cure them of their dis/ability. Essentially resulting in escaping their autism, and ultimately their captor.

For this inquiry, metaphor was used as a method to structure and draw parallels between Patrick and Beverly’s experiences with that of a siege. To this end, Patrick’s school and school district will be portrayed as the outside force “surrounding and attacking” Patrick and his mother, not autism. The exclusionary practices used by the school and the school district will be depicted as the agents of “isolation”, strictly limiting access to educational and occupational opportunities, rather than the historic connotations suggesting isolation from an opportunity to become “normal”. Lastly, these same exclusionary practices will be seen as, “lessening the resistance of the defenders”, as seen in Patrick’s compliant behavior and Patrick’s mother limiting her outward expression of resistance and eventual surrender. Although both participants experience the siege in different ways, I contend that the result is
a forced paralysis that surrounds, isolates, and physically and emotionally squeezes them both into submission.

**Autoethnography**

In the early stages of this inquiry, my intention was to create portraits of Patrick, and his mother, and also create a portrait of myself as the student’s teacher. While analyzing the data, I felt that the themes uncovered through this investigation revealed significant findings related to the use of exclusionary practices by Patrick’s school and school District. At the onset of the study, I wanted to prioritize student and family voice in the telling of their lived experiences. I felt that by including a portrait of myself that it would in many ways interfere with the telling of Patrick and his mother’s lived experiences. Instead, I chose to focus on the specific exclusionary practices and outside forces actively working against Patrick and Bev in educational settings. To accomplish this, I chose to use my personal experiences to “illuminate the culture under study” (Ellis, 2008, p.50), which are seen throughout this inquiry.

As Marshall and Rossman (2014) suggest, “at their best, autoethnographies are counter-narratives that challenge the predominant grand narratives of a particular aspect of the social world by providing alternative, deeply personal viewpoints” (p.24). As a special education teacher working against the grain of traditional positivist epistemologies, my goal of this inquiry was to create a research environment that allowed these counter-narratives to be told. In doing so, I used my personal experiences and professional judgment to adapt and modify research methods to meet the needs of the participants which made it difficult, in positivist terms, to remain objective. Instead, I chose to, “acknowledge and accommodate
subjectivity, emotionality, and [my] influence on research, rather than hiding from these matters or assuming they don’t exist” (Ellis, Adams, & Bochner, 2011, p.274).

With this study I conducted ten three-way group discussions over dinner that allowed me to share my personal experiences with both Patrick and Bev. This created a research environment that allowed us to have a group conversation in a relaxed research environment, ask each other questions, share our educational experiences, and make connections with and between our experiences. Although my experiences as an educator of students labeled as SD were in many ways different compared to Patrick and Bev, this study provided the opportunity for us to come together and try to understand the role that we all play in educating Patrick, and how the labels attached to him are reflected in his education. Through the process of co-constructing these portraits, listening to the experiences of the participants, and reflecting on my own experiences, I was able to illuminate themes related to the experiences of a student labeled as SD and his family accessible to not only insiders, but outsiders as well (Ellis, Adams, & Bochner, 2011).

**Data Collection**

This study was conducted using the bricolage methodology which provided the methodological flexibility for me to adapt and modify research methods to meet Patrick’s needs and the situation at hand. Although methods evolved during the data collection process, I have provided protocols for the methods that I used during the data collection process. Table 3.1 displays all the data types used during the data collection process.
Table 3.1

*Data collection types and sample sizes*

<table>
<thead>
<tr>
<th>Data Type</th>
<th>Sample Size (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews with Patrick</td>
<td>17</td>
</tr>
<tr>
<td>Interviews with Beverly</td>
<td>17</td>
</tr>
<tr>
<td>Three-way discussions over dinner</td>
<td>10</td>
</tr>
<tr>
<td>Art Journal Entries</td>
<td>863</td>
</tr>
<tr>
<td>ILR Sessions</td>
<td>14</td>
</tr>
<tr>
<td>Original Storybooks</td>
<td>37</td>
</tr>
<tr>
<td>Researcher memos</td>
<td>17</td>
</tr>
</tbody>
</table>

*Note.* Table 1.1 displays all the data types used during the data collection process and provides the sample size for each.

**Art Journaling**

This investigation yielded 863 art journal entries, created by Patrick, that consisted of art renderings depicting events that happened over the course of 96 school days at UCA between January 2019 and June of 2019 that were conducted at Patrick’s home as part of this research study. To help initiate conversation during the interview process and to get a detailed look at Patrick’s educational experiences while attending UCA, I had Patrick keep an art journal in which he recorded six to ten entries, each day, to recap the events of the school day. The journal had two major components, each with a prompt. The prompts included “draw what happened at school today” and “how did each event make you feel?” The goal of this art journal was to gain insight into Patrick’s educational experiences at UCA, how these experiences made him feel, and if those feelings changed over time. The journal
was used not only as a conversation starter to break the ice during the interview process, but also provided some very detailed accounts of his experiences.

To accompany the daily journal, Patrick was provided with a variety of art supplies, and a sketchbook to encourage him to create works of art throughout the course of this investigation. In addition to the daily art journal, Patrick independently created 37 original story books that followed the adventures of a boy named “Jarren” and or a boy named “Tristan.” These books that he created provided me valuable insight into Patrick’s educational experiences by providing me with a detailed collection of art renderings that I could use to compare with his art journal. Specifically, I was able to compare how he drew emotions, both on the faces of and in the body language of people in his books to the emotions that he drew on himself and his friends in his art journals. In Figure 1, Patrick writes a story called *Jaren Get in a Fight*, and on the cover, Patrick draws two characters looking angry, with downward facing eyebrows. I was able to compare the drawings in this book with his art journal entries to show that Patrick is able to accurately depict negative emotions in his drawings. This allowed me to examine and analyze situations when he described himself as experiencing a positive emotion such as “happy”, but his drawings showed him with a seemingly angry face with downward facing eyebrows.
Note. Two characters are expressing emotions of concern, while the other two appear to be angry.

In addition to serving as an insightful entry point into Patrick’s creative talents, these books provided me with insight into Patrick’s interests, allowing me to build rapport with him that helped during the interview process. For example, many of the Jarren and Tristan stories involve Jarren and Tristan taking public transportation and watching particular videos on YouTube. In one book Jarren was watching Tom and Jerry Boo the Woods and used this to ask Patrick if he ever watched this video at school. He then proceeded to describe times when he watched the video in math class, which I then used as an opening to ask him to describe what he does in math class. Patrick’s art renderings allowed me to examine his
educational experiences, served as a way to elicit more detailed interview responses to questions about academics, and most importantly provided me valuable insight into how he perceived his life spaces.

**Free Draw**

The free draw book began as a slightly different opportunity for Patrick to create art, in addition to the art journal, to help gain insight into his educational experiences. The protocol for the free draw book was that Patrick could draw anything that he wanted to in his free draw book, and use as many pages as he wanted, but first he was encouraged to complete the daily art journal.

The purpose of the free draw book was to get a closer look at Patrick’s lived experiences at a particular place in time. During this study Patrick decided not to use the free draw book, and instead, created his own original books by stapling together white printer paper. As mentioned previously, the books detailed Patrick’s original characters Jarren and Tristan involved in various adventures including, *Jarren Trouble with Money, Jarren go to Camp, Jarren Lean*[^19] *About Strangers, Tristan Goes to School, Tristan’s Bedtime,* and *Tristan with Dad* just to name a few. The topics brought up in each book served as good conversation starters for interview questions. By looking at what Patrick drew freely and asking him to elaborate on their drawings (by speaking[^20], in writing, or with other supports), I gained a better understanding of how he experienced the world, what he enjoyed, what he

[^19]: Some of Patrick’s written responses and artistic renderings include misspellings of words. With this inquiry my goal is to privilege Patrick’s voice and honor the ways in which he shares it, for that reason I will include Patrick’s voice verbatim throughout this investigation and not attempt to correct any perceived misspellings.

[^20]: Drawing on the work of Botha et al. (2020), this study acknowledges that the term “non-verbal”, which is commonly used to refer to autistic individuals that do not speak, is not synonymous with “non-communicative, or non-thinking” (p.1). This study instead uses the term “non-speaking” to highlight that many autistic individuals choose to communicate in less socially valued ways, by speaking in some environments and not in others, and rejecting the idea that speaking and non-speaking are dichotomous (Botha, Hanlon, & Williams, 2020).
desired, and this helped me tailor my interview questions and my methods based on his thoughts and feelings.

**Interviews**

During this study, 17 interview sessions were conducted with both Patrick and his mother. Each session typically began at three o’clock in the afternoon before Patrick came home from school. I began by interviewing Bev in her living room for approximately forty-five minutes each session until Patrick came home on the bus from school. Once Patrick was unpacked and situated there was an overlap of about fifteen minutes that consisted of one-to-one interviews with Bev that sometimes transformed into three-way interviews involving Patrick, myself, and Bev. The interviews that I conducted with Bev required no specific individualized supports and consisted of traditional back and forth conversation. I began with a list of specific questions that were generated after analyzing the interview sessions from the previous week, and based on Bev’s responses, additional questions were asked. Patrick’s sessions followed a routine and predictable schedule; however, many times we deviated from the plan based on Patrick’s responses.

At the beginning of this inquiry, I used the special educational instructional strategy of least to most intrusion to create an interview protocol that included differentiated opportunities for Patrick to respond using his preferred method of communication. This strategy assumes that the student is capable of accomplishing a task with little to no assistance. If Patrick was showing difficulty with the task, I provided assistance that began by providing the least amount of support, and if Patrick was still having difficulty, the level of assistance progressed to the most amount of support. During interviews with Patrick, least to most prompting started with spoken interactions between him and myself; if Patrick was
having difficulty elaborating on the questions asked, I provided him the option to write down his answers or draw pictures to respond to my questions; if he was still having difficulty, I provided him with visual supports in the form of visual picture symbols to aid in communication during interactions.

Patrick’s interview sessions began by making casual conversation, led by Patrick, that typically began by him asking me how things were at FDS, what train station I visited recently, and how my family was. Next, he would complete his art journal entry depicting what happened during the school day. We would then review his art journal entries for the week, I would ask him specific questions based on these drawings, which would lead to follow-up questions based on his responses. When we were done reviewing the art journal entries, I would typically ask him some additional questions based on his drawings or to follow-up on specific topics that he didn’t elaborate on. The last part of the interview consisted of responding to a series of questions to the beat of a chosen song, the protocol for which will be discussed in the following section.

In proposing this study, I planned on creating audio, as well as visual recordings of the interviews to capture body language, emotion, and self-stimulatory behavior that could not be captured with audio alone. Instead, during the data collection process I chose to use only audio recordings of interviews and took notes about Patrick’s body language during interview sessions, to protect his privacy. Many students labeled as SD exhibit physical manifestations of emotions based on their current feelings and moods. In certain situations, if someone is feeling anxious, he or she may not be able to describe their emotions through speaking, but they might exhibit a specific physical response to anxiety. For example, an individual might rock back and forth in their chair, twirl their hair, or click their pen
whenever a sensitive subject becomes the topic of conversation. By recording these movements in my notes, I was able to notice the intricacies of Patrick’s communication style, not just through spoken, written, and visual communication, but also through body language.

**Improvisational Lyrical Remixing**

During one of the first interview sessions with Patrick, I noticed that he enjoyed listening to music in the background, often moving his body and humming to the beat of the song. I reflected back to our time together in Sensory Arts class when we would listen to one of several routine playlists of songs that consisted of *Kidz Bop* remixes of popular songs sung by kids. Oftentimes during instruction, I found myself giving directions to the beat of the song playing in the background, and if I asked questions during instruction, Patrick would respond back to me singing to the beat of the song. With this in mind, I developed a method that I call Improvisational Lyrical Re-mixing (ILR).

According to Knobel and Lankshear (2008) remix means “to take cultural artifacts and combine and manipulate them into new kinds of creative blends”. ILR blends music improvisation (an intervention used in music therapy) with lyrical improvisation (influenced by freestyle rap and the cypher) to create a remix of a popular song that is then used in qualitative research. With ILR Patrick selected a familiar song of his choosing and sang or rapped over the original track by improvising original lyrics that adhere to set guidelines. For example, if Patrick selected, “The Wheels on the Bus”, I would pose a question to Patrick to the beat of the song and Patrick would then respond to the question by following the beat of the song and changing the lyrics to answer the question. If Patrick digressed from the topic or got off track, I would then guide him back to topic by asking a follow up question through song by changing the original lyrics and keeping the same familiar beat.
Much like music improvisation in music therapy, ILR is a moment-by-moment process where I had to pay close attention to the Patrick’s responses, as well as body language in order to assess whether he should continue improvising lyrics, and/or ask follow up questions to keep Patrick on topic (Kim et al., 2009). ILR supported Patrick during interviews that required joint attention by using a predictable musical structure (familiar song), which supported him in accessing thoughts, feelings, emotions, and experiences, as Liu et al. (2009) suggests, by bypassing the supervisory areas of the brain that may be hampering the recall of these expressions. This method helped Patrick enter the “psychological flow state, which describes a subject’s complete immersion in creative activity, typified by focused self-motivation, positive emotional valence, and loss of self-consciousness” (Liu et al., 2009, p.6). After experimenting with ILR for the first time, we had some early success, but I wanted to do some research into the brain to help me understand how this method could potentially be used to help Patrick share his experiences and desires through music.

Navigating medical journals through a DSE lens proved to be an incredibly laborious and difficult task. I found that the articles that specifically addressed the brain in autistic individuals were heavily rooted in the medical model of disability, refusing to see difference as anything other than pathology. What I did discover was that many individuals have differences in joint attention, and the research suggests that using ILR could potentially limit physiological and environmental obstacles that serve as barriers to communication and create the optimal condition for the uninhibited “flow” of expressions.

The prefrontal cortex is the area of the brain that, among other things, is responsible for executive functioning (Courchesne et al., 2011), which refers to higher-order processes
that include planning and strategy formation, verbal fluency (including speaking), and cognitive flexibility (Bramham et al., 2009). Using structural neuroimaging, Carper and Courchesne (2005) identified differences in development in the frontal lobe structures of a small sample of autistic children, which included a localized enlargement of the prefrontal cortex (Bramham et al., 2009). In a study comparing postmortem tissue from the prefrontal cortex of autistic children to that of their neurotypical-peers, Courchesne et al. (2011) found that the autistic children had 67 percent more neurons in the prefrontal cortex than those in the control group. These findings suggest that differences in language, communication, social interaction, and cognitive functions could potentially correlate with differences in the prefrontal cortex.

In addition to differences in language, communication, social interaction, and cognitive functions, some autistic children may also approach joint attention differently than their same-aged peers. In the context of interviews, joint attention refers to the process of two-way spoken and/or non-spoken communication between the researcher and the participant, whereas both are mutually interested in the same object or event and share attention with each other (Vaiouli, Grimmet, & Ruich, 2013). Differences in joint attention can create some significant barriers to communication when using traditional qualitative interview methods that presuppose a child’s ability to share experiences with another person. Music has been used by therapists as an intervention for supporting communication, joint attention, and social engagement in autistic individuals (Simpson & Keen, 2011). One research-based strategy is known as music improvisation (Vaiouli et al., 2013). With music improvisation, the music therapist uses live music to interact with the client by providing a predictable, empathetic, and supportive musical structure to attract and engage the child.
In addition to facilitating motivational and interpersonal responses in autistic children, music has also been shown to engage these students for longer periods of time than their neuro-typical peers (Simpson & Keen, 2011). The implication for these studies supports the notion that music-based strategies in qualitative research could potentially be used to engage autistic children for longer periods of time, as well as support them in sustaining joint attention during the interview process.

Missing from the scholarship are empirical studies that use music and/or music improvisation as a research method to support autistic children in qualitative studies. Although music-based research methods are limited in the literature, literature on free-style rap and lyrical improvisation provides some insight into how the brain functions under improvisational conditions which may have significant implications for the use of ILR as a research method. In a study of spontaneous lyrical improvisation using functional magnetic resonance imaging (fMRI) on the brain, Liu et al. (2012) found that, “improvised performance [was] characterized by dissociated activity in medial and dorsolateral prefrontal cortices, providing a context in which self-generated action is freed from the conventional constraints of supervisory attention and executive control, facilitating the generation of novel ideas” (p.1). In other words, during improvisation the prefrontal cortices are bypassed, and different regions of the brain are used to generate lyrical content. The implications for this research suggest that lyrical improvisation allows an individual to access and recall information using different parts of the brain. Using music improvisation as a research method could potentially help the participant bypass areas of the brain responsible for executive functioning and provide the “cognitive flexibility” to generate original creative content from a different region of the brain (Liu et al., 2012, p.5).
Through ILR, Patrick was able to share his educational experiences, as well as his educational desires in an innovative way that provided him an opportunity to share his voice as naturally and uninhibited as possible.

**Three Way Discussions Over Dinner**

During the course of this investigation 10 three-way discussions over dinner were conducted, which included Patrick, his mother, and myself. These sessions began as three-way discussions in a casual and relaxing research environment where we chatted about our educational experiences, personal interests, and had general discussions about current events. These discussions evolved naturally during the data collection process and began with Beverly sharing a pizza she had ordered during one of our interview sessions and quickly turned into Beverly insisting that she introduce me to some traditional Cape Verdean dishes such as rock beans, Cachupa, and rice and beans the way her family had traditionally made it. After a few weeks of Beverly and Patrick inviting me into their home to conduct interviews, every session transitioned to a three-way conversation in Beverly’s dining room with all of us eating homemade food and having casual conversation. After most dinners Patrick would make dessert which consisted of seven chocolate chip cookies, one for me, one for Bev, and five for himself. On one occasion I jokingly said that I wanted to have two cookies, so he made eight instead of the usual seven.

While the cookies were baking in the oven, our three-way discussions transitioned to the living room where I would ask Patrick a few follow-up questions to our early interview or what was discussed over dinner until the cookies were done. While we were eating the cookies, I would conduct member checks and review the data that I collected from the previous week with Patrick and Beverly and verify that the trends that emerged accurately
represented Patrick and his mother’s experiences. These discussions also provided an opportunity for each participant to expand on emerging themes through three-way conversation. Actively engaging each participant in discussion and questioning helped identify new trends that were not always revealed through interviews, providing new entry points for future interviews.

During one specific conversation about emerging trends, the data I had collected suggested that Patrick could concentrate better in noisy environments. I had noticed that whenever I interviewed Patrick there was some sort of background noise present, usually the noise came from something that Patrick had turned on, like his phone, computer, desk fan, etc. Beverly then remembered instances where Patrick would create his books with the television on, YouTube on his computer, and while he was listening to his music, all the while he was able to answer any question that she asked him. Patrick then expounded on this idea and discussed how he liked the sound of train screeching when he was making his art and didn’t like working in silence. This conversation provided me with valuable insight into how Patrick navigates his life spaces which emerged because of our casual three-way discussion over dinner.

**Data Collection Timeline**

During this investigation, I collected data in four phases: *getting to know the family*, *coming together*, *data analysis*, and *creating narratives*. This section will begin by providing an overview of the research timeline, Table 3.2, containing all four phases of the data collection process, followed by a detailed presentation of each distinct phase.
Table 3.2

Data Collection Timeline

<table>
<thead>
<tr>
<th>Date Range</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>April 2018</td>
<td>Dissertation Proposal Approval</td>
</tr>
<tr>
<td>September 2018</td>
<td>IRB approval</td>
</tr>
<tr>
<td>September - October 2018</td>
<td>Search for informants, Selection of informant and family, Signed consent forms</td>
</tr>
<tr>
<td>November 2018 – January 2019</td>
<td>Phase 1: Getting to know the student, Build trust and rapport, Daily Art journal and free draw, Weekly or bi-weekly interviews</td>
</tr>
<tr>
<td>January - June 2019</td>
<td>Phase 2: Coming together (Ongoing daily journals, free draw, and bi-weekly interviews with student), Interviews with Patrick and Bev, Three-way discussions over dinner</td>
</tr>
<tr>
<td>Ongoing</td>
<td>Transcription of interviews, Coding, Looking at trends for interview questions</td>
</tr>
<tr>
<td>July 2019 - July 2020</td>
<td>Phase 3: Data Analysis (Ongoing daily journals, free draw, and interviews), Community and In-school observations</td>
</tr>
<tr>
<td>July 2020 - April 2021</td>
<td>Phase 4: Creation of Narratives, Member checks</td>
</tr>
<tr>
<td>Fall 2021 - Early 2022</td>
<td>Dissertation Defense</td>
</tr>
</tbody>
</table>

Phases of the Research Process

During Phase 1, see Table 3.3, I began by building on the pre-established rapport that I developed during my seven-year relationship with Patrick and Bev to help determine an entry point for interviews. In addition, this also allowed me to determine if the chosen research methods needed to be modified or replaced.
Table 3.3

*Phase 1: Getting to know the family*

<table>
<thead>
<tr>
<th>Method</th>
<th>Participant(s)</th>
<th>Frequency</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Art Journal</td>
<td>Patrick</td>
<td>Write in together during interviews</td>
<td>varied</td>
</tr>
<tr>
<td>Free Drawing</td>
<td>Patrick</td>
<td>Optional</td>
<td>varied</td>
</tr>
<tr>
<td>Interviews (based on journal entries)</td>
<td>Patrick &amp; Bev</td>
<td>Weekly</td>
<td>30 – 60 minutes</td>
</tr>
<tr>
<td>Teacher Journal and memos</td>
<td>Myself</td>
<td>As needed</td>
<td>varied</td>
</tr>
<tr>
<td>Transcription of interviews</td>
<td></td>
<td></td>
<td>ongoing</td>
</tr>
</tbody>
</table>

During Phase 2, see Table 3.4, I interviewed Patrick and Bev on a bi-weekly, and sometimes weekly basis in their living room. Each interview was audio recorded and ranged from thirty to forty-five minutes for each participant. I began each session by interviewing Bev and continued until Patrick’s school bus arrived and he hung up his backpack and changed into his comfortable clothes.

Each interview session with Beverly began by reviewing notes from the previous interview to verify accuracy, as well as ask follow-up questions. With Beverly, I started with several predetermined questions and often ended up generating more based on our discussion. Following the work of Charmaz (2014), many of the questions were left open-ended, and created opportunities for unanticipated stories to emerge. For example, on one occasion I started the interview by asking Beverly how she would describe “autism” to another parent. This transformed into Bev detailing the touching and emotional exchange between her and the maintenance person at her apartment building. In chapter five she
describes the moment when Patrick’s autism diagnosis finally hit her and revealed very personal and honest feelings about having a son with autism. Through this particular exchange I realized that I needed to focus more attention on Beverly’s lived experiences as a mother of an autistic son and include her as the second protagonist of the story that was unfolding in her living room.

During each interview with Patrick, I began by reviewing art journal entries and his free drawing book entries from the previous week. We would look through the artwork together and I would ask him questions based on these drawings. After reviewing each piece of artwork, he created, I reviewed with Patrick what we had discussed the previous week to make sure that my findings and interpretations were accurate. This was followed by asking Patrick specific questions based on the drawings that he made, leading to discussions about his educational experiences that helped answer my research questions. Once we were finished reviewing the artwork, I conducted an improvisational lyrical remixing session to provide Patrick an opportunity to respond to interview questions with two to three songs of Patrick’s choosing. The first song was a warm-up and I usually asked him questions to the beat of a song of his choosing that connected to his interests, for example, what he ate for lunch, what he did at school, what his friends were doing, and/or what train station he wanted to sing about, etc. During the second and subsequent songs I asked Patrick questions directly connected to the research questions of this study. During Phase 2, I interviewed Patrick and Bev 17 times, and conducted 10 three-way discussions over dinner.
Table 3.4  

Phase 2: Coming together

<table>
<thead>
<tr>
<th>Phase 2: Coming together</th>
<th>January – June 2019</th>
</tr>
</thead>
<tbody>
<tr>
<td>Method</td>
<td>Participant(s)</td>
</tr>
<tr>
<td>Interviews</td>
<td>Patrick &amp; Bev</td>
</tr>
<tr>
<td></td>
<td>Bi-Weekly</td>
</tr>
<tr>
<td></td>
<td>60 – 90 minutes each</td>
</tr>
<tr>
<td>3-way discussions over dinner</td>
<td>Patrick, Bev, and myself</td>
</tr>
<tr>
<td></td>
<td>Bi-Weekly (ten times total)</td>
</tr>
<tr>
<td></td>
<td>45 – 60 minutes</td>
</tr>
<tr>
<td>Art Journal</td>
<td>Patrick</td>
</tr>
<tr>
<td></td>
<td>Write in daily</td>
</tr>
<tr>
<td></td>
<td>Each school day</td>
</tr>
<tr>
<td>Free Drawing</td>
<td>Patrick</td>
</tr>
<tr>
<td></td>
<td>Optional</td>
</tr>
<tr>
<td></td>
<td>varied</td>
</tr>
<tr>
<td>Improvisational Lyrical Remixing</td>
<td>Patrick</td>
</tr>
<tr>
<td></td>
<td>Bi-Weekly</td>
</tr>
<tr>
<td></td>
<td>2 - 3 songs each session</td>
</tr>
<tr>
<td>Interviews (based on journal entries)</td>
<td>Patrick</td>
</tr>
<tr>
<td></td>
<td>Bi-Weekly</td>
</tr>
<tr>
<td></td>
<td>30 – 60 minutes</td>
</tr>
<tr>
<td>Teacher Journal And memos</td>
<td>Myself</td>
</tr>
<tr>
<td></td>
<td>As needed</td>
</tr>
<tr>
<td></td>
<td>varied</td>
</tr>
<tr>
<td>Transcription of interviews</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>ongoing</td>
</tr>
</tbody>
</table>

Due to the sheer volume of the data collected in the first two phases of this investigation, Phase 3, see Table 3.5, took longer than originally anticipated. During Phase 3 I finished transcribing all the interview sessions, three-way discussions over dinner, and Improvisational Lyrical Remixing (ILR) sessions, analyzing and coding a total of 757 pages of transcription. I used a transcription service for most of the interviews, but the transcribing of interviews that took place in phase one, and all the ILR sessions were transcribed by the researcher. Since the ILR sessions contained music in the background, the transcription service would not transcribe these sessions. In addition, the data analysis involved coding and examining 863 art journal entries, and 37 of Patrick’s original story books with each containing 15-20 pages of artistic renderings.
Using grounded theory initial coding (Charmaz, 2014), I reviewed each of these data types and I created codes to begin to explain how each participant responded to their experiences in the Dagobah Public Schools (DPS), what meanings these experiences held, and how and why these experiences evolved (Charmaz, 2014). I then studied, sorted, and categorized these data with focused coding.

**Table 3.5**

**Phase 3: Data Analysis**

<table>
<thead>
<tr>
<th>Method</th>
<th>Participant</th>
<th>Frequency</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member Checks</td>
<td>Patrick &amp; Bev</td>
<td>As needed</td>
<td>As needed</td>
</tr>
<tr>
<td>Coding</td>
<td></td>
<td></td>
<td>ongoing</td>
</tr>
<tr>
<td>Identifying themes</td>
<td></td>
<td></td>
<td>ongoing</td>
</tr>
<tr>
<td>Transcription of interviews</td>
<td></td>
<td></td>
<td>ongoing</td>
</tr>
</tbody>
</table>

During Phase 4, see Table 3.6, I created the final narrative portrait of each participant which involved meeting with Patrick and Bev, as needed, to verify the accuracy of each narrative. I created Beverly’s narrative using data collected from both our one-on-one interviews and the three-way discussions over dinner. For Patrick’s narrative, to foreground the variability of his voice, I used data collected from each data type to honor the many ways that he chose to share his educational experiences. As a result of the Covid-19 pandemic, I conducted the member checks between February and May of 2020 over the phone, with the final member check conducted in person over dinner in June of 2021\(^1\).

\(^1\) This final member-check was conducted after all three of the participants had received two doses of the Covid-19 vaccine.
Table 3.6

Phase 4: Creation of narratives

<table>
<thead>
<tr>
<th>Method</th>
<th>Participant</th>
<th>Frequency</th>
<th>Duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member Checks</td>
<td>Patrick &amp; Bev</td>
<td>As needed</td>
<td>As needed</td>
</tr>
</tbody>
</table>

Data Analysis

In this grounded theory study, I used the bricolage methodology to adapt and modify my research methods as needed during the data collection process. That being said, the type of data that was collected in this study determined which specific approach I used to analyze the data. I began by coding my data while actively collecting data in the field. As Charmaz (2014) describes, “coding means naming segments of data with a label that simultaneously categorizes, summarizes and accounts for each piece of data” (p.111). With this study I not only used grounded theory coding to code spoken and written data sources, but also artwork and visual representations of experiences. In the context of interviews, coding allowed me to move beyond concrete statements in the data to analyze and make sense of experiences, stories, statements, and visual representations of communication made by the participants (Charmaz, 2014). When describing the benefits of grounded theory coding, Timmermans and Tavory (2007) state that, “the discipline imposed by coding word-by-word, line-by-line, paragraph-by-paragraph, even observation-by-observation, pays analytical dividends” (p.498). Coding allowed me to become acquainted with the data, which helped me form theory from the “ground up” (Marshall & Rossman, 2014, p.18)

Charmaz (2014) describes grounded theory coding as the process of generating “the bones of your analysis” and integrating theory “will assemble these bones into a working
skeleton” (p.113). By becoming more familiar with my data while analyzing it during the data collection process through coding and categorizing, I was able to collect more focused data, which allowed theory to emerge (Bryant & Charmaz, 2007). In other words, as I began to see themes emerging in the data, I was able to specifically target and address these themes in interviews with participants, which allowed me to develop more abstract categorizations of them. Or as Charmaz (2014) suggests, “coding is the pivotal link between collecting data and developing an emergent theory to explain these data. Through coding, you define what is happening in the data and begin to grapple with what it means” (p.113). Using the grounded theory method with this study allowed me to provide a comprehensive examination of what was happening on the ground level, and through the data I collected, I was able to construct theories based on what I found in the field. As the study unfolded, I began noticing how race and dis/ability were impacting both Patrick and his mother’s experiences and turned to Disability Studies and Critical Race Theory in Education (DisCrit) to analyze and make visible the ways in which racism and ableism affected their educational experiences (Connor, Ferri, & Annamma, 2016).

**Research Quality**

As previously discussed, special education follows the medical model of disability and is heavily rooted in positivism. The rationale and goals of this study were informed by the social model of disability and required different standards of research quality; equally rigorous standards informed by constructivist ontology and epistemology. I conducted this inquiry using Guba and Lincoln’s (1989) criteria for fourth generation evaluation, with the goal of achieving credibility, transferability, dependability, and confirmability.
This study took place over a period of two years, which allowed me to establish rapport and build trust with all participants through prolonged engagement and persistent observations (Guba & Lincoln, 1989). In addition, the main participant in this study was a former student that I had the pleasure of working with for seven years, and the other participant was his mother that I also had a well-established relationship with. I conducted member checks with Patrick and Bev throughout the data collection process to ensure the accuracy of my emerging hypothesis and interpretations. With this grounded theory study, I went back and forth between data and analysis to form my theory and discover emerging themes (Charmaz, 2014).

By immersing myself in context for a long period of time, I was able to create a thick description of the phenomena in its natural time, setting, culture, and context (Lawrence-Lightfoot & Davis, 1997). This allowed me to obtain a high level of transferability (Guba & Lincoln, 1989). With only three participants in this study, I was not able to make generalizations about the phenomenon under study; however, the findings of this study are transferable to similar contexts and settings.

Using bricolage as a research methodology in this study allowed me to change my methods as needed and evolve them over time. In the positivist paradigm, changing methods decreases reliability, but using the constructivist paradigm views these changes as expected and are signs of a successful inquiry (Guba & Lincoln, 1989). Lastly, I assured that my data, interpretations, and results were accurate representations of the contexts with both Patrick and Bev to ensure a high level of confirmability (Guba & Lincoln, 1989). To account for this, I conducted confirmability audits to ensure that my interpretation of the phenomenon was confirmed based on the data collected. Confirming the data through the student, the
family, and myself helped to corroborate the research in question (Marshall & Rossman, 2014).

By taking these necessary steps to safeguard the credibility, transferability, dependability, and confirmability of this study, I was able to produce a robust narrative that provided the most accurate representation of the lived experiences of a student labeled as SD, his family, and his teacher given the context in which these experiences occur.

**Conclusion**

Bringing the strategy for creating an environment that set Patrick up for success, this investigation embraced Patrick’s love for music and performance, and his talent for illustrating and creating his own books to support him in sharing his “voice.” Instead of creating a quiet and sterile research environment for Patrick to tell his story, based on our established relationship and years of working together, I was able to create a unique individualized research environment, building on his strengths, that set Patrick up for success from the inception. From the beginning I valued removing barriers that could potentially hinder Patrick in telling his story over the convenience and comfort of the researcher and created the conditions for my methodologies to adapt to Patrick rather than forcing Patrick to adapt to my methods. This is an example of how research done with students that learn differently can be individualized, creating an inclusive experience where adapting the research environment can support the participant in telling their own story rather than having someone else tell it for them. With these supports in place, Patrick shared his educational experiences as a freshman student at Urban Collegian Academy, the results of which provide a robust and detailed look at the experiences of a student labeled with SD navigating a restrictive educational placement in a large urban school district.
CHAPTER FOUR

KING PATRICK IN THE CASTLE AT WALT DISNEY WORLD

Introduction

Patrick Talbot (a pseudonym chosen by the participant), also known as the self-proclaimed “King Patrick in the Castle at Walt Disney World”, is a fifteen-year-old aspiring math teacher of Cape Verdean descent, with a love of the transit system, all things fast food, an occasional Wiggles video on YouTube, the companionship of his close friends, and most of all, school. In fact, since he began his educational career eleven short years ago, school has been more than a compulsory obligation, it has served as the center of his entire life. His love of school began soon after his first team meeting was held to develop an individualized education plan (IEP) and provide him with special education services in kindergarten. The team consisted of Patrick’s mother, Beverly Mendes\(^\text{22}\), a school administrator, his special education teacher, his general education teacher, his speech and language pathologist, and his occupational therapist. This was a group of people that knew Patrick the best and were charged with developing an educational plan that would provide the individualized supports

\(^{22}\) Beverly Mendes, a pseudonym, used throughout this chapter to protect the privacy and confidentiality of the participant. Pseudonyms are used throughout this chapter when referring to specific people and places that could potentially identify the participants and/or the school district in which the study takes place.
necessary for Patrick to accomplish his educational goals. Acting as a counter-narrative to the IEP, deeply rooted in the medical model of disability that defines Patrick by his perceived deficits, this chapter will instead, informed by Disability Studies in Education (DSE), use an asset-based framework to provide a firsthand account of Patrick’s educational experiences.

As Patrick’s Sensory Arts teacher for seven years, I had the privilege of getting to know Patrick from an early age. Teaching Patrick two to three times per week from the ages of eight through fifteen provided me the unique vantage point to see his communication skills and his creativity blossom firsthand. It wasn’t until this inquiry that I got a glimpse of how Patrick perceives his educational experiences and uses his creativity to purposely arrange his physical learning environment, both at home and in school, to navigate his life spaces. This chapter will provide an asset-based, humanizing view of Patrick, illuminating how he perceives his educational experiences, and how he has found unique ways through the arts and technology to adapt to his educational environment, and truly shine. For Patrick this involved learning how to use the arts to communicate and express his wants and needs, both by speaking and through the use of visual depictions, as a way of communicating and expressing himself creatively.

While highlighting Patrick’s unique creative talents, this chapter is organized into six distinct sections: The Big Yellow School Bus, The Artist, The Choreographer, The Composer, The Conductor, and A Week in the Life of Patrick. I begin by looking at two huge transitions in Patrick’s life: when he transitioned from pre-school to the Frederick Douglass School (FDS) and then from the FDS in eighth grade to the Urban Collegiate Academy (UCA) for high school in “The Big Yellow School Bus: A Tale of Two Transitions”. This exploration of Patrick’s creativity will then look at Patrick as “The
Artist”, providing a glimpse into how the arts have influenced not only his creativity, but also served as a means of communication for Patrick at an early age. Next, Patrick’s love of music and dance and how these influenced his creative expression is explored in his role as “The Choreographer.” Third, as the “The Composer”, Patrick’s unique ability to control the conditions of his environment with the use of technology is presented, revealing that Patrick works best when he is surrounded by multiple sources of sensory input. Next, Patrick’s love of the Urban Public Transit System (UPTS) is discussed with Patrick as “The Conductor,” suggesting that the role that the UPTS played in Patrick’s life was more than a mode of transportation, but a means of organizing how he perceived his life spaces. Lastly, Patrick’s accounts of a typical school week will be presented in, “A Week in the Life of Patrick at Urban Collegian Academy.” Each of these sections compose the different layers of a data-centered portraiture of Patrick that follows the tradition of portraiture scholar Lawrence Lightfoot (1997). Interviews, three-way discussions over dinner, visual depictions, and lyrical expressions were used as data sets to complete this portrait of Patrick. With such an in-depth and personalized look at ways in which Patrick has been excluded from inclusive educational placements since he began school at FDS, the data I present here suggests that Patrick’s educational journey has been influenced by three walls of exclusion, administrative exclusion, academic exclusion, and exclusion from his school community.

The Big Yellow School Bus: A Tale of Two Transitions

When Patrick was five, he was given a diagnosis of autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD) by Urban Medical Hospital (UMH). He
was described as non-verbal\textsuperscript{23} and he had a difficult time expressing his wants and needs in the traditional methods of spoken and written communication. He would often get frustrated when he couldn’t express what he was feeling. At home, in the classroom, and in the community, he would have intense temper-tantrums, purposely clog the bathroom drain and flood the second floor of his apartment, kick the back of his mother’s car seat with all his might, and often display self-stimulatory (stimming) behavior like rocking back and forth or moving his arms up and down. In addition to stimming, only a few things seemed to calm him, art and music therapy, and his weekly sojourns with his mother on the transit system.

He would board the train or bus, sit up on his knees on the bench, and stare out the window for hours on end. Public transportation soothed him; it followed a routine and predictable schedule, it traveled the same route every time, and provided the consistency and reliability he needed to navigate the complexities of his environment.

It was only fitting that his first transition to public school began with a ride on a big yellow school bus, the larger-than-life contraption that symbolized tranquility in his young life. The school bus was more than just a large metal vehicle with four large wheels, it served as a method of transporting Patrick to his favorite place on earth, school. During Patrick’s early school years, his young mind couldn’t comprehend the concept of a day off from school, and even vacations. Patrick would wake up on a Saturday and say to his mom “I goo schoooo, say I allegiance” (I go to school and say the pledge of allegiance), and his mother would have to drive him to the school building to prove to him that no one was there. She once made the mistake of scheduling a doctor’s appointment during the school day. On

\textsuperscript{23} The use of the term “non-verbal” here refers to how Patrick was described by his doctors and educators because at the time he was non-speaking; however, he was able to communicate in other ways other than through spoken words.
the way there, Patrick turned to her and said, “don't take me out of school, I don't like to be pulled out of school, school is important, wait till we get to the hospital. I'm going to drive you and that doctor crazy,” and he did. To this day, Patrick calls school vacation “punishment,” and views going to school as “his job,” rarely missing a day. Even when he broke his foot while dancing during art class, he refused to tell anyone about the pain he was experiencing because he was afraid of being sent home. Early in 2018, during his first day back from winter break, Patrick wrote across the whiteboard in his classroom, “thank God we’re back at school and thank God vacation is over!” Here I asked Patrick what he thought about school vacation:

Patrick: Punishment

Chris: (laughs) Vacation is punishment? Why is it punishment?

Patrick: Because I don't like it

Chris: How come?

Patrick: Cuz I want to go to school all day

Ever since he stepped off the bus on the first day, school has been the center of Patrick’s universe.

Patrick attended the same school, The FDS, for over ten years, and during this investigation, Patrick had just transitioned to a public high school on the other side of the city named UCA. His first day of high school started off just like every other day of his educational career, on that very same school bus that would transport him to his favorite place on earth, school.

Much had changed since that first journey over ten years ago. Patrick was now communicating by speaking, getting himself up and ready for school independently, he could
navigate his way to any location in his urban environment using the public transit system, and on top of it all, he was a budding author and spent hours on end writing and illustrating his own books. He had dreams of his YouTube channel, consisting of his own rendition of his favorite Wiggles songs, getting to one million subscribers. Looking back at his journey it wasn’t difficult to see how far he had come. At his now former school, he had been given all the tools he would need for success in high school, years of occupational therapy, speech therapy, special education services, music therapy, adapted arts instruction, plenty of inclusion opportunities, and community engagement and social interaction with his peers. Patrick was ready for the next chapter in his life, high school.

Transitions from one activity to the next, from school to home, and between grades had always been a challenge to Patrick, especially when he was non-speaking and learning to express his wants and through speech. To provide a clear view of just how much progress Patrick had made from kindergarten to ninth-grade, parallel vignettes of the two major educational transitions that Patrick had made in his young life, daycare to kindergarten and middle school to high school, will be presented using a split view. Patrick’s journey began in the same place that it did on any school day, in the parking lot of 77 Murray Avenue, and although each account shared similar destinations, the two experiences were strikingly different. As the harsh September sun peeked out over the apartment building across the street and illuminated the beads of condensation dripping off the cars in the crowded parking lot, Patrick walked out of his apartment with his backpack stuffed with school supplies as the screen door shut behind him. It is the first day of school…. 
<table>
<thead>
<tr>
<th>Transitioning from daycare to kindergarten</th>
<th>Transitioning from K-8 to High School</th>
</tr>
</thead>
<tbody>
<tr>
<td>Waiting anxiously outside of his</td>
<td>Waiting patiently outside of his</td>
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<tr>
<td>two-bedroom townhouse-style apartment,</td>
<td>two-bedroom townhouse-style apartment,</td>
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<tr>
<td>peeking around his mother at the sound of</td>
<td>wearing his headphones, and watching</td>
</tr>
<tr>
<td>anything that resembled a school bus,</td>
<td>his favorite YouTube videos, Patrick</td>
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<tr>
<td>Patrick clenched tightly in his hand a</td>
<td>held his cell phone in his hand. It</td>
</tr>
<tr>
<td>small toy school bus. It was the very</td>
<td>was the very cell phone that his</td>
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<td>school bus that his mother had purchased</td>
<td>mother had purchased for him so he</td>
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<td>to prepare him for his first day of</td>
<td>could stay in communication with his</td>
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<tr>
<td>preschool. The big day was here, and he</td>
<td>friends from his old school, watch</td>
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<tr>
<td>was ready. A couple of weeks before, his</td>
<td>his YouTube videos, and listen to his</td>
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<td>new teacher made a home visit to meet</td>
<td>favorite music. The big day was</td>
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<td>Patrick and his family in an effort to</td>
<td>here. This would be the day that</td>
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<td>ease the transition from daycare to</td>
<td>Patrick would meet his new teachers;</td>
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<tr>
<td>preschool. She introduced herself to</td>
<td>until today, he only knew their names.</td>
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<tr>
<td>Patrick and his family and provided him</td>
<td>As the pick-up time grew closer,</td>
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<tr>
<td>with some visual supports that he could</td>
<td>Patrick shuffled between his favorite</td>
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<td>carry with him during his bus ride on the</td>
<td>clips of The Wiggles, The Mask, and</td>
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<tr>
<td>first day of school. As the pick-up time</td>
<td>the ending scene of Toy Story 3 in</td>
</tr>
<tr>
<td>grew closer, with his name pinned to each</td>
<td>Spanish. He had taken this journey</td>
</tr>
<tr>
<td>article of clothing he was wearing, as</td>
<td>many times before, but today he was</td>
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<tr>
<td>well as his backpack, Patrick held his</td>
<td>headed to a new school. Patrick is</td>
</tr>
<tr>
<td>school bus tightly in his right hand and</td>
<td>now speaking and communicating in</td>
</tr>
<tr>
<td>looked down at the bracelet that he had</td>
<td>spoken and written words, relying less</td>
</tr>
<tr>
<td>on his wrist. Since</td>
<td>on picture symbols. His cell phone</td>
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Patrick was non-speaking at the time, this bracelet was his visual support and road map to the journey that he was about to embark on. It contained all the necessary components of an itinerary, visual pictures of the school bus he would take, pictures of the school he was traveling to, and most importantly, a picture of his teacher that would greet him as he descended the staircase and stepped off the bus. Patrick could hear the sound of the bus screeching around the corner, and quickly looked down at his bracelet. He looked at the bus entering the parking lot, then down at the bus that he held in his hand, and finally at the picture of the bus that he had on his bracelet, he knew that the time had come for him to go to school. The bus stopped right in front of their apartment, the double doors swung open, and before Patrick’s mother could stop him, Patrick let go of his mother’s leg and ran full speed to the bus. Through the doors and up the stairs as the his compass on this journey, allowing him to follow the route of the bus on Google Maps while he figured out in his head which mode of public transportation would get him to school faster, what bus number and train line combination would create the optimal route, and at the same time, listening to Woody from Toy Story scream “¡no creo que sea la luz del día!” Patrick could hear the sound of the bus screeching around the corner, he put his bag over both shoulders, adjusted his headphones, and prepared to board the bus. As the bus entered the parking lot, he glanced down at his cell phone to check the time to make sure the bus was on schedule. He was ready for his first day of high school. In fact, he has been preparing for this day for the past few years, getting himself up and ready for school independently each day. Patrick’s mother watched him get on the bus from her second-floor bedroom window, his
name tag that was pinned to his backpack flapped in the breeze. Patrick’s mother could barely see his tiny head engulfed in the enormous green vinyl seat, but the look of joy and happiness in his eyes said it all. The doors closed, the bus slowly drove off, and Patrick peered down at his bracelet to see what the next stop was on this new adventure.

As the bus arrived at school, Patrick was greeted by his panicking mother, in her pajamas, disheveled and in tears. Patrick had no idea that immediately after the bus pulled away from his home, his mother jumped in her car and drove frantically to the school. When she arrived, there was no bus in sight. She picked up her phone and feverishly dialed Patrick’s old teacher and lost it, screaming, “you bitch you had me put him on the fucking bus, and the bus isn’t fuckin here!” The teacher told her to calm down, that there was nothing to worry about, and that the bus needs to pick up a five foot eleven, two-hundred-and-thirty-pound body engulfed the tiny green vinyl seat as he peered down at his cell phone to follow the bus on route to his final destination, high school.

As the bus arrived, Patrick was greeted by a sea of students gathered outside of the high school waiting to get in the building. He joined the crowd of students and slowly walked through one of the six sets of doors that lead to the metal detectors that he needed to pass through in order to enter. This was an experience that he wasn’t prepared for, he was “lost and confused”. As his mother put it, “he was just thrown to some people that he had to meet on day one, without knowing any background of him, or who’s Patrick, or how is Patrick, or what’s Patrick, or anything like that.”

During the first week at his new school, while waiting for his bus to arrive at dismissal, Patrick took a seat in the
whole bunch of kids before they go to the school. After what seemed like an eternity, the bus finally pulled up and Patrick’s mother walked him off the bus, through the school doors, and into his new classroom. Every day she would drive to the school to “try to catch them” and walk Patrick into his classroom. After a week or two Patrick pushed his mother out of the class, closed the door, and never looked back.

corner of the room away from his peers and adults. As the time grew later and later, Patrick started to show signs of anxiety, rocking in his chair, and placing his hands in and out of his pockets. A staff member noticed what was happening in the corner and made a report that Patrick was touching himself inappropriately in class and filed a 51A with the State for suspicion of abuse or neglect. Patrick had attended the same school for most of his life and built many relationships along the way, but he soon realized that “he didn’t have his team that he could have went to” to help him through this confusion.

Patrick was now beginning his freshman year in high school at UCA, and through these two parallel vignettes, it is not hard to see how much progress he had made. During his ten-years attending kindergarten through eighth grade at the FDS, Patrick had learned how to communicate by speaking, and had grown academically, socially, artistically, and was now independently following a morning routine and getting himself out the door in time to catch the bus at 6:30 am every morning.
The Artist: Creative and Resourceful

When Patrick first began attending daycare at the age of three, the staff had some concerns about Patrick. He was still not speaking, he had difficulty with transitions, and he often threw himself to the floor and had loud tantrums during the day. Bev shares that the only teacher that he connected with was the Art Therapist Roberta, “she was the art therapist, and he would only respond to her whenever she came in to do arts therapy.” It would calm him down, soothe him, and he could concentrate much longer than during any other activity. In addition to being an Art Therapist, she was also a Music Therapist and during most sessions she would provide Patrick with a mix of art and music, using strategies that stimulated his senses. Here during a three-way discussion over dinner, I ask Patrick about Roberta:

Chris: Can you tell me a little bit about Roberta?

Patrick: Yes, Roberta was a lady that played near Orange station. And that was fun.

Chris: What did you like about Roberta?

Patrick: Making books

Chris: What else? Was she nice to you?

Patrick: She was

Bev: What did Roberta teach you?

Patrick: feelings

Bev: yeah….what else did she teach you?

Patrick: English, drawing, arts
Bev: Remember when you couldn’t talk and you drew the fruit loops on the table?

Patrick: Yes

Bev: and she did what else with you?

Patrick: Music therapy

Chris: Do you remember what it was like when you couldn’t talk?

Patrick: Yeah

Bev: Remember when you tried to tell me something and you couldn’t tell me you use to get on the floor and do this [pounds the floor with foot]. Remember?

Patrick: yeah

Bev: and in the car you use to kick the back of my chair

Patrick: [using imitation annoying mother voice] you’d say Patrick stop it…..stop it

When Patrick first started going to see Roberta, he was non-speaking and only communicated using gestures, by pointing to things, and uttering unrecognizable sounds. Bev shared that he would get frustrated when she didn’t understand what he was asking for and it usually ended in him having an outburst. Bev began seeing a difference in how Patrick was communicating soon after he began working with Roberta.

Once Roberta showed Patrick how to use crayons, he began using them to communicate his wants and his needs. Here Bev shares the moment when she began seeing Patrick express himself visually:
And then once Patrick was working with Edwina and the school, his vocabulary started to pick up. I remember one day he was sitting right there, right there at the table, and he drew on the paper, no he said unghie. I was like unghie, what the hell is unghie? And he drew a yellow circle, a red circle, a green circle, and a purple circle and he gave it to me, and I'm like [makes a bewildered expression]…….. and he kept saying unghie unghie unghie unghie...and I’m like [makes a bewildered expression], it so happens to be I was right there, I turned, and it was a box of Fruit Loops he wanted. So I said Patrick is this what you want? And he just looked at me so I poured it in the bowl, and I bought some milk and he just started woofin it down.

This marked a huge milestone in Patrick’s education, he now figured out how to communicate in his own unique way, and from this point on he would learn how to communicate and express himself through the use of visuals and through the arts.

Soon Patrick moved from making two dimensional artistic renderings using crayons and markers to using everyday items he found around the house to create three dimensional renditions of the city that he loved so much. During a three-way discussion, Patrick and Bev talked about how Patrick would sit for hours creating his own model cities out of whatever he could find around the house, including zip ties connected to straws to represent streetlights, electrical wires he would create using ripped thread from towels to connect the electricity to the pole, traffic signals with green, yellow, and red stickers on them, and of course buses and trains. Here I asked Patrick why he enjoyed making his model town:

Patrick: I like it, I wanted it to be my town.

Chris: Your town? That's cool

Bev: And after he met you, Patrick show Mr. Chris the street lights
Patrick: And the straws

Bev: After he met you he became more creative. Get the zip ties and stuff, look what he did.

Chris: This is so cool

Patrick: I used it with tape

Bev: He used to build cities. After he met you. He started putting streetlights, pulling my towel thread. Chris, you owe me so much towels.

Patrick: What’s that called outside?

Bev: The electricity wires…. he used to wire them here, to the next one

Patrick: I put some tape there

Bev: He made streetlights for his city. After he met you. What about the signs?

Patrick: [looking through drawer] that one, the crayon, the glue stick, and the marker

Bev: Where’s that stuff you made me buy you

Patrick: At Thrifters [a local thrift shop]?

Bev: Chris, I had to buy these stickers

Patrick: Sea creatures

Bev: I use to peel the towel, the string coming out, I had to buy him zip ties. You use zip ties?

Chris: yep. He is so creative
Bev: Take the Lego blocks, put them in, go pull the string from my towel and sit there and tie this one to the next string to the next one to the next one.

Patrick: Some streetlights have both sides, why do they have both sides?

Bev: He would make stop signs out of paper

Patrick: I used to make the stores, house, and the streets

Chris: This is so cool. Do you think this is something that you like to do someday, build streetlights, cities? You love math.

Patrick: Yeah, that's what I do. I only get zip ties for Christmas, right? I need to get some some zip ties

Before being introduced to the arts, Bev shared that he couldn’t sit still for more than a couple minutes unless he was riding the train or bus. According to Bev, the arts “tranquilized him” and “calmed him down,” they served as an additional way for him to regulate his body and concentrate. He would work on his model city for hours on end, all the while listening to his music and as Bev says, “doing his thing.”

Once Patrick began attending school at the Frederick Douglass School (FDS) when he was five years old, his first teacher provided a visual rich environment in her classroom. All the objects in the classroom were labeled with picture symbols, she used a visual schedule that had picture symbols for each transition during the school day, and Patrick had his own communication board that included picture symbols to help him communicate. For students like Patrick that are non-speaking, picture symbols are an alternative method of communication. Figure 4.1 below shows an example of a communication board with picture symbols that helps students communicate by pointing to the pictures.
Figure 4.1

Example of a communication board with picture symbols

Note. Communication Boards are typically used by educators to communicate with students using visual picture symbols. They also aid in back-and-forth conversation where students can point to images that represent what they are communicating.

Eventually Patrick was able to point to the pictures and express what each picture represented by speaking, for example, he could point to a picture that represented “toy train,” allowing him to communicate that he wanted to use the toy train. Once he was able to utter single words, he then began three-word sentences like “I want train” or “I feel happy.” Here I asked Bev if she noticed an improvement in his behavior once he started talking, “once he started talking it started balancing out. Once he started talking his behavior wasn't as bad as it was, but he still had the behavior. But transitioning for him became a piece of cake.”
It wasn’t long before Patrick was able to communicate in full sentences and art transformed from a method of communication to an enjoyable way for Patrick to express himself creatively, and as a way to self-regulate his body. The first time that I met Patrick was when he was in second grade, and I began teaching a class called Sensory Arts at the FDS. It was my first year of teaching and I was hired to create a class that would provide students in the FDS Autism Program with a class that mixed visual arts with music and movement and met the individual needs of the diverse group of learners in substantially separate classrooms. With minimal experience working with autistic students, I spent a lot of time reading, planning, observing other teachers teaching, and learning everything I could that would help me master my craft. It wasn’t long before I began making connections with students, learning how they communicated, and providing them with the supports they needed to access the arts at their individualized level. Here Bev describes how she first learned about Sensory Arts at the FDS:

Patrick was in Rebekah’s class, and he kept coming home telling me you got to go see Mr. C. I'm like who's Mr. C? He said we dance, we move, we draw, out of nowhere he said like Roberta. So, I was like yeah well, I'll go one day. Every day he we get off the bus and say mommy come see Mr. C, mommy go see Mr. C. One day I was like I gotta go meet this damn Mr. C. And whatever you played at school, he would come home and have me put it on the radio, I had to find the damn songs.

For Black History Month, Patrick and his classmates created a construction paper mosaic of Rosa Parks, Martin Luther King Jr., Barack Obama, and Oprah Winfrey out of 18,000 small pieces of construction paper. This was the first time that I had attempted an art project like this, and I was amazed at how Patrick excelled working with this medium.
According to Bev, this activity “calmed him” and helped him “slow his thinking and focus.” We would sit down for forty-five minutes straight, listening to music and dancing to the beat, and making art. After about three weeks of hard work, we showcased our eight feet by eighteen-foot mural at our school to rave reviews. Reflecting on the first time we met at the unveiling of our mural Bev shared, “I told you it needed national attention. And then I got in contact with Fox [in the city], and then from there... you are shy Chris.” This marked the beginning of our advocacy work together, I would focus on creating larger-than-life mosaics, and Bev would contact the media to share this amazing work. I shared with Bev during a three-way discussion over dinner that at the time we made the mural I didn’t realize that this was such an extraordinary accomplishment because, influenced by the work of Biklen and Burke (2006), I started with the “presumption of competence” and designed the project with the assumption that our students could create this mosaic with the proper supports.

It wasn’t until I spoke to Bev, and she shared with me the experiences of families with autistic students that I really began to understand the gravity of what this artwork represented. She described me as, “the spark that was missing” at the FDS. During the unveiling of this mural another parent shared with me that families with autistic children only hear from the school when something bad happens and seeing this work and what her child had accomplished gave her hope. At this moment I made it my goal to show the general public what autistic students could accomplish if provided the proper supports to do so; and thanks to Bev’s advocacy and Patrick’s talent, we received national attention for our work. Below, Figure 4.2 displays a mural we created of Barack Obama, and Figure 4.3 shows a mosaic from 2015 of the New Kids on the Block made of 108,000 tiles, both of which Patrick played a leading role in creating:
Figure 4.2

Construction paper mosaic from 2013

Note. This image contains 30,000 small pieces of construction paper

Figure 4.3

Foam tile mosaic from 2015

Note. This image contains 108,000 small foam tiles
When Patrick wasn’t creating these huge collaborative art pieces, and playing a supportive role unveiling our New Kids on the Block Mosaic on the Donnie Loves Jenny Show, he was dancing, singing, and creating art. Around this time, Patrick began authoring and illustrating his own books. Bev shares that she spends a small fortune on paper, art supplies, and staples so Patrick can create his books, something that she never thought he would be capable of doing just a few short years ago. Bev shared that, “because of you, Patrick sits down calmly patiently and does his books. He writes a lot, [holding one of Patrick’s books] Travis goes to the Frederick Douglass School.” During a three-way discussion we reflect on Patrick’s book creation:

Bev: Patrick wouldn’t sit down and do shit you know, now he sits down, and he writes these books. Patrick, where are those books? [grabs books] Because of you this is what Patrick does….

Patrick: I made it myself with no help Mr. Chris

Chris: That is so awesome

Patrick: Thanks Mr. C.

As an author and an illustrator of his own books, Patrick had found a creative outlet to express himself through the arts, providing a glimpse into how he experienced the world. The boy that doctors described as having “severe ADHD” would sit for hours on end listening to his music and YouTube videos through his headphones and writing his books. Visual arts seemed to provide Patrick a way to stimulate his creativity, keep him focused for long periods of time, and help him regulate his body and stay calm. Patrick’s talents were not limited to visual arts, once he began experimenting with music and performing arts, he
truly began to shine. This next section will discuss Patrick’s love of music and dance, and how they provide him with an additional outlet for his creativity.

**The Choreographer: Musings of Music and Movement**

At FDS Patrick was in his element. With the help of visual communication supports and access to adapted arts, Patrick was able to express himself in his own special way through his drawings, his books, and his YouTube channel. During one of our first interview sessions in November of his first year at UCA, I asked Patrick to reflect on his experiences at his former school:

Chris: What did you like the most about the Frederick Douglass School?

Patrick: Sensory Arts

Chris: Oh, good answer. You can tell me the truth though if you didn’t think it was the best.

Patrick: I like dancing to the music

Chris: Dancing to the music, what else do you like?

Patrick: I liked painting pictures, talking about animals, superheroes.

In addition to “dancing to the music” during Sensory Arts class, we often listened to music when creating art. We would listen to a similar playlist of songs and many of the songs, whether it was from listening to them during class or in his free time on YouTube when he got home, Patrick knew all the words to. Patrick was always singing along to the songs, moving to the beat of the music, and genuinely in his happy place. Many times, we would have back and forth exchanges singing to the beat of the song but changing the words around. For example, if I was teaching about warm colors, painting, and listening to “Suit & Tie” by Justin Timberlake and Jay-Z, I would change up the lyrics to assess Patrick. Using
the original lyrics, “I can't wait 'til I get you on the floor, good-looking, Going out so hot, just like an oven. And I'll burn myself, but just had to touch it,” I would change them up to go something like this:

Chris: I can’t wait for you to tell me about warm colors…. there so hot, so hot, just like an oven. And you’ll burn yourself, so please don’t touch them. Can you show me a few things, can you show me a few things?

Patrick: Well as long as I got my red, orange, and yellow, I’m gonna leave them all on the page tonight, I’ll show you a few things, show you a few things.

Through these daily exchanges I was creating an environment where Patrick could flourish, we were creating art, we were pushing our creativity to the limits, and best of all, we were having fun. Reflecting back on these experiences, I decided to take this element that worked so well in my classroom and apply it to the research environment that I was creating for Patrick that above all else, privileged ways of him expressing his voice as uninhibited as possible.

Using Improvisational Lyrical Remixing (ILR)\textsuperscript{24} I quickly noticed that Patrick was beginning to open up more, describing his experiences in more detail, staying on topic, and really enjoying our weekly performances. I always let Patrick pick the song that we would sing to, and quickly this seemed to open up his world. He used the tape-recording device as his microphone, he often stood up to perform like any charismatic lead singer, and it was difficult to end our sessions together because he was having so much fun, we both were.

\textsuperscript{24} ILR is a method that involves the researcher and the participant co-constructing dialogue to the beat of a familiar song, changing the original lyrics to ask and respond to interview questions. See Chapter 3 for a more detailed explanation of ILR.
This first experience with ILR brought me back to the time when Patrick was dancing in my class when he was in fifth grade. During a rendition of “Gangnam Style” by PSY, while doing a galloping motion, he jumped up a little too high and landed wrong on his foot. Unbeknownst to me, he had broken his foot, but just kept on dancing. He kept quiet until he got home from school because as he describes it, “I didn’t want to miss out on dancing.”

With strict orders from the doctor to wear an orthopedic boot on his foot and avoid physical activity for six to eight weeks, nothing could keep Patrick away from the dance floor, but in this situation, in order to insure he would heal, I made him the “Dance Inspector” of the classroom. His official uniform was complete with a badge and a clipboard. He would watch the other students dance, support them by doing the moves from a seated position, provide suggestions on how they could improve their moves, and draw on a clipboard what he saw. By using Patrick’s love for music and dance I was able to create an environment where he was an active member of the group, and even though he had a broken foot, he was accessing the material at his level, he was engaged, having fun, and he was learning. Eight short weeks later he was back on the dance floor expressing his creativity like he never missed a beat.

Whether Patrick was expressing himself through visual art, music, or through dance, Patrick flourished when he was provided access to the arts. According to his mother, upon arriving home after his first day of high school at UCA, Patrick was visually upset and the first thing he said when he got off the bus was, “what kind of school is this with no Sensory Arts?” In this inquiry, through interviews, artistic renderings, and lyrical expressions, Patrick expressed that Sensory Arts provided him with the sensory input that he needed to help regulate his body and express himself creatively. During our interview sessions together
throughout the course of this investigation, I began to notice that Patrick had difficulties staying focused and conversing with me when the research environment was quiet. Soon I began to realize that when there was no background noise, Patrick would find a way to create some. Whether it was putting on some music, a YouTube video, turning on a fan, or using his body movements to create motion and noise, Patrick was resourceful and found ways to adapt to his environment and create the conditions that were necessary for him to navigate his environment. Next, Patrick’s ability to blend together visual art, music, dance, videos, and sounds from his environment to create the ideal conditions to navigate his environment will be presented.

**The Composer: A Creative Mash-up**

As Patrick’s art teacher for seven years, I had the opportunity of watching Patrick grow socially, academically, and artistically. Although I had a good idea of ways in which to adapt and modify the curriculum for Patrick to be successful, it wasn’t until this investigation that I began to understand how Patrick navigated and perceived his life spaces. What may have presented as nervous ticks or repetitive movements, sometimes asking questions he already knew the answers to, making humming sounds under his breath or whispering to himself, or rocking his body back and forth, were in actuality ways for Patrick to arrange his environment and regulate his body. When describing his self-stimulatory behavior, or stimming, Patrick shares that he “always stims” and that it is something that he “needs to do.” According to Patrick, he typically “shakes his arms” up and down and sometimes over his head when he is at school, makes sounds or talks out loud, and afterwards he “feels happy.” He expressed on a few occasions that if he isn’t given the opportunity to stim, he “gets mad.” As Patrick describes, when he is at home, he “puts his hands on the wall” and
pushes off the wall in a rocking motion, his mother says that she worries that he is going to knock the wall down. Bev describes the first time that Patrick’s grandmother saw him stim, “my mother, when she first seen him stim, you know and heard Patrick talking to himself, she said he got the demon in his head and needs to pray [laughs].” In addition to self-regulating his body through self-stimulatory behaviors, Patrick used technology to produce the same effect, and when he did, it presented as a more socially acceptable form of self-regulation, often times taking the form of wearing headphones and listening to songs, video clips, and sounds on his phone or his computer.

During an interview session, Patrick enjoyed repeatedly playing a video of a train pulling into his favorite train station. When the train stopped at the platform it emitted a loud screeching sound that produced a similar full body visceral reaction as that of the sound of fingernails on a chalkboard. The sound drove his mother crazy, to the point where she had contemplated “throwing his computer out the window.” During our session the train noise wasn’t the only thing that Patrick was focused on. In addition to playing the train video clip on his laptop, he was also watching a video on his phone of one of his best friends Darius, at the same time as he was conversing and answering interview questions. Thinking back on our previous interviews, I began to recall that there was always some sort of background noise during our sessions, whether it be the fan running, the television, his computer, music, his phone, there was always something playing in the background. Maybe he couldn’t concentrate in silence, maybe he needed that auditory stimulation to regulate his body to help him feel comfortable in his own skin. I asked Bev if she had ever noticed this before with Patrick:
Bev: But he's always been like that. Always. Always, always, putting so many things at once I told him, you put that train noise, I'm going to throw that shit out the window. I wonder if that's what makes him concentrate, but now that now that you said it, he will not sit there in silence and write a book.

Chris: But it's interesting though, because if you think about it, maybe that's how he perceives the world. Maybe that's how he experiences the world. I'm in your house right now and it's just you and him. And other than the noise he's making with the television right now, there really isn't any other noise. Right. So maybe, maybe he just can't, maybe he just can't focus in silence. Maybe he's just so used to having stimulation and his senses are so heightened. Maybe he needs that sensory input to make him feel normal.

Bev: He doesn't focus in silence, because even when he writes his book, his phone's on and his own computer.

For many people the various sounds playing in the background would be very distracting, but for Patrick it had the opposite effect, having many different sounds playing at once helped him concentrate. Here I ask Patrick why he listens to three things at once:

Chris: But why do you put all that stuff on?

Patrick: Well, they want to do it.

Chris: Does it make it harder or easier for you?

Patrick: Easy.

Chris: Easy. Do you like to do your work when it's really quiet or noisy?
Patrick: Noisy like music.

Notably, when asked why he puts on many different sounds at once, Patrick responds by saying, “well, they\textsuperscript{25} want to do it.” It is not clear whom Patrick meant by responding “they”, but he could potentially be referring to himself in the plural sense. If he does in fact have three distinct creative sides as I have presented, the artist, the composer, and the conductor, he could be using this technique to self-regulate all three of his creative sides. All of the sounds playing in the background not only helped Patrick regulate his body and concentrate, but he could explain what was happening on the laptop, the television, and at the same time, he could answer the questions being asked of him. It was as if he was a disc jockey (DJ) mashing up a cacophony of tracks, adding some sound effects and synthesizers, and producing a remix that was distracting to most, but for him it was the perfect melody. Here Bev expands on this notion:

And then he'll have the train and the TV. And he'll be there like this, and he knows everything what's going on. And I'm in my room shut that fuckin noise off because it just cuts through you like a knife. But he functions, he'll write books, he'll put away his laundry. He'll, he does everything. Now. When he sits there to do the books, whatever the hell he's listening to is playing, music on his thing. God forbid if I plug that TV in. And he'll tell you everything.

Patrick’s propensity to create background noise when his environment became quiet would explain how he soothes himself when he stims. Both stimming and listening to sounds from two or more different sources could serve as a means for Patrick to regulate his body and make him comfortable in his own skin. Patrick’s mother shares a concern of hers that

\textsuperscript{25} Emphasis added
she feels he acts “more autistic at school” and when he is at home, he’s “a regular kid.”

Given that Patrick may not always have access to the technology he needs to create his original melody of train sounds and YouTube videos at school, rocking back and forth, moving his arms up and down, and making his own noises, seems to serve the same function. Perceiving Patrick as acting “more autistic” at school, would support the ableist perspective that these types of movements are reserved solely for autistic individuals and serve as one of the few physical manifestations of an invisible dis/ability. In both situations he is creating the conditions to help him regulate his body, the only difference is that from an ableist perspective, wearing headphones and listening to music and train sounds is much more socially acceptable because it keeps autism invisible to the outside observer.

The multi-tasking skills that Patrick demonstrates here, specifically the ability to focus on three things at once, carry on a conversation, and be able to recall all of the events happening, suggest that he is capable of much more than he is given credit for. It is unknown when Patrick developed the ability to naturally focus on so many things at once but this is a great example of how over his ten years attending school in DPS, Patrick has found ways to adapt to his environment. Whether it is through technology, or through self-stimulatory behaviors, Patrick arranges his environment in such a way that allows him to regulate his body and express himself creatively, artistically, and by speaking. Patrick has always responded well to a routine and predictable schedule, not only in his learning environment, but also in his local community. From an early age Patrick has been fascinated by the Urban Public Transit System (UPTS), whether it was riding the trains with his mother for hours when he was non-verbal, taking the bus to school each day and studying the streets he passes on the way, or taking the bus or train to the city to explore, public transit plays a huge role in
Patrick’s young life. The arts serve as a way for Patrick to feel comfortable in his environment, but the UPTS provides Patrick the means to navigate the physical spaces of his community in a routine and predictable way. This next section will explore Patrick’s passion for the UPTS and the ways in which it helps him navigate his life spaces.

**The Conductor: Making Connections Through Location**

Through the arts, music, dance, and YouTube, Patrick is able to create the environmental conditions necessary to help himself feel comfortable in his life spaces. Once Patrick feels comfortable in his environment, the method that he uses to navigate the physical spaces in which he resides is heavily influenced by his love of trains and the public transit system. For Patrick, the UPTS serves as not only a navigational reference point, but also as a cipher that holds the key to how he perceives and makes sense of his environment. Here Patrick begins to describe the physical layout of his school:

Chris: How many floors are in the school?

Patrick: Let me see, um, third floor, second floor, first floor, b, rb, and sb.

Chris: That’s big

Patrick: I’m just pretending that the elevator was the UPTS’s, like the gym would be the airport.

In this example Patrick shares a glimpse into his thinking and how his frame of reference is influenced by the organization of the UPTS. Throughout this inquiry Patrick seemingly pretends he is a train conductor and when I asked about some of the specific locations of places he visits on his various school excursions or after school hours, he either provides the exact street address or the UPTS station that is nearby. Here I explain to Patrick how we will be creating storyboards to help recount his school day:
Chris: When somebody makes a movie, they have these things called storyboards, where they take each scene they want to do and they draw a picture of it. I thought it would be cool to make a storyboard about your day at school.

Patrick: All right.

Chris: That sound cool? What are you going to use for supplies?

Patrick: Like, Urban Collegian Academy is in Dearborn, on 20 Floyd Street near Community College.

Chris: There you go.

Patrick: Jackson High is across from Urban Collegian Academy.

When asked about his school day he immediately described his school in terms of location including the street address of the school, the train station it was near, and other landmarks in the vicinity.

In a matter of a few seconds, Patrick was able to provide three reference points that would give an outside observer the means to navigate directly to his school. In our first interview when talking about his art therapist Roberta, Patrick describes her as, “Roberta was a lady that played near College Station, and that was fun.” Soon I began to notice that anytime that Patrick was asked about an experience he had, he would then describe where the experience happened and how to get there. While going over his daily schedule I asked Patrick where he goes swimming on Wednesdays, and Patrick responded, “we walk right past Floyd Street on the Pink Train.” During our first Improvisational Lyrical Remixing session, Patrick was asked to sing about recycling, and to the tune of “Born This Way” by Lady Gaga, Patrick sang, “We have to go to the Central Offices on the Yellow Train, I like
the Yellow Train. Going on the Commuter Train, Red Station to Hopedale.” These are just a few examples of Patrick’s propensity to link an experience with location and then determine the closest UPTS train stop in the vicinity. For me, I can smell a particular scent or listen to a particular song and be able to recall experiences from my past, where they occurred, and how they made me feel. For Patrick, the mentioning of a specific location and/or train stop helps him recall experiences from his past just like I am able to with the help of a familiar scent or song. These navigational techniques seemed to be Patrick’s way of not only navigating through his physical environment, but also provided him with a reference point to link his experiences to.

During an interview session, Patrick was talking about the first time that he met my kids at a school event and then became very curious about their experiences riding on the UPTS:

Patrick: Did they been on the UPTS?
Chris: Yeah. They've been on the UPTS.
Patrick: Like the Pink Train, Orange Train, Brown Train, Yellow Train-?
Chris: They've been on the Yellow Train, the Commuter Train, maybe the Pink Train.
Patrick: What about Orange?
Chris: I don't think they've been on the Orange.
Patrick: River Street Trolley? Amtrak?
Chris: I've never been on the River Street Trolley. That'd be cool to do someday though.
Patrick: How about the Amtrak?
Throughout our interview sessions together, Patrick consistently made these connections between events and locations. I became curious if Patrick was able to generalize his knowledge of the UPTS and describe how to get to places around the city. Here I asked if he could tell me how to get to his school using the UPTS:

Chris: If you were going to leave your house right now and go to Urban Collegian Academy, how would you get there?

Patrick: The UPTS bus, Rolling Hills.

Chris: Oh, which number is the UPTS bus?

Patrick: 77.

Chris: Where does it pick you up?

Patrick: It basically drops me off at Rolling Hills.

Chris: So, say you left your house. How would you get there from 77 Murray Avenue?

Patrick: Like two hours.

Bev: Where's the bus stop at?

Patrick: Over there [points across the street].

Chris: Mm-hmm. And then you get on the 77 bus, and where does that bring you?

Patrick: Rolling Hills station. Orange Train Commuter Rail bus connection.

Chris: Nice.
Patrick: Take the Orange Train. Get off at Common Street, Yellow Train and then Pink Train. City College. Floyd Street.

Chris: Does the... Wait, does the Orange Train go to Common Street?

Patrick: No, the Yellow Train-Pink line does. That goes to City Crossing.

Chris: Oh, so then you have to get off the train at City Crossing. And then where do you go from City Crossing?

Patrick: Yellow

Chris: Yellow? To where?

Patrick: Pink.

Chris: Where's the Pink?

Patrick: At City College.

Chris: Oh wait a minute. Hold on. Listen. One more step. So, you get on at City Crossing, you need to take the Yellow Train to what station?

Patrick: Common Street.

Chris: Common Street. And then you go from Common Street?

Patrick: The Pink line.

Chris: The Pink line? What letter?

Patrick: B.

Chris: B Train?

Patrick: Yes.

Chris: Nice. Towards what? Towards Event Center?

Patrick: No, City College.

Chris: City College. There you go. What's the stop name?
Patrick: Floyd Street.

Chris: Floyd Street.

From memory Patrick was able to provide detailed directions to navigate to his school using not only the train system, but also the bus system as well. Even when I tried to trick him a little bit by asking him if the Orange Train connects at Common Street he responded that it only connects at the stop before and you have to switch to another train to get to Common Street. It was obvious that Patrick knew the ins and outs of the transit system, but he was reluctant to navigate the UPTS alone. Here, during a three-way discussion over dinner, I asked Bev if she thought that Patrick could take the UPTS by himself:

Chris: Could he get himself there on public transportation from your house?

Bev: Yes, he could.

Chris: Wow. We'll have to do that.

Bev: Yes he could. Yes, because Saturday when we had to go to the aquarium with a community group, he went, he just, I just followed him. And I keep asking him, Patrick, do you feel like you could take the train and bus by yourself, and what do you tell me?

Patrick: Maybe.

Bev: And what did you say?

Patrick: All right.

Bev: What if I...

Patrick: What if I get lost?

Bev: Yeah.

Chris: All right.
Bev: He knows how to, but he's scared.

Exploring the local community during supervised field trips is part of Patrick’s educational programming at UCA, and with the help of his educators, Patrick hopes to gain the confidence needed to ride the UPTS independently.

When describing locations that are in and around the Metro Center that Patrick resides in, he was able to make connections to his experiences using the UPTS as a reference point; however, when Patrick described experiences outside of the UPTS zone of transportation he often used specific landmarks to help him make connections to his experiences, taking the form of popular restaurants and stores. During a three-way discussion over dinner Patrick asks me questions about my hometown of West Rockville, here Patrick asks some specific questions about my community:

Patrick: What did you have for dinner yesterday Mr. Chris?

Chris: What did I have for dinner? Broccoli soup.

Patrick: We had Olive Garden, we love it. Is there an Olive Garden in West Rockville Mr. Chris?

Chris: No. When my wife and I first started dating there was one Olive Garden and it was in Newport. We used to drive all the way to Newport because it was so good.

Patrick: What else is in Newport? Annie’s Pretzels?

Chris: They have a lot of stuff down there.

Patrick: They have a lot of places, Sears, Old Navy, McDonalds….

Chris: Yep

Patrick: Buffalo Wild Wings?
Chris: They must have that.

Patrick: Burger King?

Chris: I haven’t been there in a while but probably.

Patrick: Do your kids like Burger King or McDonalds?

Chris: They like them both, I think they prefer McDonalds.

Patrick: Is there a Papa Ginos in West Rockville Mr. Chris?

Chris: No, there is a Papa Ginos in Waterville which is right next to West Rockville.

Patrick: Yes there is, I saw one near Petco.

Chris: Let me think…. Petco

Bev: That’s Springfield, he calls West Rockville Springfield

Chris: Is there one in South Rockville…. hmmm?

Patrick: Yes, and Dick’s Sporting Goods. There used to be an Uno’s Pizzeria in Springfield, but they got rid of it.

Chris: Yep.

Patrick: Thrifter’s, Starbucks Coffee, Walmart…Remember when we saw you in Walmart?

Chris: Yes, that was so funny.

Patrick: Does Springfield have a Home Depot?

Chris: No, there is a Home Depot in my town West Rockville.

Patrick: You can’t take the UPTS to West Rockville.

Chris: The closest stop is the Commuter Train in East Rockville which is the town over.
Patrick: On the Rock Line?

Chris: Yes.

During this exchange Patrick seemed to be assimilating knowledge by first trying to connect my hometown to locations that he was familiar with, and then once he recalled some familiar locations, he then tried to connect my town to a familiar reference point by asking about West Rockville’s physical vicinity to the UPTS. Once he was able to make that connection, he then could move onto the next topic of discussion. It seemed as though he needed verification before changing the subject.

During this above three-way discussion over dinner, he would often speak over his mother if he didn’t get the answer he was looking for from me, or if I hadn’t fully answered his question to the extent that he had hoped for. After approximately two minutes of conversation between Bev and I about where they shop for their groceries, Patrick asked, “is there a Staples in West Rockville? How about a Panera?” Once he got the answers that he was looking for, the conversation then changed from talking about my community to talking about his former school. It became apparent that Patrick had a unique way of processing information, and it seemed fitting that he was able to use his knowledge of the UPTS and his love of restaurants to help him do so. This next section will look at a typical school week at UCA according to Patrick’s accounts.

A Week in the Life of Patrick at Urban Collegian Academy

During the 2018 - 2019 school year at UCA, on paper, Patrick followed a routine schedule broken down into fifty-seven-minute blocks that included academic subjects, life skills classes, specialty classes, lunch, and time to practice social skills. In addition, the written schedule also included his weekly excursions to the Central Offices to clean and
recycle, to the local community center for swimming, and to a local boat house to practice rowing. Comparing Patrick’s accounts of his school day to his printed schedule suggested that his schedule is more of a list of suggestions rather than an agenda of compulsory academic obligations. In order to provide context to Patrick’s typical week, looking at his schedule, as well as first-hand accounts of his educational experiences through interviews, artistic renderings, and lyrical expressions, a review of his weekly schedule, pictured below in Figure 4.4, will begin on Wednesday.
Note. The names of Patrick’s teachers and any identifying information have been redacted.

Every Wednesday is a half day at UCA, and Patrick and his classmates go take the bus to the local YMCA for swimming. Before swimming Patrick typically participates in morning meeting with his homeroom teacher Mr. Marcus26, where he shares what he did over

26 A pseudonym
the weekend, talks about the weather, and discusses what he had to eat the night before. Soon after that, he has some free time to watch YouTube videos on the computer before getting on the bus and going to the YMCA. When the weather is good, they walk there. Patrick spends an hour or so swimming independently, supervised by a staff lifeguard, and receives no direct swimming instruction. When the hour is up, they get changed and return to school, where they have just enough time to eat lunch and go home. Very little academic instruction takes place on Wednesdays. Patrick looks forward to swimming every week and his favorite thing to do is “swim in the deep end.” Here Patrick describes his experience:

Patrick: Yeah. I like swimming, I like the deep end, I like swimming underwater.

Chris: Ooh nice.

Patrick: Wavy lines, water. That's me swimming, swimming like a fish.
Note. All of Patrick’s art journal entries where he goes in the pool, he depicts himself alone. The top frame text reads, “I swim in the pool underwater” and Patrick describes himself as feeling “cool.” The bottom frame text reads, “and I played with a ball in the pool, bouncy ball” and Patrick draws himself with a smile with no expressed emotion.

Swimming was one of the only activities that he regularly included in his daily art journals, of the 19 weeks that he made journal entries, swimming appeared in 16 of them.

On Thursdays, Patrick takes a bus to the District Headquarters to perform his “job.” This is one of Patrick’s favorite things to do. His mother believes that the only reason he likes to go to the District Headquarters is because he gets an opportunity to ride the bus and go up and down in the elevator, but nonetheless, Patrick looks forward to this day every
week. In Figure 4.6 Patrick depicts himself on the bus headed to the Central Offices to do his job.

**Figure 4.6**

*Patrick’s art journal entry depicting himself taking the bus to work*

*Note.* Text reads, “and we hop on the bus to work today” and Patrick describes himself as feeling “cool”

Thursdays start off just like other days, Patrick arrives at school, has breakfast, goes to morning meeting, does math, and then spends some time watching YouTube videos on his computer. Soon after he boards a bus for a six-mile trip to the District Central Offices to do
his job, which consists of washing windows, doors, and collecting the recyclables from the offices. One of his favorite things to do at his job is riding in the elevator between floors because he liked to pretend, “that the elevator was the [train station].” In Figure 4.7, Patrick depicts himself performing his job duties.

**Figure 4.7**

*Patrick’s art journal depicting him performing his job duties*

*Note.* The left frame text reads, “I clean the windows and the doors on it” and Patrick describes himself as feeling “fun.” The right frame text reads, “and we ride on the elevator going down” and Patrick describes himself as feeling “great”
On multiple occasions, Patrick shares that he really enjoys doing his job at the Central Offices and looks forward to it every week. Here I asked Patrick what he liked about his job so much:

Patrick: Cleaning the doors and windows.
Chris: You like to do that?
Patrick: And I like to sit outside and chill, look at the city.
Chris: That's nice.
Patrick: Yeah. I love doing that.

Patrick also expressed several times that he preferred doing his job at the Central Offices over cooking class:

Chris: Did you go to the Central Offices this day to do your job?
Patrick: The Central Offices?
Chris: Yeah.
Patrick: Oh. They said we're not going to work. We're going to do cooking.
Chris: Oh, cool! So, what did you cook?
Patrick: I didn't cook anything because I just wanted to go to the Central Offices instead of cooking.
Chris: Oh, do you like to go do your work instead of cooking?
Patrick: Yup.
Chris: Nice. What do you like best about your work?
Patrick: Cleaning the doors, windows, go on the elevator, look at newspapers.

In addition, he would much rather do his job than work in the school store. When asked about what she thought about Patrick’s job, his mother responded:
I mean Patrick is higher functioning, why should he be doing that recycling shit? You know, why don't they have the regular ed kids do recycling too? They use the paper and everything else, I'm sure their names are somewhere across the lines, but why is it that only OUR kids are able to do that?

At his previous school, the FDS, Bev was not only a vocal advocate for Patrick, but also for all of the students in his program. Every year she would raise money through several fundraisers, using the various connections she had made over the years, and harnessing the support of small businesses and the local community. Bev organized an annual trip to a local apple orchard where Patrick and his classmates would take a school bus to go apple picking, eat apple cider donuts, and have a great time in the petting zoo. The price for transportation to and from the apple orchards was the bulk of the cost of the trip, and the school and school district never provided any funds to help pay for this annual outing. When she first asked about her thoughts on Patrick’s weekly trip to the Central Offices, she responded, “They don’t have a bus for a free field trip. They don’t have a bus for anything. But they have a bus for recycling?” In this case, the district did have the funding for transportation and provided a school bus every week to transport Patrick and his classmates to and from the Central Offices to wash windows, the doors, and collect all the recyclables for all over the building. This can take up a good deal of time, so when Patrick arrives back at school, he goes right to lunch and then sometimes he has science which often consists of watching episodes of The Magic School Bus. Here Patrick describes what he typically does after returning to school:

Patrick: I did science in Mr. BMC’s room, we watched The Magic School Bus for like, ten minutes.
Chris: Nice. What was The Magic School Bus episode? Do you remember?

Patrick: Inside Ralphie's.

Chris: Inside Ralphie? And then what did you talk about after you watched the video? Did you talk about anything?

Patrick: Nope.

Chris: That's it? You just watched a video and then you left?

Patrick: Uh huh.

Chris: Are you sure?

Patrick: Yes.

**Figure 4.8**

*Patrick's art journal entry depicting his class watching “The Magic School Bus”*

*Note. The text reads, “in Science we watched The Magic School Bus” and Patrick describes himself as feeling “happy.”*
Once he is done with science, he has gym time where he “plays with balls,” sometimes plays Duck Duck Goose, and then watches YouTube videos while he waits for his bus to go home. In Figure 4.9 Patrick depicts himself and his friends playing “Duck Duck Goose” in the gym.

Figure 4.9

Patrick’s art journal entry depicting himself and his friends playing “Duck Duck Goose”

Note. The text reads, “and I played Duck Duck Goose with my friends” and Patrick describes himself as feeling “terrific.”

In addition to traveling to the YMCA and to the District Headquarters, Patrick also takes a “van” to go rowing at a local boathouse on Fridays, depicted in Figure 4.10.
Figure 4.10

Patrick’s art journal entry depicting himself taking the school van to the local boathouse

Note. The top frame text reads, “and I ride in the van to rowing near [Jackson] Feild” and Patrick describes himself as feeling “wonderful.” The bottom frame text reads, “I roloing back and for on the machine.” and Patrick describes himself as feeling “lovey”

It is a four-mile round trip from the school to the boathouse. Patrick and his classmates use the rowing machines to practice for when they get the opportunity to row a crew boat on a local river, which he hopes to do once the weather gets warmer. This adventure takes about two hours to complete from door to door, and when he returns, he goes right to lunch. Typically, Patrick does morning meeting, math, and then watches YouTube videos on his computer while he waits to take the bus to rowing. After lunch there he typically goes to the
gym with a para educator to “play with balls” before he takes the bus home. On Fridays, Patrick only participates in academic classes during the morning when he takes math, the rest of the day is dedicated to rowing, eating lunch, sometimes Science, and then “playing with balls” in the gym with the para educators in his room and his friends. When Patrick goes to the gym the Physical Education teacher, Mr. Mike, is present but the para educators supervise the students in unstructured gym time:

Chris: Does Mr. Mike play with you guys and show you how to use the equipment, or does he just give you the ball and let you play?

Patrick: He just lets us play, but he says we aren’t allowed to eat in the gym.

Chris: You’re not allowed to eat in the gym?

Patrick: No, he’ll get mad.

Chris: So, when you are in the gym, is it just you and your class?

Patrick: Yes

On occasion Patrick spends his time watching videos on his phone with one of his closest friends on the bleachers. In Figures 4.11 and 4.12, Patrick depicts himself and a friend using a cell phone in the gym.
Figure 4.11

Patrick’s art journal entry depicting himself and a friend watching videos on his phone in the gym

Note. The text reads, “and last [Darcy] give me back my phone at the gym” and Patrick describes himself as feeling “nice.”
Figure 4.12

*Patrick’s art journal entry depicting himself and a friend watching a video on his phone in the gym*

*Note.* The text reads, “Last I watch Tom and Jerry at gym on my phone” and Patrick draws himself with a smile on his face.

After spending some unstructured time in the gym, Patrick gets his things together and boards the bus to go home.

On Wednesdays, Thursdays, and Fridays, Patrick traveled out of the school to participate in community activities and/or practiced life skills in action. These trips took up a
large majority of Patrick’s school day, leaving Monday and Tuesday as the only full days that Patrick could potentially attend academic classes. According to his schedule, Patrick has fifty-seven minutes of morning meeting/math with his homeroom teacher five days a week, English Language Arts for fifty-seven minutes two days a week, and Science for fifty-seven minutes four times a week. When following his schedule down to the minute, Patrick spends at most 10.5 hours out of his 35-hour school week participating in academic instruction. This assumes that Patrick is spending the entire fifty-seven-minute block doing academic work, and only accounts for the days that Patrick follows his written schedule. Wednesday was a half day of school every week, on the other days, Patrick would spend fifty minutes in the gym (not including transition time) before getting ready for dismissal.

Every Tuesday Patrick would participate in an organized adapted physical education program with a certified educator where he would typically play soccer, depicted in Figure 4.13.
Note. The text reads, “and I did Exsports we play socore” and Patrick describes himself as feeling “fantsatic”

On the other days of the week, Patrick went with the para educators in his classroom to the gym, in his words, “to play with balls.” This was an unstructured time that was not being supervised by a certified physical education teacher.

Although there was a routine schedule for Patrick’s classroom on Mondays and Tuesdays, it seemed that oftentimes they deviated from that schedule due to staff absences among other things. For example, when his homeroom teacher was absent, or had to attend a meeting, math time was often replaced with watching YouTube videos, which occurred on at least five occasions. Patrick describes what he did during math class when Mr. Marcus was absent during an improvisational lyrical remixing session:

Chris: Did you do math today?
Patrick: No. Because Mr. Marcus was absent yesterday. I watched Rango on the computer. I watched the Wiggles Big Red Car. I watched the Red Train at Wake Forest. I watched Tommy Jerry over the river and boo the woods. I talked to Maria. I watched Young Justice. I watched the Night Kitchen. I watched Star Fall on the computer. I watched some trash and I watched Wal-Mart.

His English Language Arts Teacher, who was also his science teacher, was absent or in a meeting on at least ten occasions according to Patrick’s accounts, and each time instead of doing academic work Patrick either watched YouTube videos on the classroom computer or his phone, or watched episodes of the Magic School Bus:

Chris: Let me ask another question. So, what is your favorite class between math, science, or ELA?

Patrick: I think science.

Chris: Science? What are some of the things you do in science class that you like?

Patrick: Watch the Magic School Bus.

Chris: Oooh. Do you watch the Magic School Bus every class?

Patrick: Yeah.

Chris: Did you watch the magic school bus the whole time?

Patrick: Yes.

Although Patrick’s educational experiences did not always align with the written schedule that guided their week, Patrick thoroughly enjoyed his weekly excursions to do his job, go swimming, and visit the boat house for rowing. Here I asked Patrick what rowing
was and if he liked doing it, he responded, “when you do like this [motions with his body the rowing of a boat] indoors near the river….it was fun.” When I asked Patrick about some of his favorite activities at UCA during an improvisational lyrical session, he responded to the beat of “I Need Your Love” by Calvin Harris, “I like the sports, access sports, in the gym, we go downstairs, we have fun. I love swimming to the world, swimming is good, I like swimming in the water.” What is unclear is whether Patrick’s overall positive outlook on his educational experiences was a result of the academic programing he was provided at UCA, a reflection of the positive experiences he had when leaving the building on his weekly excursions, the opportunity to regularly watch YouTube videos in class, or a combination of all three. Either way, comparing Patrick’s written and official weekly schedule to his accounts of a typical week at UCA revealed two strikingly different educational experiences, the former portraying a rigorous plan for daily instruction and the latter suggesting that the schedule presented wasn’t always implemented with fidelity, supporting Bev’s insistence that UCA is only “babysitting” Patrick.

**Conclusion: Creating Walls of Exclusion**

Returning to the vignette at the beginning of the chapter that highlighted his strikingly different first-day transitional experiences, according to Bev, during the first week of school, Patrick found himself in a new school without “his team” to help him navigate the complexities of the new educational high school placement that he found himself in. At FDS, Patrick had made so much progress academically, socially, artistically, and even learned how to communicate by speaking, something that his mother had long feared that he would never be able to do. Looking back on his journey it is easy to see the positive accomplishments that he made despite the restrictive educational placement that he found
himself, first at FDS, and now at UCA. In a few short years of school, he was able to learn how to communicate by speaking, could independently get himself ready for the school day, express himself creatively through the arts, and even navigate anywhere in the city on the public transit system. Looking back on when Patrick was first placed in a substantially separate classroom, here I asked Bev if the FDS had ever mentioned anything to her about placing Patrick into an inclusion classroom:

Bev: The thing is with him about going into inclusion is because he's, he gets distracted easily. So, I mean you've seen him yourself. Would that be a good fit for him?

Chris: I don't know. I guess given the alternative of recycling and rowing and swimming, I mean I can't imagine it wouldn't be, I don't know. I just think that if he's distracted that they should give him supports to make him not distracted, you know? Help him.

Bev: They're not going to put a para in the room with him.

Chris: They should

Bev: They’re not.

Chris: I just see Patrick as a good candidate for at least some social inclusion, like even art or music or some kind of class like that. I think he would excel, and at the very least-

Bev: I think at high school they keep the kids together

According to Bev she felt that he was not ready for inclusion because he was “easily distracted.” Even as a school that fully embraced and specialized in inclusive education, the idea of Patrick receiving an official inclusion placement at FDS was not a viable option.
Although inclusion was never officially written into his IEP while he attended FDS, Patrick had multiple “unofficial” opportunities throughout the day and the school year to interact with his same-aged peers as an active member of the school community. Whether it was sharing rows of lockers with general education students, eating lunch in the same cafeteria, attending specialty classes like art and gym, going to the school dance, or taking field trips, Patrick often found himself learning and socializing alongside his same-aged peers. The same cannot be said about his experiences at UCA. It is important to note that throughout his freshman year at UCA, Patrick had remained optimistic and only shared positive accounts of his school, his teachers, and the education programming that he had received, despite being placed in a restrictive educational setting and limited to receiving meals and a majority of his educational programming in two isolated classrooms.

When Patrick was first diagnosed as being autistic, according to Bev, the doctor told her that he “had autism, it was going to be severe, and he had ADHD.” The doctor offered to prescribe Ritalin\(^{27}\) to help with his attention deficit hyperactivity disorder (ADHD) symptoms, but Bev refused. It is not clear if Bev’s perception of Patrick being “easily distracted” resulted from the ADHD diagnosis he received from the doctor, or was influenced by educational testing results that she received from Patrick’s school, but the data presented in this chapter suggest that Patrick is only “easily distracted” when he cannot control the environment that he is placed in.

Patrick can sit for hours on end writing books, drawing in his art journal, constructing three dimensional cities, and making content for his YouTube channel when he is able to control the conditions of his environment. By wearing his headphones and listening to his

\(^{27}\) A central nervous system stimulant used to control hyperactivity and impulse control, commonly prescribed to treat attention deficit disorder (Sinha, 2021).
videos on his laptop, while at the same time playing music from his phone, Patrick can create the supports he needs to regulate his body and stay focused on whatever he is working on. The issue of distractibility seems to only occur when those supports are removed, and Patrick is left to regulate his body without the use of technology. Ultimately Patrick is still able to calm himself down and regulate his body, but his self-stimulatory behavior might present to the casual observer as nervous ticks, repetitive motions, talking to himself, and generally appearing to be unable to sit still, or in other words, “easily distractible.”

What is clear is that Patrick is a resilient young man that excels when he is provided a supportive learning environment and has a deep-rooted passion for learning. Over the years he has learned to be resourceful and use the tools he has available to create the physical and physiological supports in his environment that he needs to be successful. Visual arts, music, dance, and his love of the UPTS played and continue to play a huge role in Patrick’s success, and without access to these outlets for his creativity, Patrick is labeled as “easily distractible” by his teachers. Without these supports, the school is creating the conditions in which Patrick is viewed as disabled. With the determination of educational placements hinging on a student’s ability to approximate ableist notions of normalcy and thus a judgment call (Baglieri et. al, 2011), in combination with the organizing of Patrick’s learning environment in a way that privileges other students but does not meet his individual needs (Biklen & Burke, 2006), it is not out of the realm of possibilities that an autistic student that is perceived as “easily distractible” would be placed in a restrictive educational setting rather than an inclusion classroom.

Patrick does not share any discontent towards his educational placement or his educational programming but given his untapped creative potential that seemingly lays
dormant at UCA, one is left to wonder if Patrick is content because he doesn’t realize his true potential or if as Bev suggested, “he loves school so much that he doesn’t realize that they are fucking him up.” It is hard to deny that Patrick loves school, he values his social experiences with friends, he is a talented artist, and he navigates his life spaces in a truly unique way. The next chapter will discuss some of the specific exclusionary practices that impact Patrick’s educational journey and present these practices using the metaphor of a siege to suggest that Patrick frequently finds himself surrounded by different walls of exclusion. I suggest that Patrick has experienced three different dimensions of exclusions: excluded administratively, academically, and environmentally.
I was struck by the general atmosphere of the school. The locked rooms, security staff, and lack of opportunities for students to use the library and playing fields during free time all contributed to an impression that the school was under siege.

— (Peters, Klein, & Shadwick, 1998, p.104)

Introduction

Despite the exclusionary practices that Patrick\textsuperscript{28} experiences in Dagobah Public Schools\textsuperscript{29} (DPS), he presents himself as a happy go lucky teenager who loves school and values his educational experiences and his close friendships. This chapter will illuminate some of the specific exclusionary practices used by the DPS and the Urban Collegiate Academy (UCA) that have impacted Patrick’s educational journey, and in many situations, impeded his success both academically and socially. Patrick goes to great lengths to describe his adoration and dedication to his teachers, school, and the education he is receiving at

\textsuperscript{28}A pseudonym chosen by the participant in the study.

\textsuperscript{29}Dagoba Public Schools, a pseudonym, is used throughout this chapter to protect the privacy and confidentiality of the school and school district. Pseudonyms are used throughout this chapter when referring to specific people and places that could potentially identify the participants and/or the school district in which the study takes place.
UCA; whilst his mother provides overwhelmingly negative accounts of these same experiences. Given the seemingly second-rate educational experiences that Patrick and his mother describe, on the surface it is unclear whether or not Patrick’s accounts are genuine reflections of the educational programming he is receiving, his silent acquiescence, or just another example of Patrick adapting to his environment, staying positive, and making the most out of the situation.

Patrick and his mother provided contradictory accounts of the same events in different time-spaces that needed to be examined closely. To accomplish this, I chose to explain the complexities of Patrick’s experiences, as well as that of his mother, through the use of a metaphor. This chapter will begin by taking a brief look at the use of metaphor in autism discourse and provide a framework for applying the metaphor of a siege to Patrick’s educational experiences. Next, this chapter will examine the progression of the siege beginning with “Phase One: The Fortification,” which will explore the administrative, academic, and environmental obstacles that Patrick faces at UCA, suggesting that each of these creates a wall of exclusion. In “Phase Two: The Blockade,” this inquiry will examine the educational attrition faced by Patrick at UCA created by a lack of quality educational programming. Lastly, in “Phase Three: Surrender”, I suggest that the siege progresses, much like what Levithan (2013) compares to a “ratcheting gear,” creating a forced paralysis for Patrick, surrounding, isolating, and forcing him into submission (p.48).

**The Use of a Metaphor**

Metaphors have been used historically in popular literature and media surrounding autism to pathologize the experiences of autistic individuals by obfuscating their humanity through a damaged narrative (Broderick & Ne’eman, 2008). Most notably, in her book
entitled *The Siege*, Park (1967) describes her experiences as a mother of an autistic daughter, drawing comparisons of autism to an outside force besieging and fortifying her daughter into forced isolation:

Existing among us, she had her being elsewhere. As long as no demands were made upon her, she was content. If smiles and laughter mean happiness, she was happy inside the invisible walls that surrounded her. She dwelt in a solitary citadel, compelling and self-made, complete and valid. (p.12)

In this chapter, I will cautiously use the metaphor of a siege as a means of illuminating the external discriminatory and pathologizing educational structures acting upon Patrick and his mother, rather than using this metaphor as a means of perpetuating the false, and often one-sided, perception of autism as a besieging force paralyzing an individual.

**The Siege as a Metaphor**

According to Levithan (2013), in historic warfare, “the siege followed a regular, predictable pattern--a progression that was in the mind of the commander as he began the siege” (p. 47). In this chapter, drawing on the work of Levithan (2013) and Egan (2016), I have created a framework to describe each phase of the siege progression in order to draw parallels to re/tell Patrick’s educational experiences during his freshman year at UCA through the use of the siege metaphor. Phase one of the siege, “the fortification,” describes the three walls of exclusion erected around Patrick that excludes him administratively, educationally, and environmentally. Phase two of the siege, “the blockade,” describes how Patrick is forced into surrender through educational attrition. Lastly, phase three of the siege, “the surrender,” explores the conditions of Patrick’s ultimate surrender and resulting in physical captivity.
Leviathan (2013) suggests that each stage of the siege progression is deliberately controlled by the besieging commander. Using this metaphor, I suggest that DPS represents this besieging commander, methodically and deliberately forcing Patrick into literal physical and figurative surrender using a series of exclusionary practices that limit his academic, occupational, and social success. The first step in this process begins with the fortification.

**The Siege, Phase One: The Fortification**

According to the Eurocentric view of ancient Roman warfare, the siege was commonplace and typically began in one of two ways, both of which involved fortification (Egan, 2016). Depending on the time period, fortification involved creating protective walls around a town or village in order to keep the enemy out, and usually included “high, thick walls, reinforced gates, and towers” (Egan, 2016, p. 441). According to Levithan (2013) the first way a siege would begin was when an army would attempt to attack an enemy that was secured behind a fortified wall, the other way was when one army would retreat into a fortified place to protect themselves from outside forces.

When applying the siege metaphor to Patrick’s experiences, it is important to clarify a distinction between fortification in its battlefield application and the fortification I suggest that Patrick experienced as a result of exclusionary educational practices. In the battlefield application of fortification, impenetrable walls are constructed around the circumference of the town, by choice, to protect the town from intruders. Applying this metaphor to Patrick’s experiences, I argue that the fortification, consisting of three walls of exclusion, were not constructed of Patrick’s own volition; rather, they were erected by DPS and UCA, deliberately containing and confining Patrick administratively, academically, and physically within his learning environment. These three walls of exclusion that fortify Patrick
cognitively, physically, and socially will be discussed further beginning with administrative exclusion, exploring how the guiding administrative document, the Individualized Education Plan and educational funding impact Patrick’s educational experiences.

**Administrative Exclusion**

*Forming of the individualized education plan team and the special education process.* The first administrative step in the special education process is determining whether a student has one of the thirteen categories of disability, as set forth in the Individuals with Disabilities Act (IDEA), and whether this dis/ability prevents that student from making adequate academic progress (IDEIA, 2004). Once a student is identified as having a recognized disability and meets the requirements for special education services, as set forth in the IDEA, a team is assembled by the school or school district to create an Individualized Education Plan (IEP). Each member brings with them their unique and specialized skills set and expertise to the IEP team. The team typically includes the student’s family, at least one general education teacher, at least one special education teacher, a school district representative, an expert that can interpret the student’s test results, it may include itinerants like occupational therapists and speech pathologists, and it can also include students themselves. This group of people know the student the best, and therefore are best suited to create an educational plan that will provide the student with all the services and supports needed for them to be successful. In addition to creating the plan, the IEP team is also responsible for executing the plan and making sure that the plan is carried out with fidelity.

Before the educational goals for the student are listed and discussed in the IEP, team members typically create a short narrative to introduce the student, listing their specific
strengths, areas of growth, and their educational aspirations and desires. For Patrick, the educators wrote his IEP at FDS \textit{with} him by asking what he wanted to do after he graduated high school, providing him an opportunity to include his voice in the document. Whereas his IEP at UCA was written \textit{about} Patrick and did not include his voice in the document. Below, Figure 5.1 shows a side-by-side comparison of the narratives for Patrick’s self-regulatory IEP goals from his previous school the FDS and his current self-regulatory IEP goals from UCA:
**Figure 5.1**

*Patrick’s Self-Regulatory IEP Goals from Frederick Douglass School Compared with Urban Collegian Academy*

<table>
<thead>
<tr>
<th>Frederick Douglass School (FDS)</th>
<th>Urban Collegian Academy (UCA)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patrick stated he would like to be a teacher when he graduates High School, he is challenged with independently generating ideas for what skills he would need to be successful at this vocation, but with guiding questions he stated he needs to use nice words and tell students to raise their hands. Patrick is able to independently follow along his daily classroom routines given a visual schedule for reference. He unpacks his backpack in the morning and packs it up in the afternoon without teacher assistance. He currently engages in a coffee club where he fulfills coffee orders, collects recycling, and assists with classroom maintenance with basic cleaning activities given occasional cueing back to task.</td>
<td>Patrick has made a good transition into UCA. He has worked on building relationships with teachers and peers. He has adapted to the program and the variety of activities that he is asked to participate in on a daily basis. Patrick transitions between classes with independence. Patrick participates in community outings and shopping experiences. Patrick has been participating in recycling at UCA and supporting the UCA school store. Patrick participates in the UCA in various ways each week.</td>
</tr>
</tbody>
</table>

Patrick’s previous IEP, written by teachers at the FDS, incorporated Patrick’s desires to be a teacher, as well as, acknowledged that Patrick would like to graduate high school. Looking
at the IEP from UCA, there is no mention of Patrick’s desire to be a teacher and/or graduate from high school and provides a far more generalized account of his current performance levels.

Regardless of whether or not the school or the IEP team felt that becoming a teacher was a realistic expectation for Patrick, if Patrick and his mother express the desire to provide Patrick the educational programming to match his chosen profession, it is incumbent on them to provide him access at his level of understanding. Given that Patrick is in a substantially separate classroom, he would need individualized supports to help him work on the necessary skills to become a teacher, and his program may look much different than the traditional route; however, many of the skills needed to be a teacher could easily be embedded into his IEP. Here I asked Bev her thoughts on UCA providing Patrick with the educational supports to learn how to become a teacher:

Bev: Patrick all along said that he wanted to be a teacher. Patrick, all along said he wanted to go to college. I mean, what are the odds of being a teacher? But he could have been a para (para educator). You know what I mean?

Chris: Yes.

Bev: I don't know, Chris. Now I know why parents turn around and just say, "fuck it." Now I know why.

It is critically important that before creating the IEP that the team gathers, and reviews data related to the student’s current level of performance so they can create goals for the students that are both cognitively rigorous and achievable given the individualized supports to accomplish these goals. The problem being that for some students it may be
difficult to accurately measure their current performance levels if the measuring tool used and the environment in which they are assessed are not modified and/or adapted to meet the needs of the learner. For example, if the student is non-speaking and they communicate fluently in visual picture symbols and the assessment is given solely in spoken and written words, the assessment will not capture an accurate representation of the student’s current levels of performance (Biklen & Burke, 2006). The student could potentially possess the skills to perform at the similar levels as their same-aged peers; however, without the use of visuals, the assessment will measure their performance at the far end of a bell curve.

To correct for potential inaccuracies in assessment and to create a more accurate picture of a student’s academic performance, the IEP team typically administers a wide variety of assessments to provide a landscape view of the student across education contexts, including academic skills, developmental skills, and social skills. Even with all these measures in place, an IEP can often provide a skewed look at a student through a deficit lens, and the resulting educational programming developed from a skewed perspective, may not be providing the student with a rigorous and/or appropriate course of study. The IEP marks the starting point and the road map for laying out a student’s educational path; it serves as an administrative document that has both intended and unintended consequences. The intended consequences of providing the least restrictive environment for students to learn in, but if the data in making this determination is inaccurate, it will have the unintended consequences of administratively excluding students from a Free and Appropriate Education (FAPE).

Although the IEP serves as the document that guides a student’s educational journey, it is not the only way that students can be administratively excluded from a FAPE. In Patrick’s case, by not honoring his voice and acknowledging his aspirations of becoming an
educator, UCA is administratively excluding him from access to his chosen career. To better contextualize the implications of administrative exclusion, it is important to closely examine how a student’s diagnosis, educational placement, socio-economic status, as well as, whether they are native English speakers can significantly impact the amount of funding that is allocated to educate them in a public-school setting.

**Funding.** Once the IEP is written and educational placement for the student is determined, in order to provide the students with the supports and services written in the IEP, the District needs to allocate funding for these supports and services based on labels that are given to the student (Reid & Knight, 2006). According to the district website, the urban school district that Patrick attends uses what is called a “weighted student funding model.” This model allocates money based on students and their needs rather than based on a specific program, staffing needs, or other measures. Baker (2002) argues that this type of education funding is premised on the idea that a “model student” exists, and special services are required for students, such as Patrick, that are pushed outside of this model. Each school in the city receives a base amount from the district, after that, the funding that the school receives is based on the number of students and the needs of those particular students. Students with dis/abilities, English Language Learners, and students experiencing poverty receive a greater amount of funding allocated to them so their needs will be met. These students require more supports to access the general education curriculum, with the idea that more money is needed to provide these supports. For example, the base rate for a general education student in the ninth grade for fiscal year 2020 was $5,600, and the high school where the student attended would have this sum allocated in their budget. That same high school, for a student in the ninth grade with a diagnosis of autism receiving education in a
substantially separate classroom for fiscal year 2020 would receive the base rate of $5,600 plus an additional $16,700, for a total of $22,300. If that student was also an English Language Learner, they would have an additional allocation of $2,600 added to the $22,300, for a total of almost $25,000 allocated to the school in their budget to educate this student (Dagobah Public Schools, 202030).

If Patrick stays enrolled at UCA from ninth grade until he reaches the age of twenty-two, over the course of his tenure, the school will receive approximately $156,000 from the budget office to educate Patrick. The total money spent to educate the fifteen students in Patrick’s classroom from the ninth grade until they turn twenty-two adds up to $2,340,000, compared to the $588,000 it would cost to educate fifteen general education students for seven years, a difference of $1,752,000. It is important to note that the extra money allocated to Patrick and his classmates is intended to provide them with highly qualified special education teachers, para educators, occupational therapists, speech and language pathologists, applied behavior analysis (ABA) therapists, Board Certified Behavior Analysts, adapted physical education teachers, special education administrators, and other support staff.

Using the siege metaphor to examine the funding practices for special education students in this urban school district suggest that Patrick’s school could potentially have a financial interest in keeping him enrolled in the Skills for Life (SFL) Program until he turns twenty-two, rather than providing him with the educational programming necessary to earn a high school diploma. Much like the battlefield tactic of surrounding a fortified city and

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30 This citation is a pseudonym for the real school district budgetary information found on their website. Including a detailed citation here will break confidentiality, which is why I chose to include a pseudonym for this document.
preventing resources from entering and exiting the town, the data suggest that DPS has cut off the resources that Patrick is entitled to, mainly inclusive opportunities, support services, and focused academic instruction, and instead, continue to collect the funding that has been allocated to him through the student weighted formula (Reid & Knight, 2006).

Looking at Patrick and his mother’s accounts would suggest that the educational programming that Patrick and his peers are receiving, which will be discussed in detail later, may not reflect the monies provided to the school through the student weighted formula, potentially leaving excess funding for the general budget of the school to be allocated elsewhere. The student weighted formula provides equity to special education students by providing them the funding for the supports they will need to have access to an equitable education, and many of these supports are expensive, hence the extra funds to support them. What is clear is that when Patrick attended the FDS, the money allocated for Patrick through the student weighted formula was used to provide him with not only all the services written in his IEP, but also to pay for an Inclusion Specialist to provide him and his classmates with opportunities for inclusion, as well as para educators to support him in that setting. What is unclear is how all the money that is allocated for Patrick and his classmates is being used at UCA.

Throughout this investigation, neither Patrick nor his mother share any accounts of inclusive opportunities provided to Patrick at UCA, in fact, they only describe situations where Patrick is being actively excluded from the school community. These opportunities entail attending class in two isolated rooms away from his same-aged peers, accessing lockers, eating meals in the cafeteria with the rest of the school, and being educated all day in a restrictive self-contained classroom with no interaction with general education students.
The few additional support opportunities that Patrick receives from the SFL Program have included the use of a school van for weekly field trips to the Central Offices to clean the doors, windows, and do the recycling, to the local Community Center for free swim (not requiring a swim instructor), and to a local boat house to practice rowing. By using a school van and community partnerships, the cost of these trips is minimal. Using the siege metaphor would suggest that by administratively excluding Patrick from the allocation of funding not only denies him inclusive opportunities in the classroom and school community, but also provides a financial incentive to UCA for providing Patrick with an education focused on functional life skills rather than providing him with an inclusive academic experience. In other words, as Bev and Patrick’s accounts would suggest, the school is not using the extra money to provide Patrick and his classmates with equitable access to education.

By administratively excluding Patrick from inclusive opportunities, he is left with little choice but to embrace what he is being provided, making the most out of his situation, and staying positive. Inclusion in a school setting can be expensive, and often requires an extra teacher, para educator, applied behavior analysis therapists, occupational therapists, and other support services. On the surface, the life skills program that Patrick is enrolled in at UCA does not seem to warrant the price that is allocated in the budget, and as Bev suggests, the money meant to provide services for Patrick and his classmates could potentially be used elsewhere in the school. According to Bev, “They’re there to take the money. They probably use the money for other things. I’ve asked to see the budget for the past five years. I’m still waiting on that.” Earlier in the school year Patrick complained to his mother that his
classroom didn’t have as many computers as his previous school. Below Patrick shares that his classroom has one computer for student use:

Bev: How many computers do you have in your class?
Patrick: Ah...Mr. BMC has two ones. He has the purple and the red
Chris: Purple and the red?
Patrick: Yeah
Bev: And how many does Mr. Marcus have?
Patrick: One, Jeremy right?
Bev: And how many kids are in your class?
Patrick: Did you tell Mr. Marcus?
Bev: No, I’m asking you
Patrick: [provides the names of seven students]
Bev: 8
Patrick: Yes
Chris: And one computer?
Patrick: Ah huh

To secure consistent access to a computer, Patrick would have to bring in his laptop from home. When Bev was informed of this, she immediately contacted the school administration, complained, and demanded that computers be purchased for Patrick’s classroom:

Bev: They could give a rat's ass. Because, like I told you, they had no computers. I was told by the teacher that they've been fighting for it. I turn around, and flip the script on them, and told [the administrator] that Patrick wanted to bring his laptop in. That's what got the ball
rolling. Are they using our money for ... Are they using our kids as pawns?

Chris: Makes you wonder?

Bev: Of course they are Chris.

Chris: Sounds like they are.

Bev: Of course it is.

Chris: Yep.

Bev: Because if one side of the building has laptops, the other one doesn't. They give one for our kids, but you know what though? I'll be that bitch...

Soon after Bev learned of the limited availability of technology in Patrick’s classroom, she called the Head of Special Education for DPS and demanded that his class receive laptops.

During Patrick’s first IEP meeting in October of 2018 at UCA, the occupational therapist recommended that Patrick be removed from direct service occupational therapy. Instead, the occupational therapist would consult with the classroom teacher once a month and provide suggestions on how Mr. Marcus, his homeroom teacher, could support Patrick in the classroom. According to Bev, the rationale behind this decision is that when students enter high school, they shift the focus from building writing skills from pencil and paper to writing skills using a computer. Here is what the occupational therapist proposed to be written into Patrick’s IEP, “More online platforms to utilize, along with Chromebooks/software. Build soft skills, typing, creating documents, team all agreed to embed recommendations.” On this proposal summary under parent concerns, it stated, “parent concerns: warned about writing skills.”
Logically it would make sense for Patrick to shift from pencil and paper to learning how to use technology when he entered high school, but it isn’t as simple as providing him a Chromebook and his occupational therapy services are no longer needed. For many students with an IEP, they need to be explicitly taught how to use a computer to develop the fine motor skills to type the keys with the proper force, and they need to work on the hand-eye coordination to use the keyboard, all of which fall under the domain of occupational therapy. In addition, UCA was recommending that occupational therapy services be removed from Patrick’s IEP in favor of learning computer skills, but Patrick’s classroom is equipped with only two computers for the entire class. Not only are they UCA removing essential services from his IEP, but through the allocation of funds, they aren’t providing him with the means to implement the recommendations given by the occupational therapist. Through this administrative exclusion, Patrick is left in a position where he cannot advance his writing skills because he doesn’t have individualized supports, and he can’t advance his technology skills because he doesn’t have access to a computer.

Returning to the siege metaphor, Patrick is experiencing administrative exclusion, and as a result he is trapped. He is too “autistic” to be included with his same-aged peers academically and he is not “autistic enough” to be eligible for the IEP services that are typically provided to students in restrictive educational placements, including occupational and speech therapy.

**Academic Exclusion**

**Patrick’s desire to become a math teacher.** It may have been difficult for Patrick to explicitly express ways in which he was excluded at the administrative level because his mother was navigating this space for him; however, the educational experiences that he
shared while attending his freshman year at UCA revealed the ways in which he was both
directly and indirectly excluded from equitable access to an education. At the beginning of
this investigation in November of his freshman year of high school, I asked Patrick what his
favorite subject in school was, and what his occupational plans were for when he left UCA.
Here Patrick shares some insight into his educational aspirations:

Chris:    What do you like learning the most at school?
Patrick:  Math

Chris:    Why do you like math so much?
Patrick:  Cuz I like the numbers

Chris:    What do you think you are going to do with math?
Patrick:  Add

Chris:    Add?  What you want to do for a job when you leave school?
Patrick:  Be a teacher

Chris:    What kind of teacher?
Patrick:  A math teacher

Patrick expressed several times through interviews, as well as, through his artistic
renderings that he wanted to be a math teacher and he understood that in order to be a math
teacher UCA needed to provide him with supports to learn how to teach. When directly
asked numerous times if he felt that the school was adequately preparing him to be a math
teacher, he shook his head yes and by speaking expressed that he felt that they were doing so.
Figure 5.2 displays an image that Patrick drew of what he would look like as a math teacher.
On another occasion, Patrick expressed that he wanted to go to college to be a teacher, here he shares how Mr. Marcus is preparing him to become a math teacher:

Chris: A Math teacher. Do you think Mr. Marcus is giving you all the Math skills you need to be a good teacher?

Patrick: Yes.

Chris: What are some of the things he's teaching you?

Patrick: Three equals 9 x 7.

Chris: 9 x 7?

Patrick: 63.

Chris: Oh there you go. What else do you know? What about 9 x 8?

Patrick: 9 x 8 is funny. I have my calculator. 9

Patrick: 72.

Chris: 72. What else do you know? Without the calculator?

4 x 5.
Patrick: $4 \times 5 = 20$ and $5 - 5 = 0$

Chris: All right, let's test you. Ready. What's $10 \times 3$.

Patrick: 10

Chris: What's $10 \times 3$.

Patrick: 20.

Chris: $10 \times 3$? $10 \times 2$ is 20. What's $10 \times 3$?

Patrick: $10 \times 3$ is...

Chris: 10, 20...

Patrick: 30.

Chris: 30. $10 \times 3$ is 30.

Patrick: Forest Heights plus Downtown Station [both train stations in the city].

In his last response, Patrick provides a glimpse into how he stores new knowledge. He is unfamiliar with what ten multiplied by three is and in order for him to assimilate it into his current understanding, he applies his method of relating things to location. Although “Forest Heights plus Downtown Station”, both train stations, may not make sense to the casual observer, it makes perfect sense to Patrick, and he has shown great success with this method.

Upon further investigation, Patrick expressed both by speaking and through his artwork that he routinely is assigned math work that includes basic addition and subtraction problems. Even when describing below grade-level educational curriculum in math, Patrick expresses joy in doing math problems like $2 + 2 = 4$, and coloring in a kindergarten color-by-number math worksheet that is shaped like a dinosaur with markers seen in Figure 5.3.
Figure 5.3

Patrick’s student work sample of color-by-number math worksheet

Note: The color-by-number math worksheet that Patrick completed above was found in a Google search by typing in the search terms, “math worksheet for early childhood students.”

Figure 5.4

An art journal entry of Patrick’s recounting math work he did in school
During our interview, I asked Patrick what he did in math class today and he reached into his bag and handed me the “dinosaur quilt” worksheet pictured above. Here I asked him to tell me about what he did in math class that day:

Chris: What are some things you're working on in math today?

Patrick: Three minus three. I had three slices of chocolate cake and I ate three.

Chris: And how many did you have left?

Patrick: Zero.

Chris: Zero. Do you do worksheets like this a lot in class? With the dinosaur quilt, with the color in the numbers?

Patrick: Yes.

Chris: All right Patrick, so tell me about this dinosaur picture you did here.

Patrick: Well, the dinosaur is green, and I did that on 3/27/2019.

Chris: Which class did you do this in?

Patrick: Mr. Marcus’.

Chris: Was it a special math thing or did everyone do this?

Patrick: Yes. Like a dinosaur quiz. That's a volcano.

Chris: Oh, that's pretty cool.

Patrick: That's in Dinosaur Land.

Chris: So, we got: six is green, seven is purple, eight is brown, and nine is blue and ten is orange.

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Note. Text reads “I did that in Mr. [Marcus’] Room 4 + 4 = 8. I feel cool in the pool”
Patrick: Look at my name. My names in a pattern.

Chris: Patrick, orange, purple, green, blue, and brown. Patrick in the jungle.

Patrick: Yes. A dinosaur.

During an Improvisational Lyrical Remixing (ILR) session, Patrick expanded on this notion when I asked him to tell me about math class to the beat of “Thrift Shop” by Macklemore and Ryan Lewis:

Patrick: It was morning day at Urban Collegiate Academy. I did my math off the Red Train Sycamore Station computer, and I watched Tom and Jerry Over the River and Boo the Woods, and I watched castle, and I did recycling in the hallway. I watched shopping at Target. And watched the Red Train at Bay Station. Talked to Jayden. That's what I did at Urban Collegiate Academy. Now why don't you look at this Mr. Chris. it was good.

Chris: Tell me A little bit more about math class

Patrick: I did two plus two equals four. Chocolate cake on a plate. It was yummy. Mr. Darius and Albert miss the Frederick Douglass School. It was good. Incredible.

Chris: In Math class. Did you watch some videos?

Patrick: Yes. The Red Train Almont Station. It was very good. I liked it.

Chris: How long did you watch those videos for Patrick?

Patrick: 15 minutes

Chris: Did you do some math, or did you only watch some videos?
Patrick: I watched the videos with the Red Train. Almond Station. I watched Tom and Jerry Over the River and Boo the Woods I did a castle. It was very good.

Above, through ILR, Patrick described how his math class consisted of watching videos of the Red Train and people shopping at Target, a cartoon of Tom and Jerry, talking to his friend, and doing math problems consisting of simple one digit addition. When asked how long he watched videos for, Patrick responded, “15 minutes” and went on to describe how after doing his basic math problems, he proceeded to watch more YouTube videos instead of working on foundational math skills.

The Math Foundations course that Patrick participates in as part of the Skills for Life Program describes the math curriculum on their website as:

Math Fundamentals is a course for students in the Skills for Life Program to work on building their math skills through practice and application. Students work to improve their functional math skills in the area of money skills, computation, number sense, and problem solving. Each student in the class works on growing their individual skills through daily practice.

In order to practice their money skills, computation, and problem solving, Patrick and his classmates regularly eat lunch at a nearby food establishment where they have the opportunity to order their food, figure out if they have enough money to pay for what they ordered, and count out the money needed to pay for the food. Once they receive their change, they can then count it to make sure they received the correct amount of change and compare it to the receipt. During our discussion, Patrick shares that he had a sixteen-dollar
lunch, much to his mother’s chagrin, “What kind of lunch you have for sixteen dollars? Shit.”

Here Patrick describes his experience at lunch:

Bev: So, what did you buy with your twenty dollars?

Patrick: For my French fries, pizza, nuggets, and Coke.

Mom, where's your earrings?

Bev: So, you had twenty-four, and now you have, how much you have left?

Patrick: Eight.

Bev: Eight. So, what's that? How much you spend?

Patrick: One. One.

Bev: You have twenty-four dollars.

Patrick: Twenty minus eight?

Chris: Twenty-four minus eight.

Patrick: One, two, three, four, five, six, seven, eight, nine, ten, eleven, twelve, thirteen, fourteen, fifteen, sixteen, seventeen, eighteen, nineteen, twenty.

Bev: That’s scary, and a danger.

The stated goal of the math foundations class is for students, “to improve their functional math skills in the area of money skills, computation, number sense, and problem solving.”

This is something that is accomplished, “through daily practice;” however, during each occasion that Patrick describes purchasing food or goods in the community, he has a difficult time completing the transaction without the help of the cashier. When asked if he practices buying products in the classroom before he tries purchasing products in the real world, Patrick wasn’t sure.
Throughout the course of this investigation through interviews, artistic renderings, and ILR sessions, Patrick continuously described his math class involving practicing single digit addition and subtraction problems. Oftentimes these math problems consisted of word problems involving food, such as, “if you have four pieces of chocolate cake and I take two away, how many pieces do you have left?” When he doesn’t describe calculating below grade-level math problems, he typically shares what YouTube videos he watched during math class, here he described his “break time” in math class:

Chris: What do you think tomorrow morning when you go into Mr. Marcus’ class, what's the first thing you're going to do tomorrow morning?

Patrick: Math work.

Chris: Math work?

And then what happens after Math work?

Patrick: My break time.

Chris: Ooo, how long is your break time?

Patrick: For 20 minutes.

Chris: 20 minutes?

Patrick: Uh-huh.

Chris: Is that every day?

Patrick: Yes. Every day in Urban Collegiate Academy.

Chris: So there in Math class you get 20 minutes of break time. And what do you do during that time?

Patrick: Switch. Until the bell rings.

Chris: Do you use the computer, do you play with toys, what do you do?
Patrick: Stay on the computer. Watch some videos.

Chris: Oh nice. What are you going to watch for videos tomorrow?

Patrick: I'm going to watch Midnight Kitchen.

Milk in the batter, milk in the batter. Serve it, squeeze it, bake it.

This “break time” wasn’t just a common occurrence in math class Patrick shared that he has a twenty-minute break in science classes, as well as an hour-long break in his English Language Arts (ELA) class.

At first it seemed as though Patrick's accounts were inaccurate; however, over the course of this investigation, Patrick consistently described longer break times during academic classes throughout the school day and his teachers being regularly absent during the year, both resulting in an increase in his watching of non-academic videos during academic instruction time. The exclusionary practices highlighted here not only prevented Patrick from accessing grade-level math curriculum at his individualized level, but also eliminated critical instructional time that could be spent targeting specific academic skills that would help Patrick, “improve [his] functional math skills”, which is a stated goal of the Math Foundations Program he is enrolled in. Instead, this valuable instructional time was filled with watching non-academic videos such as Tom and Jerry and people shopping at Target. These data revealed that this is a common theme throughout each data set.

Exclusion from his Environment; Physical Exclusion

The breakfast room of isolation. On any given morning at UCA, Patrick enters the school through the metal detectors, past the security guard, and walks down the hall into the SFL room, commonly referred to as the breakfast room, to eat his breakfast. In his previous school, Patrick would eat his breakfast and lunch in the gigantic cafeteria, intermingled with
general education classrooms and his same-age peers. At the UCA, Patrick eats all his meals in a secluded room located off of the cafeteria with all of the students in the substantially separate program. When asked why he eats his meals in the SFL room, Patrick responded, “because that’s what Mr. Marcus said.” Patrick doesn’t argue or attempt to resist, he simply sits at his table and eats lunch with his friends, which he enjoys very much, as seen below in Figure 5.5.

**Figure 5.5**

*An art journal entry of Patrick’s recounting what he ate at lunch*

![Art journal entry](image)

*Note.* Text reads, “For lunch I rice fish and milk. I feel Yummy” And “Next I watch ....”

Patrick shares that his favorite part about lunch, other than eating “yummy food” is spending time with his friends, see Figure 5.6 below.
Figure 5.6

*An art journal entry of Patrick’s recounting spending time with friends at lunch*

![Art Journal Entry]

*Note.* Text reads, “Next I talk to [friends]. I feel happy”

Typically, Patrick and a couple of his friends will huddle around his cell phone and watch a variety of programming ranging from the Wiggles, kids smashing Little Caesars Pizza on the ground, and watching people shop at Target, as seen below in Figure 5.7.
Figure 5.7

An art journal entry of Patrick’s recounting watching videos at lunch

![Image of an art journal entry]

Note. Text reads, “Then I watch the Wiggles ‘We Be Wiggling.” “I feel cool”

Through these illustrations and many others, Patrick expressed joy and happiness when interacting with his peers at lunch time and enjoyed watching his favorite YouTube videos with his friends. This was Patrick’s happy place. Eating food and watching videos on his phone with his friends is one of Patrick’s favorite pastimes while in school.

Many of Patrick’s classes take place in the SFL room, and he spends a great deal of time here throughout the school day. Patrick describes it as, “huge, it looks like a house, it has a washing machine, a refrigerator, and stove.” Here I asked Patrick if he eats lunch in the cafeteria:

Patrick: No, we don't eat lunch in the cafeteria we eat in the breakfast room

Chris: I know, so you eat in the breakfast room, how many kids eat in the breakfast room when you eat lunch?

Patrick: A lot
Chris: How many? Tell me, how many do you think?

Patrick: One, two, three, four, five, six, seven, eight, nine, ten...Ten

Chris: Ten kids are in the breakfast room?

Bev: Is it just Mr. Marcus’ class and the other class?

Patrick: Yes

Bev: It’s only the ASD class

Chris: Where do the other kids eat lunch?

Patrick: In the cafeteria

Chris: How does that make you feel? Does that make you happy or sad that you eat lunch in the breakfast room?

Patrick: It feels a little bit happy

Chris: How come?

Patrick: Cause I like eating in the breakfast room.

Chris: What do you like about the breakfast room?

Patrick: It's good, it has a kitchen, and a washing machine

Chris: That's good, would you want to eat with the other kids in the cafeteria?

Patrick: Yes

Chris: Do you want to eat lunch with the kids in the breakfast room?

Patrick: Yes. I can’t wait till the first day of school

Chris: So, you do art in the breakfast room, you eat lunch in the breakfast room, what else do you do in the breakfast room?

Patrick: We sit, we eat breakfast

Chris: It sounds like you spend a lot of time in the breakfast room
Patrick: Uh huh

Chris: Is that where you do your cooking class, in the breakfast room?

Patrick: Yes, and when the bell rings [makes dinging sound] we have a switch

Although Patrick shares that he likes eating meals in the SFL room because it “has a kitchen
and a washing machine”, he also expresses that he would like to eat in the cafeteria with the
other kids, in this case referring to his same-aged peers.

When Patrick’s mother was asked how she felt about the SFL room, she replied,
“honestly high school is a day care for the kids, that’s just you know……just come here and
sit here for fucking eight hours and we’ll keep you entertained and that’s that…” Patrick
commonly carries around his jacket and backpack because he and his classmates do not have
access to lockers, they are only for students in general education. Here I ask Patrick if he has
access to a locker at UCA:

Patrick: No. We're in high school, not middle school because we don't wear
uniforms.

Chris: Where do you keep your stuff at?

Patrick: In Mr. Marcus’ room.

Chris: And where do you eat breakfast?

Patrick: In the breakfast room

Chris: So, you eat lunch and everything in your room?

Patrick: Yes, ma'am.

Here Patrick is referring to when he had lockers at the FDS when he wore a uniform, now
that he is in high school, he keeps his belongings in Mr. Marcus’ room. Not having access to
lockers was a bit of a culture shock for Patrick, who had been independently storing his
belongings in a locker since he entered the sixth grade. His privileges were limited in comparison to his last school, and he rarely had the opportunity to interact with general education students during the school day. Bev unapologetically shares her criticism of the SFL Program at UCA, and specifically the Headmaster of Mr. Lawrence:

    [Lawrence] don't know jack shit about having autism in his building. Because if he did, why are they restricted to only two classrooms? That's all they go through the whole day. They have no lockers. They have no... they don't eat in the cafeteria. They are limited on what they can do. Shit they had no computers. They had no laptop. They have no after school activities for them.

At his previous school Patrick and his classmates typically had inclusion opportunities in physical education, art, and science class. But at UCA, according to Patrick’s accounts, when he wasn’t participating in Access Sports (an adapted physical education class), physical education consisted of “playing with balls” in the gym, secluded from the rest of the school. Patrick was supervised by a para educator who would bring him to the gym to run around and play with a bag of random balls to keep him and his classmates occupied. As Bev argues, “[Patrick] is just going there to be babysat, chaperoned, not educated.” When asked how Patrick handled the adjustment from a kindergarten through eighth grade school that he had attended most of his life to high school, Bev responded:

    Bev: He loves school so much he doesn’t realize that they are fucking him up.

    Chris: Yep, he always aims to please.

    Bev: The first day he came back from school [UCA] he said, how can a school not have Sensory Arts?
Bev: He was going through the compare and contrast. How come I don’t get homework? How come I don’t get Science like Mr. Takei’s class? That went on for a while, and then by October it was the norm. But at first… it was hard adjusting… and he doesn’t realize what he’s missing out on, and his potential

The small selection of inclusive opportunities at UCA is not limited to just the school day, but it also extends to after school programming for students in the substantially separate classrooms. UCA provides no extracurricular sports or activities for Patrick and his classmates, “our kids aren’t playing football, our kids don’t play baseball, they don’t play soccer, we are restricted on sports”, complained Bev, “they limit us, basically it’s like a babysitter.” This was a new experience for Patrick. At his last school, although there were not many extramural sports, Patrick had several inclusive opportunities, including playing in the student and staff basketball game, attending Camp Endor (a pseudonym) for a three-day outdoor adventure experience, class trips to a local amusement park, various clubs, and participating in the inclusive after school enrichment program. When asked about the difference between inclusive opportunities at UCA and Patrick’s former school, Bev responded, “it’s like taking your child from a first world country and throwing them into a third world country. It’s totally different. That building [UCA] just houses our kids.” It is important to note that although he is isolated from the rest of the school for a large majority of the school day, Patrick does very well when he is in small groups and has a predictable schedule with little to no changes in routine.

With limited opportunities for inclusion, Patrick is in class with the same students, in the same room, eats lunch at the same time, at the same table, and he even has the same food
on the same day of the week. For students like Patrick, this could be considered the optimal learning environment. It is unknown if being educated in this sheltered environment with little to no changes in routine will prepare Patrick for the complex and complicated outside world. What is also unclear is whether this physical environment was created by the school in order to provide students with a safe learning environment, or as a means of segregating special education students from the general population of the school. The former would suggest that UCA is using best practices for educating autistic students in the optimal learning environment, but the latter would support Bev’s notion that: “They don't care about our kids. They don't give a damn about them…. they are just housing our kids and collecting the money.”

Taking a closer look at these exclusionary practices of isolation at UCA through the siege metaphor could suggest that by physically isolating special education students away from their same-aged peers, the school is essentially cutting them off from the outside world. In Patrick’s case, this is potentially creating an environment where he is grateful for whatever resources he receives because he is unaware of what he is missing out on. By keeping Patrick isolated in the school and providing him with experiences that he enjoys, like taking the school van or public transportation on community outings and watching YouTube videos, he remains in a perpetual state of compliance with educators and administration at UCA. Never critically examining the educational programming he is provided, potentially because Patrick doesn’t want to miss out on the outings and experiences that he values and enjoys, further socially and academically excluding him from learning the individualized academic and functional living skills he needs to reach his goal of attending college and “working in a school to help kids.”
Consequently, Patrick finds himself trapped behind another wall of exclusion, a conceptual framework of these walls of exclusion can be seen in Figure 5.8 below. He is not provided with inclusive educational opportunities alongside his same-aged peers, and instead he is restricted to two classrooms in the school for a large majority of the day, physically and cognitively isolating him from his school community. In the words of Patrick’s mother, at UCA Patrick and his classmates, “are seen but not heard.” The next section will explore ways in which UCA uses non-academic experiences as a way of lessening Patrick’s resistance, leading to his eventual metaphoric surrender.

**Figure 5.8**

*Conceptual framework of the three walls of exclusion surrounding Patrick, administrative, academic, and environmental walls.*

*Note.* This image is a visual depiction that I created to display my conceptual framework with Patrick in the middle and the three walls of exclusion trapping him with-in and creating
a forced paralysis leaving him with no room to move. The young man in this image is not Patrick, it is taken from a stock photo to protect the identity of the participant.

The Siege, Phase Two: Lessening the Resistance

The Blockade: Starvation Through Educational Attrition

The blockade is a distinct form of siege warfare designed to surround, isolate, and starve the enemy into submission, resulting in surrender through attrition rather than force (Egan, 2016). In ancient warfare, blockades involved surrounding the enemy secured behind fortified walls, preventing entry or escape, cutting off communications, supplies, and reinforcements (Levithan, 2013). In Patrick’s situation, he did not retreat behind a wall or create a secure fortification around himself; rather, the metaphoric walls of administrative exclusion, academic exclusion, and physical exclusion from his learning environment were erected around him by the school district DPS, as well as his school UCA, trapping him inside multiple layers of exclusion. Through this systemically enforced fortification and resulting blockade, I point to the ways in which DPS and UCA are possibly surrounding, isolating, and “starving” Patrick into submission. It seems - through educational attrition and unfettered access to YouTube videos instead of access to inclusive educational opportunities - that his resistance to the restrictive nature of his educational placement is lessened.

Non-educational video watching. In eighth grade at Patrick’s former school, his English Language Arts (ELA) teacher Ms. Harris had a strict policy for using the classroom computers, and she regularly enforced it. During instructional time, computers and devices were only allowed to be used by Patrick and his classmates for accessing educational content. This would include educational websites like Khan Academy, Razz Kids, and other websites that provided educational activities that helped build ELA and/or math skills. Ms. Harris
allowed students to access YouTube and other websites featuring non-educational content only during a specified “choice time” or at the end of the day awaiting dismissal. Patrick describes a classroom experience when he was trying to watch a Geico commercial during academic time in Ms. Harris’ class:

Patrick: You know Ms. Harris, when I was on Ms. Harris’s computer last year Ms. Harris said, Patrick don’t use my computer because her computer is not an option. I was watching a Geico commercial

Chris: Oh, that’s what it was? What does Ms. Harris let you watch on the computer? Does she let you watch anything good on the computer?

Patrick: No, she said I can’t watch videos, her computer is only for working, not for free time.

Chris: Oh, that’s good

Patrick: Only the black one’s available

Chris: What does Mr. Marcus say about his computer? If you want to watch videos on his computer

Patrick: Ask him I said, Mr. Marcus can I have your computer please? He was like sure, sure.

Chris: Does he let you watch whatever you want to watch?

Patrick: yes

Chris: So, what do you usually watch on the computer? On Mr. Marcus’s computer.

Patrick: Catfish and Target, the Wiggles

Chris: What’s Catfish?
Patrick: Oh, the catfish? It's like a fish with whiskers

Chris: Oh, like an actual catfish, I thought it was a show

Patrick: Like a turtle. A man feeding the fish, and the cat and the turtle, fish and worms.

Chris: When you were in Ms. Harris’s, I know Ms. Harris likes to let kids use the computer to practice math, reading. Did she do that for you?

Patrick: yeah, she did

Chris: What about Mr. Marcus? Does he have any of those for his computer?

Patrick: yes

Chris: What are some of the things you do for that?

Patrick: I do, videos.

Chris: videos? What type of videos?

Patrick: Like…. ah...I watch…. a Geico commercial…

Chris: Catfish?

Patrick: uh huh

Chris: Wiggles?

Patrick: uh huh

Chris: Ok

Patrick: The City Transit System A Train at University Station. Boom!

In one of Patrick’s art journal entries, as seen in Figure 5.9 below, he depicts a scene where he is watching a video of the Orange Train at Washington Street Station during an academic block. His teacher Ms. Harris is portrayed with rigid body language, her stiff arm pointing at
Patrick with the other arm on her hip, and downward facing eyebrows, creating what appears to be the feeling of anger and disapproval.

Figure 5.9

An art journal entry of Patrick recounting a conversation he had with Ms. Harris when she wouldn’t allow him to watch YouTube videos during class time.

Note. Ms. Harris is a pseudonym for Patrick’s former ELA teacher. The text of the conversation reads “When Ms. [Harris] so Patrick on her computer. Hey Patrick. Hi Ms. [Harris] said Patrick. I’m watching the [Orange Train] at [Forest Grove Station] today. That’s my computer said Ms. Harris”

From January 8, 2019, through June 7, 2019, for a total of 96 school days, Patrick documented his daily educational experiences at UCA in his art journal. The art journal consisted of storyboarding templates that provided Patrick with space to illustrate and narrate

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32 Some of Patrick’s art journal entries include spelling and grammatical errors and have been purposely transcribed verbatim to provide a first-hand account of Patrick’s experiences, sharing his story in his own words.
each of his class periods throughout his school day for every day of the week. These art journal entries provided a comprehensive and first-hand account of Patrick’s educational experiences at UCA in a detailed and authentic way. Below is the summative data from Patrick’s 863 art journal entries where he documented his daily school activities at UCA. According to Patrick’s account, as seen in Figure 5.10, 51% of his art journal entries recounted watching YouTube videos, compared to 12% focused on social activities, 10% devoted to what he ate and drank, and 9% described academic activities.

**Figure 5.10**

*Patrick’s school day makeup gathered from art journal entries*

Note. Chart displays the eight categories of Patrick’s art journal entries

As each week progresses, over the course of 863 individually illustrated journal entries, Patrick’s accounts of his school day began to transform from what would be considered a typical school day which included attending academic classes, going to lunch,
hanging out with friends, and going to specialist classes, to a school day that consisted mainly of watching YouTube videos on his computer. Out of the 863 art journal entries, Patrick depicts himself watching YouTube videos on his computer during the school day 443 times, or just over 51 percent. In addition, closely examining Patrick’s detailed illustrations of his school day revealed that from January to June there was a gradual increase in the number of entries documenting Patrick’s viewing of non-academic YouTube videos on his computer. Figure 5.11 shows that during the first week of January, Patrick recounted 3 times that he watched non-academic videos during the week, compared to the last week of data collection in June where Patrick recounted watching non-academic videos 38 times during the week.
Figure 5.11

*Patrick’s non-academic video watching accounts in his art journal from January 8, 2019, through June 7, 2019*

Notes. These data were collected over 96 school days.

It is not uncommon to see the use of YouTube videos in a substantially separate classroom as a means of providing positive reinforcement for students completing a required activity. Typically, after a student earns a certain amount of tokens on a token board for following classroom expectations, or at the completion of a specified task, student will be given a set amount of time to play with a toy, do a special activity like use an iPad, take a break, and/or watch YouTube videos, among other things. The idea is to provide positive reinforcement when the student meets their short-term goal by rewarding them with a few minutes of something that motivates them. For many students, watching YouTube videos is extremely rewarding, and a great motivational tool. Best practices would suggest that if a student is motivated by watching YouTube videos, they can earn a set amount of time on the
computer to watch YouTube as positive reinforcement once they complete a desired task. For example, after doing his math work, Patrick could earn five minutes on YouTube. The teacher would set a timer and give Patrick a one-minute warning before the timer goes off to make it easier for him to transition off of the device and back to doing academic work. The scenario that Patrick describes on several occasions does not seem to follow best practices:

Chris: So, what is your favorite thing in school? What is your favorite thing to do at school?

Patrick: Watch videos.

Chris: Watch videos?

Patrick: Yeah. Patrick watch a bunch of videos.

Chris: You watch videos at home, though. Why do you like to watch them at school?

Patrick: Because they will be good and so I can relax.

Chris: Oh, nice. Relax.

Patrick: Yeah. I put my headphones instead of turning the volume down.

Chris: Mm-hmm (affirmative). What are some of the things you like to do besides videos at school?

Patrick: I always show people someone. They ask me, Patrick, what are you watching? I said, something.

Chris: You share the videos with other people?

Patrick: Yes.

At the beginning of the school year, Urban Collegian Academy sent a letter home to families welcoming them to the Skills for Life Program (SFL), see Figure 5.12, sharing some
of the curriculum priorities for the year, and reminding them to review the Code of Conduct, which describes “how students can be respectful of the learning environment, and responsible for their actions and education.” The first sentence in paragraph three reads, “Remember, students are not allowed to use personal electronic devices during the school day.” Below is a copy of the letter sent home to families:

Figure 5.12

*Welcome letter from UCA that was sent home with Patrick*

*Notes.* The highlighted portion states the UCA policy for the use of personal electronic devices including cell phones and reads, “Remember, students are not allowed to use personal electronic devices during the school day.”
Although the letter clearly states that personal electronic devices, including cell phones, are not allowed during the school day, Patrick regularly uses his phone to watch YouTube videos, by himself and with friends, during academic times, waiting for the bus, as well as during lunch and gym. When asked about Patrick’s cell phone usage in school, Bev responded, “But the school said that they, in the initial letter, stated that cell phones weren’t allowed in class and all that BS, and it’s not true.” Patrick talks about his cell phone usage through interviews, lyrical expressions, as well as in his daily art journals. During our second interview when his mother asked him when he can use his cell phone at school, Patrick expressed, “the teacher say there's no phones allowed, only in the cafeteria mom, only phones in the cafeteria.” As the school year progressed, Patrick was using his cell phone much more frequently and his usage was no longer limited to just the SFL room. Patrick expressed that he watched Spiderman, trains, The Wiggles, Popeye, the Olive Garden, the elevator, shopping at Target, Burger King, basketball, Home Alone 2 on his phone. In addition, he enjoys showing pictures to his friends, making videos in the gym, and playing angry birds.

Looking at this practice through the siege metaphor suggests that watching non-academic YouTube videos during the school day is further isolating Patrick and excluding him from educational opportunity, as well as excluding him from inclusive opportunities with his peers. Watching videos seemingly keeps Patrick happy, engaged, and occupied, all of which keep Patrick in compliance, lessening his resistance and making him vulnerable to surrender. The teachers at UCA could potentially be reinforcing his love for YouTube videos by providing him access to videos during the school day, and he doesn’t question the lack of academic instruction he is receiving because he stays engaged, occupied, happy, and
compliant. Through the elimination of resources and inclusive opportunities, this blockade results in educational attrition, academically starving Patrick into submission, eliminating any opportunity that he had for higher educational attainment. In addition to this educational attrition, Patrick is not only excluded from being an active member of the UCA school community through inclusive opportunities, but he is also physically partitioned and isolated from the rest of the school, forced to spend much of his school learning in two rooms far away from his neurotypical peers. Next, I will explore Patrick’s exclusion from the broader school community in both the physical and cognitive sense.

The Siege, Phase Three: Surrender

The Capture: Surrounded and Isolated

The ultimate goal of a siege was forcing an enemy into submission as quickly as possible, and the quickest way to accomplish this was through the use of physical and psychological force (Levithan, 2013). Blockades, which are a tactic used in siege warfare discussed in the previous sections, were common but did not usually end in a quick surrender of a town or city, they often took weeks, months, or even years to “[starve] the besieged population into submission” through attrition rather than force (Egan, 2016, p. 441). In Patrick’s situation, I argue that the blockade began during his freshman year at UCA, beginning with the erection of the three walls of exclusion seen in phase one, progressing to the cognitive and physical isolation he experienced in phase two, and culminating with the educational attrition leading him to eventually accept and make the most out of the inferior education that he was receiving from the school. It is unclear the exact moment when Patrick surrendered to his besiegers DPS and UCA, but I contend that looking at his artistic renderings provides a glimpse into the siege progression that Patrick experienced over time.
and captures his outward appearance of being held captive. This next section will compare Patrick’s early artistic renderings to later ones created during the last month of school.

**Isolation over time.** I present below in Figure 5.13 some of Patrick’s art journal entries from the first week in January next to his journal entries from the first week in June. When comparing the two, the journal entries for the first week of January looks like a typical school week, with Patrick attending academic classes, talking to his friends, having lunch, attending specialty classes, going to and from the Central Offices and the Boys and Girls Club, and working on the computer. Looking closely at his entries from January, in most of the illustrations, Patrick drew himself with either a teacher or his peer(s). He was fully engaged with an academic or life skills activity, and only two of the twenty-six frames picture Patrick watching videos on the computer.

Looking at Patrick’s journal entries from the first week of June provided a strikingly different account of Patrick’s educational experiences. Compared to the first week of January, Patrick is pictured alone and sitting at a desk for most of the journal entries, isolated from his peers and his teachers, looking more like a prisoner than a student. For eighteen of the twenty-six journal entries, Patrick illustrated himself watching videos on his computer, alone at his desk. His week consisted of watching “some ropes”, the Wild Wild West, Young Justice, The A Train at Orange Station, Monty Game, his old school, Howard and the Purple Crayon, shopping at Walmart, Pizza Hut, “sports”, the Wiggles Wiggly Wiggly Wiggly, Tennis, the A train at Orange Station, Geico Gecko commercial, Spiderman, the Night Kitchen, the water slide, the alligator, the Raiders, Mouse Trap, Noggin, Home Depot, and the Red Sox. The only academic activities he participated in was when he “did [his] best job words” on two occasions, and “made a dragon on paper” in art class. Beside the absence
of peers and teachers, notably missing from his illustrations during this week were Patrick’s weekly excursions to the Central Offices to do his job, to the Boys and Girls club for swimming, and to the community rowing facility to use the rowing machines.

**Figure 5.13**

*Patrick’s art journal entries from the first week of January and the first week of June*

<table>
<thead>
<tr>
<th>Art Journal Entries for the first week in January</th>
<th>Art Journal Entries for the first week in June</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1" alt="Art Journal Entries for the first week in January" /></td>
<td><img src="image2" alt="Art Journal Entries for the first week in June" /></td>
</tr>
</tbody>
</table>

*Notes.* The top frame text reads, “I made a circle with a fox” and Patrick describes himself as feeling “happy.” The bottom frame text reads, “I had juice, chicken, broccoli with milk” and Patrick describes himself as feeling “yummy”

*Notes.* The top frame reads, “Frist I did my best job words” and Patrick describes himself as feeling “good.” The bottom frame reads, “Next I watch the Mask on computer” and Patrick describes himself as feeling “funny”
Notes. The top frame reads, “In science we watched The Magic School Bus” and Patrick describes himself as feeling “happy.” The bottom frame reads, “Axa sports is like indor scoor” and Patrick describes himself as feeling “exsolent”

Notes. The top frame reads, “Next I watch the Wiggles on computer” and Patrick describes himself as feeling “awesome.” The bottom frame reads, “For art I made a dragon on paper” and Patrick describes himself as feeling “fun”

Notes. The top frame reads, “I did 4 + 4 = 8 this morning” and Patrick describes himself

Notes. The top frame reads, “I watch the [Orange Train] at [Forest Grove]” and Patrick
as feeling “happy.” The bottom frame reads, “I had computer, I watchine the Wiggles, The Mask for like 5 min” and draws himself with a smile but doesn’t share an emotion describes himself as feeling “groovy.” The bottom frame reads, “I watch water slide on the computer” and Patrick describes himself as feeling “great”

<table>
<thead>
<tr>
<th>Notes. The top frame reads, “I did class in Mr. [Marcus’] room” and Patrick describes himself as feeling “happy.” The bottom frame reads, “And I did my math work for 20 min” and Patrick describes himself as feeling “fun”</th>
<th>Notes. The top frame reads, “For lunch I had pizza and milk” and Patrick describes himself as feeling “yummy.” The bottom frame reads, “After that I watch the elevator” and Patrick describes himself as feeling “terrific”</th>
</tr>
</thead>
<tbody>
<tr>
<td>as feeling “happy.” The bottom frame reads, “I had computer, I watchine the Wiggles, The Mask for like 5 min” and draws himself with a smile but doesn’t share an emotion describes himself as feeling “groovy.” The bottom frame reads, “I watch water slide on the computer” and Patrick describes himself as feeling “great”</td>
<td>as feeling “yummy.” The bottom frame reads, “After that I watch the elevator” and Patrick describes himself as feeling “terrific”</td>
</tr>
</tbody>
</table>
Notes. The top frame reads, “Next I watched the Mask on computer” and Patrick describes himself as feeling “funny.” The bottom frame reads, “So walk to the [train station] from [Main] Street” and Patrick draws himself with a smile but doesn’t share an emotion.

Notes. The top frame reads, “I watch Monster Inc. on computer” and Patrick describes himself as feeling “perfecto.” The bottom frame reads, “Last I watch was shopping at Walmart” and Patrick describes himself as feeling “fantastic.”

Notes. The top frame reads, “I jump in the pool and swim water underwater” and

Notes. The top frame reads, “It was morning I did my best job words” and Patrick describes
Patrick describes himself as feeling “cool.”
The bottom frame reads, “For lunch I had rice and chicken milk” and Patrick describes himself as feeling “yummy”

himself as feeling “excellent.” The bottom frame reads, “Frst on computer I some ropes today” and Patrick describes himself as feeling “cool”

| Notes. The top frame reads, “I did math class in the world” and Patrick describes himself as feeling “fun.” The bottom frame reads, “Next we when on the bus to work” and Patrick draws himself with sharp teeth but doesn’t share an emotion |
| Notes. The top frame reads, “Next I talk to [friends]” and Patrick describes himself as feeling “happy.” The bottom frame reads, “Next I watch The Wild Wild West on computer” and Patrick describes himself as feeling “good” |
Notes. The top frame reads, “So we went up in the elevator I clean the door” and Patrick describes himself as feeling “good.” The bottom frame reads, “When I came back had fun and eating lunch in the world” and Patrick describes himself as feeling “yummy”

Notes. The top frame reads, “I watch Young Justice on computer” and Patrick describes himself as feeling “fantastic.” The bottom frame reads, “Then I talk to [a friend] in the hall” and Patrick describes himself as feeling “okay”

Notes. The top frame reads, “For cooking I had pasta and chicken” and Patrick describes

Notes. The top frame reads, “Next I watch the [train] line [train station] street” and Patrick
himself as feeling “good.” The bottom frame reads, “After that I talk to my best friend in the world” and Patrick draws himself with a friend and doesn’t share an emotion

describes himself as feeling “fun.” The bottom frame reads, “I watch opening to Monster Inc. on computer” and Patrick describes himself as feeling “groovy”

Notes. The top frame reads, “We didn’t go rolline so instden did balloing” depicting Patrick bowling a ball at pins, and Patrick describes himself as feeling “good.” The bottom frame reads, “For lunch I had pizza and milk it was good” and Patrick describes himself as feeling “yummy”

Notes. The top frame reads, “For lunch I had hot dog and milk” and Patrick describes himself as feeling “yummy.” The bottom frame reads, “I watch the [Frederick Douglass] school” and Patrick describes himself as feeling “perfect”
Notes. The top frame reads, “This morning I was in a bad morden in school” with Patrick depicting himself with a straight line for his mouth, and Patrick describes himself as feeling “okay” depicting himself with a straight mouth and downward facing eyebrows. The bottom frame reads, “I did science in [Mr. BMC’s] room” and Patrick describes himself as feeling “fun.”

Notes. The top frame reads, “I watch Harold and the Purple Crayon” and Patrick describes himself as feeling “funny.” The bottom frame reads, “Last I watch shoppinz at Walmart” and Patrick describes himself as feeling “triffic.”
Notes. The top frame reads, “Next I talk to [Darius] at lunch bunch” and Patrick describes himself as feeling “fun.” The bottom frame reads, “And last I went to the library I seen [the librarian]” and Patrick describes himself as feeling “cool”

Notes. The top frame reads, “It was morning frist I watch Pizza Hut” and Patrick describes himself as feeling “fantastic.” The bottom frame reads, “Next I watch sports on the computer” and Patrick describes himself as feeling “good”

Notes. The top frame reads, “Today I had computer in Mr. [Marcus’] room watching Batman” and Patrick describes himself as feeling “good.” The bottom frame reads, “I did science in [Mr. BMC’s] room we watch The Magic School Bus” and Patrick describes himself as feeling “fun”

Notes. The top frame reads, “Next I talk to my bubbly in hallway” and Patrick describes himself as feeling “grovy.” The bottom frame reads, “I watch The Wiggles We Be Wiggling” and Patrick describes himself as feeling “cool”
Notes. The top frame reads, “It had chicken nuggets and cheese bite for lunch” and Patrick describes himself as feeling “yummy.” The bottom frame reads, “After that we had a circle time to talk to [a friend]” and Patrick describes himself as feeling “cool”

Notes. The top frame reads, “Next I watch Young Justice on computer” and Patrick describes himself as feeling “excellent.” The bottom frame reads, “Then I watch tennis on the computer” and Patrick describes himself as feeling “good”

Notes. The top frame reads, “I went to the library I got fairytales in the world” and
Notes. The top frame reads, “For lunch I rice fish and milk” and Patrick describes himself as
Patrick describes himself as feeling “wonderful.” The bottom frame reads, “And it was good I played with [friends] in the world” and Patrick describes himself as feeling “funny.” Feeling “yummy.” The bottom frame reads, “Next I watch Monsters University on computer” and Patrick describes himself as feeling “great.”

During both weeks, Patrick had full access to markers, crayons, and colored pencils, but the journal entries during the first week of June, Patrick used only a colored pen. This further suggests a possible feeling of isolation and exclusion in each frame. Much like the siege progression, these journal entries quickly progress. In January, his journal entries vibrantly depicted Patrick engaged throughout the school day and outwardly expressing the joy he experienced interacting with his peers. In June, his journal entries seemed to reflect Patrick’s isolation, exclusion, representing the embodiment of his surrender. In most individual frames he is pictured alone, in front of a computer watching videos at his desk, created using one solitary color, resembling a depiction of captivity rather than inclusion.

Although it may not be clear from the positive emotions that Patrick ascribes to each frame in his art journal in both January and June, closely examining his entire selection of art journal entries suggests that his outward expressions of positive emotions may not accurately represent what Patrick is truly feeling. Next Patrick’s journal entries that provide expressed emotions that differ from his artistic renderings will be examined and implications for these contradictions will be presented.

**Emotional cover up.** Patrick’s verbal accounts of his educational experiences at UCA are overwhelmingly positive, and he rarely shares a negative experience. Taking a
closer look at his artistic renderings suggests that although he outwardly ascribes positive emotions to his experiences, his drawings may tell a different story.

For each journal entry that Patrick created, he was also asked to describe the emotion he was feeling at the time of the entry by writing the emotion or drawing his facial expressions in a little box on the bottom of the entry. He was provided with an emotions worksheet that visually depicted thirteen common expressions to choose from, including, happy, sad, scared, mad, etc. Figure 5.14 shows the emotions chart that we used:

**Figure 5.14**

*How are you feeling? Visual emotions chart*

<table>
<thead>
<tr>
<th>How Are You Feeling?</th>
<th>Happy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sad</td>
<td></td>
</tr>
<tr>
<td>Scared</td>
<td></td>
</tr>
<tr>
<td>Mad</td>
<td></td>
</tr>
<tr>
<td>Calm</td>
<td></td>
</tr>
<tr>
<td>Embarrassed</td>
<td></td>
</tr>
<tr>
<td>Sick</td>
<td></td>
</tr>
<tr>
<td>Tired</td>
<td></td>
</tr>
<tr>
<td>Frustrated</td>
<td></td>
</tr>
<tr>
<td>Silly</td>
<td></td>
</tr>
<tr>
<td>Bored</td>
<td></td>
</tr>
<tr>
<td>Proud</td>
<td></td>
</tr>
<tr>
<td>Confused</td>
<td></td>
</tr>
</tbody>
</table>

*Note.* This chart was used as an optional visual support for Patrick during interviews to help him express how his experiences made him feel.
Most of the educational experiences that Patrick describes leave much to be desired to the casual onlooker, but Patrick speaks of them very fondly. In many of his accounts, including his artistic renderings, Patrick describes seemingly sub-par educational experiences in a positive light and in an enthusiastic manner. Looking at his daily art journal entries, on several occasions he expressed positive emotions when recounting the events that took place during the school day; however, his self-portraits show a different story, directly contrasting his expressed emotion, depicting himself looking angry or upset, many times alone, with sunken or angry eyebrows, stiff body posture, and sometimes with a frown or a sad face. In this entry from January 9, 2019, and presented in Figure 5.15, Patrick expressed that he had “fun” in math class, but in the image he drew he looks rather melancholic because of the neutral horizontal line used for his mouth, the head draw at a slight downward angle, and the overall feeling of emptiness created by Patrick sitting at a seemingly empty room.

**Figure 5.15**

*An art journal entry of Patrick’s recounting doing math work in school*

*Note.* The text reads, “And I did my math work for 20 min” and Patrick described himself as feeling “fun”
In this entry from March 3, 2019, presented in Figure 5.16, Patrick expressed that he was “happy” while doing math work in Mr. Marcus’ room, but in the image that he drew he appears to be sad and lonely because he depicts himself with downward facing eyes, lowered brows, and sitting alone in an empty room except for his desk and chair.

**Figure 5.16**

*An art journal entry of Patrick’s depicting him doing math work in Mr. Marcus’ class*

![Image of the art journal entry](image)

*Note.* The text reads, “Today in Mr. [Marcus’] room I did my math work” and Patrick described himself as feeling “happy”

In the next entry from January 10, 2019, in Figure 5.17, Patrick was feeling “good” while cleaning the doors at the Central Office, but in the image he drew, he appears to be angry with rigid body language with his hand on his hip and lowered eyebrows.
Figure 5.17

An art journal entry of Patrick’s depicting him cleaning the elevator doors at the Central Offices

Note. The text reads, “So we went up in the elevator I clean the door” and Patrick described himself as feeling “good”

Then in this entry from February 2, 2019, in Figure 5.18, Patrick shared that he had “fun” cleaning the window and doors at the Central Offices, but the image that he drew seems to communicate the feeling of ambivalence because of the emotionless face, drawing his mouth with a horizontal line.
Figure 5.18

*An art journal entry of Patrick’s depicting him washing the windows at the Central Offices*

![Art Journal Entry]

*Note.* The text reads, “I clean the windows and the doors on it” and Patrick described himself as feeling “fun.”

In the following entry, Figure 5.19, from March 21, 2019, Patrick expressed that he was feeling “excellent” while washing doors at the Central Office. However, Patrick, pictured on the left, depicted himself with raised angry looking eyebrows, suggesting he was not happy cleaning the doors and windows.
Figure 5.19

*An art journal entry of Patrick’s depicting him cleaning doors and windows at the Central Offices*

*Note.* The text reads, “And we clean the doors and the window” and Patrick described himself as feeling “excellent.”

In his journal entry from April 4, 2019, shown in Figure 5.20, Patrick said that he was feeling “incredible” while washing doors at the Central Office, but in this image, Patrick depicts himself with his eyebrows down and his tongue sticking out, perhaps pointing to his dissatisfaction with the job he was performing.
Figure 5.20

An art journal entry of Patrick’s depicting him cleaning the doors and windows at the Central Offices with his tongue sticking out

Note. The text reads, “And we clean the doors and windows” and Patrick described himself as feeling “incredible”

On seven occasions Patrick shared that he, or a friend of his, was feeling negative emotions. Contrary to the art journal entries above where Patrick expressed that he was feeling a positive emotion, and depicts himself seemingly experiencing a negative emotion, in all the journal entries where Patrick expresses that he or a friend was experiencing negative emotions, the images that he drew matched the emotions that he was experiencing. In the images that he drew to depict these negative emotions, he used facial expressions to show how he or his friend felt using downward facing or sunken eyebrows, faces with frowns, rigid body language, and his tongue sticking out of his mouth. In the next image
from January 11, 2019, Figure 5.21, Patrick expressed that he is feeling “okay” and the image he drew shows him with sunken eyebrows and a sad face.

**Figure 5.21**

*An art journal entry of Patrick’s depicting him in a bad mood at school*

*Note.* The text reads, “This morning I was in a bad morden in school” and Patrick described himself as feeling “okay”

In the image in Figure 5.22, from January 15, 2019, Patrick responded, “I don’t lik getting hit from the ball”. He depicts himself with downward facing angry eyebrows with a frown.
Figure 5.22

An art journal entry of Patrick’s depicting him expressing that he doesn’t like getting hit by a ball

Note. The text reads, “I don’t lik getting hit from the ball”

In the next image, Figure 5.23, also from January 15, 2019, Patrick expressed that he gets “sad” when he doesn’t go rowing, and he depicts himself with a sad face with an exaggerated frown, a tear going down his cheek, sunken eyebrows, and his head down.
Figure 5.23

An art journal entry of Patrick’s depicting him expressing that he gets sad when he doesn’t go rowing

Note. The text reads, “I gets mad that I didn’t go rollow” and Patrick described himself as feeling “sad”

On April 3, 2019, Patrick said that after drinking some water in the bathroom, he felt “nasty.” In Figure 5.24, the image he drew matched this emotion, depicting sunken eyebrows and a squiggly angry looking mouth.
Figure 5.24

*An art journal entry of Patrick’s depicting him drinking water in the bathroom*

Note. The text reads, “And I drink somes it water in the bathroom” and Patrick described himself as feeling “nasty”

In this image from February 7, 2019, Patrick expressed that his friend offered him a salad and he felt “yucky”. The image that he drew in Figure 5.25 depicts him exhibiting rigid body language with one arm blocking his face and the other arm outstretched to block Darius from giving him the salad. His facial expressions show Patrick with an exaggerated frown, raised eyebrows, and his tongue sticking out. His detailed depiction truly expressed the disgust that he felt at this moment or in his words, how he felt “yucky”.

207
Figure 5.25

*An art journal entry of Patrick’s depicting him refusing to eat salad*

*Note.* The text reads, “So [Darius] asked me if I won salad. I said no it was” and Patrick described himself as feeling “yucky”

Then in an image from February 12, 2019, seen in Figure 5.26, Patrick said that a friend was having a bad day and that Patrick felt “bad”. In the image he drew, Darius was visually angry with downward facing angry eyebrows and a scowl on his face.
Figure 5.26

*An art journal entry of Patrick’s depicting his friend being mad and grumpy*

Note. The text reads, “And nothing went good. [Darius] was mad and grumpy because he was playing on the iPad” and Patrick described himself as feeling “bad”

Figure 5.27 shows an image that Patrick drew on March 3, 2019, Patrick showed that while recycling, his friend Darius was mad and Patrick felt “bad”. In the image that he drew, both Darius and Patrick are depicted with exaggerated frowns, and Darius with downward facing angry eyebrows.
Note. The text reads, “I did recling and [Darius] was mad on the floor” and Patrick described himself as feeling “bad”

In every instance throughout this investigation when Patrick expressed through his drawings that he or a friend was experiencing negative emotions, the artistic renderings that he created matched the stated emotion, including depictions of figures with downward facing eyebrows, exaggerated frowns, tears coming down their cheeks, their tongues sticking out, etc. It is important to note that in several of his art journal entries, where Patrick depicted himself doing his job of cleaning doors and windows, as well as doing academic work, he
expressed positive emotions, such as, happy, fun, and excellent, but his artistic renderings tell a different tale of his experiences.

In applying the siege metaphor to Patrick’s experiences, it has been my intention to reveal some of the ways in which Patrick’s learning environment creates the conditions in which Patrick becomes disabled, and how this makes him feel. Looking at Patrick’s art journal entries where the stated positive emotions that he experienced contradict the emotions depicted in his artistic renderings possibly provides a glimpse into his thinking. He states several times that he is experiencing a positive emotion doing his job of cleaning doors and washing windows and then drawing himself with downward facing eyebrows and his tongue sticking out. These two contradictory accounts could potentially be Patrick subconsciously expressing that in actuality he doesn’t enjoy doing his job or it could just be an example of him miscommunicating his emotions. The former would support the notion that Patrick has come to terms with the educational programming he is receiving from his UCA and is trying to stay positive given the situation he finds himself in. The latter suggests that this contradiction was a simple mistake. In isolation it is easy to see that this could potentially just be a simple mistake, for example he may have inadvertently drawn the wrong expression on his face or wrote the wrong emotion in the box; however, given that in every journal entry where he draws himself or a friend experiencing a negative emotion the artistic rendering does not match the expressed emotion, it seems more likely that this wasn’t a mistake. In other words, I contend that although the emotions that he expresses in his drawings are positive, Patrick may think negatively about these same experiences. At a minimum, these contradictions reveal that although on the surface Patrick may be content with the education that he is receiving at UCA, in actuality he may not be.
Conclusion: The Forced Paralysis of Exclusion

Through interviews, three-way discussions, artistic renderings, and improvisational lyrical remixing, Patrick provided a comprehensive look at his educational experiences at UCA. These experiences suggest that three walls of exclusion - administrative, academic, and environmental - are significantly impacting Patrick’s educational opportunity, as well as impeding him from actively participating in the broader school community beyond his classrooms that he speaks so highly of. The implications of which could significantly impact his ability to reach his true potential and, according to Patrick, “work in a school and help kids.” In addition to providing educational programming that appears to fall short of meeting Patrick’s individual needs (i.e., working on math skills that are challenging to him rather than coloring in a worksheet designed for first graders), he and his classmates are also physically isolated from the rest of the school. Bev has said many times that the students at UCA, “are seen but not heard”; however, the data would suggest that they are neither seen nor heard within the confines of isolation.

Looking at Patrick’s experiences through the siege metaphor provides a vantage point that illuminates the exclusionary practices that he is experiencing at not only the academic and environmental levels, but also the administrative level. Each of which have strictly impeded his ability to succeed both academically and socially. The three walls of exclusion that have been presented and discussed in this chapter serve as external environmental obstacles actively contributing to the social and cognitive disabling of Patrick, keeping him in a restrictive educational placement and preventing him from learning alongside his same-aged peers. Each wall of exclusion, the administrative wall, the academic wall, and the wall environmentally segregating and excluding him from his broader school community, work in
tandem and are surrounding, isolating, and trapping him within. I am framing this as a “forced paralysis” that encloses Patrick behind these seemingly impenetrable walls compelling him to occupy an in-between space, perceived by DPS and UCA as “not academically advanced” enough for an inclusion classroom and “too academically advanced” for his current placement in an educational program that prioritizes learning functional life skills over academic instruction. Nonetheless Patrick is optimistic and ascribes positive value to his educational experiences; however, the positive value he ascribes seems to contradict his artistic renderings of these educational experiences that tend to depict Patrick performing jobs that involve cleaning up after his neurotypical peers and Central Office employees.

Given the troubling history of the use of metaphor within autism discourse (Broderick & Ne’eman, 2008), I used the siege metaphor cautiously to reveal commonalities between Patrick’s educational experiences during his freshman year at UCA and actual war-related battlefield tactic known as the siege. It is important to note that the siege metaphor has been historically used to illustrate the perceived paralysis trapping autistic individuals within a fortress of isolation and solitude with little hope of escape (Park, 1967). In Patrick’s case, the forced paralysis I explore in this chapter was not a result of a perceived self-imposed isolation and fortification resulting from a disabling disorder; rather, these data would suggest that this paralysis was a result of a series of entangled exclusionary structural practices that created a learning environment that disabled Patrick. These practices trapped Patrick within an environment that hampered his progress both academically and socially, creating the environmental conditions that paralyzed Patrick. As a freshman in high school, he was left with little chance of escaping the confines of his restrictive educational
placement, at this point in his education journey, and instead he was forced to acquiesce to this reality and make the most of his situation. The next chapter will look at these exclusionary forces from Bev’s perspective as the mother of an autistic student who is navigating the complexities of special education in a large urban school district while advocating for the educational care of her son for the past ten years.
CHAPTER SIX

I DIDN’T PICK AUTISM, AUTISM PICKED ME: A MOTHER’S BATTLE AGAINST SYSTEMIC BESIEGEMENT

Introduction: Autism as a Mother’s Battle Ground

This chapter will present the experiences of Beverly Mendes\textsuperscript{33}, Patrick’s mother, navigating the complexities of special education in a large urban school district. The siege metaphor that was introduced in chapter five will be used again to organize Bev’s encounters, frustrations, and victories within Dagobah Public Schools\textsuperscript{34} (DPS), taking a closer look at how the battles she fought on the administrative, academic, and environmental battlefields not only impacted Patrick, but how these battles also affected her mental health and the spaces of her daily lifeworld.

During an early interview, when asked how she would describe autism, Bev responded, “a parent’s worst nightmare.” By presenting the data in this chapter using the siege metaphor and closely examining the outside forces squeezing her into surrender

\textsuperscript{33} A pseudonym.

\textsuperscript{34} Dagoba Public Schools, a pseudonym, is used throughout this chapter to protect the privacy and confidentiality of the school and school district. Pseudonyms are used throughout this chapter when referring to specific people and places that could potentially identify the participants and/or the school district in which the study takes place.
provides some clarity as to what this “nightmare” entails. I contend that this “nightmare” that she describes is not intended to pathologize autism through an ableist viewpoint, rather, this nightmare is reflective of the forces of exclusion weighing heavily on Patrick, which in turn, completely encompass and squeeze Bev to the point of mental and physical exhaustion and hopelessness.

Using the siege metaphor to examine Patrick’s educational experiences at Urban Collegiate Academy (UCA) in the previous chapter revealed three distinct walls of exclusion - administrative, academic, and environmental - data collected from 17 one-to-one interview sessions with Bev and 10 three-way discussions with Bev, Patrick, and myself will be used to explore the battlefields Bev found herself faced with at each of these distinct levels.

This chapter begins with Bev’s origin story as a zealous advocate for her son and other autistic students will be explored in “Origin Story: Autism Found Me”. Next, this data presentation will describe Bev’s experiences on the administrative battlefield, highlighting the defamatory nicknames given to Bev by educators and administrators because of advocating for her Black son in “The Administrative Battlefield: The Autism Bitch.” Bev’s experiences on the academic battlefield will then be explored in “The Academic Battlefield: I Had to Move Buildings and Kick People Around”, revealing the tension between Bev’s desires for Patrick to have educational programming focused on grade-level academics and UCA’s insistence on providing educational programming that prioritizes functional life skills. Next, Bev’s experiences dealing with inclusion in both the school and local community will be discussed in “The Environmental Battlefield: Autism is a Life Sentence.” In “Caught in the Cultural Crossfires of Autism” Bev’s experiences having an autistic son in her Cape Verdean culture will be discussed, drawing attention to UCA’s failure to provide
Patrick with an education that reflects and honors his cultural ways of knowing. Lastly, in “Losing Hope: Autism Becomes Your World” the impact of fighting and advocating for Patrick on the administrative, academic, and environmental battlefields on Bev’s mental health will be presented, drawing attention to the feelings of isolation and hopelessness felt by Bev because of the exclusionary practices used by DPS to obstruct Patrick’s access to a Free and Appropriate Public Education (FAPE).

Origin Story: “Autism Found Me”

Every superhero and every villain in comic books, movies, and popular culture has an origin story. The origin story is a retrospective account of how a character in a story became a protagonist or an antagonist. For example, in the Star Wars movie franchise “The Force” is a mysterious energy field created by life that connects everything in the universe, it is a power that can be harnessed to protect or destroy life (Lucas, 1977). Both Darth Vader and Luke Skywalker discover at a young age that they are Force-sensitive and can use the spiritual energy of the Force to levitate objects, control the minds of others, and see the future, among other things. Darth Vader uses the dark side of the Force to attempt to conquer the galaxy through brute force and destruction, while Luke Skywalker uses the light side of the Force to unite and heal the same galaxy. Many times, the origin story of a superhero is very similar to that of a villain, the only difference is the choices that the characters make along the way, and whether they use their talents or gifts for “good” or for “evil.”

Bev Mendes was no exception. Her origin story started on September 6, 2008, at 10:40 am in the morning when she made the conscious decision to take the bus and the train to Urban Medical Hospital (UMH), instead of driving in, to find out the results of some
diagnostic testing that was performed on Patrick. Deep down she knew that something was different about Patrick, but she never suspected it was autism. Bev explains that when Patrick started day care, “they knew something was wrong, but they didn't know what was wrong because they never had to deal with autism.” Bev describes the exchange that she had with Roberta, the art therapist that worked at the daycare, when she asked Bev if she was familiar autism:

I was like, why would anyone want to talk to me about autism, Patrick's not autistic.

She was like, based on my profession, I’m seeing signs. And I basically told her fuck you and your fucking profession. You don’t know my kid, I mean he's my kid, how you going to come up here, you just met him, and you know...

Roberta didn’t give up on Bev, week after week Roberta consistently encouraged Bev to get Patrick tested to see if he was showing signs of autism, and every time she refused. When Roberta couldn’t convince Bev to have Patrick tested, she turned to the administrator of the daycare to see if she could convince Bev to get the testing done. It all came to a head when Bev was confronted by the administrator of the daycare one afternoon before picking Patrick up, as Bev recalls, “I went to the daycare and the director threw me against the wall and said Bev get the fucking test done, she was like there's no pins there's no needles just get the fucking test done.” But still Bev refused. In order to have a student tested for special education services, the parent or guardian needs to provide a written request for testing, in this case, Bev was adamantly opposed to having Patrick tested. Deep down she knew that something was different about Patrick, but resisted the testing, among other things, because the implications of an autism diagnosis in Cape Verdean culture would be difficult for her to accept.
The daycare circumvented protocol and went behind Bev’s back, filled out all the necessary paperwork and finally convinced Bev to sign her consent to have him evaluated by the Dagobah Public Schools. According to Bev:

…. they filled out the thing and told me there's a meeting and said we have a meeting for you to come to. So I went to the meeting that was Roberta, Laura, Nanci, the whole team there and that at that point I was like, you know me, this fucking test is going to come back negative, I need an apology. So, it was at the Bayside School I took Patrick there and they said he was showing signs of autism. But I still kept fighting it.

After the team meeting, Bev decided to have further testing done at UMH. On the morning of September 6, the morning of her appointment to go over the results, she decided to take public transportation into the hospital because she feared that she would be in no condition to drive herself home, or as Bev put it “my heart that day told me [hitting hand on chest] don't drive in.” Her intuition was correct, here Bev describes the moment when the doctor told her that Patrick had autism:

She was like BOOM! Patrick is autistic it's going to be severe, he has ADHD, and I can give you Ritalin. Where do you process? What do you do? Where do you go? What do you do? What don't you do? What do you attack first? And you don't even know the condition I’m in, my mental state, where it's at, if someone drove me to the hospital or anything. Chris, I froze I couldn't ask, I knew nothing about autism and then I was like, any resources or anything?

Bev left the doctor’s office with a bitter taste in her mouth, she was not impressed by the doctor’s bedside manner and her lack of empathy given the fragile condition Bev was left in.
She felt alone with so many questions and didn’t know where to turn or who to ask to answer them. It took a significant length of time for Bev to begin processing the results of Patrick’s evaluation, for a woman who was known for speaking her mind, she was speechless.

In her mind she was recalling all the times she had made excuses for Patrick’s behavior or rationalized in her head that the reason he was behaving differently than other kids his age was because she was a single mother, and it was just the two of them. She recalled that at an early age, “Patrick had no facial expressions, laughing, crying, whatever, nothing,” how he, “used to line cars up and run back and forth and just look out the corner of his eye and if anything was out of place he would tear everything down,” and all of those times they use to ride the same train she was taking home for hours and, “he would look out the windows and he was having the time of his life.” In the early years, riding the train was the only time that Patrick would stay calm which allowed Bev to get some well-deserved “me time.” By the time she began processing those “life altering words,” she had arrived back at 77 Murray Street, stepped off the bus and once the bus pulled away, she started crying to the point that she began shaking, “I cried, I cried, I cried, I cried, I was listening to all that shit people used to say coming back and stuff saying, where did I go wrong? How did I miss this?” Once she came to the end of the parking lot before her apartment, she grabbed the first person she knew, Mike the maintenance person, whom she was very friendly with. After crying in his arms for twenty minutes, she began to calm down, Mike gave Bev some simple and sound advice, “deal with it”, here she describes the epiphany she had because of this encounter with Mike:

He shook me, and then he said, “deal with it”. I'm like, deal with it? What kind of shit is that? That's all you got for me? He was like, what are you going to do, throw
him in the sewer and have another kid? I was like no. He was like you going to throw him in some residential program? He was like, then dealt with it. Bev, look at who autism picked. I was like what do you mean? He was like what do you fear? I said nothing. He said look who autism picked, you didn't pick autism but autism picked you for a reason, so deal with it. Chris I never cried that day after, never did.

From that moment on, “deal with it” is what she did, and beyond. Whether it was going toe to toe with the Superintendent during a televised public meeting because they were trying to close down her son’s school, stomping out of an IEP meeting and slamming the door behind her as hard as she could when they tried to remove services from Patrick’s IEP, walking right past security and barging into the Mayor’s office and demanding that he visit her son’s school to see autism firsthand, or calling and visiting every business in her local community to raise money so her son and his class could go apple picking; Bev was intelligent, informed, driven, and motivated. When asked if she considered herself an advocate for autistic students Bev responded:

People say I’m an advocate, people say I make things happen…… but I didn't pick autism, autism picked me. So, since it picked me ......once I came to terms that it was autism, I looked at my past and everything, I came to determine that yeah, I'm built for this shit, you know, this is me, you picked me so…… let's go whoop some ass

(Bev laughs)

During the early years of Patrick’s education, Roberta played a key role in his success. Through music, movement, and the arts, Roberta was able to connect with Patrick in ways that no one else could. In addition to being one of Patrick’s therapists, she served as a mentor to Bev, introducing her to the world of autism. Bev speaks very fondly of Roberta,
crediting her for Patrick’s early success and encouraging Bev to become the zealous advocate she is today, “she taught me who, what, when, where. What to do, what not to do, how to fight, how not to fight, how to get this, how to get that, she was a phenomenal person.”

Bev’s passion for autism and advocacy was nurtured by Roberta, but it wasn’t until Roberta passed away suddenly that Bev dedicated her life to helping autistic children. Bev has always made it her goal to make sure that “our kids are seen and heard,” and although she has never explicitly expressed it during this study, this goal may have begun the day that Roberta was laid to rest. Bev recalls a beautiful tapestry draped over Roberta’s casket that read “may all that I have done speak loud for me,” and speak loudly they did, some through words and others through the arts. As Bev so eloquently describes it, “Everything she did for Patrick, verbally he couldn't say it, but through arts and sensory and music he showed them Roberta's way.”

While still in the hospital as she entered the final stages of her cancer treatment, Roberta asked Bev to visit her for what would be her last time. Unbeknownst to Bev, Roberta was adamant about speaking with her before she passed away, as Bev describes, this was the moment that provided her the fuel for her fire in the fight for autism:

It’s hard to talk about it because the last time I seen her, just the way she grabbed my hand and told me to never stop fighting for autism, and she said make me proud with Patrick. That's what keeps me going.

From that point on, autism became her world. To this day, Bev reminds Patrick every morning, “Patrick you have autism, but autism doesn’t have you.” It wasn’t long before Beverly Mendes found herself fighting the administrative, academic, and environmental walls of exclusion erected around Patrick by this urban school district.
The Administrative Battlefield: The “Autism Bitch”

At every turn during Patrick’s educational journey, whether it was trying to enroll him in the model school for educating autistic students in the District, having individualized supports that she felt he needed written into his Individualized Education Plan (IEP), or getting funding for a bus to take a field trip to go apple picking for Patrick’s class, Bev was met with hostility by school administrators and the Central Office leadership team from DPS on the administrative battlefield. Here Bev expresses her frustration of having to fight for educational services for Patrick soon after he was given an autism diagnosis by Urban Medical Hospital:

No parent should have to go in and fight for ABA time, no parent should have to fight for OT, therapy and all that other stuff. A parent, especially with a new diagnosis, a teacher should sit down and hold that parent’s hands, the school system should sit down and hold that parent’s hand and help them, you know?

Her zealous and vocal advocacy, as well as her persistence during a seemingly endless battle with DPS over securing academic and support services for her son, earned this self-educated advocate and single mother the nickname “Autism Bitch” from a group of educators and administrators that Bev refused to identify. When asked what she thought of this nickname, Bev chuckled and responded, “you know what? I like it.” She proudly wears this title like a badge of honor on her sleeve, but the negative connotations of this nickname she was labeled with by white educators and administrators speaks volumes of how she is perceived as a Black, disabled, and outspoken single mother advocating for her autistic son within this large urban school district.
Throughout this inquiry when describing her experiences interacting with the Central Office leadership team at DPS, as well as the administrators at UCA at the administrative level, Bev commonly uses discourse that is militaristic in nature. She uses terms like “battle”, “fight”, “swinging my baseball bat”, “dropping bombs”, and “attack” to refer to her normal daily interactions with DPS and UCA. It is unclear if these terms became part of Bev’s vernacular as a result of the hostile experiences that she had with the school and the district, or if the perception of her as the “Autism Bitch” influenced her word selection. Either way this speaks to the blatantly racist labels given to this Black mother by educators and administrators that vilify an educated and outspoken single mother for “fighting” for services for their children, while a white mother in similar situations tends to be praised for “advocating” for these same services (Babio-James, 2020).

Bev was known for wielding what she refers to as her rhetorical “baseball bat” whenever she needed to fight for her son or one of his classmates during an IEP meeting, school committee meeting, or when confronting administrators at UCA. As Bev puts it, “I just go in there with my baseball bat and start asking a lot of questions and turn a lot of heads.” According to Bev, parents and families run DPS, not the educators or the administrators, and she never missed an opportunity to remind school and district administrators that she may not run the school, “but I pay the mother fucking water bill, I pay the mother fucking tax bill, and must I remind you I pay your salary?” (Beverly Mendes, personal communication, June 6, 2019). She was adamant on families playing an active role in the shared responsibility of operating the schools, as well as being respected as an equal stakeholder in the education of their children.
With the reputation for what she refers to as, “calling a spade a spade”, it wasn’t long before Bev became a seasoned veteran when it came to battling the DPS because she wasn’t afraid to ask tough questions and openly criticize school administrators in public spaces. She refused to take “no” for an answer, and she was dangerous; not because of the social capital that she had acquired during her ten-year career of advocating for educational services for Patrick, or through the connections she made with politicians at the local and national level through her advocacy work, but because her secret weapon was time.

Bev had been receiving Social Security Disability Insurance benefits since a debilitating car accident left her dis/abled and unable to work, and according to her she “had lots of free time on [her] hands”, and she used this time to her advantage. Bev was known for threatening to call the State Department of Education when UCA wasn’t honoring Patrick’s IEP, threatening to audit the school budget to ensure the monies allocated to special education students had been spent on these same students, or threatening to contact the media about the District’s many shortcomings, such as their lack of high school programs that were designed for autistic students or that students in Patrick’s classroom only had access to two computers while the general education students had an entire computer lab full of them.

When asked how she felt about the administrative leadership at UCA, Bev responded:

And like I told the state... the education department, this [headmaster] don't know jack shit about having autism in his building. Because if he did, why would they only be restricted to two classrooms? That's all they go through the whole day. They have no lockers. They have no... they don't eat in the cafeteria. They are limited on what they can do. Shit they had no computers. They had no laptop. They have no after school activities for them.
Throughout this inquiry, Bev expressed several times that she was skeptical of the administrative leadership at UCA, specifically the headmaster. She felt strongly that in order for an administrator of a school building to successfully operate an autism program, they need to have a “personal connection to autism.” Although the headmaster at UCA has a child with special needs, Bev feels strongly that he “doesn't know autism.” In addition to the lack of resources and quality educational programming that Bev speaks about at UCA, she also feels that the leadership team, including the headmaster, is not qualified to handle the nuances of educating autistic students. According to Bev, this became clear to her on Patrick’s sixth day of high school.

The day the home school relationship deteriorated. On day six of his freshman year at UCA, the school contacted the Department of Family and Children\(^{35}\) to file “a 51A\(^{36}\)” with the State on Patrick for suspicion of neglect or abuse, after a staff member said they witnessed Patrick touching himself inappropriately in class. This situation destroyed any potential home-school relationship that could have been forged between UCA and Bev because now Patrick was, “put in the system where he didn’t belong.” From that point on Bev met every move by the school with skepticism and hostility. Here she describes her response to the school after the 51A incident:

I am Bev Mendes. I am Patrick's mother. Nothing gets discussed or changes made without confronting me. The last time, you guys did a bitch move, and contacted the State, only to see that you guys are the ones who look like fucking idiots. But let me

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\(^{35}\) A pseudonym for a government agency in charge of overseeing family and children

\(^{36}\) A 51A is filled with the Department of Family and Children when there is suspicion that a child is being abused or neglected. In the state where this study takes place, educators are considered mandatory reporters and required to file a 51A if they believe that a child is a victim of abuse or neglect.
tell you something. Piss me off. I'll come in here with the Feds, not even the State, and I'll have this place audited.

Typically, if an incident of this nature had occurred at FDS, which was common, there were protocols in place to determine whether the incident was a direct result of the student’s dis/ability or if this situation could potentially be a result of abuse or neglect. Before any administrative action was taken by the school, the student’s teachers, educational service providers, and the school principal would meet to determine how to resolve the situation. Bev felt that the leadership team at UCA was inexperienced in educating autistic students and the policies and practices of the school administratively created the conditions where they “were seen but not heard.”

Bev was adamant on “our kids”\(^{37}\) being both “seen and heard” and was not afraid to confront the leadership at UCA to address their shortcomings. During a heated discussion with the headmaster at UCA over the lack of resources for “our students” at UCA, Bev told the headmaster, “You can't treat your parents like shit. You can't treat your students like shit.” She was motivated, informed on how to navigate the complexities of this urban school district, and had the time to follow through on her threats, or as she explains it:

\[
\begin{align*}
&\text{You know what though, if I have to be the whistleblower here, I have no problem.} \\
&\text{And just to let you know, I have the best weapon in my corner. They’re like what? I was like, I have time on my hands. And, I said, go ahead, push my buttons.}
\end{align*}
\]

For a school district, an informed parent with time on their hands can disrupt the status quo, and in Bev’s situation, being a racialized Black and dis/abled mother that openly criticized building administrators quickly earned her the label “Autism Bitch” that attempted to

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\(^{37}\) Bev consistently uses the term “our kids” to refer to autistic students in both the school buildings in DPS, as well as the broader community.
delegitimize her plight for her son and further marginalize her within the broader school and district community.

Although Bev would win many short-term battles at the administrative level during the ten or so years that Patrick attended FDS by refusing to sign IEPs if they didn’t reflect her wishes for Patrick, calling the head of special education when she had issues at the school, or just walking into the school and demanding to speak with Patrick’s teachers and/or administrators. Her short-term success at FDS would soon fizzle out when Patrick reached high school because, according to Bev, “they just didn’t care.” When threatening to file a compliance complaint with the State Department of Education because the school was not providing occupational therapy services that were written in Patrick’s IEP, a special education administrator for the district told her to, “go ahead they aren’t going to do anything other than mandate training” and it will take “forever” to resolve the issue; when she showed up to Patrick’s IEP meeting and the only teacher she wanted to talk to had a scheduled personal day, they encouraged her to reschedule the meeting to a later date; when she asked for an independent occupational therapy evaluation, it took the school almost three months to hold a meeting with her due to ongoing staff absences and scheduling conflicts; and whenever Bev called the head of special education for the District to voice her concerns about Patrick’s school, there only solution was to move him to another school for the following year.

Every chance she had, Bev gave UCA a taste of the “particular set of skills” that she was known throughout the District for. This confident, fearless, and dis/abled Cape Verdean single mother with a heart of gold spent many years fighting for Patrick on the administrative battlefield, so much so that her hands had become callused from swinging her bat for so long
to no avail. The district’s plan for dealing with Bev’s concerns seemed to consist of strategic maneuvers geared towards proposing short-term solutions to fix deeply rooted structural problems and/or pushing the problems farther down the road delaying a resolution of the problem and/or avoiding fixing the problem altogether by offering to provide another educational placement for Patrick and moving him to another school. Each of these administrative strategies involved a loss of critical instructional time for Patrick and other students that were being educated in his substantially separate classrooms.

For Patrick time was of the essence. Each day that passed without the district providing services that Patrick was entitled to in his IEP marked another day closer to when he would turn twenty-two and age out of the system. On Patrick’s twenty-second birthday, he will age out of the public school system and no longer be provided educational services at UCA and instead will transition to adult life. For Bev, Patrick’s twenty-second birthday once seemed like a milestone far off in the distant horizon, and with each day that passed this milestone grew closer and closer and her motivation and stamina to keep fighting for services he was entitled to in his IEP was beginning to wane.


After the passing of Roberta, Bev realized that time was of the essence and if she was going to forge a clear path for Patrick in DPS, she was going to have to fight for it. During her early years of advocacy, while still distinguishing herself, Bev used aggressive tactics, persistence, and sometimes brute force to procure the educational supports and services that she believed Patrick not only needed to be successful but was entitled to. Her first order of business on the academic battlefield involved getting Patrick enrolled into the model school for educating autistic students in the district, the FDS. With no understanding of how school
placement worked in the DPS, Bev stormed into the resource center, refusing to leave until Patrick was enrolled at FDS. Bev was soon met with her first roadblock, the woman behind the counter explained to Bev that there is a process that needs to be followed before a student gets enrolled in a school in DPS, and she didn’t have the right to storm into the office and make demands. Bev responded, “the fuck I do, this is what I came here to do, I’m not leaving here until I get it done.” Once they came to the realization that Bev wouldn’t leave until her son was enrolled at FDS, they gave Patrick the last seat available. The woman behind the desk told Bev that Patrick was enrolled, and they would fill out all the necessary paperwork and send her a copy. Bev informed the woman, “no it doesn't fucking work like that, this is technology you fucking click, paste, copy, you give me my copy, you keep your copy, I go home I don't see you, you don't see me, fucking case closed.” So, she waited. With a huge smile on her face Bev describes the moment Patrick was accepted, “so they copied, they clicked, they pasted it, they gave me his acceptance to [Dagobah Public Schools], and then we started on that day.”

Bev had won her first skirmish in a long string of battles with DPS on the academic battlefield, and with every encounter it seemed, she was met with opposition. This surprised Bev because she was under the impression that once Patrick was enrolled in DPS, they would provide him with everything he needed to be successful academically and her job was done. She was sadly mistaken, as she put it, “the fight had just begun.” When it came to schooling, Bev’s Cape Verdean culture instilled in her an expectation of “professional expertise to be delivered in a categorical manner” (Kalyanpur, Harry, & Skrtic, 2000, p.127). Here I ask Bev what she felt her role was in Patrick’s education as his parent:
The fighter. Ever since Patrick got diagnosed with autism, it's like the boxing gloves went up. Like I told you before, I can handle the streets, I can handle society, but god damn I shouldn't be fighting the schools, or the hospital…. once Patrick started school, I turned around and I threw my boxing gloves away, I had to go look for them.

She soon became a formidable opponent when fighting for academic supports and services for Patrick with the school district, and as she continued educating herself about autism, making connections through parent groups and community organizations, her confidence grew and so did her skills as an advocate, and ultimately a fighter.

There was a sense of urgency in every tactical move that Bev made for Patrick because in order for Patrick to reach the level of academic success she had hoped for by his twenty-second birthday (when he would age out of the system), in her mind there wasn’t much time for diplomacy. When asked about the methods that she used to get the academic supports she wanted for Patrick, Bev responded:

I had to move buildings and kick people around, I had to take care of business. Am I proud of some of the things I did? No, but oh well, if I didn't do it he wouldn't be where he is today.

It didn’t take long for Bev to realize that she was in this fight alone, and she stopped caring what other parents, teachers, and administrators thought about her methods and demeanor because as Bev put it, “it’s all about the dog in you….and I am here to fight for mines.”

Soon Bev began to embrace the nickname “Autism Bitch” that she had been labeled with by White educators and administrators at Patrick’s former school, and took every opportunity she could to “call a spade a spade” and hold the school and the district accountable:
You know what, it just sucks having a child, it sucks having a child with disabilities, it's a constant fight, you gotta fight fight fight. And you as a parent you get labeled as a, God only knows what they called me, but who cares I like it [Bev chuckles]

In her mind, she was not only fighting for Patrick, but in turn, she was opening up doors and paving the way for so many families that were in similar situations but were unable to advocate for their children. This is a leading role that she has assumed responsibility for, but with this role, she often finds herself fighting the battle by herself. Bev is well known for attending meetings at City Hall, and for taking out her rhetorical “baseball bat”, swinging it around, and raising a lot of questions with no one by her side. Here Bev describes the frustration she feels being forced to be the “big Black loudmouth bitch” because she feels that she is the only one willing to speak up, “I got nobody by my side. I understand a lot of people can’t advocate, I understand language barriers, I understand, but goddamn stand by me.” This is not the only time and place that Bev experiences a sense of isolation being a parent of an autistic student.

From the moment that Patrick began attending school at FDS, until the moment he walked across the stage to transition into high school, Bev was very successful in procuring educational supports and services for Patrick on the academic battlefield. She came out of Patrick’s first IEP meeting with her guns blazing, but soon she began building relationships with Patrick’s teachers and school administrators and was able to slightly relax her defenses. During this time she witnessed Patrick academically progress in math and ELA, fully communicate by speaking, and witnessed him blossom into an independent young man at FDS. Maybe it was a result of her letting her guard down, or that she was starting to get battle fatigue, but when Patrick transitioned to high school, her world began to change.
Empty Bag Empty Dreams: Academic Desires in Black and White.

One of the main goals of special education is to provide individualized support to students with dis/abilities based on their specific needs. The IEP is the main guiding document that spells out in detail the individualized supports, as well as the special services that are necessary for the student to reach their educational goals. In theory and in practice, the family has the right to recommend, as well as decline any support or service that they feel the student may or may not need. The UCA website provides an overview of the special education services that the school offers, as follows:

UCA proudly enrolls Students with Disabilities across a wide spectrum of need. Most students are served in an inclusion setting with their general education peers, some students are served in smaller substantially separate classes based on their Individualized Education Plans (IEPs), and high school students with severe cognitive and/or physical handicaps are served in our [Skills for Life (SFL)] program.

The key sentence here is, “some students are served in smaller substantially separate classes based on their Individualized Education Plans (IEPs)”, which in essence means that the educational programming that Patrick is being provided should be guided by what is written in his IEP. Here I ask Bev about her experience at Patrick’s first IEP meeting at UCA:

Chris: At any point during the IEP meeting, did they ever ask you about what your-

Bev: Goals are?
Chris: Desire for him? Do you want him to go to college? Do you want him to graduate? Do you want him to do life skills? And at no point they asked you if it would be okay for him to do a life skills type class? No?


Chris: No point did they ever ask you if you wanted him to graduate from high school?

Bev: Nope.

Chris: Have they ever asked you what you potentially would like him to do when he grows up, as far as a job or independence?

Bev: Nope.

Chris: None of that stuff?

Bev: I told them that I wanted Patrick to be pushed more into educational. As opposed to life skills.

Chris: At UCA?

Bev: Yes, when I first met them.

Chris: So, I wonder what the options are. So, let's just say that you wanted to change his course of study, his educational programming, and get rid of the life skills.

Bev: Well, that's what they're going to say to me. Too bad. This is how our fucking program is built. You either accept it or anything…….

Kurth (2015) suggests that “placement decisions have a long-lasting impact”, and this exchange would suggest that Bev’s desire for Patrick to be placed on an educational track focused on grade-level academics was never taken into consideration when creating his IEP.
(p.255). If her desires are not written into his IEP, the school is not responsible for implementing them. In other words, UCA essentially placed him on an educational track geared towards learning functional life skills instead of focusing on academics as Bev had expressed, she wanted for her son.

In chapters five and six, Patrick speaks in detail about his experiences participating in the Skills for Living (SFL) Program, a program focused on learning functional life skills, where he spends a lot of time performing occupational duties and watching non-academic YouTube videos rather than receiving academic instruction. The balance between academic programming and life skills has always been a point of contention for Bev. Although she does state that Patrick enjoys cleaning, recycling, and working at the school store, she fears that the reason he enjoys it so much is, “because that’s all they have to offer” and that, “he loves school so much he doesn’t realize they are fucking him up.” Given that Patrick only has seven years left in public school, Bev feels adamant that UCA should be focusing heavily on providing him targeted academic instruction to help him gain the skills he needs to earn a high school diploma and/or learn the skills necessary to find a job and live as independently as possible. In addition, she feels that UCA should be consistently providing him with homework on a regular basis. Bev asks Patrick to get his book bag and show me the contents inside of it. Patrick brings over his empty bag containing only his lunch box (see Figure 6.1).
Figure 6.1

*Figure 6.1 A Photograph of Patrick’s Backpack After Returning Home from School*

*Note.* The backpack only contains Patrick’s lunch box.

According to Bev, his backpack comes home empty every day, and only contains his lunch box and occasionally she receives school correspondence of an upcoming meeting or school event. When he was at FDS, Patrick would regularly bring home books to read, math worksheets to complete, among other things. Bev shares her frustration that Patrick consistently comes home with an empty backpack because in her mind, “they know he’s a level 2 reading at grade 2 level” so why not send him home books so he can practice? This was not the workload that Bev expected Patrick to be doing in high school, she adds:

They're not going to tell you that when your kid goes to high school your kids going to be doing life skills. They don't tell you that. And you're thinking he's in school, he's going to do regular work like the other kids, no. Your kid will come home with an empty bag, and your normal kid will come home cracking his back with all the homework.
With limited opportunities to independently do homework, in combination with the main focus of educational programming for Patrick centered around life skills, there wasn’t much academic time left during the school week for Patrick to learn the academic skills that his mother hoped he would gain when he started attending UCA. Given that Wednesdays were a half-day and Patrick went swimming for most of it, Thursdays were reserved for Patrick’s weekly trip to the Central Offices for cleaning and recycling, and on Fridays Patrick would go to the boat house and practice rowing, the only two full days that Patrick could potentially receive academic instruction were Mondays and Tuesdays.

It is important to note that recycling has always been a sensitive topic for Bev. When Patrick attended FDS, he was part of a team that was responsible for doing all of the recycling for the school. Bev’s stance has always been that given that Patrick has more educational needs than a general education student, he should be using the extra time that is allotted for recycling, and other occupational tasks, for learning more grade-level academics at his individualized level of understanding. As Bev puts it, “why challenge them only for recycling when there’s other things that they can do? What the fuck does recycling have to do with is future?” In addition, she raises a good question, “why is it that only our kids recycle? Why not the regular ed kids?” Bev feels that “the kids that act up in school, give them [recycling] for punishment. Why is it only our kids? They don’t give a damn, they just don’t give a damn.”

To further escalate her anger surrounding the issue of recycling, Bev was under the impression that it was Patrick and both substantially separate classes going to the Central Offices to clean the windows, the doors, and collect all the recycling from the building. After this exchange, Bev learns that only the B Group travels to the Central Offices:
Bev: So, I think that, at their level, does Daniel go to the [Central Offices]?

Patrick: No, Daniel is in A Group.

Bev: So, who goes with you?

Patrick: Mr. J., Jose.

Bev: What?

Chris: What other kids go with you?

Bev: Patrick's the only one that goes!

Patrick: Darius and Albert!

Chris: Darius and Albert? Just the three of you?

Patrick: Yes.

Bev: And look, Albert can’t say for himself he doesn't want to go.

Darius and Albert attended FDS with Patrick, but they were a year ahead of him.

Both Darius and Albert need supports to engage in spontaneous communication by speaking, with Albert needing more intensive supports such as one-to-one assistance using an augmentative and alternative communication (AAC) device. This exchange above revealed that Patrick is not only being excluded from inclusive opportunities with his same-aged peers, but the substantially separate program that he is part of further excludes Patrick by sorting the SFL Program into two groups based on perceived ability. On top of that, students that are in the B Group, may or may not have the supports necessary, or the opportunity to communicate their willingness or refusal to participate in occupational experiences involving cleaning and recycling. Bev believes that if a student is passionate about recycling, the school can “aim them that way,” and provide them with the supports to develop the necessary skills for working in waste management, but if, because of their perceived ability all they
offer them is recycling, then they are “failing our students.” Given the limited vocational skills that Patrick is being provided at UCA, he seems to be following a path leading to working in an occupation different from his chosen profession, “working in a school to help kids.” What is unclear is how UCA is preparing Patrick for this career choice.

During the creation of Patrick’s most recent IEP, as discussed in chapter five, UCA essentially erased all traces of Patrick’s desire to be a teacher, and instead, as the data suggests, gave him the same educational programming that all the other students in the SFL Program were receiving, life skills focused on recycling, cleaning, and working at the school store. The results of a transitional survey administered by UCA stated that, “Patrick would like to get employment in cleaning and washing dishes.” For which Bev responded, “that’s bullshit.” The results of the transitional survey seem to contradict what was written in Patrick’s IEP from FDS, as well as the narrative in Patrick’s annual review completed by UCA, which read:

When completing a visual transition assessment, Patrick indicated that he wanted to live in [the city] with his mom. Work a job 6 to 8 hours a day and work in a school to help kids. He also stated he wants to be able to go into the community and do activities like bowling, swimming, and the gym.

When Patrick left FDS, Bev had anticipated that UCA, “would pick up where FDS left off”, but that did not seem like the case, she adds:

You would hope that once they transition to another school, life would carry on. But at [UCA], it's different. They're just setting him up for recycling. They're not focusing on the educational part of it. And from what I'm gathering, even if Mr. Marcus wants to focus on the educational part, he's getting the no-go. And that's not fair. Because
here's a kid who has a chance. Because he has autism attached to his name. He has a chance to succeed, but yet because he has autism, you're just going to fail him? And that's not right. That's dirty. Fuckers.

As Bev so directly puts it, “because they go in with the autism attached to them, it's automatically, it's a life sentence,” and by not taking into consideration Patrick’s desire to become an educator, the school is, “setting him up to collect a check.”

**Environmental Battlefield: Autism is a Life Sentence**

Soon after Patrick began his freshman year at UCA, Bev found herself not only fighting for her son on the administrative and academic battlefields with the school and the district, but also on the environmental battlefield fighting for inclusion within the school as well as Patrick’s broader urban community. As a mother of a student with an invisible dis/ability Bev was forced to fight for inclusion for Patrick in both the structural and ideological sense with DPS, and also in the local urban community. This presented a whole new set of challenges that she was not accustomed to dealing with, further impacting Patrick’s future and her mental health.

During his entire educational career at FDS, Patrick was provided with an inclusive environment where he had the opportunity to interact with his same-aged peers on a regular basis as an active member of the school community. When he arrived at UCA, Patrick found himself excluded from the rest of the school, spending most of his school day in an isolated room denying him the opportunity to actively engage in the school community. Bev now found herself battling for inclusion, something for which she had taken for granted and never had to fight for while Patrick was at FDS. Quickly Bev was beginning to see that the structural and ideological forces of exclusion placed on Patrick at UCA presented her with
some significant obstacles. When asked what she thought of inclusion at UCA, Bev responded, “They limit us Chris, they limit us. Basically, it's like a babysitter, you know….and they don’t do inclusion, they don’t.” The first obstacle, the structural partitioning of space, prevented Patrick from physically accessing his same-aged peers, and the second, the ideological forces of exclusion that limited Patrick’s intellectual development, prioritizing functional and occupational skills over academic ones. Having attended a K-8 school that prioritized inclusion in both the academic and social sense, this type of partitioning was new to both Patrick and Bev.

As Patrick progressed through the FDS, Bev saw Patrick overcome just about every obstacle that he came up against. Whether it was becoming comfortable communicating by speaking, following the school routines, or learning how to independently get himself ready for school in the morning, Patrick had truly blossomed into an amazing young man. The FDS was the model school for educating autistic students in the district, it had onsite occupational therapy, speech therapy, applied behavior analysis therapist, adapted arts, adapted physical education, and it had highly trained and skilled special educators that knew how to create the optimal environment for autistic students to be successful. This was a lifeline for Patrick, but as Bev soon learned, the FDS kept Patrick “well protected and sheltered”, in comparison to the UCA which provided Patrick with an environment much closer to the realities seen in the outside world. This isn’t necessarily a negative attribution because at some point Patrick will need to learn to function outside the protective bubble he is comfortable operating in, but for Bev it was a swift reminder that Patrick would soon be transitioning out of high school and into adulthood. Patrick got a taste of the harsh realities
of the real world on his sixth day of school, but this was not his only brush with the sometimes-harsh reality of living with an invisible dis/ability.

**Black, Autistic, and in the System.**

As a result of UCA filing a 51a report with the State Department of Family Services for suspicion of abuse and neglect, or in Bev’s words, now that Patrick, “has three strikes against him….one he’s black, two his autistic, and three he is in the system”, she worries about Patrick because “autism is an invisible disability.” She has “never feared autism”, but now that he is six feet tall, two hundred and fifty pounds, and he is Black, she is terrified. As Bev explains, “cognitively he’s a little kid, but in reality…. he’s big and he’s stocky and stuff”, and people think he is a man, and that “special needs is different for black than white.” The difference became apparent when Bev and Patrick were shopping at Thrifters, a popular thrift store in a predominantly white suburb of the Urban City in which they live, and had an encounter with the local police.

When Patrick and Bev shop at Thrifters, Bev usually goes her way, and Patrick usually goes his. Patrick enjoys walking around and looking at the merchandise, specifically the toy department, the book section, and the DVD rack. On this trip, Patrick had his phone out and he was taking pictures of people in the store, one of these individuals was a little white girl. This prompted a white store employee to call the police on Patrick, the scary part was, as Bev puts it, “they didn’t identify Patrick as a kid. They identified him as a man, and they called the cops.” When Patrick described this terrifying experience, he spoke in a low tone and didn’t make eye contact, Bev said he “was shaking like a leaf.” According to Patrick, “there was a lady, and I took pictures of the girl, and I got scared. And the police said are you with your mom? I said yes, and then I apologized, I don’t want to get banned.
I’m not scared anymore.” Later on, in the story Patrick goes on to “call her a B word” and is adamant that it was the girl’s fault not his. Fortunately, this innocent misunderstanding remained a misunderstanding because the police officers that showed up went through specialized training on how to interact with individuals on the autism spectrum. Bev was grateful that the police officers showed up to teach Patrick a lesson; however, the dangers that faced Patrick in the community as he grew older began to sink in for Bev.

Given the current cultural, social, and political context of being “Black, autistic, and in the system”, had Patrick begun engaging in self-stimulatory behavior and invading the officer’s personal space and/or reaching into his pocket for his cell phone to show the officer the pictures he took, at best he would have left the store in handcuffs, at worst he may have become a victim of police brutality. The former would work to further impede Patrick’s dream of becoming a teacher by placing a permanent stain on his Criminal Offender Record Information (CORI), the latter would make Patrick just another statistic adding to the growing list of unarmed young Black men that have become victims of unjustified violence by law enforcement officers. Bev describes the same struggle that she has every day as a parent of a student with an invisible dis/ability:

It's a no-win with a child with special needs it's not…… And then you know as they get older and stuff like that, you think of the future…. what’s society going to do, how's it going to deal, is my child going to be safe on the bus? Is my child going to be safe here? Will he be able to work? Will he be able to function? I mean you as a father, I'm quite sure you go to bed with one eye closed, one eye open, cuz you're always thinking about your kids. Imagine what we go through. if you're not closing one eye, I ain't closing no eyes.
Bev had no choice but to keep both eyes open because as Bev puts it, “you think when they’re young you have problems, but you don’t…. the older they get the scarier it gets because right now you’re just dealing with school. Going into society and all that stuff…. it’s a nightmare.” In addition, since autism is an “invisible disability” and given the intersectionality of race and dis/ability, in combination with the long history of police brutality towards people of color, Bev worries that, “God forbid he does something, he’s going to go to jail.” Bev fears that Patrick will become a victim of the system.

As the clock continues to tick, as Bev describes it, Patrick is getting closer and closer to the age of twenty-two when he will age out of public education. Bev is fearful that UCA will not provide Patrick with an education that will prepare him for his transition to adulthood, and the realities of living and working in the local community.

**Fighting for Inclusion in Society**

For Patrick to graduate from high school and receive a standard diploma in the State where Patrick resides, he must meet the Competency Determination (CD) standard, which requires students to achieve a passing score on the Urban Standardized Test (UST), a pseudonym, in addition, he also has to meet school and district requirements. Even if he meets all of the goals and expectations written in his IEP and receives all As and Bs on his report card, if the CD requirements are not met, he will leave high school with a certificate of completion, rather than a standard diploma. Figure 6.2 displays a copy of Patrick’s first term report card, showing that Patrick has a 3.57 grade point average (GPA), and he hasn’t missed a single day of school.
Urban Collegian Academy prides themselves in having more rigorous high school graduation requirements than that of the district, and their website states, “In addition to providing a rigorous core curriculum, [UCA] requires students to engage in meaningful community service, obtain and participate in senior internships, and take part in the school’s annual project-based project week.” Full graduation requirements include:

- 4 Humanities courses
- 4 years of ELA
- 4 math classes (including Algebra II)
- 4 lab science courses
- 2 world languages courses
- 1 arts course (or equivalent)
- 1 physical education course (or equivalent)
- a position paper in senior year
- a 6-week internship in senior year
- 40 hours of Community Service
- a Competency Determination (CD) in MCAS ELA, math, and science

I asked Bev if she was ever asked if she wanted Patrick to graduate high school or if the high school graduation requirements at UCA were ever shared with her, and for both questions she answered no. Bev feels very strongly that the purpose of special education is to provide students with the individualized supports necessary to access the academic curriculum at their individualized level. In the case of the UST test, she feels that Patrick should be able to take an adapted and modified version of the test to demonstrate his understanding at his individualized level. Every year Patrick does participate in an alternative UST test (UST-ALT), but the problem being that by taking the alternative assessment, he is statistically unlikely to meet the CD requirements for earning a standard diploma, and instead would receive a certificate of attainment. The test is adapted and modified, but the requirements are the same for all students.

I asked Bev what she thought of the high school graduation requirements and if she thought they were fair, she responded:

It's not fair, it's like another way of slapping us in the face saying this is what you get for having a child with special needs. It's not fair at all, you know? My kid’s going to come out with a high school diploma [laughter]. It's like everyone you try to talk to
on this thing falls on deaf ears. But I bet you my last American dollar if any of those people at the state board, or whoever designed that shit had a kid with special needs, shit would change.

Patrick has been receiving adaptations and modifications to the academic curriculum his entire life and when it comes time for him to demonstrate his academic proficiency, if he wants to graduate, he has to take the test with no supports. As Bev says, “you are damned if you do, damned if you don’t.” This leaves families of students with dis/abilities in a difficult predicament, especially if they are unaware of the high school graduation requirements. It is important to note that the IDEA provides students with special education services from age three through age twenty-one and if they graduate with a standard diploma before the age of twenty-two, they are no longer eligible to receive special educational services. For some students with dis/abilities, earning a standard diploma may be the best option; however, for others, receiving special education services until the age of twenty-two might be more beneficial. Either way, it is essential that the family be part of this decision-making process and made aware of all of their options. Otherwise, families will be left making last minute moves in desperation to try to procure a high school diploma for their child.

Once Bev fully understood the consequences of Patrick taking the alternative assessment, it was too late to make any substantive changes to his educational path. But the fighter in Bev is adamant that Patrick will leave UCA with a high school diploma, even if, “I need to move that goddamn [Empire State Building] .... if I have to slam one fucker against another, I will…… Patrick is coming out with a high school diploma.” Here Bev elaborates on the perspective of a student with dis/abilities that is denied a high school diploma:
You did your work, you got up, you didn't miss your bus, you had to follow the rules, the regulations and everything like that, and then based on your ability…. to be deprived from a high school diploma that's not right. That's not right, I mean, you got that [UST] test over there that they do and what does the [UST] prove?

Bev was under the impression that since Patrick was making significant progress throughout elementary school and middle school, she assumed that he would have no issues earning his diploma. As she describes it:

So basically, elementary level builds them up, get our, get the parents a hope of our children succeeding, and then once they got on to the high school level, they’re put on that fuck slippery slope just to see them [smacks hands] tank right down.

At this point in his educational journey, given the current life skills program that he is enrolled in, for Patrick to graduate and earn a high school diploma Bev will have to “fight like hell” and “move every building in [the city]” in a last-ditch effort of desperation. Desperation can be a great motivator; however, given the structural and ideological forces of exclusion working against Bev on the administrative, academic, and environmental battlefields, the fight for a high school diploma was beginning to seem futile.

Caught in the Cultural Crossfire of Autism

When Patrick was first diagnosed with autism, Bev had a difficult time accepting the diagnosis because, “the embarrassment of my culture, the letdown.” Here Bev describes the cultural implications surrounding autism in Cape Verde, as well as, in her own family:

I noticed, especially when I went to Cape Verde, they were blaming everything, like the father drinks, or the mother drinks, or the mother was malnourished. It never was autism till I went down there. Now...autism, they know of autism, but they don't
really know. But here in the states they would deny it, because no, there's no way. They'll make up a word for autism, like my mother, when she turned around back in the day when Patrick was younger, she'd make up a word for Patrick. She would say he had a reaction to the needle [laugh] from one of the vaccinations. He was born healthy strong blah blah blah, no it was a reaction from the injection, that's what he has. But to this day she will not open her mouth and say Patrick has autism. And my father won't…. my father will tell me he has problems, my father won't say he has autism. But, my others, the more modern Americanized, they'll say that he's autistic [laughs]

Through her volunteer work, servings as a mentor to Cape Verdean families with autistic children, Bev is trying to shift the deficit narrative of dis/ability within her Cape Verdean culture by promoting autism acceptance, and educating them about autism:

They’ll make every fucking excuse in the book to cover up autism, because it’s an embarrassment to turn around and say their kid was born this way. I went to Cape Verde, I woke up their eyes about autism out there, I told them it's nothing to be ashamed of.

Aside from the denial and embarrassment that Bev attributes to Cape Verdean culture, there is also a huge language barrier further impeding autism awareness and acceptance within this culture. Bev remembers the first IEP meeting she attended for Patrick and how overwhelmed and confused she was because many of the educational terms she was hearing from the occupational therapist, speech pathologist, and special education teacher had no Cape Verdean equivalent. Even if the school was able to provide a Cape Verdean interpreter, it wouldn’t help because, “there's no words that exist,” and autism gets literally
and figuratively lost in translation. Adding to the overall confusion, the words she did understand were so wrapped up in educational jargon that they were unrecognizable and made no sense to her, “it was another language for me. I remember I kept telling them, you have to speak English, their throwing all these words and shit, I can't even pronounce those goddamn words.” During the first IEP meeting, Bev found herself needing a translation of the translation in order to begin to comprehend what was transpiring at even a basic level. The cultural disconnect was glaring, resulting in confusion, frustration, and something she was growing accustomed to, exclusion.

Passing on her cultural heritage, traditions, and customs to Patrick remains a top priority for Bev. When Patrick was first diagnosed with autism, and was non-speaking at the time, Bev was encouraged by his preschool program to speak to Patrick only in English to prevent any confusion as he began learning how to communicate. This practice is what Cioè-Peña (2021) describes as “using English as a tool for domination,” where bilingual students are only given instruction in English because the schools feel that it is “more important for [students] to be normal than connected to their community.” Through policies and practices at the school and district level (in this early case Patrick’s preschool encouraging his mother only to speak to him in English, and in a later example, his high school curriculum that does not honor, represent, or acknowledge his cultural ways of knowing), Patrick was denied access to the tools necessary for him to engage with the language, traditions, and heritage of his Cape Verdean culture.

As Patrick got older, he quickly began communicating by speaking and his vocabulary grew at a high rate thanks to his love for reading. Soon Bev made the conscious decision to begin communicating with Patrick in Cape Verdean Creole, and soon he started
learning the language that his grandparents often communicated with. Patrick’s receptive language is stronger than his expressive language, but he can speak many common phrases, enough that he can communicate his wants and needs in Cape Verdean Creole. One of his favorite phrases is “Sa dodu sa crazy?”, meaning are you crazy or crazy? In addition to teaching Patrick Cape Verdean Creole, Bev believes very strongly that it is her responsibility to teach Patrick life skills, whereas it is the school’s responsibility to educate him academically. That way she can use her cultural ways of knowing to teach him how to cook traditional Cape Verdean dishes, follow traditional Cape Verdean customs, and learn his cultural heritage; all of which Bev feels that the school is incapable of accomplishing. Here Bev describes what she calls the “cultural crossfire” of life skills:

I mean he goes to school, here's where the cultural crossfire takes place, because we're Cape Verden we predominantly eat Cape Verdean American food, he's not going to depend on grilled cheese every day, you know what I mean?……Like today he said he wants Cachupa. He asked for that, it's a time-consuming meal to make. Right? They're not teaching them that. I wonder if he was Chinese, wonder if he was Haitian, or Hispanic and he had some food from his culture that he likes? I think life skills should be…. push him as far as you can education wise, because him missing out on history, English, math, how is he going to succeed out in the world when he's only able to read at the elementary level?

Once a week, as part of the SFL Program at UCA, Patrick takes part in a cooking class where he has the opportunity to cook food for himself, his friends, and sometimes for his teachers. As Bev described earlier, cooking class is far from culturally responsive to the
needs of the students in Patrick’s class. Here Patrick shares what he cooked during his first cooking class in the SFL room:

Chris: What kind of food do you cook?

Patrick: like Cake

Bev: what kind of food did you cook that you said was nasty?

Patrick: [whispers] pumpkin pancakes

Chris: Pumpkin pancakes? That sounds incredible

Patrick: Pumpkin pancakes are crap…. they are crap

Chris: Dodu? (Crazy in Cape Verdean Creole)

Patrick: Yeah

[everyone laughs]

Bev: We don’t eat that here

Patrick: It’s trash and crap. Crap. Like crap [gets very excited]

Over the past three years DPS instituted a district-wide initiative that involved educating teachers about Culturally and Linguistically Sustaining Practices (CLSP). As defined on the district website, CLSP, “draw upon, infuse and evoke students' existing schema, experiences, funds of knowledge, and perspectives to optimally facilitate learning.” In other words, teachers are encouraged and required to create curriculum and classroom experiences that imbed the cultural ways of knowing of the students in their classroom. With CLSP, Patrick’s teachers should be looking for ways of embedding elements of Patrick’s culture in their classroom. This is one of Bev’s biggest complaints about the life skills program, here she shares her frustration with the program:
But they don't care. They think that's what's best for them. Okay, if you are teaching them how to balance a checkbook account. If you are teaching them how to do dishes. Teaching them how to do sewing, home economics classes or if you're teaching them how to like load your [train pass] card then fine. That's fine. But don't come give my kid life skills when you don't know my culture and my beliefs.

For a life skills program geared towards preparing Patrick to live as independently as possible, providing him opportunities to shop for, cook, and eat meals that are common in his culture is essential for his success in adulthood. Bev shares that she has never been asked to provide any suggestions on meals that Patrick could learn to cook, and she has never been asked to come to the school and share her knowledge of Cape Verdean cuisine. Instead, Patrick cooks pancakes, which begs the question that Bev raises, “why go teach my kid to make pancakes when we eat couscous?” For Bev this is a waste of time because, “it's not the school’s responsibility to teach him life skills because culturally we're all different….and autism is one of those disabilities that are all walks of life.” Bev feels strongly that instead of teaching Patrick how to cook food that isn’t culturally relevant to his independence, the school should be providing extra academic support or at the very least, teaching him skills for independence that are relevant to his particular needs.

On one hand the school is prioritizing the teaching of functional life skills over academic instruction, on the other hand, these functional life skills that Patrick is being taught are not culturally responsive to his Cape Verdean culture. As a result, Patrick is missing out on the academic instruction necessary for him to earn a high school diploma, and instead has been provided with life skills that don’t reflect or value his cultural ways of knowing. When asked what her plan was for Patrick going forward, Bev responded, “I don't
know, Chris. I don't know. I don't know what to do. I mean I'm at my wits end” and that, “I wish I could stick him in my womb and start all over again from day one.” This was the point where Bev started showing signs of desperation, most of these signs were witnessed when discussing Patrick’s future, and whether he would be receiving a high school diploma and attend community college, or a certificate of completion and enter the workforce.

**Losing Hope: Autism Becomes Your World**

Throughout the course of this inquiry, Bev regularly shared her hopes and dreams for Patrick in an optimistic way. After Patrick’s incident during the first week of school placing him “in the system”, the five-month-long skirmish over removing occupational therapy from Patrick’s IEP, the rapidly deteriorating of the home school relationship between UCA and Bev, and Patrick’s impending “aging out” of the system at age twenty-two, Bev was growing complacent and beginning to show signs of hopelessness and defeat. As she puts it, “for years I was always happy, excited, and everything at FDS, now……I just lost. But I’m not one to say it is what it is.” Bev has described autism as “a never-ending fight” and shares the exhaustion, isolation, and helplessness she experiences on a regular basis. Here Bev describes her experience of being a single parent with a child that has autism:

You as a parent, especially as a single parent, you can't just focus on autism autism autism……you’ll go crazy. And then you come home. It's just me and him, who am I going to talk to? I'm not calling that idiot I had a child with, no because he refuses to understand. He will not accept autism under any…. he said I'm making it up for Patrick to have autism. So, at night when I try to close my eyes and get some sleep, I have like all these apps I'm trying to close down, and autism autism autism autism keeps popping up…….
Bev had devoted her entire life to fighting for autism and making sure that Patrick had the educational services that she felt he needed to be successful, so much so that it had become all encompassing, which took a toll on her mental health. Here Bev is asked what it is like being a parent of a student with special needs:

When you have a child that has special needs, nobody turns around to ask you, how are you doing? They don't know if by the end of the night if I need to smoke a joint [laughs], they don’t know if I need to drink a glass [laughs] or several, they don’t know if I need to drink a barrel of wine to calm me down. I mean it's like…. no one cares

When Bev began dedicating herself to addressing Patrick’s needs on the administrative, academic, and environmental battlefields, she selflessly put Patrick’s needs before her own. The problem being that by having to fight the neighborhood, the community, the school, and the medical profession, at the end of the day, Bev found herself alone. When asked to describe what autism meant to her, Bev responded:

A parent’s worst nightmare……when you look at it as a parent, it's just me and Patrick in the house…. but [hits knee every time] autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism autism…... What do you think that does to the inside of my head? Sure, let's talk about this, let's talk about that, but it's like you built a bubble around dealing just with autism, and that becomes your world.

Bev has always been a zealous advocate and fighter for Patrick, as she often says, “I can handle the streets, I can handle the community, I can handle my family, but I shouldn’t be fighting in the school.” It’s been over ten years since her battle with DPS began in September of 2008 when she refused to leave the resource center until Patrick was enrolled at the FDS, and although Patrick made significant progress at the FDS, when Patrick made the
transition to high school, Bev soon wished she had fought the district even harder to create better secondary education placements for Patrick and other autistic students. Here I ask Bev if her view of autism changed from when Patrick was first diagnosed and now that he is high school, and she responded:

If I knew back then what I know now I would have fought harder, I would have fought harder at an earlier age to get the high schools up and running. I would have kicked down more doors that needed to be kicked down, because right now I feel like education stops right at eighth grade, and there needs to be something for secondary education, and beyond that. Now I feel like I'm failing Patrick because they are setting him up to stay home and collect a disability check and have nothing to do. Opposed to…. he has potential, you know. I mean he can work in an airport, or you know, it doesn't have to be recycling, or trash picking, or anything like that. but if I knew then what I know now, I would have started in grade one to get high school up and running educational wise.

As Bev explains, she spent most of the early part of his education wishing for Patrick to get older, now that he is getting older, she’d rather, “have him younger because at least at the elementary level [she] can protect him and fight for him, and advocate for him. But in high school, what can you do?” Times like these she, “just wants to throw her hands in the air and say fuck it” but she realizes that if Patrick is going to get his high school diploma, she needs to keep fighting even if the fight seem futile.

Bev was well versed when it came to fighting the district for every little crumb that she could get her hands on for Patrick, but the years of fighting and disagreements were starting to catch up to her. The seemingly endless battle that Bev had been engaged in with
DPS was taking a toll on her mental health for years, but the long-term effects of this fight were beginning to physically manifest themselves, significantly impacting her overall wellbeing. Here Bev describes what happened at an IEP meeting where UCA was trying to remove occupational therapy from his IEP, for the third time:

I told you I walked out of that meeting.... I slammed the door. And then I turned around and I said, "Wait, that was the wrong hand. Excuse me." I went to slam it again. Chris, now I know why parents give up fighting, because it kills you. The following day, I had to go to the hospital with elevated blood pressure. Right, right. And all my life, throughout my pregnancy and everything, my blood pressure was low. Right? The bottom number was in the 90s. I've never seen that in my life.

In Bev’s words, “I can see why parents get frustrated. They’re supposed to do what they’re supposed to do, and they don’t, they don’t care.” Soon Bev was coming to the realization that her advocacy was no longer working and no matter how much noise she made, how loud she yelled, and no matter how hard she fought, “they just didn’t care.” Bev elaborates on her loss of hope, “I had so much hope and stuff like that but after going to this school, I’m losing it. Each and every day now gets scarier and scarier.”

Throughout his entire freshman year at UCA, Bev felt strongly that UCA wasn’t doing enough to meet Patrick’s academic needs and provide him with a meaningful life skills program that would build on his interests and his strengths and prepare him for adulthood, and regularly voiced her opposition. Instead, she felt that UCA was limiting Patrick’s vocational experiences to cleaning and waste management, when he had a passion for, “working in a school and helping kids.” All along Patrick has expressed positive feelings towards cleaning and waste management; however, Bev believes that the reason for
his interest in these vocational skills is because that is all that he has been exposed to and, “he doesn’t realize what he’s missing out on, and his potential.” Bev was unsure if Patrick’s current vocational path of cleaning and waste management was forced on him because UCA thought it was “all he was capable of doing” or if it was all that they had to offer, but either way, Bev was adamant that she didn’t want him on this path. As Bev describes, “more can be done, more needs to be done. But Chris, you get to a point where you’re like fuck it.”

Perhaps the metaphorical last straw solidifying Bev’s feelings of hopelessness and eventual defeat occurred during our final three-way discussion group over dinner on June 12, 2019. Here Patrick shared that he had a new occupation that he wanted to pursue:

Bev: Tell Mr. Chris what you told me about what you want to be when you grow up

Patrick: A garbage man

Chris: A garbage man?

Bev: from a teacher

Chris: From a teacher to a garbage man?

Bev: now he says he’s the best recycler

Patrick: Last night I took out the trash

Chris: For your mom?

Bev: he takes out the trash every night now. One time he says he isn’t gonna do it and I says you do it for the damn Central Offices but you ain’t gonna do it here

Throughout the course of this inquiry, Patrick had consistently expressed his desire to become a teacher and, “work in a school to help kids.” This marked the first point in this
study that Patrick expressed a desire to pursue a different occupation. In addition to expressing that he wanted to become a “garbage man”, during this final three-way discussion group, Patrick also insisted that, “when Mr. Chris leaves, I want to do the dishes mom, I do the dishes at school.” Bev threw her hands in the air, sighed, and responded, “that’s what they teach him in school.” For Bev, this exchange represented the proverbial “straw that broke the camel’s back.” Having advocated tirelessly for Patrick to gain the educational programing to earn a high school diploma to no avail, hearing Patrick say that he wanted to pursue the one occupation that Bev was adamantly against made her lose all hope.

**Conclusion: “Why Bother?”**

For Bev, the gravity of Patrick’s words hit her like a ton of bricks, forcing her to realize her biggest fear that even though Patrick had overcome so many obstacles, and even though she had so many hopes and dreams for him once he entered high school, his educational and occupational opportunities were limited, “because he [had] autism attached to his name.” Bev had witnessed firsthand the operational maneuvers made by UCA that seemed to limit Patrick’s educational attainment by excluding him administratively, academically, and excluding him environmentally from his school and local community. Bev had not seen so clearly how the decision-making related to Patrick’s educational programming by the school had directly impacted Patrick until now. In Bev’s words:

[They’re] setting our kids to be in the welfare system because you're building them up from k-8, raising our hopes, and once they get to high school BOOM there's nothing for them. So when they get out of here what's waiting for them? Not a job, an SSI check\(^{38}\). And stay home and rot.

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\(^{38}\) An SSI check is a Supplemental Security Income payment that provides checks to individuals with dis/abilities, an SSI check is sometimes known as welfare check.
Echoing Bev’s sentiments is the work of Erevelles (2013) that argues, individuals like Patrick with perceived cognitive dis/abilities are excluded from citizenship and forced to exist in the margins of society. When citizenship is judged by an individual’s ability to actively contribute to the labor force, then in this context, both Patrick and Beverly fall short of this unrealistic ideal because of the labels placed on them by both educational structures and society.

Looking at the complexity of this entire situation through the metaphor of a siege provides the vantage point to see that over the course of just one year of high school, once Patrick’s was placed on an educational path that prioritized functional life skills over individualized academic instruction, Bev’s optimistic outlook on Patrick’s education drastically plummeted from hopeful to fearful, fearful to desperate, and ultimately desperate to a complete loss of hope.

Bev found herself experiencing battle fatigue, completely worn down by the district’s exclusionary practices and lack of “giving a shit”, and completely surrounded her on all sides, and the ceiling was caving in, leaving her no other place to go but to her knees. To her left, on the administrative battlefield, UCA was removing occupational services from Patrick’s IEP that she had fought years to keep; to her right, at the academic battlefield, UCA was taking more and more academic instruction time away from Patrick and replacing it with function life skills that failed to prioritize his cultural ways of knowing; behind her on the environmental battlefield UCA was physically partitioning and isolating Patrick away from his same-aged peers, excluding him from becoming an active participant in his school and local community; right in front of her was a talented, motivated, caring, and dedicated student that now had three strikes against him, he was, “Black, autistic, and in the system;”
and caving in on top of her like a ton of bricks, was the weight of her personal struggles “fighting autism” day in and day out taking a toll on her mental health forcing her to “sleep with both eyes open.” Bev soon found herself coming to grips with the grim fact that because Patrick “had autism attached to his name”, the educational programming provided to Patrick would not lead to earning a high school diploma, and in her mind, because of the education he was receiving from UCA, he was destined to work “picking up other people’s trash” once he turned twenty-two and aged out of the system.

This once hopeful and optimistic spirit was completely weathered by the seemingly endless battle with UCA, fighting for basic educational needs for her son and was ready to surrender, or as Bev suggests, “you get to a point where you’re like fuck it” and give up. Bev’s experiences navigating the complexities of this urban school district suggest that even as an educated and seasoned advocate for her son, she was vilified by DPS and met with adversity every step of the way. Whereas a white mother fighting for her white son is commonly commended for their advocacy, as a dis/abled woman of Cape Verdean descent she was labeled as an “Autism Bitch” and forced to fight for “every little crumb” she got for her Black son (Babio-James, 2020). Bev’s story suggests that because of the color of her skin and her Cape Verdean cultural traditions, she was marginalized by UCA and DPS, and Patrick’s educational trajectory followed a seemingly predetermined path once he entered high school. In addition, because of racism and ableism she has had to fight “tooth and nail” with UCA and DPS at the expense of her mental and physical health to get the bare minimum of educational services for Patrick. Here she shares that although she has worked tirelessly as an advocate, because of her dis/ability, and also race, she feels that she has placed Patrick at a disadvantage in his educational attainment:
White people have the money to put their kids in private school, they can hire them the tutors, higher them the extra help and stuff. What do people like me that live off $12,000 a year do? Because of my disability, I'm punishing my son's disability, you know. Resources are not out there.

Even though Bev actively fought and pressured the district to provide a different path for Patrick, it seemed as though all of this work was done in vain because his path was seemingly predetermined by not only UCA, but also DPS and the broader society, which begs the question that Bev poses “why bother?”

Reflecting on her experiences during Patrick’s freshman year at UCA, Bev shares that, “for a parent, it sucks because, for Patrick, I’ve seen Patrick gone from nonverbal to verbal only to go in high school and lose all hopes in everything.” Here Bev adds to this sentiment:

All my years dealing with autism, the diagnosis hit you. But once I saw him going to school and blooming all along, making leaps…. it never bothered me. Now, it's kicking in. Because it's like, okay, at twenty-two, what is he going to do?

At this point in Patrick’s education journey, Bev begins to see that the doors that she had fought so hard to open for Patrick, much like the doors at the IEP meeting that Bev stormed out of, have been slammed shut. These same doors have been shut far too many times on Patrick, and for Bev, high school represents Patrick’s last opportunity for success:

At the Douglass, I had hopes of him going to a community college because they set up all these courses there. And they’re aiming more to our kids. But how are they going to get there? ….. Chris, I lost hope. I lost hope.
As Bev describes, Community Colleges in the area have specialized programs to support autistic students and are actively seeking students to join these programs; however, without a high school diploma, Patrick cannot gain entry to college. As a result, Bev has set her sights on “moving every building in [the city]” and, “knocking one motherfucker against another motherfucker” for Patrick to leave high school with a high school diploma. Bev has always been one to defy the odds, but in this situation, Bev is surrounded on all sides, alone, outmanned, and outnumbered.

When Patrick entered high school, DPS, much like a boa constrictor lies hiding in the thick grass waiting for the perfect opportunity to strike a larger more formidable opponent, wrapped itself around Bev and she didn’t even see it coming. By the time she realized that DPS had her in their grip, she began to feel this enormous serpent slowly constricting. Every time she took a moment to breathe a sigh of relief, it would constrict a little more. Every time she left an IEP meeting with her issues unresolved, it would constrict a little more. Every time that Patrick came home with an empty backpack, it would constrict a little more. Every time that Patrick left the school to recycle and clean the windows at the Central Offices, it would constrict a little more. Every day that passed marked another day closer to Patrick’s twenty second birthday, and soon Bev found herself squeezed so tight by the administrative, academic, and environmental implications of “fighting autism”, she was left gasping for air with no room to breathe.
CHAPTER SEVEN

“HE LOVES SCHOOL BECAUSE HE DOESN’T KNOW WHAT HE IS MISSING OUT ON”

“In sum, despite a widely held claim that the primary intent of special education is to serve students with disabilities, it has also served both segregationists and anti-inclusionists well. Thus, the tendency to focus on the positives of special education obscures how race and disability have been conflated, via the persistent overrepresentation of students of color, to subvert the promise of Brown and to deny equal access to educational opportunities.”

— (Connor & Ferri, 2005, p.459)

Introduction

In the fall of 2011, I began teaching a class called “Sensory Arts” at the Frederick Douglass School39 (FDS) which started as an adapted visual arts class for students in a substantially separate autism program, focusing on exploring standards-based visual arts curriculum through multi-sensory teaching strategies. The principal was looking for someone with an arts background and experience working with autistic students. At first, I felt unprepared for this new position, but the exciting part was that I had the unique opportunity to build a class from the ground up, and with it write my own curriculum,

39 Frederick Douglass School, a pseudonym, is used throughout this chapter to protect the privacy and confidentiality of the school and school district. Pseudonyms are used throughout this chapter when referring to specific people and places that could potentially identify the participants and/or the school district in which the study takes place.
experiment with different pedagogies, and create an environment that would adapt to the
learner rather than forcing the learner to adapt to the environment.

My first year of teaching was a learning experience to say the least, it challenged my
long-held assumptions about education as a one-size-fits-most model, it forced me to think
outside the box and use my creativity to provide multiple pathways to success for my
students. Looking back on that first year, I often reflect on one particular moment that served
as my motivation for pursuing a doctoral degree, and the catalyst for this inquiry. For our
first big art project, my students created a collaborative construction-paper mosaic of Rosa
Parks, Martin Luther King Jr., Oprah Winfrey, and Barack Obama to honor both historical
and contemporary figures during Black History Month (see Figure 7.1). We hung up the
completed work to overwhelming positive praise from staff and students. I created an eight
inch by ten-inch small sign that read, “created by students in the Frederick Douglass School
Autism Program” to hang with the artwork. As I was hanging it up, a staff member stopped
in her tracks and turned around with a look of dismay on her face and said, “YOUR students
did that?” That was the moment when I realized that the general public, and in this case even
highly educated individuals working in the field of education, often assume that students with
dis/abilities are incapable of accomplishing anything more than mediocrity.
Note. This mosaic contains over 18,000 ripped-up pieces of construction paper.

From that moment on, although at this time I didn’t have the words to express what I was witnessing in this educational space, I began to notice that through policies and practices, my students were being viewed through a deficit lens heavily rooted in ableism and the medical model of disability (Campbell, 2009; Gallagher, Connor, & Ferri, 2014). Unbeknownst to me at the time, as a special education teacher working in this educational space, I had been perpetuating a damage-centered and false narrative of my students (Tuck & Yang, 2014). Although I completed two master’s in education programs, the first in elementary education and the second in severe special needs, it wasn’t until my doctoral studies that I was introduced to the social model of disability (Gallagher, Connor, & Ferri, 2014) and discovered Disability Studies in Education (DSE) (Erevelles, 2000; Connor, 2005; Ware & Valle, 2010; Baglieri et al., 2011). Until that point, I had only learned about the experiences of individuals with dis/abilities through deficit-based ableist research conducted on these individuals rather than with them (Kauffman, 2000; Kauffman, Anastasiou, & Maag,
This study serves as a counter-narrative to this damage-centered research and privileges the voices and lived experiences of individuals with dis/abilities, following the tenets of DSE (Baglieri et al., 2011).

This concluding chapter will begin by revisiting the research questions guiding this investigation, exploring the exclusionary educational experiences of a Black student labeled as severely dis/abled being educated in a restrictive educational placement, their family, and their teacher. Next, I will analyze the findings of this study using a theoretical framework that combines Disability Studies in Education with Critical Race Theory, known as DisCrit (Connor, Ferri, & Annamma, 2016), revealing the ways in which race, dis/ability, and ableism impacted the educational experiences of the participants. Third, the siege metaphor used to structure the previous data chapters will be re-introduced and the larger, systems-level insights that the use of this metaphor revealed about learning and teaching in substantially separate and restrictive educational settings will be discussed. Fourth, administrative, academic, and environmental implications are introduced. Fifth, the limitations of this study will be presented, followed by recommendations for future research. Lastly, after reflecting on the results of this study, this chapter concludes with a few final thoughts calling for students, families, and educators to work together to reimagine inclusive education in the post-Covid-19 era.

**Guiding Research Questions**

For Patrick, the data suggests that his education at Urban Collegian Academy (UCA) has been defined by what he is perceived to be unable to accomplish, specifically his goal of becoming an educator. From being placed in a self-contained and restrictive educational setting, to being isolated and excluded from interacting with his same-aged peers in the
classroom and in social situations, Patrick’s true talents lay dormant at UCA: namely his passion for “working in a school to help kids”, his unique ability to navigate to any place in the urban city that he resides, and his seemingly endless supply of creativity and artistic talent, both in visual and performing arts. Supporting what Leonardo and Broderick (2011) describe as schools rewarding specific forms of “smartness” and ignoring other forms of knowledge that students may possess (p.26).

This inquiry began by using a DSE framework that privileged Patrick’s knowledge base, his interests, and the research methods were adapted and modified to support him in sharing the versatility and multiplicity of his perspective (Kincheloe, 2005). Through art renderings, interviews, and lyrical expressions, Patrick shared his lived experiences as a high school freshman being educated in a restrictive setting in a way that embraced his preferred method of communication and created a research environment that valued and privileged the variability of his perspective (Ashby, Woodfield, & Delia, 2016). This inquiry was guided by the following overarching and central research question:

What do the educational experiences and desires of a student in a substantially separate classroom, their family, and their teacher reveal about access to a Free and Appropriate Public Education (FAPE)?

First, before answering this question, it is crucial to provide some context regarding the legal implications of a FAPE as defined by the Supreme Court in two landmark cases involving the legislative interpretation of FAPE, and its classroom application. Access to a FAPE is an entitlement under the Individuals with Disabilities Education Act (IDEA); however, a universally accepted legal definition of “appropriate” has yet to be clarified in the courts. In Board of Education v. Rowley, the Supreme Court attempted to define
“appropriate,” and in their decision stated that, “it is a requirement that the education to which access is provided be sufficient to confer some educational benefit upon the handicapped child” (Rowley, 1982, p.201). In Endrew v. Douglas County School District, as a response to the Rowley decision, Chief Justice Roberts stated in the majority opinion that, “a student offered an educational program providing ‘merely more than de minimis’ progress from year to year can hardly be said to have been offered an education at all”, and receiving instruction that aims so low would be “tantamount to sitting idly….awaiting the time when they were old enough to drop out” (Endrew, 2017, p.14). The classroom implications for the Endrew ruling are yet to be seen but the parallels between this salient quotation from the Endrew decision and Patrick’s education experiences cannot be overlooked.

Patrick’s educational experiences suggest that the education that he is receiving at UCA may represent the embodiment of exactly what the above quote by Chief Justice Roberts warned about. The term “appropriate” is a subjective term that has been interpreted by the Court in two seemingly contradictory ways. The two leading cases that directly address FAPE, Rowley and Endrew, legally define an “appropriate” education somewhere between “sufficient to confer some educational benefit” (Rowley, 1982, p.201) and “educational programming reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances” (Endrew, 2017, p.14-15). In the following section I will foreground Patrick’s voice, share his educational experiences, and discuss what these experiences and desires reveal about his access to a FAPE.

When Patrick shares his accounts of his educational experiences, on the surface, he shares them in a positive light, describing them as enriching, engaging, and “fun”. Many of the experiences that he describes as engaging and “fun” involve him either using an
Patrick uses an electronic device to access non-academic YouTube videos, eating lunch with friends, or describe his community engagement, specifically cleaning the Central Offices and swimming at the Boys and Girls Club. The academic experiences that he describes in detail suggest that the instruction that he is receiving is well below his current level of performance. In math class he describes doing basic addition, for example $4 + 4 = 8$, and completing math worksheets leveled for kindergarten and first grade. In science class Patrick describes watching *The Magic School Bus* during most classes when the teacher isn’t absent, and when he is, he spends most of the time watching YouTube videos. For English Language Arts (ELA) Patrick describes reading books that are far below grade level and many times during ELA his class goes to the library and independently looks at books. Patrick receives adapted physical education once a week where he describes playing soccer during most classes, and at the end of most days a para educator brings him to the gym to “play with balls” and/or “play duck duck goose.”

When Patrick isn’t out of the building on community outings, which take place Wednesday through Friday, he describes a lot of down time where he typically watches the same YouTube videos repeatedly. In addition to having a lot of free time to watch YouTube videos, Patrick’s artistic renderings revealed that he is also segregated from his same-aged peers throughout the school day. He is limited to two rooms that are isolated from the rest of the school, he doesn’t have his own locker, he doesn’t eat lunch in the cafeteria, and the only time that he interacts with his same-aged peers is when he is collecting their recycling. In addition to isolation, his artistic renderings suggest that there may be some contradictions in his accounts.
Throughout this investigation Patrick shared positive accounts of his weekly job at the Central Offices where he cleans the doors and windows and collects trash for recycling. Although in his drawings he describes that he is experiencing positive emotions, such as “cool”, “fun”, “fantastic”, and “great”, he often draws himself with downward facing eyebrows, a frown on his face, his tongue sticking out, or depicting an overall feeling of melancholy. This suggests that on the surface Patrick may be portraying positive emotions towards his occupational duties, but in actuality, he may not be enjoying these same experiences. Since the first interview Patrick expressed several times that he wanted to be a math teacher; however, through the experiences that he shared, there is no evidence that UCA is taking into account his desire to be an educator when designing curriculum for him, and instead they are only preparing him for a career in waste management, similar to findings by Miller (2019) with high school girls of color in substantially separate classrooms. During our last interview session, after finishing an entire school year, I asked Patrick what his career aspirations were and he responded, “I want to be a trashman.” With that in mind, waste management is a great profession to enter, as long as it is a choice. In Patrick’s case, his experiences suggest that he was given no choice and this occupation was forced on him because, as Bev consistently states, “he has autism attached to his name”. In just one year at UCA Patrick’s dream of becoming an educator was completely extinguished and his aspirations transformed from “helping kids” to picking up other people’s trash.

Patrick’s educational experiences at UCA revealed several areas of concern that significantly affect his access to a FAPE. His accounts speak to his overall lack of agency and voice in the educational decision-making processes that directly affect his future. At UCA, Patrick’s aspirations of becoming an educator seem to be completely ignored by
educators, administrators, and IEP team members. Instead of placing Patrick on a path to reach his personal and professional goal of being an educator, he is positioned to pursue an occupation that involves serving the dominant class, or in this case, picking up trash and cleaning up after able-bodied members of his school and local community. The educational programming he is receiving is in no way preparing him to graduate high school and realize his dream of going to college. By surrounding him with three walls of exclusion (the administrative wall, the academic wall, and the environmental wall), he is left with no other choice but to follow a predetermined path of subjugation set by the educational structures that label, sort, and classify him by his perceived dis/ability (Kim & Pulido, 2015). The functional living skills that he is receiving in no way acknowledge or reflect his cultural ways of knowing, and his access to quality art instruction is being denied. His more complex personhood, if not humanity, is seemingly stripped away by ongoing ableist schooling policies and practices the minute he passes through the metal detectors when he enters the front door of UCA.

The lived educational experiences described by Patrick in this inquiry suggest that his access to a FAPE is being denied at UCA. His unfettered access to non-academic YouTube videos, the rigor-less academic curriculum he is provided that is far below his developmental and cognitive level, the amount of instructional time he spends learning functional life skills that do not honor his cultural ways of knowing, and the multiple hours per week he spends picking up other people’s trash and cleaning doors and windows at the Central Offices, all of these experiences support Bev’s notion that UCA is only “babysitting” him until he turns twenty-two and ages out of the system. UCA is not providing him with the appropriate education that he is entitled to, deserves, and needs in order to find future employment and
success in adulthood. Patrick’s mother believed that in the restrictive placement that Patrick was placed in, he would have access to extra funding, the extra staffing, and resources to provide Patrick with the supports necessary for him to earn a high school diploma (Kurth, 2015). Patrick’s accounts suggest that UCA is not allocating any of the additional resources that are typically provided to a student in a restrictive educational placement to benefit his educational attainment. Instead, he is essentially being warehoused, out of sight and out of mind from his school and local community, physically partitioned and isolated from his same-aged peers, literally and figuratively left to his own devices, “sitting idly…. awaiting the time when they were old enough to drop out” (Endrew, 2017, p.14).

**Answering Sub Questions Through the Multiplicity of Perspectives**

Based on the experiences and stories he outlined in his drawing journals and named during our conversations, there is no doubt that Patrick loves school and values every minute that he spends at UCA. Patrick’s mother Bev, on the other hand suggests that “he loves school because he doesn’t know what he is missing out on.” In order to discuss the profound contradictions of their perspectives and conflicting experiences with Patrick’s school system, I suggest taking a closer look at the sub-questions guiding this inquiry:

1. How does a student from a substantially separate classroom, their family, and their teacher describe their educational experiences?
   a. How do they describe pedagogy in a substantially separate classroom?
   b. How do they describe the curriculum in a substantially separate classroom?
   c. How do they describe the home school partnership and the roles of the student, the family, and the teacher in educating a student in a substantially separate classroom?
2. What are the educational desires of a student from a substantially separate classroom, their family, and their teacher?

a. What do they desire for pedagogy in a substantially separate classroom?

b. What do they desire from the curriculum in a substantially separate classroom?

c. What do they desire from a home school partnership and what roles do they feel that the student, the family, and the teacher must play in order to educate a student from a substantially separate classroom?

During the course of this study, neither Patrick nor his mother provided a clear distinction between the two terms “pedagogy” and “curriculum”, often conflating them and using them interchangeably. Whenever possible I will provide a distinction between both of these terms, but in some cases they will be used interchangeably. The previous three data chapters addressed these sub-questions above in a comprehensive way, and the following sections summarize each participant's experiences in narrative form, including Patrick, Beverly, and myself.

**Patrick Talbot**

Patrick goes to great lengths to express how much he enjoys attending UCA. He values the friendships that he has made and the relationships that he has built with the students and staff in his class. When I asked him what he looks forward to every day at UCA, Patrick responded “talking to all my friends.” Although Patrick ascribes positive value to his educational experiences at UCA, many of the experiences that he describes suggest that he is receiving a sub-par education that may not be meeting his needs as a learner. Patrick often shares that he spends countless hours watching YouTube videos during
academic instruction time, which he enjoys very much. He also speaks very fondly of his community outings on Wednesdays, Thursdays, and Fridays where he leaves the school building for community activities for a large portion of the day.

Through his artistic renderings and our discussions together Patrick expresses that he enjoys spending most of his day, including breakfast, lunch, and during academic instruction, in two rooms isolated from the rest of the school. He especially likes the breakfast room because it is “huge, it looks like a house, it has a washing machine, a refrigerator, stove, and…” When asked if he would like to eat lunch in the cafeteria with the whole school, he answered, “yes” and shared that he misses the “lockers” and his “friends” at FDS.

The curriculum that Patrick speaks about includes learning functional life skills such as recycling, cooking, and purchasing goods in the community. The academic skills that he learns typically include basic addition and subtraction in math class, watching The Magic School Bus in science class, sometimes reading books below his reading level in English Language Arts, and “playing with balls” in the gym. With the exception of gym class, all of these academic classes take place in one of two rooms isolated from the rest of the school.

Although he doesn’t directly address the home school partnership through his artistic renderings and experiences, Patrick speaks highly of his relationship with his teachers, and enjoys calling them by their first names and sending them Facebook messages in his free time. He especially enjoys spending time on overnight adventures with his teachers. When I asked him if he enjoyed going on an overnight ski trip with Mr. Marcus, Patrick responded, “yes, but he snored like a hog.” During this study, Patrick asked on several occasions how many of his former teachers from FDS were doing. Many times, he would begin our
interviews asking, “how is Ms. Harris-o doing?” He would usually follow that question by asking about each one of her dogs.

When asked what he desires from his education Patrick shares that he wants to be a math teacher and that he, “wants to work in a school to help kids.” Although he doesn’t specifically state this during this study, the data would suggest that Patrick also desires to work for the public transit service in the urban city in which he resides. Patrick can navigate to just about any landmark or lesser-known location in and around the city using public transportation independently and providing Patrick with the education necessary to work for the public transportation service would be welcomed, and an attainable aspiration for him.

As far as the pedagogy that Patrick desires, although he doesn’t specifically address this in his responses, Patrick does very well when he has access to the arts and music as part of the curriculum. After his first day of school at UCA he got off the school bus and asked his mother, “what kind of school has no sensory arts?” With such creative potential, as evidenced by his musical inclinations, artistic renderings, and his hobby of writing books and creating three dimensional cities, Patrick would thrive in an educational environment that prioritized high-quality arts instruction as part of the curriculum.

Patrick didn’t respond when asked what he desired from a home-school relationship, but from other conversations that we have had, he doesn’t like it when his teachers talk to his mother. Patrick values his privacy and prefers that if there are any issues at school that the teacher addresses them with him personally. When I asked him if he likes it when his teachers call his mother, he responded, “no! Don’t call my mother.” Although he expresses that he doesn’t like it when his teachers communicate with his mother, Patrick’s success at

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40 Patrick enjoys adding an “o” to the names of adults that he speaks fondly of, seemingly serving as his seal of approval.
FDS is largely due to the open line of communication between school and home, and the close relationship that Patrick and his mother had with his educators at FDS.

**Beverly Mendes**

When describing the educational experiences of Patrick at UCA, Bev provides only negative accounts of these experiences. The major point of contention between Bev and the school is centered around functional life skills being prioritized over academic instruction. During the first meeting that Bev had with UCA, she told the educators and administrators, “I wanted Patrick to be pushed more into educational. As opposed to life skills.” With most of the educational experiences that Bev speaks of at UCA, she uses militaristic discourse to describe how hard she had to “fight” for services for Patrick, all the “battles” she had with UCA, and how she had to “swing her bat” to get anyone to listen to her.

Bev feels that teaching Patrick how to take the train, cook, and navigate the community is her responsibility as his mother, and the responsibility of providing academic instruction falls on UCA. She is deeply concerned with Patrick “picking up other people’s trash” instead of supporting him in earning a high school diploma. Bev wants Patrick to continue with occupational therapy to improve his writing skills and feels that the administration at UCA “doesn’t know autism” and is “unprepared to teach autistic kids.” She also feels like the money allocated to provide Patrick with a quality education is being allocated to different areas of the building that benefit general education students rather than Patrick and his classmates. In addition, Bev feels strongly that UCA is simply a “baby-sitting” service and is “doing nothing” to educate Patrick. Lastly, she feels that Patrick is not receiving an appropriate education “because he has autism attached to his name.”
On day six, as discussed in chapter six, any chance of a home-school partnership between Bev and UCA was quickly extinguished when the school filed a 51a on Patrick for suspicion of abuse or neglect with the State Department of Families. When I asked how her meeting about the incident went with the school, to which Bev responded:

I said fuck all you motherfuckers, you, you guys have a tendency in this school right here not contacting the parent. She could have called me, I would have come in, we would have sat down, got my point of view, as opposed to just meeting a kid…. Oh, I lost it in there, I lost it. I grabbed my coat I said let me get the fuck out of this building.

Bev’s early experiences at FDS suggest that the home-school partnership involves active two-way communication between home and school. She described fondly the times she would “play good-cop bad-cop” with Patrick’s teachers if he ever acted out in school, be able to contact his educators before, during, and after school with help in supporting Patrick at home, or when she would work collaboratively with educators to plan and fundraise for community outings such as apple picking, and going to ride the boats at the public garden.

Bev’s educational desires are similar to Patrick’s. She supports his desire to “work in a school to help kids” but feels that he may be more suited to being a para educator rather than a math teacher. If teaching isn’t an option for Patrick, she would like to see him learn the skills to work in the “airport or in the train station” helping passengers navigate throughout the city.

As far as curriculum is concerned, Bev wants Patrick to be challenged academically, learn the skills necessary to earn a high school diploma, and go to community college. She is adamantly against UCA focusing heavily on functional life skills instead of academic
instruction. In addition, Bev would also like to see Patrick have more inclusive opportunities like he had at FDS in science, physical education, and the arts. Much like Patrick, Bev would like to see him have more opportunities to engage in the arts and music.

By the end of the study, Bev wanted nothing to do with a home-school relationship and actively avoided entering the school under any circumstance. This is much different than her experiences at FDS where she would typically visit the classroom a few times a week to check in with the teachers and provide support wherever she was needed. Although she avoids entering UCA whenever possible, from her responses, she desires a home-school relationship where her knowledge is valued, her desires for Patrick are respected, and two-way communication occurs on a regular basis.

Christopher Hall

I have been teaching at the FDS for over ten years, and through the years I have seen students come and go from our program. Many students come to the FDS for the specialized instruction that is typically provided to autistic students, namely what educational professionals would consider to be the optimal learning environment for meeting their needs. This includes a team of service providers, a sensory diet, visual supports, routine and predictability, and a highly structured learning environment, all of which align with the medical model of disability that sees autism as something that needs to be cured. Navigating these deficit spaces is challenging when our perspective on dis/ability follows the social model of disability that views dis/ability in educational spaces as a reflection of a flawed learning environment rather than a flaw in the individual.

Most of my professional practice centers around the belief that in order for students with perceived dis/abilities to be successful, I need to adapt and modify my curriculum and
pedagogy to meet their needs rather than forcing them to adapt to me. I accomplish this through Universal Design for Learning which focuses on creating flexible learning objectives that provide multiple pathways for students to meet the goal of each lesson. Working with students for up to ten years allows me to create relationships built on trust and provides me the unique vantage point to see what they are truly capable of accomplishing with the individualized supports that enhance their success.

When I reflect on my professional practice, I constantly struggle with the fact that because of the labels that my students receive they are placed in an educational program that on the surface may be meeting their short-term educational goals, but in the long term this same program may be excluding them from receiving a FAPE. Through my educational experiences after discovering DSE, I find myself asking the question, “why are students still being educated in restrictive placements?” In the case of many students with dis/abilities, the answer is simple, because they are being segregated and isolated because of their cultural and linguistic diversity.

Pedagogy in a substantially separate classroom involves being flexible and using individualized engagement strategies to reach each individual learner. For me, this involves using a combination of visual picture symbols, instructions given by speaking, music and movement activities, and video modeling. The curriculum should be individualized to each learner and be culturally relevant to the students. In my classroom this involves highlighting artists at the intersection of race and dis/ability that represent the students that are in the classroom. For example, I recently taught a lesson that highlighted the work of Kambel Smith, an African American and autistic artist that makes cardboard sculptures of buildings.
seen in urban landscapes (Autisarian, 2021). Curriculum changes based on the needs and interests of the learners.

Two-way communication is critical in forging lasting relationships with families of students in substantially separate classrooms. I contend that this relationship is far different than the typical home-school relationship and involves building trust over a long period of time. For many of my families, much like Patrick and his mother, these relationships are built over several years and continue long after the students have moved onto high school. I find myself very fortunate to have some of my students for over ten years, allowing me to create trusting relationships with families over a great number of years.

As an educator, I desire the opportunity to use my pedagogical skills with autonomy and continue presenting information to students that fully engages them in academic content. For my curriculum, I also desire autonomy because I feel that I know my students better than anyone else, and I pride myself on embedding their interests, as well as including their cultural and linguistic diversity in the curriculum I design.

I feel strongly that the home-school relationship needs to operate as a partnership built on trust where each member of the partnership does their specific part to benefit the student. Sometimes this means having the family say what the educator cannot and having the educator advocate where the family is unable to. With the goal of supporting the student through consistency, each member of the partnership needs to do their part to make sure the student succeeds.
Analysis of Findings Through the Tenets of Disability Studies and Critical Race Theory in Education (DisCrit)

The three data chapters presented prior to this chapter provided an in-depth look at the educational experiences of Patrick, and his mother Beverly, while battling the racist and ableist educational structures in a large urban school district. In the following section I will use a Disability Studies and Critical Race Theory in Education (DisCrit) framework, particular DisCrit’s main tenets (Connor, Ferri, & Annamma, 2016), to further analyze some of the experiences I have shared in this dissertation, and I will also explore how race, dis/ability, and ableism work in-tandem to exclude Patrick from receiving a FAPE in DPS (Connor, Ferri, & Annamma, 2016). As a special education art teacher working within DPS for ten years, every year I have the pleasure of teaching one hundred and eighty students in our substantially separate program. I will use these experiences to add to the broader conversation surrounding the intersection of dis/ability and race at UCA and in DPS.

DisCrit Tenet 1: “DisCrit focuses on ways that the forces of racism and ableism circulate interdependently, often in neutralized and invisible ways, to uphold notions of normalcy.”

Baglieri et al. (2011) pose the question, “Where, after all, is the cutoff between nondisabled and mildly disabled, between mildly disabled and moderate or severely disabled?” (p.271). On the surface this presents as a question that must be answered with quantitative assessment data, compared to preconceived categories of performance, followed by an assessment of a student’s level of perceived dis/ability; however, Baglieri et al. (2011) suggest that determining the level of severity of a student’s perceived dis/ability is a “product of judgment” (p.271). The problem being that if the average student is deemed as white,
privileged, at grade-level, and self-regulated (Fritzgerald, 2020) or when, “Whiteness and ability are seen as normal” (Ladson-Billings, 1998, p.9), then students that do not live up to these definitions of normalization are destined to be cast in a deficit light. Suggesting that this judgment call involves determining to what extent can this student approximate normalcy, and in this case, White and able-bodied. For students of color, like Patrick, being compared to white European ideals of normalcy often means being placed in a more restrictive educational placement than their same-aged, white peers, and receiving education in a classroom composed of only students with perceived dis/abilities, because “students of color, the poor, and immigrants lie outside the predominant norm and, therefore, belong in special education” (Reid & Knight, 2006, p.19).

This practice of placing students in more restrictive settings because of their race and perceived dis/abilities is a racialized and normalizing process that is rarely questioned by educators, administrators, and oftentimes, students and their families (Connor, Ferri, & Annamma, 2016). In my experience working in DPS, the dominant narrative administrators convey to educators, families, and students is that the decision of educational placement is less about the teacher recommendations and has more to do with whether there are openings, or “seats”, available in less restrictive placements in the district (Kurth, 2015). The determination of placement typically rests with the special education administrator, and when it comes to receiving a placement at one of the four model schools for inclusion in the District in which Patrick grew up, many times these decisions fall along the lines of race and English language proficiency of the student and the family (Hernández-Saca, Khan, & Cannon, 2018; Tefera, 2019). For example, at the Washington School, which is by many accounts considered the model school for inclusion in the district, roughly thirty-two percent
of the student population is White compared to fifteen percent for the district and five percent at the FDS. In addition to serving a population of White students that is twice that of the district and six times higher than FDS, the Washington School is provided with the funding by the district to have each class instructed by both a general education and a special educator; whereas, the FDS is only allotted enough money for a teacher and a paraeducator in each inclusion classroom.

Navigating the medicalized spaces of special education involves interacting with individuals that value the discovery of perceived deficits and “curing” said deficits through targeted educational interventions based on Euro-centric notions of normalcy (Lovaas, 1987). The problem being is that by normalizing the “curing” and “fixing” of students through educational interventions that do not live up to unrealistic and racist and ableist expectations of normalcy, these individuals are perpetuating and legitimizing that dis/abilities need to be ameliorated, thus creating the conditions for ableism to circulate and infest the classroom in ideologically invisible ways (Campbell, 2008; Campbell, 2009).

Oftentimes the “fixing” involves targeted interventions which can be an invasive means of teaching specific isolated skills in a one-to-one setting rather than providing supports for students to learn these skills in the context of a whole-class or real-world setting (Simpson, 2001; Tutt, Powell, & Thorton, 2006). For Patrick, he can do basic mathematics in isolation, but when he buys lunch in the community, he has a difficult time adding up what his lunch costs and how much change he should be receiving, relying on the cashier to help him pay the correct amount of money. This practice is rarely questioned because specific skills that are written in a student’s Individualized Education Plan (IEP) are targeted, and since educators are held accountable for students meeting their specific IEP goals, this type
of training is a way to demonstrate that students have mastered the content. The problem with this practice is that many students can only demonstrate mastery in specific isolated situations and have a difficult time generalizing these skills in the context of a classroom or real-life setting. When Patrick practices basic addition in math class, he is easily able to add ten plus ten or forty minus twenty, but when he brings his wallet to school to buy a sweatshirt, he can’t figure out how much money he needs to pay the school store. It was assumed that he had “mastered” these math skills coming into high school based on his educational performance data, but when it came to applying these skills to real-life situations, Patrick had a great deal of difficulty. This suggests that Patrick may have more success learning these skills in context rather than in isolation.

DisCrit Tenet 2: “DisCrit values multidimensional identities and troubles singular notions of identity such as race or dis/ability or class or gender or sexuality, and so on.”

My experiences as a special educator suggest that many times an educational placement in an inclusive classroom has more to do with a student’s skin color and their English language proficiency rather than their actual perceived academic ability (Connor & Ferri, 2005). I began noticing soon after discovering DSE that although my school was the model school for educating autistic students in the district, a large majority of my students were students of color and/or English Language Learners (ELLs). The White autistic students that I did have typically received more related services, more Applied Behavior Analysis (ABA) hours, and many times had a one-to-one paraprofessional to support them in the classroom. On several occasions that I can recall, I witnessed White students that would be considered higher-need students compared to Patrick, move to inclusion schools soon after attending the FDS (Kurth, 2015). Many times, the change of placement was not made
by the teacher, rather, it was suggested by the special education administrator that represented the District in the IEP meetings. Whereas, I have seen teachers and families zealously advocate for less restrictive placements for their students of color or ELLs to no avail. This practice of sorting students by “ability” further contributes to the overrepresentation of Black and Latinx students in special education because it allows school districts, through the use of special education policy, to sort students along racial lines (Connor & Ferri, 2005).

Throughout his entire educational journey, Patrick’s educational placement in a substantially separate classroom was never questioned by the IEP team (Kalyanpur, Harry, & Skrtic, 2000). He was never given the opportunity to be placed in a less restrictive setting and instead was segregated and isolated from his same-aged peers (Jones & Hensley, 2012). The most concerning part is that his placement in this restrictive educational setting was never second-guessed, and it was assumed that because, as Bev so eloquently put it, “he had autism attached to his name,” and I would add, and he was a Black Cape Verdean student, he was automatically segregated from his same-aged peers. In Patrick’s case, as Ferri and Connor (2005) suggest, “race and disability overlap and are utilized to justify both exclusion and marginalization” (p.455). Had he been white and middle-class, I argue that he would most likely have been placed in an inclusion school long before I had the pleasure of meeting him.

DisCrit Tenet 3: “DisCrit emphasizes the social constructions of race and ability and yet recognizes the material and psychological impacts of being labeled as raced or dis/abled, which sets one outside of the western cultural norms.”
Labels in an educational setting can both open and close doors. The students that I teach, to the outside observer, have many doors opened for them because of the labels attached to their names, namely access to additional money to provide them with individualized educational support services like occupational and speech therapy (Kurth, 2015). In DPS, if a student is labeled with a dis/ability, more money is allocated to their school, in theory, to provide them with the supports and services necessary to receive equitable access to education (Reid & Knight, 2006). If the student also comes from a low socioeconomic background and/or is a non-native English speaker, then their school is allocated even more money to educate them. For the FDS, students are provided with a full-service team that includes occupational therapists, physical therapists, speech and language pathologists, ABA therapists, inclusion specialists, Board Certified Behavior Analysts (BCBA), and several other itinerant service providers. In addition, many students are given the use of a digital tablet to aid in communication, have access to a swimming pool, and two specially designed sensory rooms. From my experiences at the FDS, I have seen the money allocated to each special education student used to provide the specialized services necessary to give each student equitable access to an education.

At UCA, looking at Patrick’s, as well as his mother’s experiences during his freshman year suggest that being Black and Cape Verdean and labeled dis/abled significantly impacted the education that Patrick was receiving. Many of the supports provided to Patrick at FDS were not provided at UCA, and in some cases, the school actively worked to remove access to some of these same services. In Patrick’s case, given his difficulties with fine motor skills, when he entered high school UCA attempted to remove occupational therapy services from his IEP. The rationale being that students in high school need to shift from
writing with pen and paper to becoming more familiar with the computer. For Patrick, the school recommended that he move to using a computer to learn how to complete schoolwork and communicate through email, but his classroom only had access to one computer. With a classroom of ten students, only having access to one computer significantly limits students’ ability to learn how to use technology, to complete assignments, and communicate via email.

Looking at Patrick’s educational experiences, this is not the only example of UCA limiting his access to equitable educational resources. During this study, Patrick describes the time he spends in the gym as “playing with balls”, “playing duck duck goose”, and “watching videos on [his] phone”, with no physical education teacher leading his class in instruction. In cooking class Patrick describes learning how to make food that is not culturally relevant to his Cape Verdean background, like pumpkin pancakes. In Patrick’s words, “pumpkin pancakes are crap”, and the time that he spends learning how to make food that he will never make at home is valuable time that he could be spending learning how to make culturally appropriate food like couscous or rice and beans. Bev often shares her anger towards the education that Patrick is receiving at UCA and how he is being provided educational experiences that are not culturally appropriate, adding that it is her, “job to teach him how to cook……and the school’s job to educate him.” On several occasions Bev describes UCA as, “only babysitting [Patrick]”, and suggests that the only reason is because he has, “autism attached to his name.” Again, looking at Patrick and his mother’s experiences at UCA would suggest that his diagnosis, as well as his race play a significant role in the education that he is receiving.

DisCrit Tenet 4: “DisCrit privileges voices of marginalized populations, traditionally not acknowledged within research.”
Adding to the growing body of research foregrounding the voices of individuals with
dis/abilities in telling their own story from their perspective (Peters, Klein, & Shadwick,
1998; Biklen & Burke, 2006; Connor, 2008; Naraian, 2008; Sauer, 2012; Hernández-Saca,
2016; Cioé-Peña, 2018; Tefera, 2019), this inquiry was conducted with the goal of adapting
and modifying research methodologies to privilege the knowledge of a student labeled as
severely dis/abled. As the study progressed, Patrick’s experiences steered the direction of
this investigation, with every stage honoring the variability of his voice and his knowledge
base. The key to this investigation was the trusting relationship that I built with Patrick over
the past seven years as his art teacher. This provided me the opportunity to understand the
intricacies of his communication style, discover what type of learner he was, learn the best
ways to engage and interact with him, and develop methods of interviewing him that
complemented his learning and communication style. Patrick’s experiences were central to
this investigation and supporting him in sharing his voice through multiple means was a high
priority with this study.

In addition to foregrounding the multiplicity and variability of Patrick’s voice with
this study, this investigation also provided authentic family member perspectives by
including Patrick’s mother Bev’s experiences as well. Bev’s accounts were never intended to
speak for Patrick, rather, they were included to provide a broader context to situate and
anchor Patrick’s experiences. Patrick’s mother’s accounts highlighted the many
administrative, academic, and environmental obstacles that affected Patrick’s educational
journey, some of which Patrick was unaware of. Bev’s accounts also illuminated the long-
term educational, political, historical, and social impacts that a diagnosis of autism can have
on an individual and their family, both positive and negative. From the onset, this
investigation cautiously recognized the struggles that many families and autistic individuals experience as a result of an autism diagnosis and refused to replicate the traditional method of “documenting damage” in marginalized communities (Tuck & Yang, 2014). Rather, this study privileged the knowledge base of individuals and families, specifically centering the lived experiences of a Black autistic student and his Black dis/abled mother in telling their own stories, viewing struggle as a reflection of the environment in which it occurred rather than a flaw in the individual (Erevelles, 2000; Connor, 2005; Ware & Valle, 2010; Baglieri et al., 2011).

**DisCrit Tenet 5:** “DisCrit considers legal and historical aspects of dis/ability and race and how both have been used separately and together to deny the rights of some citizens.”

Teaching art to over one hundred and eighty students in substantially separate classrooms has provided me the unique opportunity to learn how to meet the needs of learners that require varying degrees of support. Many of my students, specifically my autistic students, have their needs met in our specialized program. When I first began teaching at FDS, we were the model school for educating autistic students in the district. As we became more successful at providing the optimal learning environment for autistic students, the district slowly began placing students in our program whose needs were not being met in other placements. Slowly we became the school for students that other schools couldn’t educate and shifted from an autism program to an ABA-based substantially separate program[^41]. The implications for which meant that the district no longer placed students in

[^41]: A classroom in an ABA-based substantially separate program typically contains eight to ten special education students representing a diverse spectrum of educational support needs. These classrooms focus on building classroom routines and environments informed by the principles of ABA, often including behavior management techniques to reduce behaviors that are perceived as interfering with learning.
our program based on a diagnosis of autism, rather, it was now common practice to place students labeled with significant behaviors that prevented them from making academic progress elsewhere, into our program; most of the time this meant students of color.

This practice speaks to what Fierros and Conroy (2002) refer to as the “double jeopardy” which highlights not only the overrepresentation of students of color in special education in general, but the overrepresentation in the most restrictive of special education placements. This holds especially true for the subjective categories of special education, including Learning Disabilities (LD) (Gallagher, Connor, & Ferri, 2014), attention deficit hyperactivity disorder (ADHD) (Vasquez III et al., 2011), and Emotionally Disturbed (ED) (Reid & Knight, 2006). As Vasquez III et al. (2011) suggest, the dis/ability categories of LD, ADHD, and ED are “usually identified by school personnel rather than a medical professional” and that overrepresentation of students in special education “does not exist in disability categories that require less subjective judgment such as visual, auditory, or orthopedic impairment” (p.85). In other words, for students of color oftentimes the difference between being placed in an inclusive classroom or a more restrictive educational placement, is simply a judgment call (Gallagher, Connor, & Ferri, 2014). As Hernández-Saca and colleagues (2018) suggest, this highlights how special education practices that began with the passage of the IDEA as a way of including all students, and soon became “a tool of inclusion for White students” and “a tool of exclusion for historically marginalized students, with the same disability” (p.290).

With a new population of students that did not necessarily have a diagnosis of autism, over the past four years, our school has slowly transformed into a placement for students whose educational needs were not being met at other schools in the district. This practice
does not seem to reflect the quality of the educational programming that students receive at
the FDS, rather, this serves as a means of labeling Black and Latinx students as “behavior
issues” and sorting them in more restrictive educational settings away from their White peers.
According to Pazey et al. (2014) these “difficult to teach students”, that tend to be students of
color that are culturally or linguistically diverse, are identified for special education services
at a disproportionate rate (p. 370). This practice reflects a system that is increasingly
unwilling to educate students that do not fit the mold of “typical” students in the “regular”
classroom (Peters, Klein, & Shadwick, 1998, p.106), further adding to the overrepresentation
of Black and Latinx students in special education. Erevelles (2000) argues that:

In fact, the actual existence of special education programs that serve children with a
variety of labels (learning disabled, emotional and behavioral disorders, mild,
moderate, and multiply handicapped) is predicated on the inability of regular
schooling to control effectively the disruptive interruptions of these bodies that
appear impervious to the rigid demands for conformity and rationality in schools (p.
34)

This overrepresentation of Black and Latinx students in special education is well
documented in the literature (Connor & Ferri, 2005; Vasquez III et al., 2011; Brown, 2012;
Pazey et al., 2014; Hernández-Saca, Kahn, & Cannon, 2018). Black students labeled with a
dis/ability are segregated within schools at higher rates than their White peers (Reid &
Knight, 2006), six times more likely to be labeled LD than their White peers (Ferri &
Connor, 2006), more likely to be placed in a restrictive educational placement (Connor &
Ferri, 2005), are expelled five times the rate of their White peers and face temporary
disciplinary removals at a higher rate than White students (Brown, 2012; Tefera, Hernández-
Saca, & Lester, 2019), less than fifty percent of Black students labeled with a dis/ability and placed in special education graduate from high school (Peters, 2010), often do not receive the same high-quality special education services as White students (Tefera, 2019), and living far below the poverty line in adulthood (Erevelles, 2000). It is no wonder that Hernández-Saca et al. (2018) argue that students of color are being educated in the “most segregated settings since the 1970s” (p.288). In these segregated spaces depending on the severity of their perceived dis/ability, the skills that students learn at best pave the way for employment located “at the lowest rungs of the social division of labor,” and at worst create the conditions for these students to become dependent on the welfare system for their daily survival as adults (Erevelles, 2000, p. 29).

By placing students that do not belong in special education in restrictive placements, like the practice discussed above at FDS, creates the conditions, in this case, where teachers and administrators are forced to choose between managing behaviors that interfere with learning or providing students with academically rigorous instruction. Suggesting that this practice could potentially serve as a means of removing students perceived as what Pazey et al. (2014) term as “difficult to teach” from their appropriate educational placement because their behaviors interfere with the learning of their same-aged White peers in less restrictive placements (Baker, 2002). As Baker (2002) suggests, this practice is an example of “preventing the ‘detractors’ from limiting the ‘progress’ of ‘the normal’” (p. 676). Instead of addressing these perceived “behavior issues” through culturally responsive pedagogical practices and honoring their cultural ways of knowing, they are inappropriately placed in special education and segregated from their same-aged peers (Vasquez III et al., 2011). This further impedes their access to equitable educational opportunity, strengthening systems of
containment and social control over bodies who are contained (Foucault, 1977). Or as Connor and Ferri (2005) argue, instead of using special education as a means of differentiating instruction for a diverse group of learners, it has been historically used to “perpetuate the marginalization of individuals based on the interconnected discourses of race and ability” (p.461).

Segregating students with perceived behavioral challenges and “difficult to teach” into restrictive placements significantly impedes the learning of not only the individual student, but also the students in our program that require additional staffing and one-to-one supports (Pazey et al., 2014, p.370). Since most of our program is composed of students of color and/or ELLs with complex support needs, this practice has never been questioned. With the educational needs of students in general education and inclusive settings seemingly outweighing the needs of students in more restrictive settings with significant support needs, through this practice, the district is potentially denying the right to equal educational opportunity to a group of students based on their race and/or perceived dis/ability. This practice is not limited to just FDS, segregating students into restrictive placements is also seen at UCA.

Patrick’s and Bev’s accounts of their experiences at UCA suggest that although there are no students in Patrick’s classroom that require additional staffing for behavior management, he is often segregated from his class because he requires less intense support. Patrick frequently recalls the countless YouTube videos that he watches during instructional time. Since Patrick is capable of independently navigating the classroom, compliant, and does not have any behaviors that interfere with learning, he is often given unfettered access to the computer while his teacher and para educators work with other students. In my
experiences at FDS, in both the substantially separate and inclusion programs, the use of computers is strictly limited to academic websites. When watching YouTube videos is used as positive reinforcement, it is typically limited to five minutes increments. Having unrestricted access to the computer denies Patrick the opportunity to advance academically, or as Bev says, “catch up” to his peers. Again, this practice of watching non-academic videos remains unquestioned because of the labels that have been assigned to Patrick based on his race and dis/ability. Highlighting how racism and ableism function together as “tools of exclusion” (Connor & Ferri, 2005, p.470).

DisCrit Tenet 6: “DisCrit recognizes Whiteness and Ability as Property and that gains for people labeled with dis/abilities have largely been made as the result of interest convergence of White, middle-class citizens.”

As part of the Skills for Life (SFL) Program, every week Patrick takes a bus to the Central Offices to clean the doors and windows and collect the recycling on each floor of the building. This weekly excursion is a point of contention for Bev, who frequently asks the question, “why don’t the general education students do this for punishment?” She brings up a very valid question here that needs to be examined. Patrick is not only being denied access to the individualized academic instruction that he needs to prepare him for his chosen profession as an educator, but in doing so, UCA is limiting his occupational opportunity by providing him no other option than to learn the skills necessary to clean up after the dominating class, in this case general education students. Through this practice, UCA is creating what Erevelles (2000) describes as “mark[ed] distinctions between mental and manual labor” (p.45). In a study looking at the educational experience of six high school girls of color, Miller (2019) documented similar experiences of her participants, finding that
the occupational duties that students performed in substantially separate classrooms typically included custodial work, namely collecting items for recycling from general education classrooms. Similar to the experiences of Patrick, the responsibilities of the participants in the study included, “wiping down,” “throw(ing) away stuff that’s bad,” and “sort(ing) stuff” (Miller, 2019, p. 153).

The only time that Patrick has the opportunity to move freely throughout UCA, when he is not confined and isolated in one of the two rooms that he has access to, is when he is collecting other student’s trash on recycling day. Miller (2019) describes the experiences of a high school girl of color with intellectual dis/abilities that are similar to that of Patrick. She describes a high school with two floors, and the only time that she interacts and socializes with general education students on the second floor is when she is collecting the recycling (Miller, 2019). In a study exploring educational placement through the perspectives of students with dis/abilities, Jones and Hensley (2012) found that the self-contained classrooms described by participants were “characterized by physical and social isolation from the general education student population throughout most, if not all, their daily school routine” (p. 38). Having the students in the SFL clean the Central Offices and take out the recycling for the school continues to operate without question and is viewed as normal operating procedures.

The idea that autistic students are only capable of cleaning up after able-bodied members of their school community remains unchallenged, and although it has never been specifically stated, through policy and practice, students in the SFL Program at UCA are only given the opportunity to interact with their same-aged peers when it directly benefits the students and staff they are cleaning up after. Bev brings up the point that DPS typically
doesn’t provide funding for buses to transport students to educational field trips, but every week they provide a bus to take Patrick and his classmates to the Central Offices to do their occupational responsibilities.

According to Patrick’s accounts, the only students that go with him to the Central Offices are either students of color and/or students that do not communicate in spoken words. As Reid and Knight (2006) argue, marking students of color as dis/abled provides a means of segregating these students with a label that is “seemingly natural and justifiable”, and is a more socially accepted category of marginalization (Connor & Ferri, 2005). Given the segregation of dis/abled students of color at UCA, the only time that students in the SFL can interact with members of the dominant class is when there is a conversion of interests. Students in the SFL Program need to learn an occupational skill, and UCA and DPS need someone to clean up their facilities. What is unknown is if UCA and DPS provide the opportunity for students in the SFL Program to clean the school and Central Office facilities because they genuinely believe that this is a benefit to the students in the SFL Program or if it is all that they believe that these students are capable of. Either way, this practice is carried out every week and is seen as the natural order of things and remains unquestioned because as Erevelles (1997) argues, dis/abled people, like Patrick, “have been located at the margins of the margins of our social world in spaces that have been construed as irrelevant to the economy, society, [and] culture” (p.1).

The work of Erevelles (2013) suggests that “ability” and/or perceived “ability”, as seen here in the practice of relegating dis/abled bodies to custodial services that directly benefit the school and the district, justifies the “oppressive logic of the social division of labor” (p. 149). Given that Patrick is an aspiring math teacher, this occupational opportunity
forced upon him in no way provides him the supports needed to reach his goal of becoming an educator. Patrick’s experiences suggest that students in the SFL Program are only viewed through the labels they are given, and they are essentially provided no other option than to take what they are given, in Patrick’s and his classmates’ case, functional life skills focused on custodial work. As Erevelles (2013) also suggests, “for people with cognitive/severe disabilities, for whom autonomy and choice are social rather than natural constructs, the freedom to choose in liberal society remains an idealistic construct rather than a material reality” (p. 170). At UCA the harsh reality is that the lack of choice and autonomy is exponentially multiplied because Patrick and his classmates exist at the intersection of race and dis/ability. Protecting the interests of general education students at UCA and White workers and non-dis/abled workers at the Central Offices remain dependent on “the creation and maintenance of oppressive practices that have required the continued subordination of the oppressed class”, and in this case, students of color that are labeled dis/abled and are educated in restrictive educational placements (Erevelles, 2013, p. 152).

**DisCrit Tenet 7: “DisCrit requires activism and supports all forms of resistance.”**

This inquiry in itself is a form of activism and resistance. By arranging the research environment to privilege the knowledge base of an autistic high school student of Cape Verdean descent, this study looks to create a counter-narrative that actively involves individuals often silenced in the literature in sharing the variability of their perspective of their educational experiences and their life spaces (Broderick & Ne’eman, 2008). As a special educator navigating upstream against dominant narratives and deficit-centered research approaches conducted about individuals rather than with them, this study attempts to illuminate the normalized racist and ableist educational systems and structures affecting
students like Patrick that remain unquestioned. For Patrick, rather than providing him individualized educational supports that honored his aspirations of becoming an educator, these data suggest that the systems and structures in place at UCA placed Patrick on a predetermined path focused on “babysitting” him and keeping him busy until, as Bev puts it, he was old enough to “collect a check and stay home and rot.” Much like Erevelles (2000) argues, Patrick will have difficulties contributing to the economy in adulthood because he did not receive the education and training at UCA that is needed for production, and instead will play the role of consumer and may be seen as “parasitic” and “despised for [his] (non) location on the social division of labor” (p.39). By investigating the inequities that I have observed through Patrick and his mother’s experiences, I hope to begin the deeper conversation focused on how race and dis/ability intersect in the classroom and how the learning environment needs to be transformed to provide students with an IEP that is both appropriate and culturally relevant.

Bev had never been a passive participant in Patrick’s education until she felt the paralyzing effects of hopelessness. When she came to the realization that because Patrick, “had autism attached to his name” that he would only be trained to pick up other people’s trash, she lost all motivation to keep fighting. She often reflects on how she had so much hope when Patrick was at FDS. She saw first-hand how he went from non-speaking to speaking and how FDA was building him up academically and preparing him for high school, but when he arrived at UCA, instead of educating him, they were just “babysitting” him. Bev’s experiences suggest that more can be done to support families in navigating the IEP process, and even with a translator, words do not exist in her language to describe the complexities of the special education process. Nevertheless, Bev, as a Black and dis/abled
woman herself, was successful in taking on the district alone, becoming not only an advocate for her son, but an activist for many other families experiencing autism firsthand. Fighting everyone alone is an exhausting, if not impossible, undertaking and eventually takes its toll physically and emotionally on a single parent. Although Bev has taken a step back from actively pursuing the district, she hasn’t given up her biggest fight, getting Patrick a high school diploma.

Above all else, although this was a small study that only had one student participant, it managed to highlight the ways in which DPS and UCA created the environment that disabled Patrick. Privileging the variability of Patrick’s voice revealed the unique ways in which he navigated his life spaces and perceived his educational experiences. All of which could have been learned by Patrick’s school by simply asking him about his interests and how he learns best. Too often Districts make assumptions about a student’s ability based on standardized measures of a student's educational aptitude, labeling them by what they are perceived as being unable to accomplish and maintaining two distinct educational systems, “one for disabled students and one for everyone else” (Erevelles, 2000, p. 25). Or as Erevelles (1997) argues, in order to cure this perceived failure in school, specialized instruction is required, which is then used to justify Patrick’s segregation from the mainstream. As a result, Patrick is given a different curriculum than his same-aged peers, that is aligned with his “designated slot along the social division of labour” (Erelleves, 2005, p. 433). By determining what Patrick was perceived to be unable to accomplish, UCA overlooked his humanity and the assets that he brings to the classroom. As a result, UCA created an educational environment that isolated, excluded, and hampered his academic achievement. It is important to note that although Patrick was in a restrictive placement and
labeled as “below-grade level” on several educational measures, it was a flaw in the learning environment grounded in the medical model of disability that created these perceived deficits, not a flaw in Patrick.

**The Siege: Suggesting a Thirdspace in Special Education?**

In this investigation, I chose to present the complexities of the lived educational experiences of Patrick and his mother using the metaphor of a siege. The siege metaphor has been historically used in autism discourse to describe autism as an outside force invading the body and trapping the “normal” individual within (Park, 1967). Given the troubled past of the siege metaphor, I chose to cautiously apply this metaphor to reveal and make visible the exclusionary practices and pathologizing education structures acting upon and against Patrick and his mother, creating a forced paralysis, significantly restricting mobility, and squeezing both into submission.

Looking at Patrick’s experiences through the siege metaphor revealed the exclusionary practices that he experienced administratively, academically, and within his environment. These “walls of exclusion” which I have termed them, serve as external environmental obstacles that actively contributed to the disabling of Patrick in this educational setting. As a result, Patrick experienced a forced paralysis, trapping him within these three walls compelling him to occupy an in-between or Thirdspace. Once trapped behind these walls, in combination with the educational attrition he experienced by UCA cutting off access to educational resources, he was left with little choice but to accept his fate, grin, and bear it. He stayed positive, made the most out of his situation, and valued his time spent with friends, and his unfettered access to watching YouTube videos.
Although Bev’s educational experiences differ from Patrick’s, the siege metaphor revealed the implications that “fighting autism” can have on a family member’s physical and mental health. Once Patrick entered UCA, she found herself being attacked and surrounded on all sides, by the school, the district, her community, her parent advisory organization, and by her family, forcing her to spread herself thin. For Bev the siege created a forced paralysis, much like Patrick, but in Bev’s case, the forced paralysis resulted from being surrounded on all sides by the cultural, societal, personal, and educational implications of “fighting autism” squeezing her into submission. For Bev, she found herself not only surrounded on all sides, but the roof was caving in on her.

In addition to drawing attention to the external forces paralyzing both Patrick and Bev, the siege metaphor also suggested that the exclusionary practices used by both UCA and DPS that Patrick experienced, forced him to occupy an in-between or as Soja (1996) describes, Thirdspace. Influenced by the work of Henri Lefebvre (1974), Soja (1996) developed the concept of Thirdspace to provide an “other-than” term signifying the “in between” position that challenges the rigid binarism defining space as a closed either/or position limited to two terms or concepts (p.60). It is a representational space that can be considered a socially constructed lived space, and for that reason, Thirdspace has multiple meanings that are constantly changing and evolving (Soja, 1996, p.62). Thirdspace, much like the social model of disability, is concerned with what value and meaning is given to the other-than choice, human diversity in the case of the social model of disability, and location, both real and imagined spaces with Thirdspace. Thirdspace epistemologies suggest that Patrick occupies several educational in-between spaces, falling between the cracks of educational dichotomies and thus occupying an in-between space, many times alone. Figure
7.2 shows a visual conception of this theoretical instructional space with Patrick stuck between two distinct levels of academics, “rigorous academics focused on grade-level academics” and “rigor-less academics focused on life skills.” He is easily able to follow the inclined plane to receive rigor-less instruction that does not meet his education needs (as represented by the arrow that reads “progression”), but in order to reach rigorous grade-level instruction, he would have to go straight up with no support (represented by the arrow pointing up), leaving him helpless. Whereas his neurotypical peer, pictured on the left, even if they are perceived to be performing at below-grade level they progress (as represented by the arrow that reads “progression”), and is placed on an inclined plane that represents the support given to the student to allow them to reach this goal.

**Figure 7.2**

*Conceptual model of academic third space experienced by Patrick*

*Note: the image used to depict Patrick is a stock-photo used to protect his privacy.*
Looking at Patrick’s educational experiences through the siege metaphor suggests that he consistently finds himself occupying a thirdspace, he is too academically advanced to be in the restrictive setting that he finds himself in and is not academically advanced enough to be placed in an inclusive educational setting. He is overqualified to be cleaning up after his same-aged peers and staff at the Central Offices, but not qualified enough to learn how to “work in a school to help kids.” Lastly, he can self-regulate himself enough where his dis/ability appears invisible with his classmates, but he is not self-regulated enough to take part in social inclusion and have lunch with his same-aged peers. In addition to occupying this third space in education spaces, work by Botha and colleagues (2021) suggest that individuals like Patrick “who can and do engage with researchers are dismissed for not being autistic enough” while individuals “who use few to no words are systematically kept out of research” (p.5). Leaving Patrick somewhere in the middle, or in a third space.

As Soja (1996) suggests, “Thirding introduces a critical “other-than” choice that speaks and critiques through its otherness” (p.61). In Patrick’s case, at UCA he often finds himself occupying the in-between or other-than position in his class. Given that the goal of special education is to provide individualized instruction that meets the needs of the learner, the fact that Patrick is occupying a Thirdspace at UCA suggests that his educational needs are not being met. Soja (1996) also describes Thirdspace as “the chosen spaces for struggle, liberation, emancipation” (p.68). For Patrick, and students that find themselves in similar situations, these spaces were not chosen by them; however, by privileging Patrick’s knowledge base and supporting him in sharing his voice, these spaces can and will be locations of liberation and emancipation as long as their voice and knowledge base are heard and valued (Soja, 1996).
Implications of the Study

Using the siege metaphor, this study revealed three distinct walls of exclusion impeding Patrick’s equitable educational access. The implications of this study will be presented with the same framework used to tell Patrick and Beverly’s stories and structured to first include the administrative implications, including educational policy. Secondly, the academic implications, including both in K-12 settings, as well as in teacher education programs. Lastly, the environmental implications will be discussed, including a look at inclusion as both an educational placement and as an experience and philosophical stance.

Administrative Implications

Valuing families and family member voices. First and foremost, this study revealed a disconnect between schools and families, highlighting the importance of a home-school connection, specifically at the administrative level. During Bev’s experience sitting in Patrick’s first IEP meeting, “like a deer in headlights” she had a great deal of difficulty processing Patrick’s educational assessment results that were tightly wrapped in exclusionary educational jargon and terminology which seemed like a foreign language to her. When she entered that first meeting, she was under the impression that the school would provide Patrick with the educational supports he needed to be successful academically, but soon found that she would have to “put her boxing gloves back on” and fight for the bare minimum level of supports and services for her son. This “fight” involved educating herself on special education policies and practices and using her newly discovered educational expertise to advocate for the services that she felt that her son needed, many of which she was never made aware of by DPS. In addition, at UCA Bev felt on numerous occasions that her voice was not being taken seriously as an equal member of the IEP team. Although she
made her desires for Patrick to be placed on an educational track focusing on learning the academic skills necessary to graduate from high school and go to college, these desires were quickly extinguished and Patrick was placed in educational programming that focused on learning functional life skills, as she so succinctly puts it, “because he had autism attached to his name.” This highlights the need for schools and families to form a genuine partnership built on trust and respect, where families can share their educational desires for their children and educators use their professional knowledge and offer guidance that takes into consideration these desires. Otherwise, this creates a hierarchy of knowledge where the educator’s professional expertise holds more weight than the family member's hopes and desires for their child and ignores their cultural ways of knowing.

Throughout his educational career, first at FDS and then at UCA, Patrick has only been educated in the most restrictive classroom placement that DPS offers, a substantially separate classroom. Patrick’s experiences and Bev’s accounts illuminate the significance of Patrick’s first IEP meeting when he was five years old, where his educational trajectory was placed on an exclusionary path from which he never strayed from. Looking back on Patrick’s educational journey retrospectively, this study revealed that when he was first placed in a substantially separate classroom at age five, he was being administratively excluded from an academic course of study that would prepare him to earn a high school diploma at UCA. Given that when Patrick was first placed in a substantially separate classroom Beverly was not aware of the long-term implications of being educated in a restrictive educational placement, this study highlights the need for schools to inform families of these implications before it is too late for them to veer from their seemingly predetermined path leading to life skills in high school. In my experiences working with
students in substantially separate classrooms, I have noticed that the longer a student remains
in a restrictive placement, the harder it is for them to transition to an inclusion classroom. In
Bev’s case, had she known the administrative implications from Patrick’s educational
placement, she would have fought harder for a less restrictive placement when he was
younger, a placement that would help him earn a high school diploma.

**Educational policy.** The passage of the Individuals with Disabilities Education Act
(IDEA) opened our Nation’s schools for students identified as having a dis/ability that
impacted their ability to make academic progress in schools. Although this act provided
access to students that had been historically excluded from entering our public schools, this
same act was grounded, and still is grounded, in the medical model of disability. The IDEA
measures students by what they are perceived to be unable to accomplish and prescribes them
with educational supports and services that are deemed necessary for them to overcome their
perceived deficits. In Patrick’s case, with a label of autism, he was administratively placed in
a substantially separate classroom, isolated from his same-aged peers. This study represents
a call for educational policy to be informed by the social model of disability, and rather than
comparing student academic performance to unobtainable measures of normalcy (i.e. white,
able-bodied, and self-regulated bodies), policy should take a more holistic approach and
instead look at ways to adapt and modify the learning environment to help students
demonstrate a more accurate representation of their academic proficiency. By continuing to
determine a student’s educational path based on inaccurate standardized measures of
achievement heavily influenced by a student’s race and English Language proficiency,
students like Patrick that can express themselves through alternative ways, such as with
visual supports, visual and performing arts, and through music, will continue to be placed in
restrictive educational placements where they do not belong. In addition, this study is a call for policy to reflect the immediate and dire need to end the overrepresentation of students with intersecting identities, namely students at the intersection of race and dis/ability, from restrictive educational placements.

When administratively determining educational placement in a student’s IEP, instead of educators having to provide a valid explanation for excluding students from the general education classroom, they should also be required to justify the student’s placement into restrictive educational settings. With this justification, based on the findings of this study, the long-term implications for restrictive placements must be explained to families so they are aware of the educational programming their student will receive, the segregated conditions they will be educated in, and other intended and unintended consequences of their decision.

The implications of this study suggest that it is time for educational structures to rethink the rigid high school graduation requirements for students with dis/abilities, specifically students labeled with severe dis/abilities. Special education was founded on the belief that some students need adaptations and modifications in order to receive equitable access to grade-level educational curriculum (Zirkel, 1983). Patrick went through his entire educational journey receiving these adaptations and modifications to the curriculum, as well as specialized services to meet his educational goals set forth in his IEP. This study revealed that for Patrick to graduate from high school and receive a traditional high school diploma, he would have to meet the same graduation requirements as all students, namely, he would have to show that he was proficient in tenth-grade academics through high-stakes testing without the use of the same adaptations and modifications that he has been entitled to since he was five years old.
In theory, Patrick can demonstrate proficiency through an alternative portfolio assessment; however, in practice, less than half of one percent of alternative assessments meet the proficiency targets to graduate from high school. As discussed in this study, for some students staying in school until they turn twenty-two might be a better option than receiving a high school diploma and leaving school at age eighteen. But in Patrick’s case, he was never given a choice to follow a path leading to graduation, and by the time his family realized, it was too late for them to change the trajectory of his educational path. This study speaks to the need to provide families with more choice on a students’ educational path and time for us to re-evaluate the value of a high school diploma and what it represents in our society. Currently, and as this study suggests, a high school diploma represents another administrative obstacle excluding students with dis/abilities from equitable access to an education, and by extension, the means of supporting themselves financially in adulthood. To promote equity in schools and in society, we need to provide these same students with opportunities to demonstrate their learning at their level, in their own individualized way, and look at their accomplishments through an asset-based perspective rather than viewing them through a deficit lens by what they are perceived as being unable to accomplish.

**Academic Implications**

**Pedagogy and curriculum in k-12 education.** The implications of this study suggest that the educational programming that Patrick was receiving at UCA was denying him access to a FAPE. This study also brought to light the inferior education that Patrick and his classmates were receiving compared to his neurotypical peers, as evidenced by the extreme isolation he experienced, his unfettered access to non-educational videos, and the functional life skills program that in no way reflected his cultural ways of knowing. The
curriculum completely ignored Patrick and his mother’s desires for his educational path. Patrick wanted to become an educator to “work in a school to help kids”, whereas his mother wanted the educational programming he was receiving to focus heavily on academics. Either way, UCA ignored student and family member voices and instead placed Patrick in a life skills program heavily focused on learning custodial skills rather than academics.

Life skills can be a valuable component of the curriculum for some students with dis/abilities as long as it is a choice. For some students, learning waste management and custodial skills will be helpful in finding gainful employment when they leave school; however, students and families should be given a choice as to whether they want to pursue this occupation and if not, be provided with other options that align with their chosen educational aspirations or future occupation. In Patrick’s case, he was automatically placed in a life skills program because of the labels that were attached to him. This study highlights the need for student and family choice in educational decision making, as well as more occupational opportunities in life skills programs for students in restrictive educational placements. Had Patrick been offered a life skills program that prepared him to be a paraeducator or reflected his passion for the public transportation system, educational programing and curriculum could have been provided to him that would specifically prepare him for a job better aligned with these two fields. Instead, with the occupational training he is receiving through his life skills program, if he does get a job working in a school or at a train station, he will be limited to sweeping the floors, washing the windows, and taking out the trash.

**Teacher education.** Before enrolling in a doctoral program, I worked for four years in special education and earned two master's degrees in education, one in elementary
education and the other in severe special needs. It wasn’t until my doctoral studies that I was introduced to the social model of disability and DSE, which was a transformative moment to say the least. The teacher education that I had received was heavily rooted in the medical model of disability that focused on diagnosing an educational deficiency and then providing interventions, supports, and services to fix this perceived deficit. Although I took a class entitled Differentiating Instruction that introduced me to the practice of providing a variety of pathways for students to meet learning objectives, I was never introduced to the idea that a student’s perceived dis/ability could reflect the learning environment rather than a deficit in the individual. This study reveals ways in which Patrick was disabled by the exclusionary practices used by educational structures heavily rooted in the medical model of disability. Teacher education programs must introduce pre-service educators to both the social model of disability and DSE to provide teachers with a contextual foundation of the social and political implications of dis/abilities in schools and in the community.

This inquiry illuminated negative educator perspectives of a Black and dis/abled mother advocating for her Black son. Through my experiences in DPS I have observed that white educators make up most teacher positions in DPS, and for restrictive special education placements, white educators hold a very large majority of the teaching positions in this setting. Although the cultural proficiency of these educators is improving as a result of more professional development centered around the use of Culturally Linguistic and Sustaining Practices (CLSP) to create curriculum that reflects the cultural and linguistic diversity of students, there is little mention of the intersection of race and dis/ability in these spaces. As a result, special educators have limited experience navigating and understanding the cultural implications of dis/ability for families that are advocating for their children. When educators
make assumptions about culturally and linguistically diverse families and privilege White, middle-class standards of advocacy and engagement, as evidenced in this study by Bev being labeled with the nickname “Autism Bitch”, they further alienate families from the already overwhelming special education process. To avoid this cultural disconnect, as well as change educator perceptions of culturally and linguistically diverse students and families, it is crucial for teacher education programs to include opportunities for educators to explore their implicit bias and learn about the cultural implications of dis/ability, as well as ways of engaging families that embraces CLSP. In addition, with a large majority of talented educators of color holding positions as paraeducators in DPS that work directly with students with dis/abilities in restrictive settings, DPS must hire more educators of color, and provide programs for supporting paraeducators, both financially and academically, in getting their educator licenses.

Environmental Implications

Building a truly inclusive community. Inclusion is an experience or philosophical stance rather than a placement (Gallagher, Connor, & Ferri, 2014). The distinction is clearly evident when comparing the mission and belief systems of FDS and UCA. FDS foregrounds inclusion in their policies and practices, whereas this study highlighted the policies and practices at UCA that actively excluded Patrick administratively, academically, and from his school community. From being limited to receiving academic instruction and eating meals in one of two rooms, having no access to lockers in the same hallways as his peers, not having a shared gym time with his peers, and being educated in a physical location in the school far away from the general education classrooms. The only time that Patrick had the opportunity
to interact with general education students, however brief, was when he was collecting the recycling from their classrooms.

At FDS Patrick was included with his neurotypical peers on a regular basis, during all of his meals, some specialist classes, at the school dances and events, his locker was intermingled with general education lockers, his classroom was directly across from the general education classroom, and he even went on the same field trips and overnight camping trips that his peers did alongside them. FDS truly embraced inclusivity throughout the school as a philosophical stance and experience rather than simply an educational placement.

Although FDS wasn’t perfect when it came to providing inclusive opportunities to Patrick and his classmates, it was apparent in the policies and practices that inclusion was more than part of their goal and mission, it was the lifeblood of the school. Patrick and his classmates were always part of the discussion when it came to planning events and providing inclusion opportunities in specialist and academic classrooms; however, at UCA, as this study suggests, they were never as much as an afterthought.

UCA was two schools in one, and the two ran as entirely separate entities, a school for general education students and the other for special education students. From Patrick and Bev’s accounts, inclusion doesn’t exist at UCA. This study suggests that to successfully include students like Patrick, the school needs to make it a proactive priority rather than a reactionary afterthought. Throughout this investigation, Bev consistently critiqued the administration at UCA for “not knowing anything about autism” and the results of this study supports her assertion. By physically isolating Patrick and his classmates from the rest of the school, UCA was creating the conditions for not only their physical exclusion in the school building, but also excluding them from an opportunity to be part of the school community.
Two of Patrick’s classmates left FDS in fifth grade to go to an inclusion program at a different school. When Patrick arrived at UCA on the first day of high school, the three of them were reunited. This supports the assertion that UCA is two schools in one, and regardless of the perceived severity of a student’s dis/ability, students in special education are segregated and isolated from their same-aged peers, even students that were once in inclusion programs.

As members of the UCA school community, Patrick and his classmates have the right to be actively involved and engaged with the rest of the school. This holds especially true during mealtimes, locker time, gym class, and community outings, at the bare minimum. The fact that UCA denied Patrick and his classmates these low-maintenance and enriching high school experiences supports Bev’s notion that UCA “doesn’t care” and that they are only “babysitting” Patrick. UCA will be Patrick’s home for eight years before he ages out of the system, and he is treated as more of a transient than a student. The findings of this study reveal not only the educational inequities that Patrick experienced academically, but also the inequities that he experienced as a marginalized member of the school community, and this is supported by the policies and practices at UCA that actively exclude Patrick from a FAPE, namely what I have termed the three walls of exclusion. For UCA to provide Patrick with a FAPE, it must first start by making him and his mother feel like they are part of the broader school community by building a strong home-school partnership. Secondly, UCA needs to actively include Patrick and his classmates whenever possible and provide them access to their neurotypical peers other than times when he is picking up their recycling. Lastly, UCA and other high schools should collaborate with K-8 schools in the district to ease the transition to high school for students like Patrick in restrictive placements. By sharing better
practices on ways to continue including special education students administratively, academically, and in their school community, high schools can create a school community that values the contributions of every member and proactively arrange the environment where all students can feel included and have the supports in place to be successful both academically and socially.

Limitations of Study

When I began this study, my first goal was to adapt and modify the research environment to support one student, who may or may not communicate in traditional forms of spoken and written words, in sharing their voice. With this in mind, I made the decision to only include one student participant in this investigation and provide a comprehensive look at their educational experiences using a variety of different research methodologies. Given the research design and the amount of data that was collected in this study, I selected only two main participants in order to ethically and purposely create a caring research narrative that honored the lived experiences of a student with dis/abilities and his family. As a result, this study has uncovered themes that can be applied to individuals that find themselves similarly situated in educational contexts and highlights the need for more thoughtful research methods that honor the communicational needs of the participants and their knowledge base. These themes uncovered include: the segregation and isolation of students of color into restrictive educational placements; the educational track of functional life skills forced on students that are racialized and labeled as dis/abled; the importance of student and family member voice in educational decision making for students with dis/abilities; the rigor-less educational programing provided to students in restrictive placements because of the labels they are given; the exclusionary practices used by educational structures on the administrative,
academic, and environment level used to exclude students with dis/abilities from a FAPE; and the pathologizing of Black mothers that advocate for their Black children by these same educational structures.

Conducting research in this large urban school district required an approval process that involved a huge expenditure of time, in addition to navigating through a great deal of bureaucratic requirements, getting approval from the school and department heads, filling out forms, and submitting for approval during only one month in the fall and one month in the spring. For this study, I decided to look for my participants outside of the school setting, in community groups that supported autistic students and their families. Given the strict requirements by the district when conducting educational research in schools, the study I proposed would be unable to be approved without being sponsored by a member of the leadership team at DPS. With the potential of this research portraying the district in a less than positive light, I made the decision to conduct this research outside of the school day in a private residence. The descriptions included in this study of the classroom, classroom routines, curriculum, pedagogy, and other classroom practices were created through Patrick’s accounts of his educational experiences in UCA. This could be seen as both a limitation and a strength. Had I observed Patrick in his educational spaces there is a chance that I would not have seen an accurate representation of the everyday workings of the classroom and the school which would be considered a strength. Relying solely on Patrick’s recollection of his educational experiences could also be considered, albeit ableist, limitation because as a fifteen-year-old student, he may be unable to recognize the nuances of the educational environment in which he is educated in and only recall what he is familiar with.
This study did not directly include the perspective of Patrick’s ninth grade teacher at UCA, and instead, I provided the teacher perspective that interpreted Patrick’s experiences. I entered this work with an open mind letting the data describe the classroom experiences, but without the perspective of Patrick’s teacher, my interpretations of these experiences could be incomplete. This research does not take into consideration the lived experiences of anyone other than Patrick, his mother Bev, and myself. The three of us were foregrounded in answering the research questions; however, providing the lived experiences of Patrick’s teachers at UCA and other students and families in his classroom would have provided a more comprehensive view of the educational experiences taking place at UCA.

My positionality as a DSE scholar and educator is grounded in the social model of disability that holds that perceived deficits in achievement reflects the flawed learning environment and not a flaw in the learner. This is a belief that goes against the grain of the popular philosophy in special education (Lovaas, 1987; Kauffman, 2000; Kauffman, Anastasiou, & Maag, 2017). Although I am accustomed to navigating these spaces, and made every effort to remain objective, there is a potential that the critical perspective I bring to this work may be visible in the analysis of these results.

This multi-methods research study involved creating portraits of Patrick and his mother through a variety of data types including art renderings, interview transcripts, lyrical expressions, and three-way group discussions. Given the vast amount of data that this study yielded, and the multiple member checks that I conducted, only the participants themselves can speak to their experiences. From the onset I set out with the goal of co-constructing narratives with the participants, for which I feel I was successful in doing, but much like they couldn’t write my story, I couldn’t write theirs.
Lastly, the perspective that I bring to this study is of a cisgender, middle-class, heterosexual white male who does not identify as having a dis/ability. Patrick and his mother are both of Cape Verden descent and identify as individuals with dis/abilities. Although I am well versed in dis/ability discourse, no article, book, or documentary could begin to help me see the world from their perspectives. This study foregrounded their experiences navigating an urban school district as both racialized and labeled with dis/abilities, privileging their cultural ways of knowing what it means to be at the intersection of race and dis/ability; however, without coming from the same culture as my participants, I could never fully see things from their perspective or completely understand the gravity of being an individual of color that has a dis/ability. As a white male that does not identify as having a dis/ability, this study required me to put myself in the shoes of my participants and truly value the knowledge and the perspective that they brought to this work.

**Recommendations for Future Research**

Following the tenets of Disability Studies in Education (Baglieri et al., 2011), this inquiry is part of a far-reaching movement focused on, and dedicated to, including individuals with dis/abilities in every stage of the research process. Research conducted about individuals with dis/abilities can and should be re-designed and conducted with, rather than about, these same individuals. This investigation is an example of how the research environment can be adapted and modified successfully to provide individuals with dis/abilities the supports necessary to share their input and perspectives (Naraian, 2008). As Connor (2009) so succinctly states, “it is time to consider what students know, think, and feel” (p.451). With this in mind, it is incumbent on researchers to look past the hegemony of written and spoken (ableist) word and embrace alternative forms of communication as viable.
methods for individuals with dis/abilities to share the variability of their voice, as naturally
and uninhibited as possible (Biklen & Cardinal, 1997; Sauer, 2012; Ashby, Woodfield, &
Delia, 2016; Woodfield & Ashby, 2016; Miller, 2019). The methodological flexibility
proved to be a valuable asset in conducting research that values voice in whatever form it
may take (Ashby, Woodfield, & Delia, 2016; Robinson, 2018; Brodeur, 2021). Future
research that includes individuals with dis/abilities, or more inclusively stated, all
individuals, should consider using the bricolage as an inclusive methodology for supporting
individuals in sharing their voice.

In this investigation, informed by Hip-Hop Based Education (HHBE) and the activist
scholarship of Bettina Love, Christopher Emdin, and Edmund Adjapong, I developed a
method that I call Improvisational Lyrical Remixing (ILR) that was a useful way to support
my participant in sharing the variability of his voice. Future research with individuals that
may or may not communicate through traditional ways should explore the use of music,
movement, and lyrical expressions as viable methods for participants to share their voice. In
this investigation, lyrical expression not only proved to be an engaging way for Patrick to
share his voice, but it allowed him to elaborate on his educational experiences with much
more depth.

The use of DisCrit as a theoretical framework allowed me to reveal special education
practices that operate in invisible ways within education structures that remain unquestioned.
One of the most glaring examples of this that was revealed in this study is access to non-
academic videos during academic instruction time. This practice remains invisible and
unquestioned because as long as culturally and linguistically diverse students labeled as SD
are isolated from their neurotypical peers and occupied, then they will not be interfering with
the education of students who are perceived to be “normal.” As a K-8 educator who recently
had to move my instructional practice to the virtual world during the Covid-19 pandemic, I
noticed the technology usage amongst my students increased significantly. This study was
conducted before teaching and learning moved to virtual spaces, but nevertheless, the
unfettered access to YouTube that Patrick experienced was concerning. In my experiences at
FDS, YouTube videos have always been used as a positive reinforcement in the classroom,
but the time dedicated to watching these videos is strictly limited. Future research should
take a closer look at the practice of using non-academic videos as positive reinforcement, and
the long-term effects that it has on students with dis/abilities.

On several occasions Bev shares that she believes that UCA is “just setting him up to
collect a welfare check.” Over the past few decades, extensive research has been conducted
on zero-tolerance and other punitive school discipline policies and how these policies
disproportionately affect students of color from disadvantaged backgrounds (Annamma,
the “school to prison pipeline.” It is disproportionately kids of color who get caught within
the inter-institutionally webbed spaces and structures of schools and criminal justice, and
students like Patrick with intersecting identities that are both Black and have a dis/ability, are
expelled five times the rate of their White peers and face temporary disciplinary removals at
a higher rate than White students, further contributing to this phenomenon (Brown, 2012;
Tefera, Hernández-Saca, & Lester, 2019). The educational experiences, specifically the
exclusionary practices revealed in this inquiry using the siege metaphor suggest that many of
these practices could be contributing to learned dependence. Future research should
investigate the long-term effects of this learned dependence resulting from impoverished
educational experiences in restrictive educational settings and if this creates a school to dependency pipeline, forcing students to become dependent on social services once they age out of the system at twenty-two.

In this investigation, family member perspectives played an important role in providing a comprehensive look at Patrick’s educational experiences. Bev’s experiences revealed the physical and mental health implications for “fighting autism” in the schools, in the community, and in extended families. As a zealous advocate for Patrick, Bev was known as the “Autism Bitch” throughout the district and among school administrators, a name that she wears like a badge of honor and proudly embraces. Future research should investigate educator perceptions of family members that advocate for their children, specifically culturally and/or linguistically diverse family members, and how these perceptions influence home-school relationships. In addition, how the lived educational experiences of culturally and/or linguistically diverse family members compare to that of white family members that find themselves similarly situated.

This study revealed that it wasn’t until high school that Bev learned the long-term implications of Patrick’s restrictive educational setting on his opportunity to earn a high school diploma. Future research should look at the long-term implications that a restrictive educational placement has on access to inclusion opportunities, educational advancement, and earning a high school diploma. Specifically, at what point are families provided with this information, if at all, and what are some best practices used by districts to inform families of these implications?

Lastly, future research should look at the curricular disconnect between K-8 schools and high schools. In this investigation, Patrick and his mother describe two entirely different
educational experiences between K-8 and high school. In addition, these experiences also revealed that in DPS, after attending a K-8 geared towards providing the optimal learning environment for autistic students, Patrick found that there was no high school program that provided a similar learning environment. Surprisingly, this investigation also suggested that the high school selection process in DPS is less about providing families choice in what school their child will attend and more about which schools have vacant special education seats available. Future research should look at the high school selection process in urban districts, and to what extent they are designed to support students with complex dis/abilities.

**Concluding Thoughts**

I began this inquiry with the intent of providing a student with dis/abilities the opportunity to share their educational experiences using their preferred method of communication, in whatever form that would take. Through these experiences, I hoped to gain valuable insight into what they desired from their education and whether these experiences were living up to their expectations. When I first proposed this study, I was concerned that the standards-based educational reform movement would have unintended consequences that disproportionately impacted the educational experiences of students educated in restrictive placements. I anticipated that UCA would closely align the goals in Patrick’s IEP with grade-level academic learning standards instead of creating an individualized plan that would address Patrick’s specific needs, resulting in Patrick’s educational needs not being met. But what I wasn’t prepared for was that based on Patrick and Bev’s experiences, it seemed as though UCA had no standards for students in restrictive placements, period. In addition, this inquiry revealed the forces of exclusion, not only passively hampering and impeding his success, but also actively blocking Patrick’s ability to
receive a Free and Appropriate Public Education, and the resulting physical segregation and isolation that he experienced because of it. These same educational structures actively worked to pathologize Bev, labeling her as the “Autism Bitch” all because she was not afraid to speak her mind, was willing to fight fearlessly, and refused to accept the bare minimum for her son.

Moving forward, this inquiry truly speaks to the importance of the relationship between a student in a restrictive placement, their family, and their teacher. This special bond is echoed throughout this investigation and shines through in our weekly discussions over dinner, the many musical performances Patrick and I performed in his living room, the numerous long phone calls filled with expletives that I had with Bev after a long school day, the seemingly thousands of times I shared with Patrick what I ate the night before, and the daily Facebook messages that I continue to have with Patrick where he asks me about all of my favorite train stations and insists that I call him “King Patrick in the Castle at Walt Disney World”. These are the moments that built the trusting home-school relationship between Patrick, Bev, and myself that allowed me to see crystal clear the educational injustices that Patrick and Bev face on a daily basis.

This inquiry is a call for students, families, and educators to work together to reimagine inclusive education in the post-Covid-19 era. If our goal is to create a society that is more accepting of differences, then it is time to change our rigid, racist, and ableist requirements for students with dis/abilities, specifically culturally and linguistically diverse students at the intersection of race and dis/ability, to be included with their same-aged peers in both the classroom and broader school communities. Representation is the key to acceptance and empathy, and by normalizing the practice of including students with
dis/abilities in every classroom, and recognizing and celebrating human variability, we will create a school community that values diversity and learning differences, rather than viewing them as perceived weaknesses.
APPENDIX A

RECRUITMENT FLIER

- Does your child have a disability, and receive educational services in a substantially separate classroom?
- Would you like your voice and the voice of your child to be heard?
- Would you like to participate in a research study that is looking at the educational experiences and educational desires of students with disabilities, their families, and their teacher?

My name is Christopher Hall of the Department of Leadership in Education at UMass Boston, and I will be conducting a dissertation research study entitled: Substantially Silent: Listening to the “Voices” from the Margins. I am a special education teacher that specializes in working with students with Autism Spectrum Disorders, as well as, students labelled as severely disabled.

With this research I am trying to better understand the educational experiences and desires of a student in a substantially separate classroom, his or her family, and his or her teacher from their perspective. I want to learn what the student, the student’s family, and the student’s teacher wants their education to look like and compare these desires to what is actually happening in the classroom.

<table>
<thead>
<tr>
<th>What will I be asked to do?</th>
<th>How long will it take?</th>
<th>What good things could happen from this?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Share your school experiences</td>
<td>The study will take about six months</td>
<td>You will have the chance to tell your story</td>
</tr>
<tr>
<td>Keep a journal</td>
<td>We will meet 3-4 times per month for 45 minutes</td>
<td>You will help others learn from your experiences</td>
</tr>
<tr>
<td>Participate in interviews and discussion groups</td>
<td>Each meeting will be scheduled at YOUR convenience in a place you feel comfortable</td>
<td>Your story will help schools better understand how you experience school and what you desire from an education</td>
</tr>
<tr>
<td>Be observed while in school and around your local community</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Findings from this study will help teachers and schools to better understand the experiences and desires of students educated in a substantially separate classroom.

If you are interested in being part of this research or have any questions, please contact:
Christopher Hall at (617) 838-3073 or Mr.Hall30@gmail.com

Food will be provided during discussion groups and a small gift with an approximate value of $50 will be given to each participant.
Parental Permission for Participation of Child as a research Subject

May 6, 2018

Dear parent(s)/guardian(s) of the student involved in the study Substantially Silent: Listening to the “Voices” from the Margins,

My name is Christopher Hall of the Department of Leadership in Education at UMass Boston, and I will be conducting a dissertation research project. As you may know, I have had the honor and privilege of serving students in the autism program as their Sensory Arts teacher for the past seven years. During this period, I have had the opportunity to build a strong relationship with these students, one based on trust and mutual respect. I feel that the rapport that I have with these students is an important part of the research study that I will be conducting, one that I hope will benefit them and their family. This study involves some research activities so I would like to explain the objectives to you fully before asking for your consent for your son or daughter to proceed with the study.

**Purpose:** I am trying to better understand the educational experiences and desires of a student in a substantially separate classroom, his or her family, and his or her teacher (me). Ultimately I want to learn what the student, the student’s family, and the student’s teacher wants their education to look like and compare these desires to what is actually happening in the classroom. To do so, I would like to invite your son or daughter, you, and your family to join me in sharing your educational experiences and desires as they relate to learning in a substantially separate classroom.

**Procedures:** Another key component of this study is that in order to honor the unique needs of the student, I will adapt and modify the research methods that will be used in order to allow them to share their story as uninhibitedly as possible. This will allow me to use research methods that the student will feel comfortable using. Although I may be using a traditional research method like conducting an interview, **it may look differently for the student.** For example, if the student has a difficult time verbally communicating their
educational experiences and desires, I will allow them to draw pictures, or use a camera to communicate. So, I have provided a list of activities that this study will involve, but keep in mind, **these activities may look differently for the student because I will adapt them to meet their individual needs.**

The study will include the following activities that the student will participate in:

(a) Writing and drawing in an art journal about their educational experiences and desires.

(b) Writing and drawing in an art journal independently on topics of their choosing

(c) Participating in interviews with me to discuss their educational experiences and desires

(d) Participating in discussion groups with their family, and their teacher (me)
   
   a. This will include: having the opportunity to discuss their own experiences and desires, as well as, ask questions to family members, and their teacher (me) about these experiences and desires.

(e) Being observed in your local community and in their school

(f) Helping co-create a narrative that best portrays their experiences and desires

**Expected Duration:** This study will take place over the course of six months, and I will meet with the student 3-4 times per month at their convenience, outside of the school and the school day in a location in their local community of their families choosing. During each month the student will participate in two to three (45) minute interviews and one (45-60) minute discussion group which will include their family, as well as, myself in my role as their teacher. In addition, I will be observing the student in his or her school four to six times.

**Possible Discomforts and/or Risks:** The primary risks associated with this study include the potential emergence of negative or distressful feelings in participating in discussing educational experiences and educational desires. If your child feels uncomfortable at any time, he or she may speak with Chris Hall to ask/request a break (either verbally or with visual supports), to end any session, or to discuss any distress or other issues related to study participation. In addition, if your child wishes to discuss concerns with a school counselor, you are encouraged to contact them, or you may contact Toward Independent Living and Learning (TILL) at (781) 302-4600 for additional services and support.

Due to the small sample size of the study (one student, their family, and their teacher [me]), other people could potentially identify the student and the family based on the details of their story. The next section explains in detail the steps that will be taken to protect your child’s confidentiality.
Confidentiality: Your child’s part in this research is confidential. That is, the information gathered for this project will not be published or presented in any way that would allow anyone to identify you. In order to protect the confidentiality of the participants and minimize the risks listed above, I will use the following safeguards:

(a) The student and family will be given fake names or pseudonyms

(b) This study will use pseudonyms for the school that the student attends, and the city and neighborhood where the student and family live.

(c) All written documents will only use these pseudonyms.

(d) All data (including notes, audio recordings, videos, and transcripts) will be stored on a private laptop that is password protected and stored in a file that is password protected with a different password.

(e) All physical documents will be stored in a locked file cabinet and only the research team will have access to the data.

(f) Videos and audio recordings will be destroyed after this dissertation is successfully defended.

Possible Benefits: Although it is not anticipated that you or your student will benefit directly through your involvement in this study, the project is expected to benefit students that are educated in a substantially separate classroom and their families by helping others learn from your experiences. Having an opportunity to share the student’s story will help teachers and schools better understand how they experience school, which may improve education for other students in similar circumstances.

Costs and compensation: There are no costs associated with your child’s/ward’s participation in this study. Compensation will include refreshments during interviews and discussion groups. In addition, to support the student’s artistic endeavors, I will offer to provide the student with additional private art lessons and give the student art supplies with the value of fifty dollars. The student will also have the choice to receive a gift card to purchase electronic music, video games, and or digital applications in the amount of fifty dollars if they do not want the art supplies and lessons.

Voluntariness: Your child’s/ward’s participation is completely voluntary. Refusal to give permission for your child to participate in this study will not result in any penalty or loss of benefits to which you or your child/ward might otherwise be entitled. Although you may give permission for your child to participate, your child may decline to participate and the child’s decision will be respected. Your child/ward may likewise discontinue participation in the study at any time without penalty or loss of benefits. I will also explain this project to your son or daughter / child you are guardian to. I will explain to them that should they decide not to participate, their relationship both personally and academically with me will in no way be affected. I will use multiple formats to describe the project and modify the consent forms so that students understand what I am
asking of them. In addition, I have included written and visual supports to provide them an opportunity to withdraw from the study at any time.

**Contact Information:** Before I start the study, I need to obtain consent from the student and their parent(s) or guardian(s) in order to participate in this study. In addition to participating in this study, I am also asking both you and your son or daughter/child you are guardian to if I may tape and or video record interviews, discussion groups, and or other interactions directly related to this study. The reason for the video recording is so I can observe the body movement and unique mannerisms of the student as they communicate their educational experiences and desires. If you have any questions, do not hesitate to call me on my personal cell phone, or through my academic advisor Dr. Patricia Krueger-Henney at the Department of Leadership in Education at UMass Boston. My cell phone number is (617) 838-3073, and the phone number for Dr. Krueger-Henney at the Department of Leadership in Education is (617) 287-7601. Or you may speak to the Institutional Review Board at the UMass Boston, which oversees all research conducted by students at UMass Boston. They may be reached at IRB, Quinn Administration Building 2-080, University of Massachusetts Boston, 100 Morrissey BLVD., Boston, MA 02125-3393. You can also call them at (617) 287-5374 or email them at human.subjects@umb.edu.

UMass Boston.

IRB Approval:

Thank you very much for your time and consideration.
Sincerely,

Christopher Hall, M.Ed.
PhD Candidate
University of Massachusetts Boston
Department of Leadership in Education
Cell (617) 838-3073
Email: Mr.Hall30@gmail.com

I have read and understand the information in this consent form and agree to allow my child/ward to participate in this research study. Although the investigator will make every effort to maintain confidentiality, I understand that research records must be made available to the University's Institutional Review Board and federal regulatory agencies for compliance auditing purposes, should they be requested. I will receive a copy of this form after it has been read and signed. By signing this form I am indicating that I am at least 18 years of age or older.
I would like to receive a copy of the results of this study:  
_____ Yes  
_____ No

Mailing Address: ____________________________________________________________

________________________________________  ________________________________
Printed Name of Participant              Signature of Participant

Date

Signature of Person Obtaining Consent   Date

UMass Boston
IRB Approval:
You have been asked to be part of a research study called SUBSTANTIAL SILENT: LISTENING TO THE “VOICES” FROM THE MARGINS. The study is designed to learn about your educational experiences inside and outside of the classroom. It is also designed to ask you questions to learn about what you desire, and really want your education to be like. The information gained from participation in this study will help us figure out if you are receiving the appropriate education based on entitlement of a Free and Appropriate Public Education.

Anyone who agrees to take part in a research study has special rights. **You have the right to be told:**
1. What the study is trying to find out.

In this study, we will look at questions like these:

- What is going well and what has been hard at school?
- How does school make you feel?
- What are some things you like about school?
- What are some things you don’t like about school?
- What are some things you would like to do at school?
- What are some things you do not like to do at school?
- Is there anything you would change about school?

2. What will happen in the study? What will you be asked to do?

In this study, you may be asked to participate in one or more of the activities listed below:

- Share your experiences at school
- Draw pictures in an art journal
- Use a camera
- Talk about school
- Write stories
- Be interviewed and video recorded
- Discuss your school experiences with your family and your teacher
- Have Chris watch you in class and in your neighborhood
- Create poems
- Work together to create to tell your story

Then you decide YES or NO if you want to participate
3. **What exactly you will be asked to do and for how long.**

In this study you will be asked to:

- Meet with Chris 3-4 times a month for 45 minutes at your convenience
- Participate in the study for six months
- Write in an art journal and create drawings of your school experiences
- Share your experiences with Chris
- Discuss your experiences with Chris and your family during a group discussion.
- Ask Chris and your family questions about your education
- Work with Chris to tell *YOUR* education story

Then you decide YES or NO if you want to participate
4. If you might be taking a risk and what that risk might be.

In this study, the risks might include:

- Other people learning you have a disability
- Other people identifying who you are from the details in your story
- Losing privacy if other people figure your identity

There will be many safeguards used to protect your identity:

- You will pick a fake name that we will use on all of the research documents
- We will not use the real names of the members of your family
- We will not use the real name of your school
- We will not use the real name of the city you live in
- Chris will protect all videos, recordings, and research documents protected on a private computer that has a password.

Every opportunity will be taken to ask you if you want to withdraw from the study or to tell Chris to discard your work.

Then you decide YES or NO if you want to participate
5. **What good things could happen to you? Will your life be better?**

- Helping other people learn from your experiences
- Having an opportunity to share your story with other people
- Giving you a chance to tell teachers and families what you want out of your education
- Hearing your story will help teachers and schools better understand how you experience school which may improve education for students like you
- This study will help you practice advocating for the educational experiences that you really want

Then you decide YES or NO if you want to participate

6. **What are your other choices? How those choices may be better or worse than being in the study.**

In the case of this study:

- Decline and not risk being in the study
- Wait and be in another study later

No matter what you decide, it will not affect your school experience. Nothing will change at school if you say no. Chris will not be mad if you don’t want to participate in the study.

Then you decide YES or NO if you want to participate
7. You can ask any questions about the study. You can ask questions before you start and at any time during the study.

Examples of some questions other people have asked:

- How long will this take?
- Can I stop if I change my mind?
- Do I have to do this?
- Why are you doing this study?
- How can I find out the results?
- How will you keep my information private?
- Who can I contact with questions?
- Will I be paid?

Then you decide YES or NO if you want to participate

8. Who do I talk to if I have questions?

Chris will answer any of your questions when he meets with you or through phone calls or emails.

You can contact her these ways:

Chris Hall  
Cell phone: 617-838-3073  
Email: Mr.Hall30@gmail.com

Then you decide YES or NO if you want to participate
9. What if I want to talk to someone else about the study?

If you have any questions or concerns about your rights as a research participant, please contact the University of Massachusetts Boston Institutional Review Board, who make sure research is done correctly and appropriately by anyone who is doing research at the university. They may be reached at IRB, the Quinn Administration Building 2-080, University of Massachusetts Boston, 100 Morrissey BLVD., Boston, MA.
10. You can say No. You can refuse to participate at all. You can say “no” right away or after the study has started. If you say no, you will not be in trouble.

Chris has explained the study to your parent or guardian, and they have said “yes” you can participate in the study.

Remember, even though your parent or guardian has said yes, you can still say NO.

Examples of ways that other people have said no:

· I don’t want to keep going
· I guess not
· I would rather not
· I don’t think so
· This won’t work for me

You have the right to decide YES or NO

To make sure you have a plan in case you want to stop participating, I will record the name and contact information of the person you would like to tell if you decide you don’t want to participate in this study anymore. We will tell that person that you trust to let me know you are going to stop. I will give both of you my contact information.

Name:____________________________________

Best way to contact them: _____ By phone

____ By email

_____ Another way

Contact information of the person:

If you decide to take part in the study, you have other rights. Telling someone yes is not enough. Researchers must get your written consent to show that they have helped you exercise your rights. After you say yes, you have a right to:
11. Get a signed and dated copy of all consent forms.

Examples:

· Ask for a copy of any forms you sign
· If a form is not provided, ask if you will get a copy in the mail.

You have a right to get copies of the forms.
12. To be told if your name, address or comments will be shared with someone who is not involved in the study

Examples: People who should not see your data without your consent include:

- Someone from a newspaper or TV station
- People who happen to live in your community
- People who read about the study later in a book or article
- People who go to school with you or live in your neighborhood
- People at another school or university who are not involved in the study

You have a right to privacy
How we keep information private:

- You will pick a fake name that we will use on all of the research documents
- We will not use the real names of the members of your family
- We will not use the real name of your school
- We will not use the real name of the city you live in
- Chris will protect all videos, recordings, and research documents protected on a private computer that has a password.
- All the documents, videos, and recordings will be kept on a secure laptop that is password protected, and then put in a folder that is password protected with a different password.
- Chris will review the results of the study with you to make sure it is accurate.

You have a right to privacy.
13. Take your time to think things over and decide if you want to participate. Don’t be pressured by other people to say yes.

Examples of some things that people do to take their time.

- Read everything over twice
- Take materials home and think about it
- Ask a friend or family member you trust to help you think it over
- Wait a few days before saying yes or no
- Make a list of questions before deciding

You have a right to make decisions without pressure
Examples: Things people say to pressure others into saying yes. People who are doing a good job will not say these things.

- There’s not much time. I need you to decide right away.
- If you want a gift or prize you’d better say yes.
- Everyone else has said yes. You should too.
- If you say no, it will be awkward.

Don’t let others talk you into doing something. Decide yourself.

I have reviewed this form. I understand my right to be informed and make decisions as part of a research project.

____________________________________________
Printed name of minor

____________________________________________
Signature of minor

____________________________________________
Signature of researcher

____________________________________________
Signature of researcher

UMass Boston
IRB Approval:
APPENDIX D

FAMILY MEMBER INFORMED CONSENT FORM

Family Member Informed Consent Agreement to Participate in Research

May 6, 2018

The following information describes the research study in which you are being asked to participate. Please read the information carefully and feel free to ask any questions that you may have regarding the research. Afterwards, you will be asked to sign if you agree to participate.

Investigator: My name is Christopher Hall of the Department of Leadership in Education at UMass Boston, and I will be conducting a dissertation research project. The name of this research study is SUBSTANTIALLY SILENT: LISTENING TO THE “VOICES” FROM THE MARGINS. This study will include one student from a substantially separate classroom, the student’s family, and the student’s teacher (me).

Purpose: I am trying to better understand the educational experiences and desires of a student in a substantially separate classroom, his or her family, and his or her teacher (me). Ultimately I want to see what these experiences and desires tell us about access to a Free and Appropriate Public Education (FAPE), which is an entitlement under the Individuals with Disabilities Education Improvement Act (IDEIA). To put it in another way, by listening to the educational experiences and desires of the student, the family, and the teacher, this study will reveal what a FAPE looks like in the context of teaching and learning in a substantially separate classroom. To do so, I would like to invite your son or daughter, you, and your family to join me in sharing your educational experiences and desires as they relate to learning in a substantially separate classroom.

Expected Duration: This study will take place over the course of six months, and I will meet with the family two to three times per month at their convenience, outside of the school and the school day in a location in their local community of their choosing. During each month the family will participate in one to two (45) minute interviews and one (45-60) minute discussion group, which will include the student, as well as, myself in my role as the student’s teacher.
**Procedures:** This study will be looking at the educational experiences and desires of a student from a substantially separate classroom, his or her family, and his or her teacher. For the family portion of this investigation, family members will participate in four ways: monitoring student art journals, individual interviews, discussion groups, and member checks. Students will be given an art journal to write in during the school week. As a family member of the student, you will be asked to monitor the student’s participation in journaling by checking to see if he or she completed the task for the week. For interviews, family members will be asked about their educational experiences as a family member of a student from a substantially separate classroom. The family will be asked questions about the educational experiences and desires as a family member, as well as questions that arise from non-confidential information gathered from student interviews. This will provide an alternative perspective on teaching and learning in a substantially separate classroom, as well as, verify or elaborate on the student’s perspective. In addition to interviews, family members will participate in (6) discussion groups, one each month, where the student, the family, and the teacher (me) will come together to share and discuss their educational experiences and desires. Participants will also have the opportunity to ask each other questions as they relate to teaching and learning in a substantially separate classroom. Each group discussion will be video and audio recorded, and each interview session will be audio recorded. Group discussions will be video recorded in order to examine the student’s mannerisms and body language during participation. Lastly, a narrative will be created based on the family members experiences and desires and I will conduct member checks with the family to ensure all information is accurate.

**Possible Discomforts and/or Risks:** The primary risks associated with this study include the potential emergence of negative or distressful feelings in participating in discussing educational experiences and educational desires. If you feel uncomfortable at any time, you may speak with Chris Hall to ask for a break, to end any session, or to discuss any distress or other issues related to study participation. In addition, you may wish to seek additional support and services, you are encouraged to contact Toward Independent Living and Learning (TILL) at (781) 302-4600.

Due to the small sample size of the study (one student, their family, and their teacher [me]), other people could potentially identify the student and the family based on the details of their story. The next section explains in detail the steps that will be taken to protect your child’s confidentiality.

**Confidentiality:** Your part in this research is confidential. That is, the information gathered for this project will not be published or presented in any way that would allow anyone to identify you. In order to protect the confidentiality of the participants and minimize the risks listed above, I will use the following safeguards:

(a) The student and family will be given fake names or pseudonyms

(b) This study will use pseudonyms for the school that the student attends, and the city and neighborhood where the student and family live.

(c) All written documents will only use these pseudonyms.

345
(d) All data (including notes, audio recordings, videos, and transcripts) will be stored on a private laptop that is password protected and stored in a file that is password protected with a different password.

(e) All physical documents will be stored in a locked file cabinet and only the research team will have access to the data.

(f) Videos and audio recordings will be destroyed after this dissertation is successfully defended.

Possible Benefits: Although it is not anticipated that you will benefit directly through your involvement in this study, the project is expected to benefit students that are educated in a substantially separate classroom and their families by helping others learn from your experiences. Having an opportunity to share the participants’ stories will help teachers and schools better understand how these students and their families experience school, which may improve education for other students in similar circumstances.

Costs and compensation: There are no costs associated with your participation in this study. Compensation will include refreshments during interviews and discussion groups. In addition, to support the student’s artistic endeavors, I will offer to provide the student with additional private art lessons and give the student art supplies with the value of fifty dollars. The student will also have the choice to receive a gift card to purchase electronic music, video games, and or digital applications in the amount of fifty dollars if they do not want the art supplies and lessons. The student’s family will receive a $50 gift card to a grocery store of their choosing at the end of the data collection process.

Voluntariness: Your participation is completely voluntary. Refusal to participate in this study will not result in any penalty or loss of benefits to which you or your child/ward might otherwise be entitled. Your child/ward may likewise discontinue participation in the study at any time without penalty or loss of benefits.

Contact Information: Before I start the study, I need to obtain consent from the student and their parent(s) or guardian(s) in order to participate in this study. In addition to participating in this study, I am also asking both you and your son or daughter/child you are guardian to if I may tape and or video record interviews, discussion groups, and or other interactions directly related to this study. The reason for the video recording is so I can observe the body movement and unique mannerisms of the student as they communicate their educational experiences and desires. If you have any questions, do not hesitate to call me on my personal cell phone, or through my academic advisor Dr. Patricia Krueger-Henney at the Department of Leadership in Education at UMass Boston. My cell phone number is (617) 838-3073, and the phone number for Dr. Krueger-Henney at the Department of Leadership in Education is (617) 287-7601. Or you may speak to the Institutional Review Board at the UMass Boston, which oversees all research conducted by students at UMass Boston. They may be reached at IRB, Quinn Administration Building 2-080, University of Massachusetts Boston, 100 Morrissey BLVD., Boston, MA 02125-3393. You can also call them at (617) 287-5374 or email them at human.subjects@umb.edu.
Thank you very much for your time and consideration.
Sincerely,

Christopher Hall, M.Ed.
PhD Candidate
University of Massachusetts Boston
Department of Leadership in Education
Cell (617) 838-3073
Email: Mr.Hall30@gmail.com

UMass Boston.
IRB Approval:

I have read and understand the information in this consent form and agree to allow my child/ward to participate in this study. Although the investigator will make every effort to maintain confidentiality, I understand that research records must be made available to the University's Institutional Review Board and federal regulatory agencies for compliance auditing purposes, should they be requested. I will receive a copy of this form after it has been read and signed. By signing this form I am indicating that I am at least 18 years of age or older.

I would like to receive a copy of the results of this study: 
_____ Yes
_____ No

Mailing Address: ____________________________________________________________

_________________________________ ________________________________
Printed Name of Participant Signature of Participant
Date

Signature of Person Obtaining Consent Date

UMass Boston
IRB Approval:
CONSENT TO AUDIO- OR VIDEOTAPEING & TRANSCRIPTION

SUBSTANTIALLY SILENT: LISTENING TO THE “VOICES” FROM THE MARGINS
Christopher Hall UMass Boston Department of Leadership in Education

Parent Consent

This study involves the audio taping (videotaping) of your child/ward’s interview with the researcher. Neither your name nor any other identifying information will be associated with the audiotape (videotape) or the transcript. Only Christopher Hall will be able to listen (view) to the tapes.

The tapes will be transcribed by the researcher and erased once the transcriptions are checked for accuracy. Transcripts of your interview may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither your name nor any other identifying information (such as your voice or picture) will be used in presentations or in written products resulting from the study.

Immediately following the interview, you will be given the opportunity to have the tape erased if you wish to withdraw your consent to taping or participation in this study.

By signing this form you are consenting to:

q having your child/ward’s interviews taping;

q to having the tape transcribed;

q use of the written transcript in presentations and written products.

By checking the box in front of each item, you are consenting to participate in that procedure.
This consent for taping is effective until the following date: December 16, 2020

Parent or Guardian Signature ____________________________

Date ________ UMass Boston

IRB Approval:
APPENDIX F

CHILD ASSENT SCRIPT FOR AUDIO AND VIDEO TAPING

QUALITATIVE RESEARCH STUDY
SUBSTANTIALLY SILENT: LISTENING TO THE “VOICES” FROM THE MARGINS
Department of Leadership in Education
University of Massachusetts Boston
100 Morrissey Boulevard
Boston, MA 02125-3393

Directions: The researcher, Christopher Hall, will review this form with you and you may sign it if you agree to everything on the form. However, you may also read it through with someone you trust to make sure you understand everything.

You understand that this study involves video and audio taping interviews and discussion groups. Neither your name nor any other identifying information will be associated with either videotapes, audiotapes, or transcripts. Only the researcher, Christopher Hall, will be able to listen or watch the tapes.

You understand that the tapes will be transcribed by the researcher and erased once the transcriptions are checked for accuracy. Transcripts of your interview may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither your name nor any other identifying information (such as your voice or picture) will be used in presentations or in written products without explicit written consent.

You further understand that immediately following the interview you will be given the opportunity to have the tape erased if you wish to withdraw your consent to participate in the study.

By signing this form you are consenting to:
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<table>
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<tbody>
<tr>
<td><strong>Having your interview recorded</strong></td>
<td></td>
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<tr>
<td><strong>Allowing interview sessions and discussion groups to be audiotaped</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Allowing interview sessions and discussion groups to be videotaped</strong></td>
<td></td>
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<tr>
<td><strong>The researcher taking notes</strong></td>
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</tbody>
</table>
By signing this form you are consenting to participate in each procedure listed above. You understand that you may withdraw your consent at any time, for any reason.

The above permissions are in effect until the following date: December 16, 2020
Signature: ________________________________

Date: ______________________________________

Researcher: ________________________________

UMass Boston
IRB Approval:
SUBSTANTIALLY SILENT: LISTENING TO THE “VOICES” FROM THE MARGINS
Christopher Hall UMass Boston Department of Leadership in Education

Participant Consent

This study involves the audio taping (videotaping) of your interviews with the researcher. Neither your name nor any other identifying information will be associated with the audiotape (videotape) or the transcript. Only Christopher Hall will be able to listen (view) to the tapes.

The tapes will be transcribed by the researcher and erased once the transcriptions are checked for accuracy. Transcripts of your interview may be reproduced in whole or in part for use in presentations or written products that result from this study. Neither your name nor any other identifying information (such as your voice or picture) will be used in presentations or in written products resulting from the study.

Immediately following the interview, you will be given the opportunity to have the tape erased if you wish to withdraw your consent to taping or participation in this study.
By signing this form you are consenting to:

- having your interviews taped;
- having the tape transcribed;
- use of the written transcript in presentations and written products.

By checking the box in front of each item, you are consenting to participate in that procedure.

This consent for taping is effective until the following date: December 16, 2020

Participant’s Signature __________________________

Date __________

UMass Boston
IRB Approval:
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364


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