Health and Well-being Perspectives of African American Learners with Emotional Disturbance

Labels: Opportunities for a Population Health Reframing of Special Education

Disproportionality

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# Disproportionality

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#### Abstract

Special education disproportionality, or the over-identification of African American students with an Emotional Disturbance (ED), remains a persistent education issue, with adverse effects on African American learners' life outcomes. Once labeled, African American learners are at an increased risk for disciplinary referrals, low educational attainment, and entrance into the correctional system. Multiple revisions to special education policy (i.e., IDEA) have occurred to address these racial disparities and inequities. However, the ineffectiveness of these policy changes indicated a need to reframe special education disproportionality. This study explored the health and well-being experiences of African American, ED learners to inform a future population health reframing of special education disproportionality. Exploring this possibility was integral to understanding overrepresentation of African American, ED learners given the high concomitance rates between emotional disorders and chronic health conditions. This study used a multi-case study design to center African American, ED learners' voices and exploring the role of health and well-being on their high school academic self-perception, their involvement with the special education system, and their awareness of racism and ableism in the design of their health and education spaces. Using a cross-pollinated version of Universal Design for Learning (UDL), intersectionality, and Disability Critical Race Theory (DisCrit) and analysis was performed on participant data, resulting in five major findings:

- 1. Participants, educational, healthcare, and familial stakeholders prioritized some health and well-being dimensions more than others.
- 2. Participants of this study experienced some form of untreated, acute trauma before receiving their ED classification and services.

- Participants had to relinquish their autonomy to utilize the supports of the institutions labeling them, which was perceived as both beneficial and disempowering by participants.
- 4. Participants were unable to name the racism and ableism in the lived experiences, specifically how these intersecting oppressions affected their educational trajectory.
- 5. Participants were aware of how their special education labels altered the design of their special education settings, in both stigmatizing and empowering ways.

Based on these findings, practice, policy, and research recommendations were made to support a future health and well-being reframing of special education disproportionality. First, it was recommended that the education and health sectors adopt the Whole School, Whole Community, Whole Child Model to ensure a balanced approach to the dimensions of health and well-being. Secondly, the introduction of an Adverse Childhood Experiences (ACEs) category into IDEA was recommended to re-situate deficit in the system rather than the learner. Finally, to efficiently and cost-effectively address the communication gap between health and education stakeholders, digital health technology adoption was recommended.

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#### Chapter 1

Chronic absenteeism or missing 10% or more of school days for an excused or unexcused reason has negative academic consequences, including missed learning opportunities, decreased social interactions with peers, and eventually, the potential of poor academic performance and failure (National Collaborative on Education and Health, 2015). In the 2015-16 school year alone, over 7 million students, or 16% of the student population, missed 15 or more school days (Office for Civil Rights [OCR], 2016). Especially problematic was that certain racial/ethnic groups experienced chronic absenteeism at higher rates than others, with African American students 40% more likely to lose three or more weeks of school compared to their White peers (OCR, 2016). Moreover, students with disabilities were approximately 1.5 times more likely to be chronically absent than students without disabilities (OCR, 2016). Finally, more than 20%, or 1 in 5, high school students were chronically absent compared to 14% of middle school students (OCR, 2016).

Chronic absenteeism was attributed to factors such as poor infrastructure, unsafe environmental conditions, inaccessible healthcare and transportation, all of which tend to converge in disadvantaged communities (OCR, 2016; Pulcini et al., 2017). Although there was not a causal relationship established between chronic absenteeism and environmental factors associated with poverty, it is telling that these same communities also experience higher rates of chronic health conditions, such as diabetes and asthma. In America, the race-wealth gap economically disadvantages African Americans, who are placed in an even more troubling position because of the association between poverty, health, and lack of exposure to educational opportunities (Chetty et al., 2020). The complex interaction between race, education, and health warrants increased interdisciplinary collaboration between researchers, policy makers, and

practitioners to make tangible, long-lasting change for African American learners in the United States public education system.

In this chapter, I presented: (a) a brief background of disproportionality<sup>1</sup>, including the role of medicine in establishing the racialized practices that undergird the issue; (b) the ineffectiveness of existing disproportionality legislation to mitigate its impact; and (c) the failure of disproportionality discourse to discuss the role of health and well-being in the overidentification of African American learners into special education. I then argue for a health and well-being perspective to reframe disproportionality in special education based on the collective use of Maslow's Hierarchy of Needs, Labeling Theory, Universal Design for Learning (UDL), Intersectionality, and Disability Critical Race Theory (DisCrit). Specifically, I utilize them to argue that health and well-being is a basic, unrecognized need that is not designed for in learning environments, and thus, becomes a normative standard used to oppress historically marginalized learners. Furthermore, I present a set of research questions that center the intersecting ableist and racist experiences of African American learners at the heart of the disproportionality discourse, while also positioning my personal experiences in relation to the topics being studied. Finally, I recognize potential assumptions and limitations that restrict the scope of this study and its findings.

<sup>&</sup>lt;sup>1</sup> At times in this dissertation I utilized terminology, such as "Mental Retardation", because it was terminology referenced in literature from a time period before these terms were deemed legally or socially unacceptable to use. However, I did recognize that with Congress' passage of Rosa's Law in 2010 terms such as "Mental Retardation" became "Intellectual Disability" because of the negative connotation associated with using "mental retardation" (GovTrack.us., 2019). Additionally, while I recognized that the current terminology in use by Individuals with Disabilities Education Act (IDEA, 2004) is Emotional Disturbance (ED), the terms Serious Emotional Disturbance (SED) and Emotional Behavioral Disability (EBD) will be used to acknowledge temporal and organizational-level variance in categorical definitions (Dickel & Stewart, 2011).

#### **Background of the Problem**

To understand the enduring and complex interaction between race, education, and medicine it is important to recognize the extent to which their origins are interconnected. Racism was pervasive in the early works of medicine. The medical field experimented on African Americans without their consent and utilized their research findings to bolster societal belief in their cognitive inferiority (Washington, 2006). Physiological studies comparing cranium sizes from individuals of different racial/ethnic backgrounds produced supposedly objective findings that demonstrated the intellectual inferiority of African Americans and bolstered Darwinian claims to justify their low social rank (Newitz, 2014). Medical research actualized the beliefs purported by early scientific racism with equally unjust and unethical practices. This included incidents that ranged from testing early gynecological tools on free African American females, without their consent or the use of anesthetic during these tests, to the denial of therapeutic treatment in the Tuskegee Syphilis Study (Center for Disease Control and Prevention [CDC], n.d.; Scharff et al., 2010; Washington, 2006). This exploitation not only contributed to African American distrust of the medical system to provide quality care to their community, but also a lack of confidence in the medical field's ability to be transparent with historically marginalized communities (Washington, 2006). More concerning, however, was when medicine's supposedly objective knowledge base became utilized as the basis for discriminatory practices across other American institutions, such as education (Scharff et al., 2010).

The field of education utilized early findings from medicine to justify racial segregation of the public schools, and unequal distribution of resources, until the Brown v. Board of Education (1954) ruling legally required desegregation of American public schools. Although the Brown ruling (1954) was meant to increase access to all-White schools for African American

learners, it did not lead to a more equitable school system. Instead, it led to a legitimization of ability tracking, which allowed segregation era racial/ethnic inequities and disparities to continue, particularly in the identification of specific racial/ethnic groups for special education categories (Annamma, Connor, et al., 2013; Artiles & Trent, 1994; Connor & Ferri, 2005; Kozleski, 2007; Sleeter, 2010; Smith & Kozleski, 2005). More worrisome than medicine's dayto-day impact on the institution of education, however, was its role in the philosophical schism between a positivist and a social constructivist understanding of disability. From a medical perspective, disability was binary, with individuals labeled either able-bodied or dis-abled and differences perceived as deficiency within the individual (Artiles, 2013). A sociocultural approach, however, proposed that disability was socially and culturally contextualized and situated along a continuum, or you were only as disabled as the constraints and affordances allowed by your environment (Annamma, Connor, et al., 2013). Additionally, a socially constructed understanding of disability acknowledged corporeal differences in individuals but recognized that human response was what positioned some differences as disadvantageous compared to others (Annamma, Connor, et al., 2013). Whereas the medical model presented disability as fixed, a sociocultural understanding of disability presented it as temporally bound, with individuals identifying and dis-identifying as disabled at different developmental points in their lives. In other words, the medical model portrayed disability as a permanent state that could not be improved, whereas a social constructivist approach portrayed it as contextually situated, and thus, subject to change.

# Race and America's Special Education Categories

As ability tracking became the new means to maintain the racial/ethnic segregation in American public schools, disproportional representation of specific racial/ethnic groups in

certain special education categories became an issue (Annamma, Connor, et al., 2013; Artiles & Trent, 1994; Connor & Ferri, 2005; Kozleski, 2007; Sleeter, 2010; Smith & Kozleski, 2005). When segregation efforts in schools gained momentum in the mid-1960's, minority students entered predominantly white school systems, and were viewed as underperforming compared to their White peers. As a result, they were again segregated into special programs, with differentiated instruction used to meet the needs of "like grouped students", but also maintain a school system that privileged the needs of White learners. Four historic categories that were used to separate low-income and minority students who were not performing to expected standards, from White middle-class students were Mentally Retarded (MR), Slow Learner (SL), Emotionally Disturbed (ED), and Culturally Deprived (CD). MR included children who scored below 70-75 on an IQ test and could be attributed to organic causes, but the majority of students labeled as MR were deemed "cultural-familial retardees" (Dunn, 1963), which meant their condition was a result of a cultural deprivation (e.g., lack of parental value for education) in their home environments. SLs' included children who scored between 75 and 90 on IQ test and was also attributed to cultural deficiencies. While mental health specialists categorized ED children according to clinical criteria (i.e., psychoses, psychophysiological disturbances, psychoneuroses, personality disorders), educators viewed them as behaviorally disruptive children (Dunn, 1963). CD children were those who were not retarded, slow learners, or emotionally disturbed but still had learning difficulties that could be attributed to their environmental conditions. Most White students were able to avoid these labels, despite similar symptomology, until academic standards of achievement were raised. With the increased standards, more White students were at risk of school failure and their parents could not risk their difficulty with learning reflecting upon their

home environment (Sleeter, 2010). Therefore, they advocated for the new learning disability category.

A Learning Disability (LD), according to the National Advisory Committee on Handicapped Children (1968), is specific to "listening, thinking, talking, reading, writing, spelling, or arithmetic" skills, and thus, diagnosing the disorder has required the administration of a standardized reading, math, or oral language test, as long as the disorders cannot be attributed "to visual, hearing or motor handicaps, to mental retardation, emotional disturbance or to environmental disadvantage" (as cited in Sleeter, 2010, p. 229). Although both mental retardation and learning disabilities impact learning, Kirk (1972), distinguishes between the two by noting that mental retardation is a general difficulty with learning, whereas LD is a difficulty with a specific aspect of learning. Sleeter (2010) argues that the category of learning disability emerges from the competitiveness of the Cold War Era, in the late 1950's and early 1960's, created changes in schools that negatively impacted learners whose achievements was relatively low. LD category appears scientifically sound because it was created under the deceptive ideology of individual differences and biological determinism. The LD category was perceived as having organic origins because it was based on Cruikshank's findings about the impact of neurological impairments on learning. Attributing learning differences to organic origins suggests that the issue can be isolated to a treatable area, whereas other special education options for students with learning difficulties were attributed to cultural, environmental, and individual deficiencies

In other words, because they could be perceived as treatable, learning disabilities could be "overcome" with appropriate pedagogical strategies or medical treatment. Educators believe that categorization of children not only accurately reflect their learning differences, but also that

such sorting enables them to better instruct these learners. However, reliance on these categories to make pedagogical choices reveals our implicit support for the school's role in accommodating society's changing economic values and accompanying labor needs. Kirk and Chalfant (1984) proposes that parents advocated for an LD category because they did not see their children as mentally retarded and refused to have them placed in classes for the mentally retarded.

Additionally, schools did not provide reading or language interventions for students with serious reading or language needs unless the child was identified for special education services. Sleeter (2010), however, has argued that White middle-class parents advocated for the creation of the LD category to distinguish their low achieving White children from low achieving minority students. If their children's low achievement could be attributed to a learning disability then these White learners could avoid the consequences of disability labels typically assigned to other non-White achievers during the 1970's (e.g., mentally retarded).

# **Disproportionality**

The racialization of ability tracking gave rise to the interminable issue of disproportionality, or the over- or under- representation of a specific population or racial/ethnic group in special or gifted education programs compared to their overall representation in the public-school system (National Association or Bilingual Education, 2002; National Education Association & National Association of School Psychologists, 2007; Artiles & Trent, 1994).

Occurring at different levels (i.e., national, state, district) and in various forms, such as level of setting restriction and segregation, racial disproportionality reports were first published by Lloyd Dunn (1968), when he noted that 60% to 80% of students in day classes for mild and mental retardation (MMR) were from "low-status backgrounds", specifically minority ethnic groups and low socio-economic status (SES) groups. Although the issue remained at the forefront of special

education discourse, it was not examined on a national scale until Jeremy Finn (1982) utilized the *Elementary and Secondary School Civil Rights Compliance Report data* to note both overand under- representation of different ethnicity minority groups. Finn (1982) found that African American students were overrepresented in both classes for MR and ED, Native American students were overrepresented in learning disability (LD) classes, and Asian American students were underrepresented in almost every category.

Since the recognition of disproportionality as a special education issue (Dunn, 1968),
African American overrepresentation in special education has persisted (Skiba, Simmons, et al.,
2008), resulting in both a decrease in the number, and quality, of their learning experiences
(Donovan & Cross, 2002; Harry & Klingner, 2006; Losen & Orfield, 2002; Wells et al., 2003).
The effects of labeling and segregating learners into less effective learning settings increase their
likelihood of disciplinary referral, future incarceration, and lower educational attainment
increases (Hosp & Reschly, 2002; Kozleski & Smith, 2009; Skiba, Michael, et al., 2002; Skiba,
Simmons, et al., 2008). As a consequence of these negative effects, labeled African American
students are not consistently present in their learning space, and inevitably receive fewer
educational opportunities.

#### **Theoretical Framework**

This study borrowed from Maslow's Hierarchy of Needs, Labeling Theory, and a crosspollinated version of UDL, intersectionality, and Disability Critical Race Theory (DisCrit; Annamma, Connor, et al., 2013; Goffman, 1963; Maslow, 1943, 1954). First, Maslow's Hierarchy of Needs provided a premise for focusing on health and well-being. Secondly, Labeling Theory was offered as support for reframing special education disproportionality, with an interdisciplinary approach mitigating the use, and negative effect, of redundant labels across

the medical and education sectors. Finally, a crosspollinated version of UDL, intersectionality, and DisCrit was offered as a critical and emancipatory analytical lens, with which participant voices could be textualized in a manner to inform new understandings of special education disproportionality. Following is detailed explanation of each of these theories and the ways in which they relate to the focus of this study.

## Maslow's Hierarchy of Needs

Maslow's (1954) hierarchy of human needs posits that human motivation can be explained by the relationship between deficiency and growth needs, with the former explained as lower level needs and the latter of higher-level needs. Deficiency needs include: (1) physiological, such as hunger or thirst; (2) safety/security or staying out of danger; (3) belongingness and love: affiliate with others and be accepted; and (4) esteem or to achieve, be competent, gain approval and recognition. Growth needs include: 5) cognitive or the ability to know, to understand, and explore; 6) aesthetic appreciation for symmetry, order, and beauty; 7) self-actualization, or attempting to find self-fulfillment and realize one's potential; and 8) self-transcendence, or to connect to something beyond the ego or to help others find self-fulfillment and realize their potential. While each level of deficiency needs must more or less be met before moving to the subsequent level, growth needs can only be pursued once deficiency needs are satisfied. Moreover, if a deficiency need becomes unsatisfied at some point in the future the individual will have to address those needs before focusing fully on growth needs.

This study's proposed reframing of disproportionality from a health and well-being perspective is premised on Maslow's (1954) hierarchy of needs. Specifically, I posit that health and well-being is a basic, lower level need akin to safety. According to Maslow (1954), the health-safety connection is most evident in infants in whom illness seems to make

to make the child feel unsafe. For instance, vomiting, colic, or other sharp pains seem to make the child look at the whole work in a different way. At such a moment of pain it may be postulated that, for the child, the appearance of the whole world suddenly changes from sunniness to darkness, so to speak, and becomes a place in which anything at all might happen, in which previously stable things have suddenly become unstable. Thus, a child who because of some bad food is taken ill may, for a day or two develop fear nightmares and a need for protection and reassurance never seen in him before his illness (Maslow, 1943, p. 377).

In other words, chronic illness can leave a child with a sense of anxiety because it makes the world appear to be unjust, unpredictable, and unsafe (Maslow, 1943). Moreover, without a consistently positive state of health and well-being an individual cannot achieve enough of a sense of security to pursue growth needs, and eventually achieve self-actualization and self-transcendence. Translated for the educational context, as long one's health as these needs are even minimally unsatisfied the individual will not be able to develop their higher-level growth needs (Alderfer, 1972). Included in these higher-level growth needs is the capacity to be engaged in a learning experience, with the health and wellness of a learner integral to their ability to self-actualize. In other words, individuals with chronic health conditions that do not have access to the high-quality resources needed to effectively manage their health and well-being in learning settings will be challenged to focus on physiological needs instead of concentrate on being problem-focused and/or optimize their own personal growth experiences.

## **Labeling Theory and Stigma**

Stigma is the consequence of external factors exerted onto an individual, resulting in the incommensurate distribution of power that leads to labeling, separating, stereotyping,

discrimination, and status loss to a specific individual and/or group (Link & Phelan, 2001; Major & O'Brien, 2005; Thornicroft et al., 2007). Self-stigma, however, may be inflicted by the individual onto themselves due to the perception that they are rejected because of their personal traits (Link & Phelan, 2001; Tucker et al., 2013). According to labeling theory, both stigma and self-stigma increase as a result of the label assigned to an individual or group (Goffman, 1963; Link & Phelan, 2001). This particularly happens when labels are used to distinguish specific individuals and groups from socially accepted norms, and negatively influence their self-identity and behavior (Goffman, 1963; Link & Phelan, 2001). Moreover, according to Annamma's (2018) *hyper-labeling* these assigned labels may be formal, but can also be informal, and often act in compounded ways to name the multiple, societally unaccepted aspects of an individual's identity, such as their race or disability. In this study, I posit that reframing disproportionality from a health and well-being perspective is one way to address the *hyper-labeling* found in special education.

IDEA's (2004) special education categories, particularly those associated with negative life outcomes for specific racial/ethnic groups, unnecessarily created new labels for students in an effort to contextualize existing medical, psychiatric, and psychological criteria for disabilities within learning contexts. While some hyper-labeling, or the creation of redundant formal labels, occurred to contextualize learner needs for the education environment other hyper-labeling occurred to meet perceived socio-cultural demands. For example, although both White and Black learners met the criteria for ED identification, White learners were often identified for the newly created LD category that was designed to "protect White families" (Sleeter, 2010). Subsequently, the special education identification categories became one more formal mechanism to "other", or marginalize and oppress, students that were already being "othered" by society. In the example

above, White students in the LD category were less susceptible to the increased disciplinary referrals Black students in the ED category experienced (Hosp & Reschly, 2002; Kozleski & Smith, 2009; Skiba, Michael, et al., 2002; Skiba, Simmons, et al., 2008).

Rather than appropriate the criteria for various disability categories and rename them, special education should reduce potential for stigma by using the label from other sectors and make distinctions for the learning context in the category's criteria. Not only would this improve clarity for cross-sector service provision and policy change collaboration, but it would allow for the reframing of long-standing issues in special education, such as the health and well-being reframing of disproportionality proposed by this study.

# Cross-pollinated UDL, Intersectionality, and DisCrit

The UDL framework was inspired by the architectural concept of universal design, which proposed that the initial designs of a building should account for the most diverse range of user needs, since retrofitting buildings to accommodate newly identified needs proved to be costly. Similarly, the UDL framework proactively designs curricula to remove barriers to learning. In doing so, it aims to improve instructional accessibility by providing learners with multiple means of representing content, engagement, and expressing their expertise (Center for Applied Special Technology [CAST], 2011; Edyburn, 2010; Meyer et al., 2014). To create such diverse learner pathways UDL leverages the adaptive capabilities of digital technology to support student personalization of their learning experience.

UDLs' capacity to support flexible and personalized pedagogy counters a single, onesize-fits-all approach to learning and indicates its' potential as an emancipatory tool (Bhattacharya, 2017). However, its existing literature base reveals a contradictory reality, with little recognition of categorial identifiers or the oppressions associated with them. For instance, in a literature review conducted by Ok et al. (2016), about the academic and social impact of UDL based instruction, it was found that categorical identifiers, such as race/ethnicity and SES were often not accounted for despite being integral to *designing to the edges* Sailor (2015). Specifically, of the 13 studies selected for review, only 6 reported complete data about the ethnicity of participants and 8 studies did not provide socioeconomic status (SES) data for participants. These findings supported Rao et al.'s earlier (2014) recommendation for disaggregated data, emphasizing the collection of specific demographic data for participants to understand the comparative effect of UDL-based instruction for different learners. In other words, use of UDL alone lacks the criticality necessary to proactively design for intersecting oppression and achieve its emancipatory potential (Crenshaw, 1989; Bhattacharya, 2017; Waitoller & King-Thorius, 2016).

# Cross-pollination of UDL with Intersectionality and DisCrit

By omitting demographic identifiers, the extant UDL literature base also does not acknowledge the real-world, intersecting oppressions that accompany these identifiers (Crenshaw, 1991). For example, by not recognizing the race or gender of participants in UDL studies, the implementation process did not account for the intersecting oppressions of racism and sexism. However, this study's' cross-pollination of UDL with Crenshaw's' (1989) understanding of intersectionality would address this gap by accounting for the design needs of the multiply-disadvantaged. In doing so, UDL is now capable of addressing learner variation resulting from systemic inequities, and decentralize dominant ableist practices (Bhattacharya, 2017; Sailor, 2015; Waitoller & King-Thorius, 2016). Moreover, it would hold UDL accountable for fostering systems and institutions that are protective and empowering (Erevelles & Minear, 2010).

I drew on DisCrit to recognize the disconnect between fields, in this case health and well-being and education, whose interests converge but have been unable or unwilling to bridge this gap to benefit African American communities (Annamma, Connor, et al., 2013). DisCrits' seven tenets supported a macro and micro-level analysis of the historical, political, social, and economic interests that sustained this gap (Annamma, Connor, et al., 2013). This study focused on tenets one, two, four, six, and seven to expound upon this gap and call for a range of resistance grounded in voices and interests of hyper-labeled African American learners.

In situating this study in a DisCrit framework, I utilized DisCrit's Tenet One to shift the discourse from a single sector understanding of inequities to a multi-sector one. I demonstrated how medical and education institutions functioned invisibly and interdependently to uphold ideas of normalcy in the classroom (Annamma, Connor, et. al, 2013). Utilizing what Annamma (2018) calls hyper-labeling, both institutions formally and informally label learners in ways that name the multiple, societally unaccepted aspects of their individual identity, such as their race or disability. Tenet Two's conceptualization of identities as multi-dimensional allowed me to recognize that health and well-being is often overlooked as an aspect of identity. Further, it is a dimension of identity that is held to society's normative standards and is critical to understanding the oppression associated with ableism in education settings. Utilized in conjunction with the principles of UDL, which supports proactively designed curricula for learners in the margins, it provides one more design consideration for the creation of a more inclusive and flexible learning space (CAST, 2011; Edyburn, 2010; Meyer et al., 2014). Tenet Four prioritized the perspectives of hyper-labeled African American learners, to center the affordances and constraints they encountered in the classroom at the nexus of racism and ableism. Joined with UDLs' intention to design to the edges (Sailor, 2015) by addressing a diverse range of learning needs rather than

those of the average learner, this study's focus de-bunks the idea of the average learner and decentralizes dominant ableist practices (Bhattacharya, 2017). Tenet Six's recognition of whiteness and ability as property, supports an understanding of the tangible political, social, and economic benefits attributed to white normative health priorities. For example, the medical findings, established from white participant pools, dictate the hospital birthing standards for African American mothers, increasing their mortality rates (CDC, 2018a; Hogue & Bremner, 2005). Finally, Tenet Seven supports this study's' proposals for resistance through academic means and pedagogical tools (i.e., cross-pollinated UDL)

#### **Statement of the Problem**

Federal laws intended to protect students with disabilities from discrimination include Section 504 (1973), the IDEA (1975), and Title II of the American Disabilities Act (1990).

Ideally, these laws collectively created more equitable special education services and outcomes for students who had identified, and unidentified, disabilities. While both federally funded, Section 504 (1973) and IDEA (1975) served different purposes, with the former protecting the rights of individuals with disabilities in programs receiving financial assistance from the US Department of Education and the latter providing financial assistance to state and local agencies that delivered special education services to eligible children with disabilities. Although not federally funded, Title II of ADA (1990) also prevented discrimination based on an individuals' disability status, but on a state and local level, and when and individual sought employment or the use of public services. Despite these legislative protections, and subsequent amendments to improve their efficacy, inequities, and disparities for racial/ethnic minorities have persisted.

Disproportional representation of African American students in special education categories with the most negative cultural implications continued, despite local and national recognition of the

issue (Dunn, 1963, 1968; Finn, 1982; Skiba, Simmons, et al., 2008; Sleeter, 2010). To date, federal and state policy remains focused on refining reporting mechanisms that monitor the representation of specific racial/ethnic groups in certain special education categories, rather than identifying and addressing factors contributing to the over-identification of these groups for the special education categories they are over- or under- identified into.

The multiple reauthorizations of IDEA (1997, 2004) inadvertently acknowledged the shortcomings of existing protective measures included in previous special education legislation, with each new iteration attempting to mitigate the impact of disproportionality through new identification methods (Albrecht et al., 2012). In both the 1997 and 2004 reauthorization of IDEA the federal government accounted for disproportionality on the state and local level by including numerical monitoring indicators, which accounted for the classification, placement, and suspension of students with disabilities by race and ethnicity. Although the 2004 reauthorization of IDEA (2004) continued to prioritize the previous emphasis on monitoring and enforcement, it also included important provisions about mandatory interventions and the allocation of 15% of the district's IDEA funds for early intervention services in cases where racial/ethnic disproportionality was recognized as integral to identification, placement, or discipline (Government Accountability Office [G.A.O.], 2013; Skiba, 2013). However, these changes were made on a federal level. On a state and local level, the IDEA accountability standards proved to be ineffective, with State Educational Agency (SEA) and Local Educational Agency (LEA) interpreting them in ways that circumvented their intended purpose (Albrecht et al., 2012). The range of understandings by SEAs and LEAs indicated a need for clarifying regulation and policy rulings, particularly in relation to calculating the numerical criteria used to determine state disproportionality thresholds. The measurement inconsistency, or whether states

used a risk ratio or weighed risk ratio, resulted in states underreporting disproportionality in special education; because they had set such high threshold criteria that achieving compliance was not difficult (Bollmer et al., 2007). Furthermore, their calculations were done on a statewide level, neglecting to recognize differences in disproportionality between local districts. Therefore, any protective measures in IDEA to hold LEAs and SEAs accountable for disproportionality were undermined. As a result, unless these policy weaknesses are resolved or disproportionality is reframed, it will remain a significant issue in special education (Albrecht et al., 2012).

To conclude, special education disproportionality has persisted because discourse has concentrated on policy or debating the existence of the issue. Policy has focused on the extent to which disproportionality exists on a national, state, and local level. Academia, on the other hand, has been engaged in a continuous debate about whether the disproportionality issue is the overrepresentation or underrepresentation of minorities in certain special education categories (Morgan et al., 2015; Skiba, Artiles, et al., 2016). Moreover, disproportionality research has prioritized the voices of all educational stakeholders (e.g., teachers) except for the racial/ethnic groups whose voices could offer new insights into the issue, such as African American ED learners (Waitoller et al., 2010).

## **Purpose of the Study**

Racial inequities and disparities, as well as a history of abuses against marginalized communities, is rife throughout the history of medicine. In fact, the field of medicine used their so-called objective knowledge to portray marginalized groups as deficient, while also using these same groups to advance the field (Burke & Castaneda, 2007; Washington, 2006; Annamma, Connor, et al., 2013). Medicine was used to segregate and disempower the African American community, by portraying their differences from white normative standards as disability

(Annamma, Connor, et al., 2013). Consequently, medicine and special education have had a contentious past, with the formers' history of deficit-based thinking limiting the latter's' capacity to explain disability as a biopsychosocial construction. However, newer, socially constructed understandings of *health and well-being* provide opportunities to overcome this division and collaboratively address persisting issues of racism and ableism in both fields. These socially constructed understandings offer a new means to reframe issues such as disproportionality, which have persisted despite multiple efforts to address the problem with reauthorizations of IDEA (1997, 2004; Albrecht et al., 2012; G.A.O., 2013; Skiba, Simmons, et al., 2008; Skiba, Artiles, et al., 2016).

Since its introduction, disproportionality discourse has centered on whether the issue is overrepresentation (Dunn, 1968; Skiba, Artiles, et al., 2016) or underrepresentation (Morgan et al., 2015) of African American students in special education, the impact of biased teacher perception on the increased referral for special education services that African learners encounter (Neal et al., 2003; Podell & Soodak, 1993), and the most appropriate point of intervention during the referral or evaluation process (Dever et al., 2016; Utley & Obiakor, 2012). Moreover, scholars such as Turnbull et al. (2007) have argued that the increasingly stratified disability classification system of IDEA (2004) is discriminatory in itself and promotes the "othering" of African American learners in the ED category because it is a socially constructed means to acquire more political, social, and economic control. However, the role chronic health conditions, among ED learners, play in their over-identification has been under-explored, despite the critical disqualifying role health symptoms should play before labeling students as ED (IDEA, 2004).

With high rates of certain chronic health conditions among African Americans accompanied by adverse psychological outcomes, I argued that the symptoms of this comorbidity were being misinterpreted as educational deficits in classroom settings established on ableist and racist norms (Annamma, Connor, et al., 2013; Byles et al., 2013; Combs-Orme et al., 2002; Egede & Dismuke, 2012; Gariepy et al., 2009). For example, the lethargy resulting from an asthmatic exacerbation may be misperceived as inattentiveness, at best, or intellectual deficiencies, at worst, in a learning setting (Donovan & Cross, 2002; Thies, 1999). In other words, the deficit was situated in the learner, resulting in short-term treatments.

This study served two purposes. First, it centered the voices of African American, ED learners at the center of the persistent overrepresentation issue. In prioritizing their voices this study gained new understandings of their health and well-being perceptions, particularly in relation to their learning experiences and interactions with the special education system. Secondly, these prioritized voices offered opportunities to change practice, policy, and research that could support a health and well-being reframing of disproportionality. Borrowing from population health, this reframing would focus on environmental factors impacting the health and well-being of specific groups, the interaction between these factors, and the policy implications of outcomes for these specific groups (Kindig & Stoddart, 2003).

## Significance of the Study

The medical and health field has previously recommended a unified systems approach to address the health behaviors and academic achievement of adolescents (Bradley & Greene, 2013). For example, the Department of Health and Human Services (DHHS) and Office of Disease Prevention and Health Promotion's (ODPHP) "National Action Plan to Improve Health Literacy" (2010) made it standard practice for health care professionals that served children and

adolescents to ask about academic achievement (e.g., grades, attendance) when collecting information about health histories. Additionally, the ODPHP's (2010) health literacy plan recommended interagency coaction steps to improve health literacy based on the National Health Education Standards, or an assessment of K-12 students' health literacy skills within the context of their educational setting. However, while an improvement in the joint efforts between the health and education sectors, the reports' recommendations continued to perpetuate medicines' historic racial disparities with no explicit steps for improving health or education outcomes for racial/ethnic groups historically discriminated against across both sectors. Furthermore, despite its call for a unified system it did not include key educational stakeholder, such as teachers, parents, and community organizations. Consequently, it continued to skew leadership and communication in favor of health stakeholders, and in reality, made little change to the existing system. Despite the shortcomings of this effort, this study used the voices of African American, ED learners to explore the possibility of an interdisciplinary reframing of special education disproportionality, but one founded in population health (Artiles, 2013; Kindig & Stoddart, 2003).

In utilizing African American, ED learners voices to inform a population health reframing of special education disproportionality, this study shifted the disproportionality discourse away from deficit-based conceptualizations of these learners. Instead, this study's reframing explored the underlying structural, causal mechanisms for the disproportional representation of specific racial/ethnic groups, particularly in relation to social determinants of health (Kindig & Stoddart, 2003; ODPHP, 2014). In other words, this study proposed that shared shortcomings between the medical and education systems, specifically a common reluctance to attribute behavioral differences to cultural mismatches within and between systems, pushed

learners from certain racial/ethnic groups into detrimental special education classifications (Graham et al., 2011). For example, African Americans are at an increased risk for chronic health conditions, such as asthma (Pulcini et al., 2017). Ineffectively managed asthma, a failure of the medical system, resulted in approximately 10.5 million absences from school and a failure of the education system, which then labels these learners as disinterested in schooling and in need of special education services (Skiba, Simmons, et al., 2008; Walter et al., 2015). Stated another way, the predominantly White teacher workforce perceive the academic capacity of racial/ethnic learners through their cultural norms, attributing deficiency to what may be cultural discrepancy (Donovan & Cross, 2002; Thies, 1999). To conclude, using the voices of African American, ED learners to explore complex interactions between determinants (e.g., medical care) and the social (e.g., income, education, employment, culture) and physical (e.g., classroom design) environments, provided opportunities to inform practices, policies, and research that could dismantle the systems working against positive life outcomes of these learners (Kindig & Stoddart, 2003).

#### **Research Questions**

How do the health and well-being experiences of African American, ED learners inform a population health reframing of special education disproportionality?

- How did health and well-being impact African American, ED learners' academic selfperception?
- How did normative expectations of health and well-being impact African American, ED
   learner involvement with the special education system?
- How did the design of education systems and spaces converged to reify the intersecting oppressions of racism and ableism?

#### **Researcher Positionality**

Qualitative research is a dialogical process in which participants are impacted by the presence of the researcher and their reaction to the presence of the researcher (England, 1994). Inevitably, researchers become data collection instruments in their research (Berger, 2013; Bourke, 2014). Consequently, according to positionality theory, researchers have multiple overlapping identities, each of which contributes a unique perspective to the meaning-making process (Kezar, 2002). This includes personal experiences, beliefs, and biases related to researcher choices and participant receptiveness to engaging with them (Berger, 2013; Bourke, 2014). In revealing their subjectivity the researcher also provides the reader with an informed lens to determine where their interests converge or diverge with the researchers' voice.

In this study, my points of commonality and divergence with my participants offer insight into how my multiple, overlapping identities informed the research process. Drawing from the Crenshaw's (1989, 1991) understanding of intersectionality and the DisCrit tenets, I highlight how my experiences afford me membership and non-membership in my participants' space. In sharing the health and education narratives of African American learners, I recognize my positioning at the intersecting oppressions of racism and ableism due to my own ethnic background, chronic health conditions, and their impact on my learning experience. Therefore, I am able to relate to their experiences with instructors adopting a deficit-based perspective of their disability label and intellectual capacity. I understood their exhaustion with, and eventual need to withdraw from, learning spaces where instructors could not conceive of intelligence existing in disabled bodies. As with my participants, this was most evident in predominantly white centered learning institutions. However, unlike my participants I do not remember having early experiences at the intersection of racism and ableism during my high school years.

Borrowing from DisCrit's Tenet Two, I was allowed to freely and safely develop a multi-dimensional identity, whereas they were not (Annamma, Connor, et al., 2013). Instead, my academic confidence and trajectory was influenced by testing into a predominantly Asian, gifted high school. In my high school, advanced placement and honors courses, teachers with doctoral degrees, and conducting rigorous empirical research was the norm. Additionally, individual difference was viewed as eccentricity instead of disability, allowing potentially stigmatizing disability labels to be cultivated into genius instead. Thus, I was protected from the negative consequences of being in white-centered, under resourced systems that may have labeled me as disabled.

Drawing from DisCrit's Tenet One, Three, and Six, I realize that my higher education experiences worked in invisible ways to reinforce the economic benefit of claiming whiteness and ability. Similar to my participants, I understood that resisting these invisible mechanisms resulted in a steep physiological and psychological toll. For instance, I expected my doctoral program to be what bell hooks calls *education as a practice of freedom* (1994, p. 207), in which all stakeholders aspired to create learning spaces with possibilities, rather than limitations, and transgress boundaries. However, I soon realized that the programs' measures of success and its' indoctrination processes were established in white narratives of what "diversity" and racial representation should look like. Like my participants, whose behaviors were often misperceived by white teachers, I learned that my "swag", my voice, and my experiences were not viewed positively in academia. Specifically, they did not imbue me with the social and behavioral markers of a successful academic. I was neither the self-deprecating woman of color, nor the jovial social butterfly, which seemed to be the only acceptable roles for me in an academic world still centered on whiteness (Gillborn, 2015). Moreover, the predominantly white gatekeepers

continued to center their narrative by maintaining control of membership into their spaces, only promoting the few racialized bodies that they deemed worthy from a community (Freire, 2000).

In response to my experiences, and borrowing from DisCrit Tenet Seven, I utilized my research agenda and service works as a form of academic resistance and activism (Annamma, Connor, et al., 2013). Much of my works were developed in direct response to the intentional and unintentional devaluation of my lived experiences as a woman of color in academia. While my participants enacted their own systems of resistance and activism, I recognize that they may not have had access to the support resources extended to me. Attending a higher education institution enabled me to access women of color mentors and leaders, who were better equipped to navigate the systems I was unfamiliar with. Their guidance allowed me to regain my voice, find confidence in my intellect again, and persist. More importantly, they reassured me that my experiences with institutional racism and ableism were commonplace, and thus, validated my experiences. This was in contradiction to white academics who discounted my experiences with racism as cultural misinterpretations or struggles with *imposter syndrome*. My participants may not have similar mentors to discuss institutional racism with them or validate their experiences, resulting in the internalization of negative perceptions of their ability. The dissonance between my perspective as a learner, and my programs' white and ableist expectations of a successful academic, inspired my research line of inquiry into the learning experiences of those at the intersection of ableism and racism. Specifically, I wanted to understand how the American public-school system, and stakeholders interacting with it, influenced the learning experiences of these learners, either expanding or constraining the future life opportunities.

#### **Conceptualization of Terms**

This section introduces and defines terminology in the study that is derived from interdisciplinary sources. I trace the progression of the following terms to demonstrate their shared usage across disciplines.

Ableism, at its root, is established on societal assumptions of normalcy, constructing some bodies as "unimpaired and abled" and others as "impaired or disabled", with the latter viewed as less than, different, and "Other" (Campbell, 2009; Hodge & Runswick-Cole, 2013). By *Othering* those with disabilities, ableism establishes a dichotomy that devalues the disabled and creates,

societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with nondisabled kids as opposed to other disabled kids, etc. In short, in the eyes of many educators and society, it is preferable for disabled students to do things in the same manner as nondisabled kids. (Hehir, 2002, p. 3)

In doing so, the ableist ideology reifies that it's better to subscribe to society's norms, and be viewed as superior, than contradict those norms and be Othered, resulting in a designation as inferior (Storey, 2007). Operating on a systematic level, ableism

oppresses people who have mental, emotional and physical disabilities. . . Deeply rooted beliefs about health, productivity, beauty, and the value of human life, perpetuated by the public and private media, combine to create an environment that is often hostile to those whose physical, mental, cognitive, and sensory abilities. . . fall out of the scope of what is currently defined as socially acceptable. (Rauscher & McClintock, 1996, p. 198)

Academic achievement borrows from the CDC's (2014) definition, and includes academic performance (i.e., class grades, standardized tests, and graduation rates), education behavior (i.e., attendance, dropout rates, and behavioral problems at schools), and subjective judgements of students' cognitive skills and attitudes (i.e., concentration, memory, and mood).

Chronic condition is defined as having

a biological basis that lasts or is expected to last for at least 3-12 months and is accompanied by one or more consequences: 1) limitations in routine day-to-day functioning; 2) reliance on compensatory modalities such as medications, special diets, and assistive devices; and 3) a need for services beyond routine medical care. (Thies, 1999, p. 393)

Disproportionality is either the over- or under- representation of a specific population in special or gifted education programs compared to their overall representation in the public-school system, resulting from the intersecting oppressions of racism, ableism, sexism, and classism (National Association or Bilingual Education, 2002; National Education Association & National Association of School Psychologists, 2007; Artiles & Trent, 1994). Inconsistency in disproportionality accounting measures may occur at different levels (i.e., national, state, district) and in various forms, such as degree of restriction in learning environment. Additionally, disproportionality may be evident in the excessiveness (i.e., intensity, duration, frequency) of disciplinary actions (e.g., suspensions, expulsions) levied against specific racial/ethnic groups.

Emotional Disturbance is a socially constructed category of disability under IDEA (2004), which excludes social maladjustment-unless it co-occurs with an ED identification-but includes schizophrenia (Bower, 1982). It is defined as a display of the following characteristics for a prolonged period of time, which adversely impacts educational performance:

- A) An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
- (C) Inappropriate types of behavior or feelings under normal circumstances.
- (D) A general pervasive mood of unhappiness or depression.
- (E) A tendency to develop physical symptoms or fears associated with personal or school problems. (IDEA, 2004)

While this remains the IDEA (2004) definition for ED, its use remains controversial, as evidenced by a range of terminology is use on a state level to describe the ED category, including Serious Emotional Disturbance (SED) and Emotional/Behavioral Disorder (EBD).

When initially created, the ED category was referred to as "Serious Emotional Disturbance," or SED, with its five characteristics derived from Bower's 1957 criteria for identifying "emotionally handicapped" California students in need of behavioral and emotional support services (Bower, 1981). Unlike Bower's original definition, however, the IDEA's SED category excluded students who were considered "socially maladjusted" from qualifying for special education services, as long as they did not meet the other criteria for ED, but included students with schizophrenia (Forness & Knitzer, 1992; Forness & Kavale, 2000; Merrell & Walker, 2004). While technical distinctions tried to be made between socially maladjusted and SED learners, with the former demonstrating a willful disregard for social-behavioral norms and the latter an inability to control their social-behavioral responses, some speculated that the "social maladjustment" exception clause was really included to prevent the high costs associated with serving students perceived to be "delinquent" and difficult to reach, rather than disabled

(Merrell & Walker, 2004). Moreover, the SED definition included in IDEA received criticism for using vague language open to a wide range of interpretations. This included its limiting criteria defined by *severity*, *duration*, and impact on the learner's *school performance* without defining the criteria for either three, resulting in subjective interpretations of their parameters, especially in understanding school performance to mean only academic outcomes (Forness & Knitzer, 1992; Forness & Kavale, 2000).

Given the contentiousness of IDEA's current ED definition it is not surprising that multiple attempts have been made to redefine it. This included attempts by the Council for Children with Behavioral Disorders (CCBD) and the National Mental Health and Special Education Coalition, both of whom created a draft of an amended Emotional/Behavioral Disorder (E/BD) definition to submit to Congress as an amendment to IDEA. Last minute concern about an influx of students that would qualify for special educations services under this new E/BD definition, however, led to a withdrawal of support from the National School Boards Association (NSBA, 1992). Consequently, the E/BD definition was posted in the Federal Register ("Invitation to Comment", 1993) to seek advice about changing the SED definition, where, despite garnered support for adopting of the new definition, the proposal was never conveyed to Congress. This proposed E/BD definition read as follows:

The term "emotional or behavioral disorder" means a disability that is characterized by behavioral or emotional responses in school programs so different from appropriate age, cultural, or ethnic norms that the responses adversely affect educational performance, including academic, social, vocational or personal skills; more than a temporary expected response to stressful events in the environment; consistently exhibited in two different settings, at least one of which is school-related; and unresponsive to direct intervention

applied in general education, or the condition of a child is such that general education interventions would be insufficient.

The term includes such a disability that co-exists with other disabilities.

The term includes a schizophrenic disorder, affective disorder, anxiety disorder, or other sustained disorder of conduct or adjustment, affecting a child if the disorder affects educational performance as described in paragraph (1). ("Invitation to Comment", 1993, p. 7938)

While Congress did not pass this new definition, some organizations such as Head Start adopted and modified it for their early special education intervention and referral purposes ("Head Start Standards", 1993). Additionally, to further complicate the special education process for learners with emotional and behavioral concerns, with the 1997 reauthorization of IDEA, the modifier "serious" was removed from the IDEA category name, changing it to Emotional Disturbance (Forness & Kavale, 2000). Consequently, by 1997, learners with emotional and behavioral concerns could continue to be labeled using the long-standing SED label, be labeled with the new ED label, or be identified under the new criteria of the E/BD label adopted by some organizations directing students into special education.

Health disparities and inequities are gaps in, or unequal distribution of resources, that adversely affect specific groups of people. These groups of people have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion (DHHS, 2010).

Health and well-being are conceptually joined for the purposes of this study. The use of the term health represents the ever-present role of institutional bureaucracy, which necessitates the labeling of individuals for diagnostic and billing purposes. Well-being is intended to capture the personal experiences of individuals as they navigate both institutional and non-institutional spaces. Neither experience, the institutional and the personal, is mutually exclusive. Therefore, the understanding of health and well-being is derived from the value-based understanding of health proposed by Badash et al. (2017) that recognized

- health as holistic, or inclusive of an individual's physical, mental, emotional, and social wellness,
- that integrated technology would be essential to delivering such a wide range of complex services to meet the totality of an individual's needs,
- the entire continuum of care, including disease prevention and management,
   comorbidities, complications, and contextual circumstances unique to the individual.

Intersectionality in this study draws from Crenshaw's (1989, 1991) conceptualization of oppressions associated with socially constructed identifiers, wherein she advocates for multiply disadvantaged groups to represent the singularly disadvantaged in order to restructure opportunity distribution (Crenshaw, 1989, 1991). Further, I emphasize Erevelles and Minear's (2010) inter-categorical/constitutive approach to identity markers, which focuses on the historical and social structures in which these categories are situated, rather than the categories themselves.

Race and ethnicity are used interchangeably in this study. I recognize that the term race has no scientific basis, and instead, racial categories "are human categories...have a history and are subject to change" (Bonilla-Silva, 2018, p. 8). While recognizing that race and ethnicity may

be socially constructed categories, I also acknowledge that they have accompanying social realities due to their role as socio-historical concepts meant to capture a specific set of social relations and historical context unique to America (Bonilla-Silva, 2018; Omi & Winant, 1994).

For example, in regard to this study, the use of the term African American as a racial/ethnic identifier is meant to convey the unique social and historical context in which African Americans experienced individual and institutional discrimination in the United States (Omi & Winant, 1994).

Racism, in America, is the result of systematic efforts to center the assumptions, beliefs, and practices of White people, or the normative experiences of Whiteness (Gillborn, 2015). This study borrows from hook's (1995) view of neo-colonial White supremacy to support our understanding of racism as a strategy of coloniality (Almeida et al., 2019), in which there was no need for a country to be conquered because "the space it sought to own and conquer was the minds of whites and blacks" (p. 109). Instead, white supremacy has been maintained in America by placing Whites in positions of authority in education and on jobs, which has resulted in African Americans "constantly and passively consuming white supremacist values both in educational systems and via prolonged engagement with mass media", allowing both African Americans and Whites to be exposed to, "a process of overt colonization that goes easily undetected" (hooks, 1995, p. 111).

#### Conclusion

Reframing of disproportionality in special education is critical given the endurance of the issue and the ineffectiveness of past policy attempts to address it. Despite the contentious past between medicine and special education, this study proposed a health and well-being reframing of disproportionality to improve the life outcomes for African American learners that are

overrepresented in the ED IDEA (2004) category. The reframing proposed by this study holds the potential to increase preventive efforts to address disproportionality, rather than continuing to focus efforts on debating the existence of the problem or its identification on a state and/or local level. Although a health and well-being reframing is unconventional, it is timely given the evolution of thought about the socially constructed nature of illness in the health and medical fields. Whereas medicine was once favored for its individually focused, diagnostic approach to treating illness, a health and well-being approach prioritizes holistic and preventive strategies for improving outcomes for specific sub-groups. These socially constructed health fields tailor strategies to address systemic disparities and inequities among certain groups, which would translate into a viable approach to remedying disproportionality in special education.

## Chapter 2

This study explored the intersecting health and learning needs of adolescent, African American learners with both an ED label and a chronic health condition in the classroom. Disproportionality in special education, specifically the overrepresentation of African American learners in the category of ED, has persisted despite federal policy meant to identify and address disparities in disability identification. Thus far, disproportionality discourse has prioritized policies and mechanisms that quantify the extent of the over- or -under-representation of specific racial/ethnic groups in certain disability categories. While a policy approach may be necessary to understand disproportionality on a governmental level, a reframing of the issue is necessary to extend the disproportionality discourse beyond its current focus on identification and monitoring (Albrecht et al., 2012 G.A.O., 2013; Skiba, 2013). This study offers such a reframing with a health and well-being perspective in order to present new approaches to address the overrepresentation of African American learners in the ED category of special education. In this chapter, a synthesis of literature is presented to demonstrate the extent to which health and wellbeing has been discussed in disproportionality literature-since medicine prioritized a socially constructed understanding of health and well-being with the Healthy People Initiatives of 2000 (Department of Health, Education, and Welfare [DHEW], 1979; ODPHP, 2017a, 2017b, 2017c).

To support the proposed health and well-being reframing of disproportionality, this chapter: (a) examines existing disproportionality research to understand recognized contributors to sustaining issue; (b) offers a synthesis of literature that constructs an understanding of what health and well-being entails in disproportionality literature, if such a conceptualization is offered; (c) and ways in which disproportionality research acknowledges health and well-being as a contributor to the issue, if it even does. As such, the chapter is divided in two sections: (a)

the search strategy utilized to create the aforementioned synthesis of literature; (b) and the synthesis of literature analyzed and structured through the collective lens of Maslow's Hierarchy of Needs, Labeling Theory, UDL, Intersectionality, and DisCrit.

#### Methods

An initial search of three comprehensive education and multi-disciplinary databases, for specific criteria related to disproportionality in special education, yielded 19 original articles. Of these 19 articles, 9 met and exclusion criteria, upon which ancestral searches were then performed. This ancestral search resulted in the addition of 18 articles met both inclusion and exclusion criteria, making the final yield for this literature review 27 articles. In the search strategy section that follows, I describe the inclusion and exclusion criteria used to select articles for final analysis, and my analysis and synthesis of the chosen articles.

# **Search Strategy**

While Google Scholar was considered as a database to be used in this literature review search, its use was eventually decided against because it would impact the replicability of this search strategy. Google Scholar produces inconsistent search results due to its everchanging search algorithm, which constantly updates the results yielded, and also has not been shown to produce the widest range of accessible sources (Atkinson & Cipriani, 2018; Bramer et al., 2016). Therefore, to ensure external replicability of the search process-or reliability, articles were gathered from specific databases accessible through the University of Kansas' (KU) online library. These databases included Academic Search Complete, Academic Premier, and Education Resource Information Center (ERIC). While all three were selected because they are comprehensive databases, they were also chosen because of the breadth of the topics they cover.

Academic Search Complete and Academic Premier have a multi-disciplinary focus, while ERIC focuses on education literature and research.

Searching the selected databases required the strategic selection of search terms, symbols, and Boolean operators to expand and contract the final yield of articles. First, to capture the racialized focus of this study both the terms racial and ethnic were used in conjunction with disproportionality to search to databases. Secondly, to capture all versions of the term disproportionality, such as disproportion or disproportionate, a truncated version of the term (i.e. disproport\*) was searched for instead of disproportionality. Additionally, overrepresentation and underrepresentation were used as search terms to capture the continuum along which disproportionality is conceptualized. The use of quotation marks around the terms "racial disproport\* in special education", "ethnic disproport\* in special education", "Emotional Disturbance", and "African American" during the search ensured that they were searched for as a unit, rather than as individual terms. For example, instead of searching for the presence of emotional and disturbance separately, the parenthesis ensured that the term Emotional Disturbance was searched for as a whole, and in that sequence. The Boolean Operator OR was utilized to broaden to search for disproportionality literature and ensure that articles that included at least any of the units "racial disproport\* in special education" OR "ethnic disproport\* in special education" OR underrepresentation OR overrepresentation were included in the results to be hand searched. Meanwhile, the Boolean Operator AND was used to narrow the results by searching for articles that discussed all the topics linked by AND as one concept ("racial disproport\* in special education" OR "ethnic disproport\* in special education" OR underrepresentation OR overrepresentation) AND "Emotional Disturbance" AND "African American" together. Finally, ("racial disproport\* in special education" OR "ethnic disproport\*

in special education" OR underrepresentation OR overrepresentation) AND "Emotional Disturbance" was searched for throughout the entire text of the articles, while "African American" was searched for only in the subject terms.

#### Inclusion Criteria

The 42 articles that were selected for final review and synthesis met specific inclusion criteria. First, reviewed articles had to be published in English, between the years of 2000 and 2019. This time period represents an evolution in American medicine when a more socially constructed understanding of health and well-being became a priority, as evidenced by the evolving Health People (HP) goals and objectives (ODPHP, 2017a, 2017b, 2017c). Whereas the first iteration of the HP initiatives had focused on extending quantity of life, by HP 2000 improving quality of life had become the focus (D.H.E.W., 1979; ODPHP, 2017a, 2017b, 2017c). As such, there was a new focus on addressing social determinants (i.e., life factors that an individual is born into) as a preventive approach to addressing historic *health inequities* and *health disparities* that had been associated with higher morbidity rates (DHHS & ODPHP, 2010). This included social determinants like educational achievement, and thus, healthcare explicitly made a connection with the educational sector a necessity.

In addition to the standards above, articles were also included for final analysis of they:

(a) were published in scholarly, peer reviewed journal; (b) available online in full text; (c) explicitly discussed special education disproportionality within the socio-historic context of the United States; and (d) discussed the issue of special education disproportionality for African American learners from a multitude of perspectives, including prior to referral, during the identification process, and as a labeled individual. Articles included for final analysis could be conceptual or empirical works and spanned methodological designs.

#### **Exclusion Criteria**

Articles that were eliminated because their topics were deemed beyond the scope of this study included those: (a) focused on disproportionality in relation to IDEA (2004) categories other than ED; (b) focused on disproportionality in school discipline or incarceration in relation for African Americans, but did not make a connection to their disproportionate representation in special education; and (c) centered stakeholders other than the African American learner themselves. Additionally, those that were literature reviews, syntheses of literature, or systematic reviews were eliminated because they were not focused on original conceptualizations of disproportionality, but rather other researcher(s) understanding of trends in the existing literature base. Moreover, articles discussing disproportionality in special education outside of the United States were excluded because this study examines this issue within the specific socio-historic context of America. Finally, disproportionality articles that focused on school discipline rather than special education were excluded.

# **Coding Process**

Both deductive and inductive coding was performed on the 27 articles selected for final review. Specific, deductive codes were developed based on the definitions and theoretical perspectives of health and well-being presented in Chapter 1. These codes were then organized into "top level nodes" (i.e., themes) and lower, "child nodes" (i.e., sub-themes) utilizing the NVivo computer software package, which supports qualitative data analysis (QSR International, 2019). For example, Badash et al.'s (2017) definition of health and well-being was used, in conjunction with the theoretical frameworks offered in Chapter 1, to create the "top level node" of "recognition and prioritization of health and well-being as a learner need" and multiple "child nodes", such as "emotional-behavioral health", "mental health", "physical health", and "social"

health". Utilizing these pre-determined coding standards, I reviewed and analyzed the 27 articles to determine if any of their included text met the standards to be coded on the existing "child nodes". If they did meet the standards, they were coded under the appropriate "child node", and if they did not they were assigned to a relevant "top level nodes" and left for later, inductive analysis. Upon completion of deductive coding, I assessed all selected text-not assigned a "child node"- for trends and patterns that led to the creation of emergent sub-themes, or inductively determine "child nodes". These trends and patterns in emergent, inductive codes are explained alongside the deductive, pre-determined codes, in the sections that follow.

# **Synthesis of Review of Literature**

This literature review involved reviewing, analyzing, and synthesizing peer-reviewed articles in order to support a reframing of the persistent issue of disproportionality in special education. After each study was reviewed to determine where they were positioned with respect to inclusion and exclusion criteria, and if they should be part of the final analysis and synthesis, they were coded based on the study's theoretical frameworks. Utilizing the literature review's guiding questions, the themes below were created to code the disproportionality literature that was selected for final analysis,

- recognized and prioritized health and well-being as a learner need (Maslow, 1954,
   1943)
- contributed to either formal or informal health and well-being labels, and inevitably,
   hyper-labeling (Annamma, 2018; Goffman, 1963; Link & Phelan, 2001)
- recognized health and well-being as a form of oppression that must be accounted for
  in the proactive design of curricular materials and classroom design

  (Annamma, Connor, et al., 2013; Meyer et al., 2014; Waitoller & King-Thorius, 2016)

 acknowledged the intersecting oppressions of racism and ableism in the proactive design of curricular materials and classroom design (Annamma, Connor, et al., 2013; Meyer et al., 2014; Waitoller & King-Thorius, 2016)

In each of the following literature synopses, I present the research basis for deductive codes-developed prior to the literature analysis, followed by the inductive codes that emerging after the analysis of selected disproportionality articles. I then offer a numerical summary of findings and trends from the coded literature. Finally, I support these findings and trends with textual evidence from coded articles.

# Recognition and Prioritization of Health and Well-being as a Learner Need

The first theme focused on the recognition and prioritization of health and well-being as a learner need. Deductive codes were developed from the World Health Organization's (WHO; 2005) definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (para. 1) and Badash et al.'s (2017) understanding of health as inclusive of an individual's physical, mental, emotional, and social wellness. As such, four dimensions of health and well-being were coded for in the selected disproportionality literature, including: (1) physical health; (2) mental health; (3) emotional/behavioral health; and (4) social health (see Table 1). In addition to these deductive codes, two inductive codes emerged after the literature analysis was completed including: (5) the acknowledgement of proxies for health; and (6) well-being, along with the recognition of health and well-being as part of a risk-resilience continuum and (see Table 1). Findings indicate that of the deductive codes emotional/behavioral health (n=32) was the most recognized dimension of health, followed by social health (n=27) and mental health (n=22), with physical health (n=17) the least recognized dimension of health and well-being (see Table 1). Of the inductive codes proxies for health and

well-being (n=22) was slightly more recognized that health as part of the risk-resilience continuum (n=20; see Table 1).

Table 1

Maslow's Hierarchy of Needs: Recognition and Prioritization of Health and Well-being as a

Learner Need in Disproportionality Literature from 2000 to 2019

Articles	Deductive				Inductive		
Atucies	1 2 3		4	<u>inductive</u> 5 6			
(Bal, Betters-Bubon, & Fish, 2019)*	1	4	3	1	2	2	
(Bal, Sullivan, & Harper, 2014)		7		1	1	1	
(Bullock & Gable, 2006)	1	2	3		1	1	
(Coutinho, Oswald, Best, & Forness,	4	<i>L</i>	1	6	3	2	
2002)	4		1	O	3	2	
(Cullinan & Kauffman, 2005)*	3	1	3	3		1	
	J 1		3	2		1	
(Cullinan & Sabornie, 2004)	2	3	3	1			
(Cullinan, Osborne, & Epstein, 2004)	2	3	3	1			
(Forness & Kavale, 2000)							
(Green, 2005)*		1	2				
(Gresham, 2005)		1	2	4			
(Harris-Murri, King, & Rostenberg,				4			
2006)	2	7	1	1	7	7	
(Hill, 2017)*	2	7	1	1	7	7	
(Kea, Campbell-Whatley, & Bratton,	1			2			
2003)					4		
(McKenna, 2013)*	1	2		1	1		
(Merrell & Walker, 2004)		4	2	4			
(Serna, Nielsen, Mattern, & Forness,					1		
2002)		_					
(Serpell, Hayling, Stevenson, & Kern,		5	4	1		2	
2009)							
(Skiba, Polini-Staudinger, Gallini,							
Simmons, & Feggins-Azziz, 2006)*							
(Skiba, Poloni-Staudinger, Simmons,	1				7	3	
Feggins-Azziz, & Chung, 2005)							
(Voltz, Brazil, & Scott, 2003)					_		
(Zhang & Katsiyannis, 2002)	1			1		1	
Total Code Applications	17	32	22	27	22	20	

Note. Numbers in the table heading represent the deductive and inductive coding sub-themes. 1-

Recognized physical health as a learner need; 2-Recognized emotional-behavioral health as a learner need; 3-Recognized mental health as a learner need; 4- Recognized social health as a

learner need; 5-Acknowledged proxies for health and well-being; 6-Recognized health and well-being as part of the risk-resilience continuum. Articles with an asterisk are part of the initial yield, while those without are the result of an ancestral search. Numbers within each cell represents the frequency with which each code was applied to a single article, with the total number times the code was applied to all literature provided at the end of the column. Asterisks denote articles that were found as a result of the initial literature search, with those without an asterisk the result of an ancestral search.

## Physical Health

Physical health was coded for a total of 17 times across the selected literature (see Table 1). Physical health involved the physiological state of the learner and the mechanisms affecting that state. There was minimal recognition of the physiological health of learners, how it develops, and how it interacts with the learning process in the classroom-particularly for ED learners. While the SAED (Epstein & Cullinan, 1998) appeared to recognize the physiological state of ED learners with the subscale Physical Symptoms or Fears, this actually measured anxiety (Cullinan & Kauffman, 2005; Cullinan & Sabornie, 2004). Therefore, findings that elementary girls with ED had greater problems with Physical Symptoms or Fears than middle and high girls with ED (Cullinan et al., 2004) and that European American students with ED showed greater problems with Physical Symptoms or Fears (Cullinan & Kauffman, 2005), were really indicators of their mental health despite the use of the term "physical".

Regarding mechanisms impacting the physical state of a learner, poverty was once again mentioned as an environmental condition that contributed to behavioral challenges (Kea et al., 2003). Specifically, learners growing up in poverty were not exposed to quality health and nutrition, increasing their risk for premature birth and low birth weight, proper pre- and post-

natal care and poorer emotional-behavioral outcomes (Bullock & Gable, 2006; Coutinho et al., 2002; McKenna, 2013; Zhang & Katsiyannis, 2002). Furthermore, according to Hill (2017) learners growing up in poverty,

often lack access to quality healthcare, which is a necessary resource for healthy development. As a result, they are more likely to suffer from health conditions that affect their school readiness. The lack of access to quality healthcare is compounded by the fact that children who endure poverty are more likely to live in areas filled with environmental toxins that are detrimental to their health and well-being. (p. 209)

Additionally, Hill (2017) discussed the physiological impact of environmental components such as crime, violence, and housing instability, recognizing that their impact often manifests physiologically in learners as a "toxic stress response". According to Skiba, Poloni-Staudinger, Simmons, et al. (2005) these factors associated with poverty leads many to assume that poor African American children are "less developmentally ready for schooling" (p. 131).

## Emotional-behavioral Health

Emotional-behavior health was coded for a total of 23 times across the selected literature (see Table 1). In the disproportionality literature reviewed for this study, emotional/behavioral health became a pejorative that described the negative behaviors and consequences associated with an ED label, with little prioritization of the positive aspects of emotional-behavioral health and well-being and how these factors could be used as preventative mechanisms (Badash et al., 2017; WHO, 2005). While some, such as Cullinan and Kauffman (2005), attempted to present these deficit views of learner behavior as objective measures of a need for special education services, they were-in fact-another subjective judgement expressed through a standardized tool.

The Scale for Assessing Emotional Disturbance (SAED; Epstein & Cullinan, 1998)

operationalized the IDEA ED definition, but still had to be utilized by teachers familiar with the student in order to rate the learner along a 4-point scale in the categories of Inability to Learn, Relationship Problems, Inappropriate Behavior, Unhappiness or Depression, Physical Symptoms or Fears, and Socially Maladjusted (Cullinan & Kauffman, 2005; Epstein & Cullinan, 1998). The subjective nature of the SAED (Epstein & Cullinan, 1998) was evident in Cullinan et al.'s (2004) study where they found that female ED learners displayed more Inappropriate Behaviors than their non-disabled peers, but with the concept of "inappropriate" determined by the individual that utilized the tool. The issue with such subjectivity became apparent in Cullinan and Sabornie (2004) when the SAED (Epstein & Cullinan, 1998) results were used to justify such deficit conclusions as "students with ED tend to exhibit few personal strengths and social resources" (p. 164). Others, such as Bullock and Gable (2006) and Merrell and Walker (2004) recognized emotional-behavioral health in terms of internalizing and externalizing behaviors, but they problematized this dimension in relation to ED by describing manifestations of internalizing behaviors in learners as unmotivated and disinterested, while describing externalizing behaviors as disruptive in any setting. Gresham (2005), on the other hand, positioned ED learners as burdens upon themselves, their parents, teachers, schools, and society stating that "the behavioral characteristics and needs of children at-risk for ED has overwhelmed the capacity of schools to effectively accommodate these students" (p. 329). Similarly, Merrell and Walker (2004) advocated for the increased investment in mechanisms that would support the labeling of students with emotional-behavioral needs as ED, given the tremendous financial sacrifices such learners required of their families to secure services for them and the negative impact their classroom presence had on the retention of instructional staff.

While there was a preponderance of deficit-based portrayals of ED learners, there were attempts to situate the emotional/behavioral indicators in greater systemic issues. McKenna (2013) and Serpell et al. (2009) discussed the contribution of racism, and racial stress, on socialization and development of behavioral issues, such as depressive and maladaptive behaviors, which then served as indicators of a need for the ED label. As such, McKenna (2013) highlighted the importance of viewing African American students as active participants, capable of learning strategies to mitigate any racist challenges in their learning environment. Additionally, Serpell et al. (2009) emphasized that it was important to recognize the racial/ethnic social competencies that African American youth brought into the school environment, which served as a protective mechanism, mitigating the impact of racism on well-being and identity. Moreover, in a study of three low-income, African American, brothers navigating the special education system, Hill (2017) indicated multiple factors that placed them at increased risk of entering the special education system. The common thread amongst these factors was poverty, which explained their attendance to underfunded and failing schools, with personnel that defaulted towards punitive rather than restorative methods of intervention, furthering a cycle of trauma that exacerbated behavioral concerns (Hill, 2017). Likewise, these behaviors inevitably impacted their academics, supporting what Bal, Betters-Bubon, et al. (2019) referred to as academics and behavior existing as "two sides of the same coin" (p. 261).

## Mental Health

Mental health was coded for a total of 22 times across the selected literature (see Table 1). Mental health involved the psychological condition of ED learners, including factors that improved or diminished this state. As with emotional-behavioral health, there was greater emphasis on negative aspects of mental health, or little priority given to a strengths-based

approach to this dimension of health. Cullinan and Kauffman (2005) attempted to utilize the SAED (Epstein & Cullinan, 1998) to objectively measure mental health with the Unhappiness or Depression sub-scale, which captured the negative mood, affect, and thinking of the learner. They found that the mental health concerns of European students were perceived to be a greater issue than those of African American students, particularly those of elementary learners being perceived by White teachers, which Cullinan and Kauffman (2005) postulated meant that either "Black teachers of younger students with ED are insufficiently observant of the emotional and behavioral problems constituting the Unhappiness or Depression characteristic" or "perhaps White teachers of such students are excessively sensitive to those problems" (p. 398). The exception to this finding was among middle school students of both races, which teachers of both races perceived experiencing greater levels of Unhappiness or Depression (Cullinan & Kauffman, 2005). Similarly, Cullinan et al. (2004) and Cullinan and Sabornie (2004) found high rates of comorbidity between mental disorders and emotional-behavioral disorders. In their study of gender and ED behaviors, Cullinan et al. (2004) found that elementary ED girls were more likely to display this comorbidity, with ED elementary girls not only experiencing poorer outcomes than those without comorbidity, but forced to rely on school-based, mental health interventions that have rarely been evaluated (Cullinan et al., 2004). To address such mental health issues among ED learners, Merrell and Walker (2004) proposed a comprehensive service system called the "A Triangle of Support for Students with Behavioral and Emotional Problems", which relied on three levels of assessments, preventive efforts, and interventions.

Protecting the mental health of children is prioritized in federal legislation, with the passage of the Alcohol, Drug Abuse Mental Health Administration Reorganization Act of 1992, the establishment of the National Institute of Mental Health established the Child and Adolescent

Service System Program, and IDEA (2004), all of which worked to develop strong mental health support systems for children with serious emotional disorders and their families (Bullock & Gable, 2006). However, the promise of these protective measures falls short of the reality of their implementation, as evidenced by the mental health concerns expressed by researchers, such as Gresham (2005) who found great disparities in the number of children needing mental health services and actually receiving them under IDEA (2004). Furthermore, Gresham (2005) argued that it is ironic that schools have not recognized the needs of these students given the large numbers of students manifesting psychiatric symptoms, and thus, qualifying them for ED identification. Instead of identifying students as ED, discussion emphasized ecological factors, particularly the contribution of poverty on the behaviors being manifested (Coutinho et al., 2002; Hill, 2017). To address environmental contributors leading to a need for ED services Serpell et al. (2009) suggested that the under-utilized skill sets of school-based mental health professionals be used to train teachers to better support the emotional-behavioral needs of African American children-redefining their cultural lens in the classroom.

#### Social Health

Social health was coded for a total of 27 times across the selected literature (see Table 1) Social health entailed interactions between the learner and others (e.g., family, peers), as well as with their environments (e.g., school, home), and whether or not these interactions were beneficial or detrimental to their development. The SAED (Epstein & Cullinan, 1998) measured social health in terms of Relationship Problems, or the challenges learners encountered with fellow students and school adults, and Social Maladjustment, or antisocial actions outside of school (Cullinan & Kauffman, 2005; Cullinan & Sabornie, 2004). Utilizing the SAED (Epstein & Cullinan, 1998), Cullinan et al. (2004) found that elementary girls with ED had greater

Relationship Problems than middle or high school girls. In the case of Bal, Betters-Bubon, et al. (2019), Merrell and Walker (2004), and Serpell et al. (2009), similar relationship concerns resulted from the segregation and isolation that occurred from being labeled ED, negatively impacting social health. Meanwhile, Harris-Murri et al. (2006) found that social health was essential to the success of learners, particularly those from specific cultural groups (e.g., African Americans), describing classrooms as "places where students and teachers live and talk with each other" (p. 792). In classrooms where students were connected to their teachers and perceived their teachers to be personally and academically invested in them, they not only worked harder but were more motivated to do so (Harris-Murri et al., 2006). To minimize misinterpretations of student behaviors, and subsequent identification for inappropriate special education services, Harris-Murri et al. (2006) recommended an assessment of the perceptions and ideologies across the home, school, and community environments. Thus, learner social health was connected to schools reaching out and forming relationships across their various ecosystems.

Environmentally, the social health of ED learners was attributed to geographic and sociodemographic factors. For example, Hill (2017) referenced Noguera's (2011) "negative social capital" as a reason why schools in poor communities struggled to engage parents in addressing factors negatively impacting social health. Similarly, Coutinho et al. (2002) discussed elements of poverty central to "problematic" emotional-behavioral outcomes such as aggression and disruptive behavior. Moreover, they noted that living in "living in an economically deprived neighborhood was found to be associated with increased levels of problem behavior, regardless of the individual-level socioeconomic status" (p. 112). While McKenna (2013) and Zhang and Katsiyannis (2002) also mentioned the link between poverty and the overrepresentation of African American learners for EBD, they utilized strengths-based language, noting that it was only extreme cases of poverty that limited access to environmental advantages. In other words, poverty does not doom one to a life of disadvantage. Likewise, Kea et al. (2003) utilized a strengths-based approach by suggesting culturally responsive schools work to motivate positive student behaviors, and social health, by drawing from relationships "with the African American family and its kinship networks" (p. 35). In other words,

To know the family, one must know the community. To know the community, family, and child, one must have knowledge of the powerful societal forces affecting their lives. Understanding the sociocultural processes of their ethnic com- munities and social-political struggles through their lenses and stories will help service providers develop and implement a culturally responsive assessment model for African American students with learning and behavioral challenges. (Kea et al., 2003, p. 28)

## Proxies for Health and Well-being

Proxies for health and well-being was coded for a total of 22 times across the selected literature (see Table 1). Although the terms health and well-being were not directly referenced frequently, there were multiple proxies used to recognize aspects of this sub-theme. Some of these proxies included poverty, economic deprivation, sociodemographic factors, environmental obstacles, and ecological factors. As an example, in utilizing poverty as a proxy for health and well-being, Coutinho et al. (2002) acknowledged its role as a negative contributor to meeting the health and nutrition needs of children. Moreover, children that lived in economically deprived neighborhoods were exposed to damaging environmental factors, such as toxins, that negatively impacted the emotional-behavioral health of children (Coutinho et al., 2002). Coincidentally while discussing the ways in which poverty was used as a proxy for race, Skiba, Poloni-

Staudinger, Simmons, et al. (2005) provided evidence of the ways that biological factors negatively impacted the development of children living at the intersection of racism and classism. These developmental consequences then go on to magnify existing racial disparities in special education categories and left students less ready for school, resulting in negative behavioral and academic outcomes (Serna et al., 2002; Skiba, Poloni-Staudinger, Simmons, et al., 2005).

While poverty was explicitly utilized as a proxy for health and well-being by some (Coutinho et al., 2002; Serna et al., 2002; Skiba, Poloni-Staudinger, Simmons, et al., 2005), other proxies were also used to discuss dimensions of health and well-being. For example, although Bal, Betters-Bubon, et al. (2019) didn't definitively mention poverty, they did reference the economic status of learners by identifying them as recipients of free or reduced lunch, both economically based labels. This status was then used to recognize intergenerational patterns regarding mental and social health in Wisconsin communities of color, specifically related to strength of school connections (e.g., frequency of school transfers) and the likelihood of special education identification. Additionally, Hill (2017) discussed the concept of access as a proxy for health and well-being. In the case study of the Joseph brothers, who were described as "lowincome, African American boys with disabilities" (p. 228), Hill (2017) associated inaccurate special education evaluation processes with limited access to quality healthcare. Similarly, Bal, Sullivan, et al. (2014) briefly mentioned health and well-being by referencing the increased likelihood of African American students being identified into the Other Health Impairment (OHI) category. Furthermore, McKenna (2013) used the concept of ecological factors as an indirect proxy for health and well-being. While making no direct reference to health and wellbeing, in using such an inclusive heading they allowed for the inclusion of the multiple

dimensions of health and well-being as contributors to student behavior in the school context (McKenna, 2013).

## Health as Part of the Risk-resilience Continuum

Health as part of the risk-resilience continuum was coded for a total of 20 times across the selected literature (see Table 1). The concepts included under the sub-theme of health as a risk-resilience continuum recognized certain dimensions of health and well-being as harming or supporting a learners' ability to overcome the odds in school, home, or life. For instance, when poverty was utilized as a proxy for health and well-being, it was identified as a risk factor by Coutinho et al. (2002). Emphasizing the risk aspect of the continuum, Coutinho et al. (2002) stressed that poverty could negatively impact a child's health and nutrition, home environment, neighborhood. Moreover, other risk factors, such as parental mental health history (e.g., parental psychopathology), experiences with trauma (e.g., physical or other maltreatment), and physical health concerns (e.g., premature birth, low birth weight, serious childhood illness) further increased the likelihood of negative outcomes for learners living in poverty (Coutinho et al., 2002). The harm caused by these health and well-being risks eventually harmed the emotionalbehavioral development of learners, leading to the development of aggressive and disruptive behavior, particularly among boys (Coutinho et al., 2002). Additionally, in their case study of the Joseph brothers, Hill (2017) discussed poverty as a proxy for health and well-being. Consequently, health and well-being factors associated with poverty, such as inaccessibility to quality healthcare and social services, increased the risk of the brothers entering the "fast track" (p. 228) into the school-to-prison pipeline (Hill, 2017). Likewise, Zhang and Katsiyannis (2002) emphasized the risk posed to learners due to the association between poverty and health and well-being disadvantages, such as inability to access quality pre- and postnatal care and nutrition, leading to an increased risk for identification into special education categories like OHI (Bal, Sullivan, et al., 2014). Furthermore, while arguing that poverty could not be used as a proxy for race, Skiba, Poloni-Staudinger, Simmons, et al. (2005) provided evidence of the developmental risk poverty poses to learners, and thus, risks their special education identification by negatively impacting their academic and behavioral outcomes.

In addition to poverty, a range of other general risk factors were discussed, which included various dimensions of health and well-being. For example, Serpell et al. (2009) discussed the ecological risks to learners associated with poverty, particularly related to their social health, or their awareness of their social status in relation to their race/ethnicity. This racial/ethnic stress experienced by African American learners placed these learners at increased risk for negative academic and behavioral performance, due to increased feelings of disenfranchisement and resulting relational tensions between themselves, teachers, and peers (Serpell et al., 2009). While Cullinan and Kauffman (2005) acknowledged the possibility of bias in teacher interpretation of African American learner behavior, they also proposed that these learners were "especially likely to be exposed to risk factors that elevate problems of low achievement and emotional and behavioral difficulties" (p. 394). However, they did not specify what these risk factors could be. Bullock and Gable (2006), on the other hand, identified the health and well-being risks posed to E/BD learners, who experienced greater educational challenges. These educational challenges included increased course failures, lower grade point averages, increased school absences, and increased likelihood of repeating a grade level (Bullock & Gable, 2006). Subsequently, these E/BD learners were at an increased risk for negative health and well-being behaviors, such as alcohol, tobacco, and drug use (Bullock & Gable, 2006). Finally, while Bal, Betters-Bubon, et al. (2019) discussed the social dynamics of African

American, Wisconsin families (e.g., incarceration and unemployment rates) in relation to the risk for disproportional identification of African American learners, they were the only researchers to pose a resilience argument. Adopting a strengths-based approach to academic proficiency, Bal, Betters-Bubon, et al. (2019) noted that higher reading and math scores lowered the odds of ED identification, with evidence of academic proficiency serving as a protective factor.

# Health and Well-being as a Contributor to the Formal and Informa Labeling of African American Learners with ED

The second theme concentrated on whether literature acknowledge that aspects of health and well-being contributed to the formal or informal labeling of African American learners with ED. Deductive coding criteria was developed based on IDEA's (2004) definition for ED, whose qualifying criteria requires the discounting and accounting of various dimensions of health. As such, articles were first coded to determine whether they addressed "exclusionary factors" (1, see Table 2), or IDEA's requirement that learners can only qualify for the ED label if their inability to learn was not due to "intellectual, sensory, or health factors" (IDEA, 2004). Secondly, articles were coded for "confirmatory factors" (2, see Table 2) or whether they met IDEA's requirement that learners demonstrate:

- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- inappropriate types of behaviors or feelings under normal circumstances
- a general pervasive mood of unhappiness or depression
- a tendency to develop physical symptoms or fears associated with personal or school problems (see Table 2).

In addition to these deductive codes, five inductive codes emerged related to academic labels assigned to ED learners: (3) the disciplinary labels assigned to ED learners; (4) the life outcome labels attributed to ED learners; (5) the ways that ED symptomology was used to justify hyper labeling ED learners; (6) and the recognition of the limitations of the ED definition; and (7) referral process (see Table 2). Findings revealed that, of the deductive codes, the "confirmatory" aspects of IDEA's (2004) ED definition (n=18) was more recognized than the "exclusionary" factors (n=7; see Table 2). Of the inductive codes, limitations of the ED definition and referral process was the most recognized sub-theme (n=31), followed by academic labels for ED learners (n=22; see Table 2). Life outcomes attributed to ED learners (n=18) was the third most recognized sub-theme, followed by disciplinary labels for ED learners (n=11) and used ED symptomology to justify hyper labeling (n=11; see Table 2).

Table 2

Labeling Theory and DisCrit: Health and Well-being as a Contributor to the Formal and Informal Labeling of African American Learners with ED in Disproportionality Literature from 2000 to 2019

Articles	Deduc	tive	Inductive				
	1	2	3	4	5	6	7
(Bal, Betters-Bubon, & Fish,			8	1	3		
2019)*							
(Bal, Sullivan, & Harper, 2014)			1		1		4
(Bullock & Gable, 2006)	2		1		1	1	
(Coutinho, Oswald, Best, &		1		1			
Forness, 2002)							
(Cullinan & Kauffman, 2005)*	3	1	1	1			
(Cullinan & Sabornie, 2004)	5		3		1	1	
(Cullinan, Osborne, & Epstein,	3	1			2	2	3
2004)							
(Forness & Kavale, 2000)							4
(Green, 2005)*			1	1		1	
(Gresham, 2005)	1	1	1	1		4	7

(Harris-Murri, King, & Rostenberg, 2006)	1	1	1			1	1
(Hill, 2017)*				5	4		
(Kea, Campbell-Whatley, &							
Bratton, 2003)							
(McKenna, 2013)*			1		1		1
(Merrell & Walker, 2004)	1		1		2	1	10
(Serna, Nielsen, Mattern, &							
Forness, 2002)							
(Serpell, Hayling, Stevenson, &	2	2	2	1	1		1
Kern, 2009)							
(Skiba, Polini-Staudinger, Gallini,							
Simmons, & Feggins-Azziz,							
2006)*							
(Skiba, Poloni-Staudinger,							
Simmons, Feggins-Azziz, &							
Chung, 2005)							
(Voltz, Brazil, & Scott, 2003)							
(Zhang & Katsiyannis, 2002)			1		2		
Total Code Applications	18	7	22	11	18	11	31

Note. Numbers in the table heading represent the deductive and inductive coding sub-themes. 1-

Recognized "confirmatory" aspects of IDEA 's ED definition requirement accounting for unsatisfactory interpersonal relationships, inappropriate behaviors, moods of unhappiness or depression, development of physical symptoms or fear; 2-Recognized "exclusionary" aspects of IDEA's ED definition requiring the discounting of "intellectual, sensory, or health factors"; 3-Academic labels for ED learners; 4-Disciplinary labels for ED learners; 5-Life outcomes attributed to ED learners; 6-Used ED symptomology to justify hyper labeling; 7-Limitations of the ED definition and referral process. Articles with an asterisk are part of the initial yield, while those without are the result of an ancestral search. Numbers within each cell represents the frequency with which each code was applied to a single article, with the total number times the code was applied to all literature provided at the end of the column. Asterisks denote articles that were found as a result of the initial literature search, with those without an asterisk the result of an ancestral search.

# "Confirmatory" Aspects of IDEA's ED Definition

"Confirmatory" aspects of IDEA's ED definition were coded for a total of 18 times across the selected literature (see Table 2). This sub-theme recognized when there was a direct or indirect reference to the following *confirmatory* aspects of IDEA's (2004) ED definition criteria:

- (A) An inability to learn that cannot be explained by intellectual, sensory, or health factors.
- (B) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
- (C) Inappropriate types of behavior or feelings under normal circumstances.
- (D) A general pervasive mood of unhappiness or depression.
- (E) A tendency to develop physical symptoms or fears associated with personal or school problems. (IDEA, 2004)

The term *confirmatory* was used to acknowledge that these criteria qualified learners for the ED label, or confirmed their manifestation of one or more of these measures of ED. Moreover, the selected literature was analyzed to determine whether it recognized that the above criteria needed to be exhibited for a long period of time, to a marked degree, and adversely impacted the learner's educational performance (IDEA, 2004).

In the disproportionality literature reviewed for this study there were few explicit references to the legislative criteria that leads to an ED identification, despite decades of concerns about the over-identification of African American learners into specific categories. The few researchers that did make direct reference to the IDEA (2004) ED definition (Cullinan & Kauffman, 2005; Cullinan et al., 2004; Gresham, 2005; Harris-Murri et al., 2006; Serpell et al., 2009), began their works by quoting it and then contextualizing their work within it. Moreover,

some of this explicit usage of the ED definition was the consequence of relying on measurement instruments derived from the ED definition criteria, as was the case with the works of Cullinan and Kauffman (2005) and Cullinan et al. (2004). In anchoring their works in the SAED (Epstein & Cullinan, 1998), Cullinan and Kauffman (2005) and Cullinan et al. (2004) recognized each of the ED definition's confirmatory criteria through its equivalent SAED subscales of Inability to Learn, Relationship Problems, Inappropriate Behavior, Unhappiness or Depression, Physical Symptoms or Fears, and Socially Maladjusted. Less direct references to the ED definition standards was also made, such as in the works of Bullock and Gable (2006) and Merrell and Walker (2004), by referencing specific qualifying behavioral symptoms without mentioning the standards themselves. For example, both Bullock and Gable (2006) and Merrell and Walker (2004) discussed internalizing (e.g., anxiety, depression) and externalizing (e.g., aggression, acting out) behaviors, without directly referring to the "inappropriate types of behavior" standard ED definition standard. Finally, only Serpell et al. (2009) mentioned that learners with schizophrenia were included in the ED category.

# "Exclusionary" Aspects of IDEA's ED Definition

"Exclusionary" aspects of IDEA's ED definition were coded for a total of seven times across the selected literature (see Table 2). The *exclusionary* aspects of IDEA's (2004) ED definition focused on whether the reviewed disproportionality literature explicitly acknowledged that an ED diagnosis could not be assigned if the student's inability to learn was attributed to intellectual factors, sensory factors, health factors, and/or social maladjustment. Moreover, the selected literature was analyzed for whether or not it acknowledged that the symptoms were not exhibited for a long period of time, to a marked degree, and did not adversely impact the learner's educational performance. While the reviewed disproportionality literature infrequently

made direct reference to the ED definition, these few explicit references acknowledged both aspects of the ED definition's exclusionary criteria (Cullinan & Kauffman, 2005; Cullinan et al., 2004; Gresham, 2005; Harris-Murri et al., 2006; Serpell et al., 2009). Only Coutinho et al. (2002) made general references to the exclusionary criteria, without contextualizing it in the explicit standards of the IDEA (2004) ED definition, by recognizing some of the health factors that impact emotional-behavioral development.

# Academic Labels Assigned to ED Learners

Academic labels assigned to ED learners was coded for a total of 22 times across the selected literature (see Table 2). Academic labels assigned to ED learners explored the ways in which an ED identification led to assumptions about the future learning outcomes of these students, whether these were empirically supported or not. For example, multiple researchers made the empirically supported statements that E/BD students are more likely to fail courses, get a lower grade point average, be absent from school, be held back a grade, drop out of school, and/or have limited access to higher education opportunities compared to learners in other disability categories(Bal, Betters-Bubon, et al., 2019; Bullock & Gable, 2006; Cullinan & Sabornie, 2004; Gresham, 2005; Merrell & Walker, 2004). Many of these academic performance concerns were attributed to the increased segregation ED students experienced in comparison to other disability groups, with many taught in special needs, rather than general education, classes (Bal, Betters-Bubon, et al., 2019; Cullinan & Kauffman, 2005; Cullinan & Sabornie, 2004; Green, 2005; McKenna, 2013; Merrell & Walker, 2004; Serpell et al., 2009). However, little of the discourse centered on the ways these empirically supported "outcomes" of ED learners resulted in once more labeling them as inevitable academic failures. As such, they inadvertently

positioned these learners on a singular pathway of failure, rarely highlighting other possible, positive academic outcomes they could achieve.

While the segregation of ED learners in general was problematic, of greater issue was the academic impact it had on specific racial groups, specifically disadvantaging Black learners with ED (Cullinan & Kauffman, 2005). For instance, Serpell et al. (2009) and Bal, Betters-Bubon, et al. (2019) acknowledged that African American males with E/BD were more likely to be segregated from general education classes than other students, sometimes spending up to 33% of their school day away from the general education curriculum and access to the non-disabled peers (Green, 2005). Additionally, Merrell and Walker (2004) and Serpell et al. (2009) recognized that African American students with E/BD were more likely to drop out of school and less likely to graduate that similar students in other ethnic groups. McKenna (2013) noted that such separation from their peers served to further stigmatize African American students with EBD, preventing their academic growth by placing them in an educational setting not aligned with the general education curriculum. Donovan and Cross (2002) referred to this disproportionality issue in special education as the "paradox of special education", or a system that was meant to provide resources and support to students in need, often resulted in their increased stigma and little improvement in the areas that justified identification in the first place. Additionally, while attempts have been made (e.g., RTI) to address the misclassification of learners into categories such as ED, the use of models that hone in on skill deficits, without diversifying the professionals making these subjective judgement about said deficits, will still result in the same groups of learners being perceived as deficient (Harris-Murri et al., 2006; Zhang & Katsiyannis, 2002).

## Disciplinary Labels Assigned to ED Learners

Disciplinary labels assigned to ED learners was coded for a total of 11 times across the selected literature (see Table 2). Disciplinary labels assigned to ED learners assessed the selected literature for the ways in which their ED identification led to them becoming targets of punitive actions. While some, such as Gresham (2005), spoke about these punitive labels in generalities, discussing them as "substantial challenges" (p. 328), the scope of their impact made it clear that ED learners were to be viewed as disruptive influences in the learning environment. As Gresham (2005) described it, the emotional, behavioral, and social challenges of ED learners "cut across disciplinary, instructional, and interpersonal domains and often can create chaotic school and classroom environments" (p. 328). Similarly, Coutinho et al. (2002) pathologized the actions of ED learners by citing the alarmist statement by Walker et al. (1999) that "Today, students who receive the E/BD label in school seem qualitatively different. The student population we currently serve seems more violent, its problems more intensely pathological, and its negative outcomes more destructive" (p. 29). Supporting the labeling of ED learners, as a whole group, as violent only sets these learners up to have their actions be perceived as warranting penal intervention.

As with most ED discourse, discussions of disciplinary labels were also racialized. For instance, both Bal, Betters-Bubon, et al. (2019) and Cullinan and Kauffman (2005) noted that an ED identification is particularly disadvantageous for African American learners because it often results in disproportionate disciplinary exclusions from school. Green (2005) acknowledged that these disciplinary exclusions were the result of higher rates of suspensions and expulsions for African American learners in special education. According to Serpell et al. (2009), African American males were suspended and expelled at higher rates, despite demonstrating behaviors similar to their White counterparts, who remained undisciplined. Moreover, the reasons provided

for their disciplinary actions were often subjective interpretations of their behavior (e.g., disrespectful behavior; Serpell et al., 2009). In Hill's (2017) case study of three African American, disabled, brothers of low socioeconomic status, these racialized concerns were brought to life. Hill (2017) demonstrated how the school system policies and practices, contributed to the labeling these brothers as disciplinary issues deserving of penal interventions. From their first disciplinary incident, Hill (2017) shows how their behaviors were then escalated into multiple school incidents that resulted in suspensions, police referrals, and arrests rather than age-appropriate referrals for social work or health interventions. As Hill (2017) phrased it, referring to the school-to-prison pipeline, "these events set the brothers on the pipeline's fast track" (p. 228).

# Life Outcome Labels Attributed to Learners with ED

Life outcome labels attributed to learners with ED was coded for a total of 18 times across the selected literature (see Table 2). This sub-theme explored the ways in which an ED identification led to assumptions about the life outcomes of these labeled learners. These life outcomes assumptions ranged from general predictions of poorer results in comparison to non-ED learners (Bal, Betters-Bubon, et al., 2019; Cullinan et al., 2004; Merrell & Walker, 2004), to specific social, emotional, and behavioral consequences as a result of being labeled. For instance, Bullock and Gable (2006) noted that learners labeled as E/BD were at an increased risk of alcohol, tobacco, and drug use. Moreover, multiple researchers (Bullock & Gable, 2006; Merrell & Walker, 2004; Serpell et al., 2009) provided empirical evidence showing that ED learners were at an increased risk of being arrested with 3-5 years of leaving high school. Hill (2017) noted that although ED learners only represented 12% of the student population, they represented 25% of the learners referred to, or arrested by, law enforcement. This risk was exacerbated for

disabled African American males, who-once labeled-were at an increased risk for disciplinary referrals and ending up in correctional institutions (Hill, 2017; McKenna, 2013; Zhang & Katsiyannis, 2002). The cumulative effect of these disciplinary and correctional records was that these ED learners eventually had fewer employment opportunities, and consequently, discouraging unemployment rates (Bal, Betters-Bubon, et al., 2019; Zhang & Katsiyannis, 2002).

# Used ED Symptomology to Justify Hyper-labeling

The used ED symptomology to justify hyper-labeling code was applied 11 times across the selected literature (see Table 2). This sub-theme explored the ways in which ED identification criteria was used to hyper label (Annamma, 2018), or formally and informally describe aspects of an individuals' identity, such as disability or race, in societally stigmatizing ways. For example, in providing advice to teachers Cullinan et al. (2004) notes that they must be prepared to manage the "ill effects of the aggression, disruption, and defiance of female students with ED" (p. 284). However, in associating this particular set of behaviors with ED learners, Cullinan et al. (2004) used their ED symptomology to informally label them as a danger in the classroom. Likewise, Bullock and Gable (2006) acknowledged that students with externalizing behavioral concerns were "viewed as troublemakers" (p. 9), while those with internalizing behavioral concerns were viewed as "unmotivated, passive, and disinterested in their schooling, whereas others may seem overanxious, phobic, or social isolates" (p. 9). Both of these descriptions center the deficit in the learner. Moreover, Bullock and Gable (2006) failed in their attempt to recognize systemic responsibility for the perception of ED learner symptomology, stating that learners with externalizing behaviors are perceived as "troublemakers" because "no one tolerates disruptive behavior" (p.9). Similarly, in making suggestions for teachers regarding learners relationships, Cullinan et al. (2004) suggested that, "teachers may need to discourage...a variety of uncooperative, coercive, disgusting, or otherwise aversive behaviors that lead to rejection by peers or conflict with adults at school" (p. 284). While the intention may have been to make relations between ED learners and others more positive, classifying their behaviors as "disgusting" only serves to further stigmatize them (Cullinan et al., 2004). Additionally, citing their behaviors as the sole source of peer rejection inherently places the deficit in the child, rather than the support systems in their environment (Cullinan et al., 2004). Cullinan and Sabornie (2004) also appeared to center the deficit within the child, with the finding that adolescents with extensive emotional and behavior problems "tend to exhibit few personal strengths and social resources that might mitigate some debilitating consequences of their maladaptive behaviors and emotions" (p. 164).

In addition to behavioral labels, ED learners were also assigned damaging labels related to their impact on family and community, as well as their academic performance. For example, fractured relationships between schools, families and the community were attributed to the misidentification of ED learners (Green, 2005). Additionally, Merrell and Walker (2004) associated teacher and classroom aide attrition, as well as familial financial strain, to the stressed involved with educating ED learners. Finally, academic labels such as "high school dropout" (Merrell & Walker, 2004) and "skill-deficit" (Harris-Murri et al., 2006) were terms that could summarize the description of ED learner outcomes in the selected literature. As Gresham (2005) described it "the behavioral characteristics and needs of children at-risk for ED has overwhelmed the capacity of schools to effectively accommodate these students" (p. 329). Once again, ED learners were informally labeled as burdens upon the very systems meant to support them.

# Limitations of the ED Definition

The limitation of the ED definition code was applied 21 times across the selected literature (see Table 2). This sub-theme explored the ways in which the reviewed disproportionality literature discussed the shortcomings of the IDEA (2004) ED definition. These shortcomings ranged from the ED definition being outdated, its' use of vague terminology, and the exclusion of symptomology that often co-occurs with an ED diagnosis. For instance, Merrell and Walker (2004) noted that when the original ED definition was developed it was already borrowing from Bower's (1981) 20-year-old definition for "emotionally handicapped", which he had proposed in 1957. Additionally, Cullinan et al. (2004) argued that the ED definition is dated, remaining relatively unchanged since it was initially passed. Even more problematic, was that criteria for the original ED category, then referred to as SED, was adopted from Bower's 1957 definition for "emotionally handicapped". Moreover, given the length of time it has existedunchanged-there have been few studies examining the ways in which the criteria for ED has impacted specific demographic groups (Cullinan et al., 2004; McKenna, 2013). Furthermore, as Forness and Kavale (2000), acknowledged three of the criteria (i.e., "inappropriate types of behavior or feelings," "pervasive mood of unhappiness," and "tendency to develop physical symptoms or fears") were based on a singular study conducted by Bower nearly 60 years ago, about the Los Angeles School District. As such, the conclusions that once justified including these three criteria has been discounted by contemporary educational research conclusions (Forness & Kavale, 2000). Finally, few assessments have been developed to document the emotional-behavioral concerns of students, and in the rare instances they were created, they often did not align with the IDEA (2004) definition standards (Cullinan et al., 2004).

In addition to being dated, the terminology of associated with the ED definition has been critiqued for being vague and subjective, leading to issues with operationalizing the definitions'

terms and implementing the criteria in ways that do not stigmatize learners. This concern with ED terminology was evident in the label's evolution, with the modifier "serious" dropped from the original category name of SED (Forness & Kavale, 2000). While this changed the categorical label from SED to ED it did not change the definition itself. Instead, the closest the ED definition has come to being changed occurred in the early 1990's when it was proposed that a definition for E/BD replace the existing ED definition (Forness & Kavale, 2000; NSBA, 1992). While the E/BD definition was never approved on a federal level, it was adopted by some organizations, such as Head Start ("Head Start Standards", 1993). Consequently, three label headings began to be used in ED discourse (i.e., SED, ED, E/BD), further confusing an already convoluted discussion (Gresham, 2005). Delving deeper into the ED definition itself, criteria such as "to a marked degree", "for a long period of time", and "adversely affects educational performance", have been criticized as being ambiguous, with their interpretation relying too heavily upon the subjective judgment of school personnel (Gresham, 2005; Serpell et al., 2009). Forness and Kavale (2000) proposed that such terminology was problematic because the subjective interpretation of their meaning could lead to stigmatization of learners. Interpretation of the ED criteria for identification became more worrisome when coupled with the knowledge that there were no objective tests or criteria to label students as ED, and the existing criteria has not been operationalized (Gresham, 2005; Harris-Murri et al., 2006). For example, Gresham (2005) argued that the ED definition criteria of "adversely impacting education performance" and "an inability to learn" were redundant, with educational performance limited to only academic outcomes.

Finally, one of the most controversial limitations of the ED definition was that certain groups of behaviors were excluded from identification. The most discussed category of excluded

behavior in the selected literature was social maladjustment. While learners with social maladjustment often displayed similar behavioral symptoms as ED learners, they were excluded from receiving the ED label because their behaviors were perceived to be a willful disregard for social and behavioral norms, whereas those of ED learners were not (Gresham, 2005; Merrell & Walker, 2004). However, Merrell and Walker (2004) argued that social maladjustment was controversial because some of its symptoms overlapped with those of an ED diagnosis, making it difficult to clearly diagnose a learner as ED or socially maladjusted. Furthermore, Gresham (2005) posited that a student may not be socially maladjusted alone and qualify for ED services, but may be ED and socially maladjusted and receive ED services. According to Gresham (2005), such logic was "convoluted, circular, and borders on oxymoronic" (p. 330), with the five eligibility criteria contradicting themselves when it came to social maladjustment. For example, one of the qualifying criteria of ED was an inability to build or maintain satisfactory interpersonal relationships with peers or teachers, which Gresham (2005) argued also held true for socially maladjusted individuals, thus, qualifying them for ED services. Making the issue even more complex, Merrell and Walker (2004) proposed that the exclusion of socially maladjusted youth from the ED identification was a politically motivated move, on the part of legislators and educational administrators, to not be held accountable for delinquent and antisocial youth that were historically difficult to reach. These politically based decisions have reified the inequitable structural forces (e.g., race, class) and education policies (e.g., IDEA identification criteria) that perpetuated disproportionality in special education (Bal, Sullivan, et al., 2014).

# Accounting for Intersecting Oppressions in the Proactive Design of Classrooms, Curricular Materials, and Instruction

The third theme accounted for the intersecting oppressions that are considered in the proactive design of classrooms, curricular materials, and instruction (Annamma, Connor, et al., 2013; Meyer et al., 2014; Waitoller & King-Thorius, 2016). I developed the deductive coding criteria by borrowing from Misselbrook's (2014) understanding of healthcare's purpose as aiming "for the state of least possible illness or disability, or of maximal functional adaptation to illness or disability" (p. 582) and the CDC's (2018b, 2018c) conceptualization of well-being as how

people think and feel about their lives, such as the quality of their relationships, their positive emotions and resilience, the realization of their potential, or their overall satisfaction with life...global judgments of life satisfaction and feelings ranging from depression to joy. (para. 1)

As such, I deductively coded articles for: (1) whether they recognized racism; (2) whether the recognized ableism; (3) whether they acknowledged the intersecting oppressions of racism and ableism; (4) whether they recognized the impact of the intersecting oppressions from racism and ableism on classroom design; (5) whether the recognized the impact of the intersecting oppressions from racism and ableism on curriculum and instruction; and (6) the extent of health and well-being's recognition as a form of oppression (see Table 3). In addition to these deductive codes, three inductive codes emerged from the literature analysis including: (7) the acknowledgement of a need for culturally responsive practices related to referrals and interventions; (8) the recognition of hiring and retention practices as integral to addressing special education disproportionality contributors; and (9) the role of teacher traits and beliefs in

special education disproportionality (see Table 3). Of deductive codes, acknowledgement of the intersecting oppressions of racism and ableism (n=105) was the most frequently applied code, while the extent of health and well-being's recognition as a form of oppression (n=32) was the second most applied code, followed closely by the recognition of ableism (n=23) and the impact of the intersecting oppressions from racism and ableism on curriculum and instruction (n=19; see Table 3). The least recognized of the deductive codes was the recognition of racism (n=7) and the impact of the intersecting oppressions from racism and ableism on classroom design (n=4; see Table 3). Of the inductive codes, culturally responsive practices related to referrals and interventions was the most frequently applied code (n=39), followed closely by the role of teacher traits and beliefs in special education disproportionality (n=38; see Table 3). The least applied inductive code was teacher hiring and retention practices as integral to addressing special education disproportionality (n=4; see Table 3).

Table 3

Universal Design for Learning, Intersectionality, and DisCrit: Accounting for Intersecting

Oppressions in the Proactive Design of classrooms, Curricular Materials, and Instruction in

Disproportionality Literature from 2000 to 2019

<u>Articles</u>	<u>Deductive</u>					Inductive			
	1	2	3	4	5	6	7	8	9
(Bal, Betters-Bubon, & Fish, 2019)*	2		7						
(Bal, Sullivan, & Harper, 2014)		1	4		6	1	5	1	4
(Bullock & Gable, 2006)		3	3	1	1	2	3		3
(Coutinho, Oswald, Best, & Forness,		2	10			4	1		
2002)									
(Cullinan & Kauffman, 2005)*	1		4			1			1
(Cullinan & Sabornie, 2004)		7	2						
(Cullinan, Osborne, & Epstein, 2004)		2	4		1		1		2
(Forness & Kavale, 2000)		3	4						
(Green, 2005)*		1	13	1	3		7		2
(Gresham, 2005)		1					3		

(Harris-Murri, King, & Rostenberg, 2006)	1	1	10		5		15	2	14
(Hill, 2017)*			5			6		1	1
(Kea, Campbell-Whatley, & Bratton,			8		2	2	3		2
2003)									
(McKenna, 2013)*	2		10	1		4			2
(Merrell & Walker, 2004)		2	1						
(Serna, Nielsen, Mattern, & Forness,						1			
2002)									
(Serpell, Hayling, Stevenson, & Kern,			9		1	1	1		3
2009)									
(Skiba, Polini-Staudinger, Gallini,			1	1		1			1
Simmons, & Feggins-Azziz, 2006)*									
(Skiba, Poloni-Staudinger, Simmons,			5			8			
Feggins-Azziz, & Chung, 2005)									
(Voltz, Brazil, & Scott, 2003)			4						2
(Zhang & Katsiyannis, 2002)			1			1			1
Total Code Applications	7	23	105	4	19	32	39	4	38

Note. Numbers in the table heading represent the deductive and inductive coding sub-themes. 1-

Recognized racism; 2-Recognized ableism; 3-Acknowledged the intersecting oppressions of racism and ableism; 4-Recognized the impact of the intersecting oppressions from racism and ableism on classroom design; 5-Recognized the impact of the intersecting oppressions from racism and ableism on curriculum and instruction; 6-Extent of health and well-being's recognition as a form of oppression; 7-Culturally responsive practices related to referrals and interventions; 8-Teacher hiring and retention practices as integral to addressing special education disproportionality; 9-Role of teacher traits and beliefs in special education disproportionality. Articles with an asterisk are part of the initial yield, while those without are the result of an ancestral search. Numbers within each cell represents the frequency with which each code was applied to a single article, with the total number times the code was applied to all literature provided at the end of the column. Asterisks denote articles that were found as a result of the initial literature search, with those without an asterisk the result of an ancestral search.

## Recognition of Racism

Recognition of racism was coded for a total of seven times across the selected literature (see Table 3). In assessing the selected literature solely for racism, I investigated the ways in which they centered the assumptions, beliefs, and practices of White people, or the normative experiences of Whiteness in the American education system (Gillborn, 2015). In doing so, I examined whether researchers acknowledged the unique impact of racism on ED learners. This was coded for if researchers simply recognized that racism undergirded the issue of disproportionality in the special education category of ED, explicitly discussed ways in which racism contributed to the ED identification process or described the impact racism has on ED learners once identified. For example, Bal, Betters-Bubon, et al. (2019) acknowledged racism by simply recognizing that African American learners encountered discrimination through the subjective interpretation of their behavior by school personnel (e.g., disrespect, insubordination). Similarly, both Cullinan and Kauffman (2005) and Harris-Murri et al. (2006) recognized that the disproportional representation of African American students in the ED category was possibly the result of educator racial bias, with not enough consideration given to "teacher attitudes, perceptions, expectations, and knowledge" (p. 787). Finally, in the most explicit recognition of racism, Coutinho et al. (2002) and McKenna (2013) discussed the impact of racism on identification. McKenna (2013) recognized that racial stress, or the byproduct of experiencing racism, contributed to the development of maladaptive behaviors that would be considered ED behavioral identifiers. Furthermore, both Coutinho et al. (2002) and McKenna (2013) discussed the increased risk for ED identification African American students faced if they attend schools in predominantly, White, high socio-economic communities. Coutinho et al. (2002) and McKenna (2013) posited that African American students became the objects of bias in such communities because their difference became more apparent.

### Recognition of Ableism

Recognition of ableism was coded for a total of 23 times across the selected literature (see Table 3). In assessing the selected literature solely for ableism, I investigated the ways in which they centered the ableist ideology that it's better to subscribe to society's norms, and be viewed as superior, than contradict those norms and be Othered, resulting in a designation as inferior (Storey, 2007). Much of what I considered normed, or socially acceptable, standards contributing to ableism was determined by the authors choice in terminology. Whether the author intended to represent their stance on acceptable norms through their terminology use is unclear, but regardless of their intention their words still contribute to the reification of ableism.

The reification of ableist ideology was often clear, with the explicit use of disparaging terminology that served to stigmatize labeled students (Bal, Sullivan, et al., 2014; Forness & Kavale, 2000). For instance, in reviewing the history of E/BD in the United States, Bullock and Gable (2006) used such terms as "aberrant" to describe behaviors that were different and noted that these differences "jeopardized their ability to fit into society" (p. 7). Additionally, they appeared to sympathize with the labeling of E/BD learners as "troublemakers types" because they display externalizing behavior problems, noting that "no one tolerates disruptive behavior" (Bullock & Gable, 2006, p. 9). While Coutinho et al. (2002) referred to empirical evidence that labeled similar behaviors as "violent" and "pathological", Cullinan et al. (2004) labeled the behaviors of ED learners as "uncooperative, coercive, disgusting" (p. 284). For learners with internalizing behaviors Bullock and Gable (2006) labeled them as "unmotivated, passive, and disinterested" (p. 9). By assuming that these E/BD learners had navigated away from some established norm of motivation and interest, and that they had done so purposefully, both

Cullinan et al. (2004) and Bullock and Gable (2006) contradicted an inherent qualifier for the ED classification.

In a less innocuous instance of using terminology to reify ableist ideology, Gresham (2005) attempted to create a binary understanding of behavioral functioning, categorizing behaviors as either functional or dysfunctional. However, as with most binary choices, one category inevitably became representative of less prevalent differences, and thus, the majority differences became a norm. For example, Cullinan et al. (2004) inevitably reinforces the norm for what is considered "appropriate behaviors" by labeling certain subjectively determined behaviors (e.g., disobedience) as "inappropriate". Similarly, even as they suggested greater inclusion of learned with ED, Merrell and Walker (2004) reproduced normed understanding of behaviors by situating student behavior on a continuum where some were viewed as "significant" problems in comparison to others. Both Harris-Murri et al. (2006) and Green (2005) suggested counteracting such ableist notions through increased cultural responsiveness in utilizing interventions and creating classroom cultures.

#### Acknowledgement of the Intersecting Oppressions of Racism and Ableism

Acknowledgement of the intersecting oppressions of racism and ableism was coded for a total of 105 times across the selected literature (see Table 3). In assessing the selected literature for ways in which they acknowledged the intersecting oppressions of racism and ableism, I investigated how the experiences of Whiteness and able-bodiedness were prioritized as superior to experiences perceived as Other, or different (Gillborn, 2015; Storey, 2007). While there was much recognition given to the categorical identities associated with racism (e.g., race) and ableism (e.g., disability category), little attention was devoted to the oppressions that accompanied these labels, particularly when they intersected. In other words, researchers

struggled to move from a singularly disadvantaged to a multiply disadvantaged understanding of oppression (Crenshaw, 1989). For example, some researchers focused on clinical categorization of ED learner's behavior, without fully explaining racial implications of these behavioral categories on historically discriminated against groups, such as African Americans (Bal, Sullivan, et al., 2014; Bal, Betters-Bubon, et al. (2019); Cullinan & Kauffman, 2005; Cullinan et al., 2004; Cullinan & Sabornie, 2004; Forness & Kavale, 2000; Merrell & Walker, 2004; Zhang & Katsiyannis, 2002). As noted by Erevelles and Minear (2010) the foregrounding of categorical identities, rather than deeper intersectional understandings of interstices at which these individuals exist gives them greater explanatory power but minimizes their personal experiences within a biased school system.

While researchers acknowledged the impact of the intersecting oppressions of racism and ableism, they neglected to center the voices of those existing at these interstices. The most blatant example of this was Hill (2017), who presented a case study about the Joseph brothers, who existed at the intersection of racism and ableism. While Hill (2017) included narratives about their experiences with an underfund and punitive school system, and stories from their grandmother navigating such a system, she almost never used their direct voice to let them narrate their own stories. Even researchers focused on cultural responsiveness did not center the learners' voice, despite the disproportionate impact ED identification had on their academic, professional, and life outcomes (Green, 2005; Harris-Murri et al., 2006; Skiba, Poloni-Staudinger, Simmons, et al., 2005; Skiba, Poloni-Staudinger, Gallini, et al., 2006). For example, Skiba, Poloni-Staudinger, Simmons, et al. (2005) and Coutinho et al. (2002) discussed the extensive impact of poverty and race on African American learners, but never included qualitative analysis that presented their voice on the matter. As Finkelstein (1988) noted, a sense

of humiliation accompanies such a relationship, when the disabled are researched by "disability experts" but not given the platform to share their own experiences in relation to the topic being studied.

Borrowing from DisCrit's Tenet 3 (Annamma, Connor, et al., 2013), which argued that disability is often presented as a biological fact rather than a social construction, I recognized that some researchers identified the ways in which disability identification is a byproduct of greater societal inequities and disparities (Harris-Murri et al., 2006; Serpell et al., 2009; Voltz et al., 2003; Kea et al., 2003; McKenna, 2013; Bullock & Gable, 2006). For example, Harris-Murri et al. (2006) acknowledged that disability labels may be socially constructed for African American learners when educators misinterpret behaviors as a result of negative experiences with cultures different from their own. Similarly, Serpell et al. (2009) recognized that racial and cultural factors influenced teacher evaluations of students, even when their judgments were mitigated by the use of standardized scales. Voltz et al. (2003) and Bullock and Gable (2006) attributed such educator bias to both limited knowledge of and ability to implement culturally responsive practices, resulting in lowered academic expectations for diverse learners. As both McKenna (2013) and Kea et al. (2003) posited, diverse students may appear academically deficient to educators because they fail to account for the cultural context in which a behaviors manifest. In other words, their supposed deficiency, and subsequent special education labeling, is really representative of the deficiency of the educational stakeholders in their learning spaces.

# Impact of the Intersecting Oppressions from Racism and Ableism on Classroom Design

Impact of the intersecting oppressions from racism and ableism on classroom design was coded for a total of four times across the selected literature (see Table 3). In assessing for the impact of the intersecting oppressions of racism and ableism on classroom design, I investigated

the ways that centering Whiteness and prioritizing able-bodiedness as the norm impacted classroom design (Gillborn, 2015; Storey, 2007). As such, I focused on classroom design as the purposeful or inadvertent structuring of the learning environment in such a way as to impact learning, or in this case, to mitigate the impact of the intersecting oppressions of racism and ableism. In the reviewed literature, this was a rare consideration, particularly in relation to the intersecting oppressions of racism and ableism. The only consistent element of classroom design mentioned was the teacher, and only in a few instances was it contextualized in relation to racism or ableism. For instance, Green (2005) noted that teachers who created classroom environments that supported the acceptance of difference and an atmosphere of emotional warmth were more likely to effectively teach African American learners. Additionally, the capacity of the teacher to create an orderly or disorderly environment became an important design consideration. For example, Skiba, Poloni-Staudinger, Gallini, et al. (2006) identified teacher skill in classroom behavior management as a predictor for minority disproportionality in special education. If the teacher classroom management skill set was not strong enough to ensure each student received individualized teacher attention, these students often spent more time removed from the general education classroom (Skiba, Poloni-Staudinger, Gallini, et al., 2006). Integral to accomplishing such goals, was the ability to overcome the obstacles encountered in schools with disproportionate numbers of African American learners. This included such challenges as a large, low-income study body or the need to provide ED students with the least restrictive setting without the resources to do so (Bullock & Gable, 2006; McKenna, 2013).

Impact of the Intersecting Oppressions from Racism and Ableism on Curriculum and Instruction

Impact of the intersecting oppressions from racism and ableism on curriculum and instruction was coded for a total of 19 times across the selected literature (see Table 3). In assessing for the intersecting oppressions of racism and ableism on curriculum and instruction, I examined how the centering of Whiteness, and prioritizing able-bodiedness as a norm, impacted the prioritization of instructional needs in the learning space (Gillborn, 2015; Storey, 2007). This effect was most evident in the treatment of diverse learning needs as an addendum to be retrofitted to the mainstreamed curricula and instruction, which historically centered Whiteness and able-bodiedness. For example, in Bal, Sullivan, et al.'s (2014) examination of school reform, one school's Leadership Team only prioritized the needs of diverse learners after past, failed, reform efforts. It was only after these failures that the Leadership Team decided to prioritize their instructional core, integrate culturally responsive curriculum and instructional practices, and incorporate UDL delivery (Bal, Sullivan, et al., 2014). More importantly, these new strategies finally prioritized the needs of students with, and at risk for, disabilities and aimed to reduce disproportionality through the use of culturally responsive pedagogies and interventions (Bal, Sullivan, et al., 2014). While this attempted retrofitting reified that the American public-school system does not inherently address the needs of diverse learners, even more concerning was the literature that spoke of culturally responsive pedagogy in aspirational terms. For example, both Kea et al. (2003) and Serpell et al. (2009), spoke of what should be done to address the cultural needs of diverse learners, including programmatic and curricular adjustments, strengths-based special education checklists, and a contextualization of excessive disciplinary referrals in the curriculum and instruction. However, none of these strategies had actually been implemented at the time of the strategy was suggested, ensuring that White centered curriculum and instruction continued to be prioritized.

While Green (2005) centered the instructional needs of students of color, by advocating for multicultural education to address the educational inequality they historically encountered, many of the proposed instructional strategies placed the onus of implementation on the learner. For example, students were expected to identify instances when they recognized their culture represented in the curriculum and to improve race relations in their schools through social action (Green, 2005). Similarly, Harris-Murri et al.'s (2006) culturally responsive education was grounded in diverse learners making relevant connections among themselves, the subject matter, and the tasks teachers asked them to perform. While their prioritization of student-centered learning was admirable, it does little to address disproportionality given that the cultural views of teachers have played an integral in the over-identification of African American learners. Instead, the onus should be upon educators to deliver individualized and effective instruction to diverse learners (Bullock & Gable, 2006; Cullinan et al., 2004)

## Extent of Health and Well-being's Recognition as a Form of Oppression

Extent of health and well-being's recognition as a form of oppression was coded for a total of 32 times across the selected literature (see Table 3). In assessing the selected literature for health and well-being as a form of oppression, I investigated ways in which health and well-being was utilized as a means to recognize some groups as superior and other groups as inferior. Sometimes health and well-being were discussed via proxy, while other times it times it was discussed explicitly. For example, in utilizing poverty as a proxy for health and well-being Skiba, Poloni-Staudinger, Gallini, et al. (2006) recognized that African American students were "disproportionately exposed to the ravaging effects of poverty, are more likely to need a higher intensity of service across all disability categories" (p. 420). As such, disabled, African American learners were portrayed as disadvantaged in comparison to disabled peers of other

ethnic groups, due to a potential lack of health and well-being services. Similarly, this lack of access the health and well-being services was attributed to developmental difficulties experienced by African American learners, which were then associated with the manifestation of academic and behavioral outcomes that could be mistaken for ED indicators (Coutinho et al., 2002; Skiba, Poloni-Staudinger, Simmons, et al., 2005). According to Coutinho et al. (2002), in viewing poverty as a proxy for health and well-being, African American learners were disproportionately exposed to risk factors associated with economic disadvantage. This exposure to risk factors, such as environmental toxins and lack of access to quality health and nutrition care, eventually lead to negative behavioral, social, and academic manifestations that created oppressive life outcomes, ranging from mental health issues to disproportional representation in special education (Coutinho et al., 2002; Cullinan & Kauffman, 2005). In Hill's (2017) case study the impact of such oppressive health and well-being issues was acknowledged in the lives of the Joseph brothers, whose lack of access to quality healthcare had wide-ranging negative consequences on their lives. First, the brothers never acquired the consistent healthcare they needed to address health conditions before they disrupted their academic progress. Second, due to their lack of healthcare, they never had access to quality social workers with the expertise needed to navigate the welfare programs and systems. As a result, they were unable to access the neuropsychological experts needed to properly evaluate them and diagnosed their disabilities, before their symptoms lead to disciplinary and correctional records (Bullock & Gable, 2006).

Given the disproportionate impact of socioeconomic factors on the health and well-being of African Americans, and the increased risk they face of being identified into disability categories such as OHI, the oppression from health and well-being was also acknowledged by some researchers through preventative suggestions (Bal, Sullivan, et al., 2014; Serna et al.,

2002). McKenna (2013), Zhang and Katsiyannis (2002), and Serpell et al. (2009) acknowledged that low socioeconomic status for African Americans made quality healthcare and nutrition inaccessible, forcing them to grow up in suboptimal conditions that then lead to the development of maladaptive behaviors, and increased the likelihood of developing disability indicators. To counteract the deleterious environmental factors associated with poverty, proposals have been made for comprehensive systems-of-care that addressed a range of needs, including educational and health (Kea et al., 2003; Bullock & Gable, 2006). Such a system should include interventions that address ecological factors known to contribute to student behavior, and thus, mitigate interactions between school context and racial/ethnic factors (McKenna, 2013).

## Culturally Responsive Practices Related to Referrals and Interventions

Culturally responsive practices related to referrals and interventions was coded for a total of 39 times across the selected literature (see Table 3). In reviewing the selected literature for this sub-theme, I investigated the ways in which they recognized culturally responsive practices in special education referrals and interventions, particularly in relation to the IDEA (2004) ED category. Discussions of culturally responsive practices in referral and interventions practices ranged from general to specific. For example, some researchers (Bullock & Gable, 2006; Coutinho et al., 2002; Cullinan et al., 2004; Gresham, 2005), simply recommended that teachers be more aware of cultural differences, consult with educational stakeholders, and that interventions be more individualized and culturally responsive. Others, such as Serpell et al. (2009) suggested that culturally specific protective factors (e.g., racial socialization) be incorporated in school-based interventions to improve student outcomes. Meanwhile, Kea et al. (2003) recommended that student referrals for special education establish whether the teacher's strategies suited the cultural learning style of the student. Additionally, standardized assessments

should be designed by professionals familiar with the cultures of diverse learners (Kea et al., 2003). Finally, diagnosticians should rely on a culturally responsive assessment model, which encouraged them to account for how their preparation could bias the assessment process, not rely solely on standardized assessments, holistically evaluate learners, and include parental observation to establish a common understanding between the home and school (Kea et al., 2003).

Green (2005) and Harris-Murri et al. (2006) made the most detailed suggestions of culturally responsive practices related to referrals and intervention strategies. For example, Green (2005) most salient point was that schools should utilize parents, university faculty, and community liaisons as cultural brokers (Gay, 1993). According to Gay (1993) cultural brokers are,

one who thoroughly understands different cultural systems, is able to interpret cultural symbols from one frame of reference to another, can mediate cultural incompatibilities, and knows how to build bridges or establish linkages across cultures that facilitate the instructional process. (Green, 2005, p. 48)

posited that these cultural brokers could help cultivate positive school climates for African American learners, making them feel valued and motivated to learn, because they understood their experiences with oppression, racism, and discrimination. As such, they had the trust of the community and the learner (Green, 2005). Consequently, Green (2005) also suggested that these cultural brokers be present on special education referral committees, offering input on the positivity of the school climate and the cultural responsiveness of the curriculum and instruction. Harris-Murri et al. (2006) noted multiple factors that must be addressed to mitigate the cultural bias inherent to many interventions, assessment instruments, and interventions. For example,

Harris-Murri et al. (2006) noted that institutional, personal, and instructional strategies utilized within Culturally and Linguistically Diverse (CLD) populations with social, emotional, and/or behavioral difficulties should have been proven effective with such populations. Additionally, assessment instruments for CLD students should be proven cross-culturally equivalent, given that most behavioral instruments are normed primarily with European American children (Harris-Murri et al., 2006). Finally, both Harris-Murri et al. (2006) and Bal, Sullivan, et al. (2014) recommended considering the bias of the referring party, typically teachers, and asking whether their own negative attitudes towards CLD learners had been accounted for in the referral process.

# Teacher Hiring and Retention Practices as Integral to Addressing Special Education Disproportionality

Teacher hiring and retention practices as integral to addressing special education disproportionality was coded for a total of four times across the selected literature (see Table 3). Teacher hiring and retention practices was discussed briefly in the selected disproportionality literature, to recognize systemic inequities and disparities, and propose culturally responsive changes to mitigate them. For example, Hill (2017) recognized that high-poverty school districts tended to hire inexpensive, inexperienced teachers compared to wealthier school districts. Additionally, urban, high-poverty school districts were more likely to have teachers on staff that had failed their certification exam and teach outside of their license area (Hill, 2017). While it would be ideal to address these professional qualification issues through federal and state level policy changes, there were often local mechanisms that could be put in place to address them. For instance, rather than focus on technical solutions, Bal, Sullivan, et al. (2014) highlighted how one school district transformed themselves to address disproportionality by grounding their

decisions in a theory of change that recognized that "disproportionality was not a special education issue, but a symptom of a much larger cultural, societal, and educational issues necessitating coordinated adaptive systemic transformation to improve quality of academic and behavioral opportunities for all learners" (p. 11). As such, they not only transformed the role of special educators in their schools, but also changed their employment practices, to hire individuals who could support high intensity interventions (e.g., reading specialists; Bal, Sullivan, et al., 2014). To address retention, some focused on reshaping the skill sets of their existing staff by prioritizing professional development. Harris-Murri et al. (2006) presented an argument for a culturally responsive Response to Intervention (RTI) approach to reduce special education disproportionality in the ED category. One dimension of this proposed culturally responsive Response to Intervention (RTI) approach involved professional development that encouraged critical reflexivity in teachers and staff, so that they could define the cultural norms being using to identify problematic behaviors (Harris-Murri et al., 2006). Additionally, greater emphasis was to be placed on the cognitive and emotional components of pedagogy, to improve recognition and understanding of identification patterns for disability categories, such as ED.

Role of teacher traits and beliefs in special education disproportionality. Role of teacher traits and beliefs in special education disproportionality was coded for a total of 38 times across the selected literature (see Table 3). In examining the role of teacher traits and beliefs in perpetuating disproportionality, I assessed the literature for a range of factors. This included recognition of the ways in which teacher personality and character traits, pedagogical knowledge, and pedagogical judgement impacted the experiences of diverse learners in their classrooms. For example, to prevent the misidentification of African American learners into special education categories like ED, Bullock and Gable (2006) and Skiba, Poloni-Staudinger,

Gallini, et al. (2006) argued that teachers should be nurturing, capable of creating a positive learning atmosphere, and be attentive to the individualized needs of these learners. Harris-Murri et al. (2006) and Cullinan et al. (2004) posited that caring teachers, perceived to be loving and trusting, motivated students to work harder, learn, and succeed. In other words, the studentteacher dynamic mattered. This was particularly true of race moderated teacher-student relationships, in which African American students were more likely to dislike school if they were not close to, or were in conflict with, their teacher (Bal, Sullivan, et al., 2014; Serpell et al., 2009). Moreover, it was suggested that teachers possess enough self-awareness to recognize when personal bias impacted their professional judgement (Bullock & Gable, 2006). Without this type of critical introspection teachers may not accurately assess the strengths of diverse students, their own professional capacity to meet these needs, and recognize whether this mismatch pushes a child towards special education referral (Cullinan & Kauffman, 2005; Harris-Murri et al., 2006; McKenna, 2013). According to McKenna (2013), such a lack of cultural competence could result in teachers utilizing inappropriate, and thus ineffective, teaching strategies with diverse learners (McKenna, 2013). For example, in wealthier school districts, African American students were more likely to be overidentified for EBD because teachers lacked tolerance for cultural differences they infrequently encountered and were not trained to adjust their pedagogy for (Serpell et al., 2009). To mitigate the potential racial bias on the part of educators Harris-Murri et al. (2006) recommended that a member of the child's cultural background, as well as their family, be involved in assessment and ED eligibility determinations. This ensured that any previous, negative, teacher experiences with learners and families from cultural backgrounds different than their own would not impede their pedagogical judgement (Harris-Murri et al., 2006).

Pedagogically, Voltz et al. (2003) and Green (2005) asserted overrepresentation of diverse learners in special education may be attributed to the difficulty some teachers experience distinguishing between cultural differences and disability indicators. In economically disadvantaged school districts this issue was compounded by inexperienced and uncertified teachers, as well as those teaching outside of their area of expertise (Hill, 2017). Consequently, Voltz et al. (2003) and Zhang and Katsiyannis (2002) argued that preparing culturally responsive teachers would involve increasing their awareness of the effect cultural diversity has on learning and behavior. Moreover, rather than expecting teachers to learn as much as they could about all cultures, Green (2005) and Bal, Sullivan, et al. (2014) proposed that they be trained in instructional practices that affirmed the cultural experiences of diverse learners. In other words, teachers should adjust instruction to meet the cultural learning style of the student rather than expecting the student to adapt to the learning style of educators or schools (Harris-Murri et al., 2006; Kea et al., 2003). According to Harris-Murri et al. (2006) culturally responsive instruction is established on the prior knowledge, interests, motivation, and home language of learners. Practically, this information can be gathered by teachers in various ways, including questionnaires, individual conferences, or observations during social interactions (Harris-Murri et al., 2006).

#### Conclusion

This literature review examined the existing disproportionality literature base to determine the extent to which constructs of health and well-being are expounded upon, if at all. A total of 21 peer-reviewed articles were analyzed using guiding questions developed from the theoretical frameworks of Maslow's Hierarchy of Needs, Labeling Theory, UDL, Intersectionality, and DisCrit. Specifically, these articles were reviewed to determine whether

they: (1) recognized and prioritized health and well-being as a need; (2) contributed to either formal or informal health and well-being labels; (3) recognized of health and well-being as a design need in the classroom; and (4) acknowledged the intersecting oppressions of racism and ableism. This inquiry revealed that there was minimal recognition of the multiple dimensions of health and well-being. While mental and emotional health were the most frequently recognized dimensions of health and well-being, they were either recognized as a contributor to labeling or a consequence of being labeled. Rarely, were they viewed as a gateway for intervention, and thus, the prevention of identification. Moreover, many studies either discussing policy or concentrating on teacher/educator perspectives as a source of bias in the special education referral process. As such, the disproportionality literature base inadvertently decenters the students perspective, and risks reifying invisible power structures of the traditional classroom. This study, however, offers an opportunity to re-center the voice of learners at the heart of the disproportionality discourse in special education.

### Chapter 3

The purpose of this multi-case study was to reframe disproportionality from a health and well-being perspective. In doing so, I borrowed from socially constructed understandings of health and well-being, specifically population health (Kindig & Stoddart, 2003), and examined the environmental factors impacting the health and well-being of specific groups of learners, the interaction between these factors, and the policy implications to address these interactions (Kindig & Stoddart, 2003). By reframing disproportionality from a health and well-being perspective, I aimed to move the somewhat static disproportionality discourse beyond identification mechanisms to interdisciplinary, preventative strategizing. To understand the disproportional representation of African Americans in special education as interdisciplinary issue, this study addressed one overarching, and three supporting, research questions: (A) How do the health and well-being experiences of African American, ED learners inform a reframing of special education disproportionality? (i) How does health and well-being impact African American, ED learners' academic self-perception? (ii) How do normative expectations of health and well-being impact African American, ED learner involvement with the special education system? (iii) How does the design of education systems and spaces converge to reify the intersecting oppressions of racism and ableism?

While chapter one offered a brief overview about the history of disproportionality in special education, and chapter two presented a review of literature that justified a health and well-being reframing of disproportionality, this chapter describes the study's research methodology. In doing so, it includes: (a) a methodological rationale for the study's research approach, (b) a description of the research sample, (c) an overview of the research design, (d)

data collection methods, (e) analysis and synthesis of data, (f) ethical consideration, and (g) issues of trustworthiness.

## **Methodological Rationale**

Qualitative methodologies "consists of a set of interpretive material practices that make the world visible" (Denzin & Lincoln, 2011, p. 3). Methodologically, such a perspective, allowed for an understanding of the complex processes that people use to make sense of, interpret, and assign meaning and values to events and objects in the world around them (Rubin & Rubin, 2012). Additionally, rather than forcing the arrival at one absolute truth and the assumption of researcher neutrality, this interpretivist positioning allowed me to prioritize data collection methods that allowed for multiple, conflicting truths to co-exist at the same time and supported a data analysis process that included researcher reflexivity (Creswell, 2013; Rubin & Rubin, 2012). Moreover, given the persistence of disproportionality in special education and its connection to systemic racism, I relied on a critical perspective to structure my findings and recommendations for practice, research, and policy in a manner that-if implemented-holds the potential to create macro-level, systemic change (Kincheloe & McLaren, 2000).

Methodologically, I utilized the critical perspective, specifically DisCrit's Tenet Four, to share the voices of those at intersections made invisible by society's censorship and oppression (Annamma, Connor, et al., 2013; Kincheloe & McLaren, 2000). Specifically, I centered the perspectives of African Americans learners that could present the affordances and constraints of those with chronic health conditions and an ED label. As such, this study design relied on Merriam's (2002) interpretivist approach to case studies, in which research participants are meaning-makers of a given situation or phenomenon and researchers serve as mediating instruments for this meaning making- attempting to understand a phenomenon, process, or

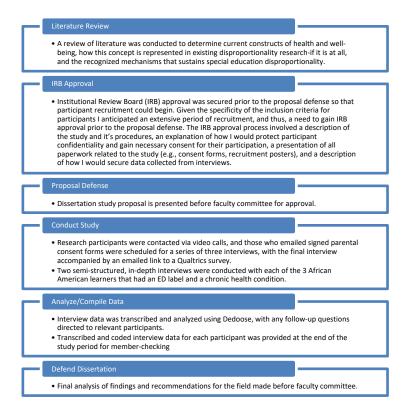
perspective of the participant. In adopting Merriam's (2002) case study design, this study acknowledged that there are multiple realities, perspectives, and thus, interpretations for a single phenomenon (Guba & Lincoln, 1994). The selection of a case study design allowed me to examine the personal health and well-being experiences of multiple African American learners from a diverse range of perspectives. This subjective approach to mean-making also allowed for a robust understanding of not only the participants' experiences, but the context in which they occurred.

## **Research Design Overview**

The process used to carry out this research study was captured in six steps (see Figure 1).

Figure 1

Research Study Overview



### **Research Sample**

Borrowing from Crenshaw's (1989) proposition that addressing the needs of the most disadvantaged in society would naturally benefit the singularly disadvantaged, this study included participants that exist at multiple intersecting oppressions. Specifically, there was a focus on participant experiences at the intersection of ableism and racism. To examine these intersecting experiences, and due to the nature of the research questions, recruitment criteria was very specific. As a result of the specificity of the recruitment criteria, purposive sampling was used to select the initial participants for this study. This was then followed by a snowball sampling strategy, or chain-referral sampling, which was utilized to recruit subsequent participants (Miles & Huberman, 1994).

#### Recruitment

This study recruited African Americans between the ages of 18 and 65, with a past or present medical diagnosis of a chronic health condition- or a family history of a chronic health condition- and an ED special education identification. This participant group included 18-year old's, as long as they were no longer enrolled in a K-12 school and were capable of legally giving consent. Participants were also considered if they self-identified as bi-racial or Afro-Latinx African American and were predisposed to a chronic health condition because of family history with the disease. Participants were also considered if they self-identified as bi-racial or Afro-Latinx African American and were predisposed to a chronic health condition because of a family history with the disease. Additionally, while I recognized that the African American community is not monolithic, for data collection purposes, they were grouped under one racial/ethnic category.

Recruitment began with the online posting of recruitment posters (see Appendix A) to the researchers private social media account (i.e., Facebook). These recruitment posters presented the purpose of the study, the inclusion criteria that participants had to meet-including the need for parental permission, and the researcher contact information. Individuals that had direct connections to individuals with ED (e.g., special education teachers, therapists) were tagged in the post, and asked to distribute to relevant parties, such as online support groups for mothers with disabled children. These individuals represented different urban and suburban population across states in the United States, such as New York and Florida.

## Participant Demographics

In order to protect participant anonymity pseudonyms were used in place of real names. These pseudonyms were used to refer to them throughout this study. Participant 1 chose to be referred to as "L", Participant 2 chose to be referred to as a famous science fiction character whose initials were "A.S.", and Participant 3 chose to be referred to as "Jak".

Table 4

Participant Characteristics

Participant Pseudonym	Gender	Age	Race	Received free or reduced lunch in high school?	Ever identified with a disability ?	Disabilit y Type	Chronic Health Condition
L	Male	19	Black (African American)	Yes	No	Unanswe red	Seasonal Allergies
A.S.	Male	20	Black (African American)	Yes	Yes	ED <sup>a</sup>	Asthma, Obesity
Jak	Male	19	Black (African American/Cari bbean)	No	Yes	ED	Seasonal Allergies

<sup>&</sup>lt;sup>a</sup>ED represents Emotional Disturbance as defined in the Individuals with Disabilities Education Act of 2004.

Data from a brief survey was used to gather demographic information about participants (see Table 4). This study included three males, between the ages of 19 and 20. While L and A.S. identified as Black and African American, Jak identified as Black and African American, but with Caribbean heritage. To understand their socio-economic standing while they were in high schools, participants were asked to identify whether or not they qualified for free or reduced lunch. While L said he did not qualify for free or reduced lunch in high school, A.S. and Jak noted that they did. This indicated that, during high school, A.S. and Jak lived in households with incomes at or below 185 % the federal poverty level (Vollinger et al., 2020). Of note, is that when asked whether they had ever been identified with a disability, A.S. And Jak stated they had and noted they were classified as ED. However, L said he had not, despite being sent to a residential treatment center for ED. Additionally, when asked whether they had any chronic health conditions, A.S. noted that he had asthma and obesity, while L and Jak noted they had seasonal allergies.

While this study did not include many participants, it's finding were still informative because of the diversity of the three participants, specifically their schooling and special education experiences. A.S. represented the "depressive" perspective on the ED continuum, whereas L and Jak represented the "disruptive and aggressive" perspective on along the continuum. Moreover, Jak and L had a deep understanding of the special education system, because of their movement between multiple school districts, schools, special education settings, and special education labels.

### **Research Site**

This study was conducted virtually for a variety of reasons. First, the specificity of the participant inclusion criteria required a national recruitment effort. Therefore, participants were

not situated in the same city as the researcher and virtual interviews were the most cost effective means of data collection. Secondly, in the latter stage of recruitment, a global pandemic resulted in quarantine conditions. As a result, in-person interviews were not possible within the time frame of the study. Finally, conducting virtual interviews allowed for more flexibility in scheduling interview times that were convenient for participants.

#### **Procedure**

Once potential participants contacted the researcher, and it was determined that they meet the inclusionary criteria to be a part of the study their parents were emailed the consent material for review. After participants reviewed, signed and electronically returned the consent documents, they were accepted into the study. Participation included completion of a brief survey and a modified version of Seidmans' (2006) Three-Interview Series Protocol, in which they discussed their lived and learning experiences at the intersection of ableism and racism, specifically as an African American learner with an ED label and chronic health condition.

The semi-structured interviews for this study were conducted virtually. A virtual site was selected for a range of reasons. First, it allowed me to offer participants compensation while still protecting their privacy to the greatest extent possible. Institutional rules initially required the collection of participant social security numbers, full names, and physical addresses in order to account for the compensation offered in the study. However, because participants were allowed to participate virtually and I secured an institutional social security waiver, participants did not have to divulge their social security number and they only had to disclose an email address. Therefore, this limited the amount of private information participants had to share to partake in the study and secure compensation. By designing the study in this way, I minimized a potential deterrent to participation, or the fear of having to share too much personal information with an

unknown entity. Secondly, utilization of a virtual site accommodated researcher budgetary constraints, which did not allow me to fund participant travel for face-to-face interviews, given that this study's recruitment efforts were national, and my study funding was limited. Finally, a virtual site also allowed participants to select a location in which they felt most secure, and thus, comfortable speaking.

#### **Data Collection**

Historically, the health field has relied on positivist ways of knowing, neglecting qualitative understandings of health experiences. Additionally, medical studies have consistently had an underrepresentation of African American participants and difficulty recruiting in the African American community, due to a history of research abuses (Shavers, Lynch, & Burmeister, 2000). In education research, although there has been less concern with African American representation, there have been few studies on the impact of health on learning (Thies, 1999). DisCrit guided the data collection for this study, attempting to bridge the cross-sector knowledge gap between health and education institutions, which are "unable or unwilling to engage in joint thinking and efforts to solve issues faced by people of color" (Annamma, Connor, et al., 2013, p. 6). Therefore, while surveys were used to collect data from participants, this data only served to supplement the qualitative data gathered from the semi-structured interviews. Semi-structured interviews were the primary means of data collection used to capture the lived experiences of African American learners navigating between health and education institutions. In foregrounding the semi-structured interviews, I hoped to counteract the ahistorical nature of science which "renders the voices of the dispossessed and marginalized group members mute" (Ladson-Billings, 2016, p. 20).

### Survey

The survey (see Appendix B) utilized in this study included 19 questions about age, gender, race/ethnicity, household characteristics, disability status, chronic health conditions, health and classroom learning, and digital health management. The survey was designed using the features of Qualtrics (Qualtrics, 2017) to offer multiple prompts within demographic questions, which prevented participant fatigue but enabled participants to choose from a range of options to describe themselves. Designing survey question in this manner contested the representation of any one group as homogenous. For example, the survey categories for race/ethnicity were an amalgam of the traditional categories utilized by the U.S. Census Bureau (2018) and Fonseca's (2017) diversity and inclusion recommendations for demographic questions. Therefore, in the category of race/ethnicity, participants are initially offered the basic options of Indigenous (e.g., American Indian or Native American, Aboriginal), Black, Asian, White, Hispanic, or Multi-racial. However, to improve the inclusivity of these racial/ethnic categories and contest the representation of any one group as homogenous, the following, more specific, racial/ethnic prompts were offered to participants after their initial selection:

- Black: African American, Caribbean, African, Hispanic
- Asian: East Indian, West Indian (Guyana, Trinidad, Jamaica), Chinese, Filipino,
   Japanese, Korean, Southeast Asian (Vietnam, Laos, Cambodia)
- White: Non-Hispanic/European, Traveler
- Hispanic: Cuban, Puerto Rican, Dominican, Mexican, Central American (Belize,
   Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama), South America
   The inclusive design of the demographic questions in the survey was also evident in other

categories of questions. In the category of Household Characteristics participants were asked about citizenship status, languages spoken in the home, housing status, members living in the household, and qualifications for free or reduced lunch. While most of these are traditional demographic questions, some were designed to offer more inclusive options. When asking about languages, English and Spanish were offered, but so were variants of Sign Language, recognizing that not all language is spoken. Additionally, the question about housing status recognized that not all learners have stable housing situations, and therefore, alternative housing options should be provided for participants to choose from. Therefore, options for this question included not only stable housing, but also homelessness, providing participants with the opportunity to specify where they stayed when they did not have permanent housing (e.g., couch surfing), or as having transient housing. Furthermore, recognizing that households are comprised of more than immediate, nuclear family members, participants were allowed to recognize extended family members who may share their household with them. These included nonbiological family members who they may be related to through intermarriage, adoption, or fostering. Finally, instead of asking participants to identify a household income level to determine economic status, which would be futile given the national recruitment efforts of the study, resulting in participants spread across multiple states. Instead, participants were asked to report whether their household qualified for free or reduced lunch, which better contextualized their income against a single federal standard. In order to qualify for free or reduced lunch participants would have had to provide documentation that their household income was at or below 130% the federal poverty level, for free school meals, and between 130-185% the federal poverty level for reduced-price school meals (Food Research & Action Center, 2019).

In addition to demographic questions, the survey also inquired about participant disability status, chronic health conditions, health and classroom learning, and digital health management. Under the category of *disability status*, the disability labels participants were offered as choices were derived from the 13 IDEA (2004) disability categories. Questions under the chronic health conditions category asked participants to select any conditions they had ever been diagnosed with by a healthcare provider. Some of the options for this question were curated from the most common chronic health conditions that impact the African American community, including asthma, diabetes, heart disease, cancer, and sickle cell disease (CDC, 2016a, 2016b; Office of Minority Health, 2019). Additionally, under this category, participants were also asked whether their healthcare provider spoke to them about how their health impacts them in school, and more specifically, while learning in the classroom. Health and classroom learning included questions about whether any educational stakeholder(s) in the school setting spoke to the learner about the impact their health has on their learning. Finally, the digital health management category questioned participants about their use of digital technology to manage their health, specifically their use of mobile phones, mobile phone apps, and/or wearables technologies.

#### **Semi-structured Interviews**

The primary means of data collection was a series of semi-structured interviews (see Appendix C) based on a modified version of Seidman's (2006) interview protocol. There were two semi-structure interviews conducted with participants, utilizing a condensed version of Seidman's (2006) Three-Interview Series. Each participant was interviewed on two separate occasions about their lived and learning experiences with a chronic health condition. Whereas Seidmans' Interview One focused only on the participants' life history, with participants reconstructing, "their early experiences in their families, in school, with friends, in their

neighborhood, and at work" (Seidman, 2006, p.17), I modified interview one to focus on participants' health and well-being history, describing their past in relation to doctor, hospitals or clinics, and family caregivers. Seidmans' Interview Two focused on "the concrete details of the participants' present lived experience" (Seidman, 2006, p. 18) being careful not ask for opinions, but instead focusing on the details participants use to form their opinions. For the purposes of this study, I focused on the detailed, place-based experiences, such as how they experienced their chronic health condition across the school and home settings. At the end of this interview, I embedded reflection questions similar to those found in Seidmans' Interview Three, during which participants are asked "to reflect on the meaning of their experience" (Seidman, 2006, p. 18). Participants were then asked to make meaning of the memories they discussed in Interview 1 and early portions of Interview 2. Specifically, in order to capture the emotional and intellectual connections between participants and their education and health experiences, this study asked them to reflect upon how management of their health and well-being impacted their learning experience.

According to Seidman's (2006) interview protocol, each interview lasted approximately 90 minutes, and were to be conducted 3 to 7 days apart. However, this protocol was modified to accommodate participant schedules and personal preferences. As a result, participants scheduled interviews 2-3 days apart. Additionally, each interview lasted approximately 60 minutes, at most. To mitigate potential fatigue from speaking with me for a prolonged period of time, participants were informed that they could take a break as needed during the interview.

Although a protocol with structured questions was used during the interview process, it was adapted based on iterative data collection and analysis as well as input from participants since this study was "not designed to test hypotheses, gather answers to questions or corroborate

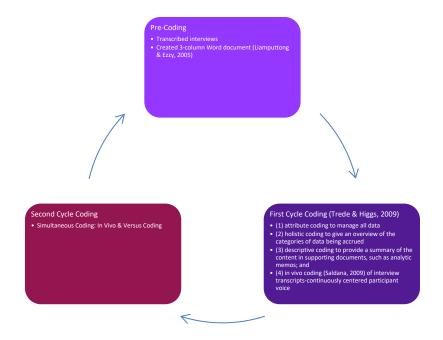
opinions. Rather, it is designed to ask participants to reconstruct their experience and explore their meaning" (Seidman, 2006, p. 92). Instead, this protocol was included as a guide with potential conversation pathways to explore (Seidman, 2006).

### **Data Analysis and Synthesis**

Within days of completing each interview, audio recordings of the interviews were transcribed into Word documents. Transcriptions of the recorded conversations were created using a clean verbatim, also known as intelligent verbatim or non-verbatim, style of transcription (Opal Transcription Services, 2020). This style of transcription suited the priorities of this study, which was an analysis of content rather than discourse, by removing filler speech (e.g., "um"), speaker idiosyncrasies (e.g., "like"), interviewer interjections (e.g., "interesting"), false starts or redirects, and non-speech sounds (e.g., "coughing"; Opal Transcription Services, 2020). Cleanverbatim transcriptions maintained the accuracy of this study's conversations, despite the removal of the aforementioned items, because they did not adjust sentence structure or any other words in the conversations (Opal Transcription Services, 2020). Once an initial transcription was created, it was reread to "correct any spelling or other errors; anonymize the transcript so that the participant cannot be identified from anything that is said (e.g., names, places, significant events); insert any punctuation, such as commas and full stops (periods) and include any other contextual information that might have affected the participant (e.g., temperature or comfort of the room)" (Sutton & Austin, 2015, p. 228). Then the multi-stage, iterative data analysis process began (see Figure 2; Bhattacharya, 2006; Layder, 1998).

Figure 2

Data Analysis Process



The transcribed Word interviews were prepared for the Pre-coding stage by borrowing from Liamputtong and Ezzy's (2005) recommendations for formatting documents to facilitate initial coding. The documents were divided into three columns, with the first column containing the transcribed interview data, the second column holding any "preliminary code notes and jottings...ruminations or first impressions [that] may help provide a transitional link between the raw data and codes", and the third column including the final codes (Liamputtong & Ezzy, 2005, pp. 270-273). The preliminary codes entered in the second column were the result of what Saldana (2016) referred to as First Cycle coding, in which multiple levels of coding may be

utilized to sort and organize data, including: (1) attribute coding to manage all data; (2) holistic coding to give an overview of the categories of data being accrued; (3) descriptive coding to provide a summary of the content in supporting documents, such as analytic memos; and (4) in vivo coding of interview transcripts. For the purposes of this study, with its' research questions that explored participants' realities and perceptions, coding that centered their voice was continuously used throughout the first cycle coding process (Trede & Higgs, 2009). As such, in vivo coding was prioritized because it used the direct words of participants rather than researcher generated terminology, eliminating one more layer of interpretation before final coding (Saldana, 2016). Any researcher interpretation was saved for the analytic memo process, which occurred concurrently with the Pre-coding Stage (Bhattacharya, 2006; Weston et al., 2001). The analytic memo process not only supported research reflexivity but also supported critical thinking about "what you are doing and why, confronting and often challenging you own assumptions, and recognizing the extent to which your thoughts, actions, and decisions shape how you research and what you see' (Mason, 2002, p. 5).

Saldana's (2016) Second Cycling Coding Stage supported the final codes entered in column two of the Word document, which were created as a result of simultaneous coding, or the application of two or more codes to the same datum. While Sutton and Austin (2015) referred to the coding process as "the identification of topics issues similarities and difference that are revealed through the participants' narratives and interpreted by the researcher" (p. 228), I attempted to minimize the extent of researcher interpretation on participant voice by once again relying on in vivo coding in this final coding stage. Additionally, I paired it with Versus Coding (Saldana, 2016), or coding that supported a critical analysis of the data, allowing me to reveal the

perceived power tensions between learners and the systems labeling them. Categories were then created from these coded units.

Descriptive data from survey analysis supplemented the case study descriptions.

Additionally, once final codes were created a formal member check was conducted to assess the internal validity, or factual and interpretative accuracy, of the transcription and coding process (Lincoln & Guba, 1985).

#### Data Yield

This study yielded 6 audio recordings of participant interviews, 6 transcribed interviews in Word documents, and demographic data from 3 Qualtrics surveys. Qualitative data also included analytic memos and initial analysis notes that accompanied each transcribed interview.

### **Ethical Considerations**

As a social science researcher, ethical considerations I accounted for in this study included the protection of: (a) a participant's right to give informed consent throughout this study; (b) the confidentiality and anonymity of participant information in the quantitative and qualitative data collected during the research process; and (c) the participant's decision-making power over the life of their data beyond the study's timeline. Although there were no anticipated ethical issues related to participating in the study, certain protections were still put in place to address the aforementioned issues.

#### **Informed Consent**

To ensure informed consent was conveyed throughout the study, participants were provided with a consent form that they had to sign and return to the researcher. This consent form informed them that they could withdraw their participation at any point in the study.

Additionally, it ensured that participants understood the intricacies associated with being a part

of the study, including its purpose and procedures, which were verbally explained to them. They were also told they could withdraw from the study at any point.

#### **Confidentiality and Anonymity**

Consent forms provided assurances of participant anonymity, recognizing that anonymity exists on a continuum, from completely anonymous to identifiable (Scott, 2005). While recognizing that true anonymity is not possible, this study tried to balance data de-identification with maintaining data integrity and value (Saunders et al., 2015; Scott, 2005). Therefore, identifiable information in this study was replaced with strategically created placeholders, which protected participant anonymity while still conveying the context of the original piece of information. First, to ensure participants controlled of how they were represented in this study, they selected pseudonyms that would replace their real names. Participant 1 wanted to be referred to as "L", Participant 2 wanted to be referred to as a well-known science fiction character whose initials were "A.S.", and Participant 3 wanted to be referred to as "Jak". Secondly, names of geographical locations and buildings (e.g., schools) were replaced with strategic identifiers, which allowed for anonymization without decontextualization. For example, for the first high school attended by Participant 1, which was located in a metropolitan area, the place holder would be their pseudonym, followed by a location descriptor, then the item being anonymized, and sometimes, a number to indicate if it is part of a sequence of similar items. Therefore, this anonymized information would appear in transcripts as [L Metropolitan High School 1].

Participant privacy in the quantitative data, collected via the survey creation program Qualtrics (Qualtrics, 2017), were protected by enabling the following Qualtrics settings for the study survey:

- by Invitation Only, in order to allow only invited participants to access the anonymous survey link
- prevent Indexing, to ensure that the survey data will not be indexed by search engines
- secure Participants' Files, to ensure that only those provided with permission, may view the responses
- survey Expiration, which will close access to the survey, three weeks from initially opening it.

#### **Future Use of Data**

Decision-making control about future use of participant data was conveyed in the consent and assent forms, which asked legal guardians and participants to grant permission to store their responses for future research. Additionally, if participants opted to, their contributions could be acknowledged at the beginning of published works, printed materials, and under diagrams, tables, and charts. However, acknowledgements would not be specific enough to make deidentified information identifiable. None of the participants opted to have more than general acknowledgement of their contributions in future proceedings derived from these study findings.

# **Issues of Trustworthiness**

Lincoln and Guba (2000) utilized the concepts of *credibility* and *dependability* as two of four criteria that assessed the trustworthiness of qualitative research. Credibility, similar to construct validity, referred to how accurate the findings were from the perspective of the participant and researcher (Creswell, 2014; Maxwell, 2013; Merriam, 1998, 2009; Miles & Huberman, 1994; Miles et al., 2014). In this study, credibility was established through member checks that relied on participants to review a transcription and coding of the information contained in their interviews. After reviewing the transcription and coded data, participants made

notes about any inaccurate researcher representations of the perspectives they expressed during the interviews. These revisions were then returned to the researcher, and when relevant to the purpose of the study, I modified the case study write-up to reflect participant feedback.

Reliability in quantitative research is the equivalent of dependability in qualitative research, and thus, refers to the consistency in data collection methods and findings (Lincoln & Guba, 2000). While Yin (2018) noted that true reliability, or the minimization of biases and errors, in case studies is a rarity, a researcher still aspired for it in principle. Even case studies are capable of meeting some measure of reliability through explicit documentation of procedure and a clear rationale for their decision-making process during the research process (Lincoln & Guba, 1985). This study established reliability by clearly documenting the research procedure, without losing the flexibility of a semi-structured interview process, which allowed for impromptu follow-up questions. In drawing form what Merriam (1998) referred to as "transparency of method", I included multiple documents that included procedural scripts for the data collection process (see Appendix D), such as the interview protocol (see Appendix C) that noted the overarching questions I anticipated asking participants, as well as potential follow-up questions.

#### Conclusion

In developing the research design for this study, I drew upon the findings from the literature review of Chapter Two. These findings indicated that disproportionality discourse has rarely centered the voice of the learners that were problematically overrepresented in specific special education disability categories or examined the ways that disqualifying factors to receiving an ED label (e.g., health factors) were accounted for in learning spaces. As such, the findings of the literature review supported this study's qualitative approach that centered the unheard voices of African American learners with ED at the core of disproportionality discourse,

while also exploring their perceptions of the role health and well-being plays in their learning experiences.

This chapter provided a detailed description of the study's research methodology. A qualitative, multi-case study design was utilized center the perspectives of African American learners in the disproportionality discourse, a group often discussed-but whose voice is rarely presented-in disproportionality literature. Participants were identified using purposive and snowball sampling and made up of 3 African Americans, between the ages of 18 and 65, with an ED label and a chronic health condition. Data collection occurred primarily through semi-structured, in-depth interviews, and was supplemented with information from a brief survey. Additionally, some participant data was informed by health documentation.

#### Chapter 4

# Findings, Analysis, and Interpretation

This qualitative, multi-case study was to center the perspectives of three African American, ED learners. I proposed that understanding these educational stakeholders' lived experiences would inform a much-needed reframing of special education disproportionality, specifically from a population health perspective. This chapter presented the key findings obtained from six, semi-structured interviews, and a brief survey. Five major findings emerged from this study:

- 1. Participants, educational stakeholders, and healthcare stakeholders prioritized some health dimensions more than others, focusing on the absence of deficiency to determine health and well-being. For example, participants in this study prioritized the physical, mental, and social dimension(s), while their educational and healthcare stakeholders prioritized social and emotional-behavioral dimensions of health.
- Participants of this study experienced some form of untreated, acute trauma before receiving their ED classification and services.
- Participants relinquished some autonomy to utilize the supports of the institutions labeling them, which was perceived as both beneficial and disempowering by participants.
- 4. Participants were unable to name the racism and ableism in the lived experiences, specifically how these intersecting oppressions affected their educational trajectory.
- 5. Participants were aware of how their special education labels altered the design of their special education settings, in both stigmatizing and empowering ways.

These findings resulted from identifying connections or themes between coded data, derived from applying in vivo and versus coding to the study's transcripts (Saldana, 2016).

Additionally, the data analysis process remained anchored in the cross-pollinated version of UDL, intersectionality, and DisCrit, presented in Chapter 1 (Annamma, Connor, et al., 2013; Crenshaw, 1989; Waitoller & King-Thorius, 2016). Therefore, coding began with participants' exact words and assessed for perceived power tensions between learners and the systems they navigated.

In the sections that follow, I present the study's main findings, sorted into analytic categories based on the three sub-research questions introduced in Chapter 1. As such, the findings were organized into the following three categories:

- 1. Health and well-being' impact on academic self-perception.
- 2. Normative expectations of health and well-being and special education involvement.
- 3. Reification of racism and ableism through designs of education systems and spaces.

Within each of these categories, findings were supported using evidence from participant interview transcripts and arranged to demonstrate the commonalities and differences between participants. Analysis and interpretation of participant experiences were then offered, supported by theoretical and research evidence.

### Health and Well-beings' Impact on Academic Self-perception

Health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 2005, para. 1; Badash et al., 2017). Utilizing this definition and DisCrit's Tenet Two, this study conceptualized health and well-being as a multi-

dimensional aspect of learner identity often overlooked in educational settings. Moreover, as I posited in Chapter 1, health and well-being is a basic need in Maslow's Hierarchy of Needs (Maslow, 1943). According to Maslow (1943), a child whose health and well-being is impaired will perceive the world as unpredictable and unsafe and seek reassurance to establish a sense of security. Whether they are provided with this reassurance impacts their capacity to move from what Maslow (1943) termed "deficiency" and "growth" needs. This transition is critical for the educational context, with higher-level cognitive skills developed once deficiency needs are met (Alderfer, 1972).

In this study, Jak had a holistic definition of health and well-being. L and A.S., however, did not. Instead, their understandings of healthiness prioritized specific dimensions of health more than others. Additionally, in evaluating learners' health and well-being, educational, familial, and healthcare stakeholders focused on particular dimensions of health. These understandings of health and well-being influenced the participant's academic self-perception, or how they viewed their academic performance (e.g., class grades) education behavior (e.g., attendance), and cognitive skills and attitudes(e.g., mood; CDC, 2014). In the form of participant's voice, the sections that follow present evidentiary support for these findings, my analysis, and interpretation of similarities and differences between participant experiences, and research support for my analysis.

# Learner Health and Well-being Priorities

Jak was the only participant that provided a holistic definition of health and well-being.

According to Jak, his health and well-being encompassed,

how are you, how are you treating yourself, your body. Just overall, just making sure that you're good, everything is ham. Just making sure everything is good and just up to date.

Keep yourself clean, hygiene wise. There's a lot that has to do with health. From hygiene to emotional to mental to physical. Just making sure that all those are up to normal standards. Either normal standards or above average.

This expectation that Jak held about "normative standards" of emotional, mental, and physical health, which he was expected to meet or exceed, negatively impacted his cognitive skills and attitude (CDC, 2014). Specifically, it affected his concentration and mood.

Jak's expectations of what his mood should be like in the school setting (i.e., calm) led to him use marijuana to self-medicate. He explained the importance of marijuana, as a mood stabilizer that allowed him to conform to school behavioral norms, recalling an experiment he once conducted:

I tried to stop myself from getting into a lot, because there would be a lot that would happen, a lot of people would say some slick stuff, look at me funny, make funny remarks. I actually did an experiment one day, I went into school sober, and I looked at how much I actually cared about people looking at me funny and saying the slick stuff they said. Then I went to school one day high and it was almost like school was over in like 2 hours, and I didn't have any problems, everyone was nothing-it wasn't a blur-but everyone was like a figment of my imagination. Go about your day, go do your thing. I would just go to school, try to do some work, and call it a day.

His marijuana use helped him manage his mood in school, but it also impacted his classroom focus and created instructional gaps. For example, he described an experience where he walked into a classroom was struggling to situate himself in the curriculum, stating,

I hadn't been to school in so long. I hadn't been in a classroom setting; I mean I had been in a classroom setting but I hadn't really sat down and grasped the concept of what they

were teaching and what I was supposed to be learning. It just went in one ear and out the other, and now that they were just trying to put that on me, I was like, "I don't know what you guys are talking about." What is focus? I don't know. I can't learn something that hasn't been taught, or that has been taught, but I haven't been paying attention.

On the other hand, both L and A.S. defined health and well-being by prioritizing one dimension of health and well-being and focusing on what needed to be absent for one to be healthy. For example, L prioritized mental health, stating that it meant, "Living on a daily basis, you know, actively and in a way where, you know, I'm not getting stressed or depressed, every day, or how I feel on a daily basis." A critical element of his definition of health was the absence of stress or depression daily, rather than the presence of a positive state of being. His mental health prioritization was understandable, given L's description of how stress impacted his cognitive skills, particularly concentration (CDC, 2014). For example, if a class activity required public speaking, his anxiety could have manifested as shortness of breath or ticking.

A.S.' definition prioritized health's physical dimension, noting that health was marked by the absence of discomfort or consistent and permanent pain. He explained his understanding of health by saying,

I guess I would define health as loosely as possible as being in a state that you consider comfortable. I mean for me, as an individual, it's just not being in constant pain or discomfort. Because I'm a pretty big person. I'm not very much in shape, at all, by traditional, medical standards. At the same time, if something comes up, like a medical issue where I hit my hand on something or I hurt myself, if it's not a constant pain or something that could be permanent, I just won't go to the doctor for it. If something isn't

preventing me from going day-to-day the way that I normally go, I just choose to ignore it, which I probably shouldn't be doing.

A.S.'s focus on physical health impacted his education behavior, precisely his willingness to engage in activities requiring him to move in front of his peers. According to A.S.,

There is a lot of self-consciousness. Sometimes when we're asked to stand in a particular palace in a room, or if I have to move to do something-I'm a pretty tall person so I have to be conscious of, "My legs my fit through there but my upper body might have a bit too much trouble, and I don't want to keep asking people to move in their chair a little bit." It was probably me being a little too self-conscious because the people I went to high school with were really nice and accommodating, with everything, so that was just a personal thing. I don't like people touching me for anything, so because I take up more space than most people, I was always more conscious about touching other people, in case they felt the same way.

# Educational and Health Stakeholder Health and Well-being Priorities

While their definitions of health and well-being were well-rounded and holistic, their descriptions of health and well-being experiences with the medical and education field were not. Neither the medical or education field connected race to their health and educational needs in a substantial way, and they each focused on some dimensions of health and well-being but not all. For example, while identifying the names and locations of the high schools he attended, Jak acknowledged how an emphasis on social health by both educational and healthcare stakeholders influenced his academic trajectory. For example, he noted that his conversations with his medical provider focused on, "...my mental. How I've been feeling lately, how I looked at certain situations, and how I would handle them. Mostly, a lot of them had to deal with emotional

distress." His educational stakeholders also reinforced this prioritization of his social and emotional-behavioral health. He reported that he was once sent to the principal's office in his first high school because a teacher said that he was not doing any work and was not social. These incidents affected his education behavior, particularly his peer interactions (CDC, 2014). The added attention to his lack of socialization bolstered his references of himself as a "social outcast", which had far-reaching consequences like limiting his interactions with his peers in social settings and affecting his academic capacity. For example, Jak described instances when his peers attempted to initiate social interactions with him. Still, his belief that he was "not outgoing...not social...an anti-social, not talkative person" prevented him from engaging with them. He attributed his social preferences to a deficiency within himself, rather than a social system that had established normative standards for social interactions that were not inclusive. Moreover, he was aware that he varied from socially accepted norms. This variance affected his self-perception as a learner. According to Jak,

It kind of impacted me a lot, because when it came to group activities or something that needed to be done with a partner I just couldn't put my best foot forward because I wasn't vocal, I wasn't one to talk.

By acknowledging this, he recognized that the instructional materials in his learning environment conveyed the importance of socialization and devalued independent work. Thus, instructionally, socialization was the normative standard of health for all learners. Consequently, those who did not socialize were deemed unhealthy and in need of remediation.

In L's academic trajectory, educational and medical stakeholders reinforced that emotional-behavioral and mental health dimensions of his health were problematic. Thus, they should be prioritized. After the violent incident with his mother, when L was held at [L

Northeastern Metropolitan Psychiatric Hospital], he noted that they did not give him a physical exam as part of his intake process. When he was moved to the adjacent social services building, a social worker did ask him about his health history, but as he recalled, it was "just basic questions." Instead, the collection of health history information focused on his emotional-behavioral and mental health. Similarly, the high schools he attended before his placement in the residential treatment facility also concentrated on these two health dimensions. When asked about whether educational stakeholders at these institutions had collected information about his health history, he said,

Other than talking about the anxiety, no...not that I know of. Well, when I got to [L Northeastern Metropolitan High School 1], I started to develop some anxiety. I would get mad over certain things and lose control at some point, but it wasn't all the time. It was every other time, or if something really happens that I didn't like, but that was also because of anxiety, and I didn't know how to control, but I did talk to the counselors and the dean. They weren't too helpful, it was alright.

This prioritization of the emotional-behavioral and mental dimensions of health and not his physical health negatively impacted his cognitive skills (CDC, 2014). When I asked him about physical cues that would have been visible to his high school teachers, indicating he was having an anxiety issue, he provided a list of them. He stated that they included "some ticking, sweaty, my hands would get sweaty, short of breath, and rapid heartbeat." Given that L had an IEP, which required collecting his health history, if educational stakeholders had prioritized the physical dimension of health, they would have understood how his symptomology manifested in the classroom. They would have gained insights about how classroom situations triggered anxiety episodes and how to personalize instructional strategies to avoid such incidents. For

example, he noted that not being in control of certain social circumstances would cause him anxiety. Therefore, teachers could have allowed him a more comprehensive array of choices in these situations.

Educational stakeholders prioritized A.S.'s mental health rather than the physical dimension of health, which is evident in A.S.'s special education processes. Despite his ability to name his chronic health conditions, specifically asthma, and obesity, A.S. was not asked by educational stakeholders about his physical health. However, more concerning was that he stated these conditions were not documented in his IEP, indicating they were not considered in his personalized education plan. Additionally, there was a lack of educational stakeholder inquiry about his depression treatment. A.S. mentioned that he was on anti-depressants "towards the end of the school year, during the summer, and I had decided that I didn't want to take it anymore before the school year started again." Despite the potential impact of starting and stopping these medications on his cognition, specifically his mood and concentration, he recalled that no educational stakeholders, including his school counselor, asked about his medication history (CDC, 2014). His out-of-school counselor also did not attempt to inform his in-school-counselor about changes in his medication history or provide any progress reports about his depression. There was no communication, or coordination of care, between his educational caretakers and his medical caretakers even though A.S. would have been open to such contact. A.S. indicated that he just wanted to be consulted before the information was shared.

#### Familial Health and Well-being Priorities

Only L and A.S. were aware of their familial priorities for health and well-being because their family's health priorities were regularly communicated to them. Specifically, L's family prioritized his physical health and well-being, with his grandmother consistently warning him

about a maternal predisposition toward diabetes. She spoke to L about the impact of diabetes on one's lifestyle and preventative behaviors. For instance, L stated,

She calls me. She makes sure I'm eating right. She makes sure I don't eat too much sugar or anything like that. She tells me about her experience all the time, expecting that it'll scare the hell out of me...Make sure to be physically active and eat good, they go hand in hand. You can't be the most physically active if you haven't been eating good: carbs and sugars, you know, junk food...Now she tells me to eat more fruit, take vitamins-all the time.

L also mentioned that he trusted her advice because when he was younger and did not heed her advice, it impacted his cognitive skills, specifically his concentration and mood (CDC, 2014). He described feeling "sluggish" and was "afraid" that he would get diabetes after he ate sugars and carbs.

Like L, a maternal figure determined A.S.'s health and well-being priorities, stating that, "My mother is always warning me about my health and stuff." His mother's role as his health and well-being advocate expanded after his planned suicide attempt, after which she championed for his rights during the IEP process. As A.S. recalled,

If it was left up to me, to do whatever work needed to get an IEP sorted out, and my mother didn't help me, I wouldn't have done it. I wouldn't have known where to start. I'm not sure I was fully aware of every choice that was being made to help me out, how classes were set up for me, how lenient teachers were, at the time at least. I felt that there was a lot of work going on from my mothers' side and from the schools' side, that I probably wouldn't have been able to do myself if my mother wasn't involved.

His mother's prioritization of his mental health ensured his successful academic performance or his graduation from high school and enrollment in college.

## Normative Expectations of Health and Well-being and Special Education Involvement

Special education has been rooted in ableist assumptions of normalcy that have deemed some "abled" and others "disabled", with the latter label viewed as less valuable (Campbell, 2009; Hodge & Runswick-Cole, 2014). This study utilized DisCrit's Tenet Two and Tenet Six to contend that the multiple dimensions of health and well-being are conceptualized according to these ableist dichotomies, with those meeting abled-bodied standards receiving tangible social and economic benefits (Annamma, Connor, et al., 2013). In contrast, unable to meet these ableist standards of health and well-being norms are viewed as different or deviant (Annamma, Boele, et al., 2013). Specifically, African American learners who are perceived to be unhealthy, because they are doubly impacted by poverty and inaccessible healthcare, are assumed to be developmentally unprepared for school, and in need of stigmatizing labels, like ED (Brantlinger, 2006; Skiba, Polloni-Staudinger, Simmons, et al., 2005). However, this study proposed that these indicators of developmental unpreparedness are behavioral manifestations of environmental barriers impacting schooling, no longer situating the deficit in the learner, but rather the system (Bhattacharya, 2017; Hill, 2017; Waitoller & King-Thorius, 2016).

In this study, L, A.S., and Jak experienced at least one, acute traumatic incident that was compounded by their interactions with various carceral institutions and systems, before their labeling as ED (Ben-Moshe, 2011). In the sections that follow, I asserted that because these learners were African American males, multiple systems chose to situate the deficit within them, rather than identify and address the structural barriers negatively impacting their schooling

experience. Additionally, even after receiving their deficit-based ED label, they were expected to exchange their autonomy for institutional supports. Using participant voice, the sections that follow present evidentiary support for these findings, my analysis, and interpretation of similarities and differences between participant experiences, and research support for my analysis.

# ED and Trauma: "I just wanted better and things just tended to get worse"

DeGruy Leary (2005) defined trauma as "an injury caused by an outside, usually violent, force, event or experience" p. 14, which positioned trauma's manifestations (e.g., disrupted health and well-being) external to the individual. Contrastingly, the ED label situated disruptions in health and well-being, or "dysfunctional behaviors," as deficits located in the individual. This distinction was integral to understanding the labeling of L, Jak, and A.S. as ED. All three participants experienced at least one acute traumatic incident. However, after these incidents, they were forced to interact with multiple, carceral systems that compounded what could have been treatable trauma (Ben-Moshe, 2011). To varying degrees, they were forced to interact with often disconnected foster care, psychiatric, child protective, court, and residential placement systems, all of which situated deficiency within them, confined them, and restricted their freedoms to varying degrees (Ben-Moshe, 2011).

L was involved in a physical altercation with his mother after he was truant and home for an extended period of time. A.S. was in the process of planning a suicide attempt when his mother intervened, which resulted in an ED label due to depression, referral for therapy, and the start of a medication regiment. Jak was involved in a violent incident with his mother, which he reported to his teachers, resulting in his entrance into the foster care system. Instability in his

foster care placements was followed by extended periods of truancy, an ED label, and interactions with the judicial system that resulted in a court-mandated placement in a residential treatment facility. Jak recalled the traumatic incident that gave the court authority over his life and academic trajectory be stating,

Well I've been in foster care since I was 11 and that all originated from my mom threatening me, to take my life and what not. Me being the young, 11-year old scared boy I was, I went to school and I told. From there I've been bouncing around from foster home to foster home and I just wasn't going to school. There was one point of my life, when I was 15 or 16, I was like, "Forget school. I don't even want to deal with it anymore." The courts recognized that and that's when they put me in [Jak Northeastern Suburban Residential Treatment Facility/School].

While Jak appeared to appreciate the courts' recognition of his desire not to be placed in another foster home and traditional school setting, his response also acknowledged the systematic way that multiple systems converged to push him on a carceral pathway. I maintained that because he was an African American male he was viewed as undeserving of the innocence and protection of childhood, and thus, systematically dehumanized, or treated more harshly and viewed as older, by multiple institutions (Christian, 2014; Goff, Eberhardt, et al., 2008; Goff, Jackson, et al., 2014). First, the foster care system created a transient housing situation that denied him the basic need of a stable home and propelled him onto a truancy path. Then the public education system labeled him as disabled, rather than attempting to treat his trauma, relabeled him as ED, and pushed him into a more restrictive special education setting. Finally, all systems allowed him to repeatedly fail until he had to interact with the judicial system and was left with no choice but to exchange his autonomy for the support he wanted. Moreover, he was labeled as ED and deficient

because he could not succeed in a system meant to demean and oppress him (Christian, 2014).

As he described it,

I was going through a lot. Between being in a foster home, not being able to go home and seeing my mom, being a social outcast in school, and just overall, just life. I just wanted better and things just tended to get worse.

In addition to the systemic failures evident in Jak's educational journey, was the denial of childhood to an African American, male body, who was only 11-years old when he encountered violence (Dumas & Nelson, 2016; Goff, Jackson, et al., 2014). Rather than pursuing alternative pathways to address the trauma he experienced, which would have required recognition of vulnerability in a Black, male body, the public education system chose to isolate his trauma from his educational challenges. Moreover, despite Jak's indications that he needed additional supports; his school demonstrated the ways they devalue the pain of Black children. For example, before being placed in the residential treatment program, he recalled that he only got into trouble in his first high school because his clothes smelled like marijuana. In these instances, he said he explained to educational stakeholders (i.e., principal) his reason for self-medicating with marijuana, stating,

I just didn't want to be interacted with. I would want to be in my own world, and I wanted to be left alone, and they were right. I literally just wanted to be left alone, to myself, and to that corner of the classroom.

Despite vocalizing the feelings of isolation that caused him to self-medicate, Jak said that the only follow-up was, "they would take me to the principals' office. They would have a long talk with me, and they would call my foster parents and I would go home that day." He was referred to a school counselor, but after his experience reporting his mother and subsequent instability

from being placed in foster care, he did not feel comfortable exposing himself in a similar way, and thus, explained his marijuana use by stating, "Everybody has days and today is just not my day." After this, there was almost no follow-up, or attempt to develop a holistic support plan for Jak. As such, he continued to self-medicate with marijuana, and miss more school days, until he had experienced so much academic failure that it negatively affected his perception of himself. More importantly, his truancy led to increasing levels of segregation from the general education population.

Like Jak, L's entrance into a restricted special education setting was precipitated by a violent incident with his mother. He remembered that his disinterest in school caused an extended truancy period, with most of his free time spent at home. However, he did not help his mother with household chores or attempt to contribute in any other way that his mother deemed productive. His inactivity at home led to numerous exchanges with his mother about how he was spending his time, with L recalling,

Since I didn't want to go to school, I was home all the time. My mom was like, "You can't just not go to school and be here all day and do anything neither." At that time, I did want to do stuff, I just didn't have the resources to do any of them. We would get into these arguments because I didn't want to do around the house. Other stuff I was like, "Why do I have to do this?"

Even though he was not doing much at home, he did not describe himself as unmotivated. Instead, he described himself as motivated to pursue his interests but frustrated by his inability to access the necessary resources. Therefore, during a similar conversation with his mother, the situation escalated to the point that his mother believed police and psychiatric intervention was required, even though L disputes the need for either institutions' services. According to L,

So yeah, we would get into arguments, and one time it escalated, and she got physical. I tried to stop her from coming at me aggressively. In a way, it seemed like I was being aggressive, but I was only trying to stop her, I restrained her. So, the cops were called, and the way she explained to them what happened, they thought that I was the aggressor, so of course, they took me.

This incident resulted in L's immediate removal from his home, and placement in multiple restrictive systems, until he was forced to interact with the judicial system, a pathway similar to Jak's. First, he was placed in a psychiatric hospital for at least a week of observation. He was then moved to a child protection agency facility, and finally, the courts mandated that he be placed in a restrictive special education setting in a residential treatment facility.

While Jak and L had traumatic incidents with their mothers that led to their segregation into restrictive special education settings, A.S.'s entrance into special education resulted from an acute mental health crisis and a contentious relationship with his father. According to A.S., his acute mental health incident resulted from motivation, self-worth, and socialization issues throughout his elementary and middle school years. However, it wasn't until high school that these converged to reach a critical point. As A.S. described it,

Toward the end of my freshman year, it got so bad that I cut an entire month of school just because I was like, "I'm not going to pass, so what's the point?" I guess the cognitive dissonance between "I am so smart, why am I failing?" and "I am having so much fun doing nothing" had me thinking "Oh, I'm not really going to do anything with my life since I'm enjoying this so much." So, I was planning a suicide attempt. No one really confronted me full force about the problems I was having until the end of the school year and then my mother did it. I'm not a very verbally expressive person with my emotions,

or at least I wasn't at the time, but I kind of broke down. I told her what I was planning.

Then I started going to therapy and I started taking medication for a few years down the line. But that's the first time I had a label for it.

Although A.S. attributed some of his emotional challenges to his elementary school peers' bullying behaviors, he also placed responsibility for his depression developing on his father, stating,

He will make a joke that's at your expense, but he does it so expertly, that he'll say something that's not enough for you to start yelling and getting angry. He'll do these little jabs so often, not intentionally trying to hurt you, that you look like the asshole if you get mad at him. I wish that I could do that with people. I wish I had that ability. He would say to me and my half-brother, I'm doing this to give you a thick skin. He never hid the fact that it made him happy to make jokes with us, or at us rather. He's like part of why I'm making jokes now is so that you can shrug it off when people say things to you later on, you'll just be so used to it that it won't bother you. I don't necessarily know if that worked. I was getting little jabs from him and full on punches in elementary school, so I don't know if that was the best approach, so I don't know if it was helping me.

The joint pressure from peers, and the strained relationship with his father, eventually led to a suicide attempt that gained him the ED special education label. However, unlike Jak and L, he was positioned on the depressive end of the ED continuum rather than the spectrum's disruptive-aggressive end. This difference in positioning between A.S. And the other two participants offered invaluable insights about how one's situation along this continuum drastically alters one's learning and lived experiences.

The Price of Institutional Supports: "I had no choice but to be there, so it doesn't hurt to try"

This study conceptualized incarceration as multi-faceted, situated on a continuum, and inclusive of a range of carceral edifices, from prisons to psychiatric hospitals (Ben-Moshe, 2011). Though I recognized that there are procedural and protective mechanisms that distinguish these edifices, I draw upon this expansive view of incarceration to trace the journey of participants between these carceral edifices, and the subsequent effect on their autonomy (Ben-Moshe, 2011). Specifically, once labeled as ED and institutionalized, L, A.S., and Jack had to relinquish their autonomy to receive the supports they needed and wanted. As noted by DisCrit's Tenet Five, traditionally, the inferiority of African Americans has been reinforced by such mechanisms, which confer service benefits while concurrently segregating and stigmatizing learners (Annamma, Connor, et al., 2013). While L and Jak viewed this exchange as disempowering, A.S. perceived it as empowering and utilized his supports as a form of activism against the system that labeled him.

In discussing his schooling history, Jak noted that the other high school he attended was a dual purpose institution, serving as both a residential treatment facility and an education provider. This facility provided him with his high school education, but it also gave him housing and access to wraparound services (e.g., psychiatric treatment, recreational facility). During his time on this campus, he became aware of problematic aspects of his emotional-behavioral health, and he credited the facility's staff with helping him manage it. Explicitly, he recognized that he "had a lot of issues, anger wise...I had a lot of pent up rage and anger" and stated that "what they [Jak Northeastern Suburban Residential Treatment Facility/School] did was they helped me with that." In attributing the awareness and improvement of his "issues" to the residential treatment facility, he revealed how these dual-purpose institutions both situate deficiency in African American, ED learners, and act as their saviors. More importantly, however, such institutions

reified the perception of Black males as aggressive, and in need of carceral monitoring, by labeling African American, ED learners according to symptomology rather than etiology.

L also had an early introduction to carceral practices due to his entrance into the special education system. After the violent incident with his mother, police officers took him to the adolescent wing of a metropolitan psychiatric hospital. He was under observation by medical doctors for a few days. There they controlled his movements, his schedule, and his social interactions. As described by L, "They were just monitoring me 24/7 to see what was going on with me, if I act out or anything, how I respond around other kids that were in the unit I was in." He was then transferred to an adjacent building that housed social services, where they held him for another 2 to 3 weeks until he was placed at the residential treatment facility and school. While held in both of these locations, he appeared to acclimate himself to the policing of his Black body and the idea that these institutions were qualified to make an unbiased judgement about his deficits. At social services, he was offered the opportunity to attend the same residential treatment facility and school as Jak. He said that the social worker described this site as

an academic campus. Basically, with other kids, kids that also have behavioral issues, or different issues. She said it's a nice campus, and it was pretty nice, and it should be better for me to at least be able to get the stuff done that I need, and go to school, and be in a different environment and have my own space. So, I visited the campus, and I told them "Sure, I'll give it a try."

Although L accepted this option, the way the site was described to him reinforced the notion that he was emotionally and behaviorally deficient in some way, and thus, needed to be segregated with learners similar to himself. Moreover, the description offered made it clear that this option

would help him achieve his goals, which he had previously believed to be unattainable because he lacked the resources to bring them to fruition. He had to accept a stigmatizing special education label and allow himself to be segregated to finally receive the support he could not obtain in his previous public high schools. As he explained, once he moved to the residential treatment facility and school,

I had no choice to be there, and at the same time, I had no choice but to talk to people to express my feelings. At that point, since I had no choice but to be there then I might as well, it's going to help me a little bit, so it doesn't hurt to try. So, it was helpful.

A.S., who was positioned on the depressive-anxious side of the ED continuum rather than the disruptive-aggressive side, was the only participant who did not perceive his ED label as indicative of any deficiency within himself. Instead, he appeared to be empowered by his teachers' awareness that he had an ED label because of depression. He was comfortable advocating for the accommodations on his IEP, and described his interactions with teachers as positive when doing so. Additionally, he was proactive about asking for these accommodations. He did not wait for teachers to mention them, viewing them as a privilege that made him exceptional rather than deficient. For example, he described an instance when he asked a teacher for extended time, stating,

my sophomore year, I kept coming late to class, sometimes on purpose and sometimes not, to my first period class which was a global history class. Because I came late so often, they had trouble putting me into a group. So groups were working on projects about a particular country, where you would talk about the history of that country within a certain time frame and you'd get up and do a presentation on it. She was like, "You'll be working on this alone, but you have extended time, you have an extra week. So the

last day that people will be presenting, you'll go last on the last day." So she gave me extended time in that way. I got extended time on a project in my junior year, on a similar assignment. I came back from break, and we were supposed to make a presentation on the same day, but I got an extra week to present it, and I would present last. I also got extra time on my standardized tests like the SAT.

# Reification of Racism and Ableism through Converging Education and Health Design

Utilizing a cross-pollinated version of UDL, intersectionality, and DisCrit this study recognized how the design of education systems and spaces converged to reify the intersecting oppressions of racism and ableism (Annamma, Connor, et al., 2013; Crenshaw, 1991; Edyburn, 2010; Meyer et al., 2014; Waitoller & King-Thorius, 2016). If education systems and spaces were designed to the edges, or to meet the needs of the multiply disadvantaged, they would decentralize dominant ableist practices (Bhattacharya, 2017; Sailor, 2015). This study demonstrated the extent to which the current education systems and spaces are designed to the edges for L, A.S., and Jak (Sailor, 2015). Specifically, borrowing from DisCrit's Tenet Four, I examined the affordances and constraints participants encountered in these existing designs at the nexus of racism and ableism.

In this study, L, A.S., and Jak explicitly stated that their high school experience was not impacted by racism or ableism. However, they also provided anecdotal evidence and reflections based on their knowledge at ages 19 and 20, which demonstrated racism and ableism did operate in invisible ways in their high school years (Annamma, Connor, et al., 2013). However, neither the education or health system had provided them with adequate historical or anti-racist curricula to label their experiences as such, and thus, have the capacity to acknowledge the ways in which both systems failed them and negatively impacted their academic trajectory. Moreover, the lack

of these curricula, was evidence of the systemic way that participants were denied the skills, language, and tools needed to advocate for their academic success and to combat the racist and ableist components in their learning spaces. Consequently, L and Jak were not disabled by the education system in ways that prevented them from connecting the stigma they experienced in school to their ED label. Instead, they related their stigmatizing special education experiences to the design changes that accompanied the various placement choices for learners with an ED labeling (e.g., self-contained). On the other hand, A.S. viewed the changes associated with his labeling as ED as beneficial to his academic performance, at times empowering his self-perception as a learner. In the form of participant's voice, the sections that follow present evidentiary support for these findings, my analysis, and interpretation of similarities and differences between participant experiences, and research support for my analysis.

Labeling Lived Experiences of Racism and Ableism: "If I would've known that in high school, I probably would've been going every day, just to show them different"

L, A.S., and Jak explicitly stated that their high school experience was not impacted by racism or ableism. However, they also provided anecdotal evidence and reflections based on their knowledge at ages 19 and 20, which demonstrated racism and ableism did operate in invisible ways in their high school years, and raised questions about systemic weaknesses that did not provide them with the language needed to name these experiences (Annamma, Connor, et al., 2013). Additionally, they represented the complex ways basic school mechanisms support the internalization of racism in African American learners. For example, Jak's evidence that his school was racially equitable was contextualized in the schools' punitive system. He stated that,

I felt everybody was treated equally. From Korean, Chinese, White, every race, we were all equally punished, we would all get equal rewards. I really can't complain, "Oh you did what he did? Ok, you both get detention then, so be it." Sometimes it would be one bad apple spoiling it for the whole bunch. "Aww man, look what you did. Look what you did." I don't think there was much discrimination when it came to how I was treated being African American.

In contrast to this example, however, when he was asked whether he believed being an African American male impacted his educational trajectory, he noted that instructional materials lacked cultural relevance during his high school years. He was unable to label this absence of African American, curricular material as "systemic racism", but he was able to describe it in racialized terms stating, "There is a lot in the textbook that they don't say in the textbooks, about African Americans, what we've been through, and the problems we've gone through and all the stuff that we've done." More importantly, he said that if he was exposed to more African American history, it would have changed his school behavior because

We've always been looked at as animals and savages, the lesser minorities. If I would've known that in high school, I probably would've been going every day, just to show them different, like, "Yo, we are different. We are the chosen ones, and all types of other stuff."

In other words, he would have adjusted the school behaviors that justified his placement in special education, to contradict the "Negro/Ape metaphor" that associates blackness with savagery and violence (Goff, Jackson, et al., 2014; Lott, 1999). Additionally, when asked about teachers' ethnic and racial composition in his first high school, he could only recall two African

American teachers. Interestingly, he made it clear that they were African American female teachers. When asked why their gender was significant, he stated that

females, no offense, but in the classroom setting that is most likely all African American, we can become pretty rambunctious, especially around our own kind. If it was a Black male, not saying that there is no such thing as female dominance, but the Black female kind of got run all over. The Black male, everybody would be attentive and paying attention, everybody would be whispering instead of talking mad loud, getting up and laughing.

Even though he said that having an African American male teacher probably would not have changed his learning experience, his description of a Black, male archetype in his learning environment revealed a desire for positive, strong representations of himself in his learning space. Jak's reflections about how his racial/ethnic identity was missing from his learning space, were a recognition of how racism is embedded in the three fundamental school components, and thus, supports the internalization of racism (Huber et al., 2006). According to Huber et al. (2006), the predominantly White teacher workforce privileged pedagogy, curriculum, and school resources that prioritized Whiteness and perpetuated racism, which is negatively impacted learners like Jak.

L expressed similarly conflicting views about the intersection of racism and ableism in his educational experience. When he was asked whether he thought race played a role in how he navigated the high school system or influenced the way people treated him, he said,

I wouldn't say really how they treated me. The main thing was that there were different expectations. The school would have different expectations for me. They know what my situation is, and they don't expect me to perform at my best or to actually be able to focus

and get this stuff done, which is why they probably moved me to that smaller classroom, secluded from the rest of the population. Since what they expected from me, they expected from the other kids in that classroom. Therefore, you put all these people together that you have the same expectations for, you that it would be easier to work to them. This is also another reason we have these low-income communities, you just put all these people together and let's figure it out from there, and that doesn't always turn out well. With low-income communities, there is a difference, there is more violence, more stuff happening, more drug-abuse, stuff like that. So, in this small classroom environment that we were in, even if I wanted to progress, I feel like I wouldn't because of the expectation the teacher had for me. He would only go at a certain pace, do everything his way, you know, do this, do that, at a certain time. If I wanted to get stuff done and try to hurry up and graduate, I couldn't, because there was an expectation that you couldn't do everything the way you wanted to, you had to do it the school curriculum way.

L attributed the intersection of racism and ableism to the discrepancy between the instructional expectations educational stakeholders had for him compared to his peers. He also believed that this difference in expectations caused his move from a less restrictive general education setting to a more restrictive special education setting, which Annamma, Connor, et al. (2013) noted can be one of the pernicious effects of employing differentiation as a pedagogical strategy. In differentiating student activities, teachers also differentiated their expectations and risk segregating and marginalizing learners like L. (Annamma, Connor, et al., 2013). In L's case, lowered academic expectations were both the cause and result of his seclusion into the special education system, with his perception of the smaller special education classes as a pragmatic way to teach learners like himself efficiently. While segregating and teaching students like himself as

a group may seem efficient, he also expressed his belief that such strategies are ineffective. He drew parallels between the segregated nature of the special education system and failure to support low-income communities that were designed to concentrate poverty in specific areas. In addition to concerns about being segregated from other learners, L indicated that his academic progress was limited by the special educator's instructional rigidity, adhering strictly to the school curriculum. Stated another way, the special educator's unwillingness or inability to personalize L's learning experience fostered a growing frustration about recovering credits and graduating.

While L demonstrated an awareness of how the intersecting oppressions of racism and ableism operated to push him into special education, there was also evidence of internalized racism, or a negative perception of his racial/ethnic group members (Huber et al., 2006). For example, when describing the racial composition of his first and second high school, he perceived the predominantly Black and Hispanic student body of his second high school as "aggressive" compared to his first high school, which was more racially and ethnically diverse. When asked if he would have benefited from learning about the impact of race on his health and well-being or navigating the public-school system, he said no. Despite the role of racism and ableism in segregating him into a less rigorous learning space, he advocated for perseverance to persist past barriers, stating that learning about racism would not be necessary because "circumstances don't define a person and race and color isn't a problem for me." However, this was in direct contradiction to his experiences in a smaller, special education classroom, which discouraged him from actively participating in his learning experience and eventually led to truancy.

In comparison to the other two participants, A.S. did not believe that the intersection of racism and ableism had any negative impact on his educational experience. He said, "I know I'm very privileged to have not experienced racial discrimination, as far as I know. Maybe there was some other time, but it just didn't register for me." Additionally, he presented an example of how his race provided him with a privilege that his classmates did not possess, stating

I said something as part of a presentation because I didn't prepare for it enough. The purpose of the assignment that we had for my English class during my senior year was to take pictures of stuff around my neighborhood. We had to do a presentation on our neighborhood, but I didn't care. When I was a kid, I didn't have friends in my neighborhood and I never went exploring because I don't care. So, I ended up winging it, and not preparing very hard. So, I got up and it was a kind of high and mighty thing to do. I took this stance of "In [A.S. Northeastern Metropolitan Neighborhood 2], we have all these streets and avenues named for these famous Black people, all these great things in society, but the dissonance between that and kids in my neighborhood taking the train a mile to [A.S. Northeastern Metropolitan Street] and stealing city bikes and bringing them back [A.S. Northeastern Metropolitan Neighborhood 1]. That's kind of wild." Because I was free balling it-a complete stream of consciousness-I said the n-word, and everyone was like "Did he really just say that?" I think the teacher was impressed that I went with such an avant-garde stance and she let it slide because it came from such a genuine place, but I think if anyone else had done that they wouldn't have gotten as good a grade on the assignment as I did.

In wielding the n-word during his presentation and recognizing he could do so without consequences, he turned a historically derogatory term into a form of empowerment and a

moment of activism in his learning space. However, similar to L, he also expressed judgments about his own racialized peers that reified negative stereotypes of African American males, particularly those identified with ED that is considered to be more aggressive and disruptive, rather than depressive. When asked whether special education teachers treated their African American and White students differently, he stated,

So, there were a couple of kids who had similar issues, but they were often somewhat belligerent. So, I don't know if it's chalked up to that or if that's a racial thing. The teachers in my high school are generally really nice people. So, it didn't really come up like that, but if it ever did, I don't know if I would attribute it to who the kids were as people or if that's how a teacher chose to handle it.

In other words, it was easier for him to situate deficit in his peers than in the invisible, systemic mechanisms that labeled their behaviors as problematic.

Design Stigma: "I was in a much smaller class...these classes were secluded and isolated away from the general population"

In Barrett et al. (2013) study about design parameters that impacted learner progression, six "design parameters" were collectively found to significantly impact learner progress: color, choice, connection, complexity, flexibility, and light. The progression of participants in this study was most influenced by flexibility or the way that classroom spaces are conducive to students not crowding each other's space and a variety of instructional activities, and complexity, or the capacity of the school building to support new and diverse learning activities (Barrett et al., 2013). While L and Jak could not always connect the stigma they experienced to their ED label, they could associate it with the changes in their built environments that accompanied the

various placement choices for learners with an ED labeling (e.g., self-contained). On the other hand, A.S. viewed the changes associated with his labeling as ED as beneficial to his academic performance, at times empowering to his self-perception as a learner.

A.S. noted that when he was diagnosed with depression and labeled ED, "they started putting me in classes with multiple teachers." Unlike L and Jak, however, A.S. viewed this additional educator attention as an empowering, gaining him privileges that his non-labeled peers could not access. For example, he observed that once he was labeled,

They were also more hesitant. Like, if they saw another student who they believed didn't have depression, like an average person, if they were like slacking, they would call them out. If they would see me somewhat slacking, they would be more understanding about how they pressed it. They were pretty encouraging. If they saw I really didn't want to do something, they would try to give me ideas of stuff I could do or motivate me pretty heavily.

On the other hand, L and Jak were acutely aware of the negative effects of their ED label. Their special education label changed the size of their instructional space, the composition of the student body (number and type), the instructional strategies teachers utilized with them, the pacing of instruction, and the autonomy they could exercise over instruction. For example, when Jak was in elementary and middle school, he was labeled as having Attention Deficit Hyperactivity Disorder (ADHD). However, at some point in his high school tenure, his ADHD classification was changed to ED, and he noted the change in his class size, saying,

With 8, it wasn't a big change, but it was kind of weird because I really felt like there were people in every single academic I went to. It was kind of tiring really, because I wanted to see some different faces, like this is boring. I'm with y'all all the time in school.

Am I going to look at someone else? That changed when I went to high school. It was 12-14 kids. It was like, ok, this is a bit much. Damn. I don't know who to start with.

While he was still in a special education setting, Jak believed that this switch moved him into general education because it was the most students he had ever had in his class. Jak also noted the variance in instructional speed that accompanied this change, noting that,

some teachers were slower than others. Sometimes a classmate would be like, "Yo, we already know this! Could you fast-forward the lesson or something already? What are you doing?" Then you would have some classrooms where the students would be like, "Could you slow down a couple of seconds? Could you go back to that other slide? I didn't catch all of that."

Similarly, in describing the consequence of being under-credited and labeled in his second high school, L said,

I was actually in a class that was slower, which was intended to be more focused on by the teachers. So the Math class, Science class, the Reading class, I was in a much smaller class with people who were more like me, and we were supposed to be getting more support from the teachers in these smaller classes, and these classes were secluded and isolated away from the general population.

While L acknowledged that the educators in this class did offer him extra support, such as breaks and extra time, he also admitted that he felt uncomfortable in such a small setting. The proximity of the teacher and additional attention from them became triggering, saying, "It was weird. It was uncomfortable, having a teacher all in your face 24/7, always asking questions, or making sure that you're ok. It was helpful, but that is also why I had some anxiety." Besides the teacher presence making him uncomfortable, he felt "weird" about his classmates in the smaller, special

education classes. L felt as though his perception of their intellectual level made him aware of his own academic short comings, stating,

Being there was uncomfortable because I didn't want to work with these kids, and I didn't want to have to answer questions or participate with them. I feel like sometimes that they were at a lower level than I was If you can understand that. I feel like I shouldn't be there because I know that I can do the work, like pass the class and do the work, but I just chose not to, because I just didn't want to be in that school.

In contrast, when Jak was in high school, he felt stigmatized by peers because he was aware that they did not have the instructional gaps that he did. He noted that,

The fact that I really couldn't keep up with all my other classmates. Let's say everybody was doing a science project or test, I would be the only one who would not show up or show up late. Or we'd do a science project, and I'd be like, "I couldn't because I didn't know what it was" and the whole class would just look at me like, "Bro we went through that all last week" and I'd be like, "Yeah, I know." That's kind of what started all the fights. People would be like, "Yo bro are you fucking retarded? Are you stupid?" and I'd be like, "Who are you talking to?" That would start a fire and it would just grow from there.

However, as he got older, he realized that he was not "slow or retarded", and that his inability to complete schoolwork was due to lack of motivation or interest. He offered his experience with the GED classes at the residential treatment program as an example of his academic capabilities when motivated and not self-conscious, stating that,

I knew that in the GED classes we were going to start from the basics. I knew that I was around other people, in a classroom setting, with the same amount of knowledge that I

had about that subject. We could all learn together, at a similar pace, instead of being in a classroom where everybody is steps ahead of me and I'm the only one literally still trying to catch up and learn what they're doing.

Rather than the numerous special education settings he had experienced thus far, L described his ideal educational environment as one in which he could work with a teacher individually. He believed that this one-to-one ratio would allow him to focus on "the academic relationship between the teacher and me." Additionally, he offered greater insight into the stigma associated with his small special education setting. He added that this type of individualized instruction was integral to his learning experience because "I would get a lot more done...Even if I get stuff wrong, or I don't understand stuff, it won't be embarrassing or anything like that." L's description of a caring and connected relationship with a teacher, who affirmed his academic abilities, aligned with Howard's (2002) suggestions of teaching strategies that positively affected the effort, engagement, and achievement of African American learners.

Besides a need for individual instruction, L also indicated that the high school system was not designed to meet his need for autonomy. Instead, the public-school system reinforced strict social control systems over the learners, prescribing behavioral norms that served to quell self-expression and identify those that could not conform, justifying a special education ED Label (Sewell, 1997; Hemmings, 2002; Watts & Erevelles, 2004). L described his frustration with having to comply with such expectations, stating, "Having to sit in a room...having to sit down during a lesson. Getting to a class at a certain time. Raising your hand, I just hated it. I felt like I was a slave, it was just terrible." L repeatedly expressed his frustration about having no choice in determining his academic trajectory. He also described feelings of disempowerment by saying,

I didn't feel like I was built for this academic environment. This day-to-day living, just high school, just going to school, doing this, doing that, having this schedule that was given to you, you had no choice but to take these classes, you had no choice but to be in these classes with these kids.

To bolster his feelings of powerlessness, L offered a comparison to his current college experience, which he loved because,

I get to pick my own schedule, my own times. I get to socialize with different people, experience different things... I could go out, come back, or do whatever I want, and still have the schedule during the daytime and going to class and doing these things. . Do different things. It felt good.

In addition to increased decision-making authority, L also appreciated the physical design of a college campus more than a high school building. He described high school classrooms as "depressing", which is why he did not like the way they looked. Instead, he preferred being in a campus setting because it was "bigger" and "huge", and he had "a lot of space, a lot of field space." Stated another way, the design factor of complexity had been missing in his high school experience but was present in his college experience (Barrett et al., 2013).

### Conclusion

A cross-pollinated version of UDL, intersectionality, and DisCrit was used to center participant experiences and the five major findings of this study (Annamma, Connor, et al., 2013; Crenshaw, 1989; Waitoller & King-Thorius, 2016). Data from six, semi-structured interviews and a brief survey presented the health and well-being experiences of African American, ED learners. These findings were:

- 1. Participants, educational stakeholders, and healthcare stakeholders prioritized some health dimensions more than others, focusing on the absence of deficiency to determine health and well-being. For example, participants in this study prioritized the physical, mental, and social dimension(s), while their educational and healthcare stakeholders prioritized social and emotional-behavioral dimensions of health.
- 2. Participants of this study experienced some form of untreated, acute trauma before receiving their ED classification and services.
- Participants relinquished some autonomy to utilize the supports of the institutions labeling them, which was perceived as both beneficial and disempowering by participants.
- 4. Participants were unable to name the racism and ableism in the lived experiences, specifically how these intersecting oppressions affected their educational trajectory.
- 5. Participants were aware of how their special education labels altered the design of their special education settings, in both stigmatizing and empowering ways.

They were organized into the following three analytic categories:

- 1. Health and well-beings impact on academic self-perception.
- 2. Normative expectations of health and well-being and special education involvement.
- 3. Reification of racism and ableism through design of education systems and spaces.

Analysis and interpretation of commonalities and differences between participant experiences were then offered, supported by theoretical and research evidence.

Survey responses contextualized those from the interview. All three participants identified as African American males between the ages of 19 and 20. However, when asked whether they self-identified as disabled, only two of the three identified as disabled and Emotionally Disturbed. Additionally, only one of the three participants self-identified with the major chronic health conditions of asthma and obesity. The other two participants only identified seasonal allergies as the chronic health condition that they consistently managed during their high school tenure.

## Chapter 5

## **Implications for Practice and Policy**

This multi-case study aimed to center the health and well-being perspectives of African American, ED learners to inform a future population health reframing of special education disproportionality. Utilizing a cross-pollinated version of UDL, intersectionality, and DisCrit allowed me to critically explore the disconnectedness between health and education systems, stigmatization associated with the design of special education spaces, and their perception of how intersecting oppressions influenced their educational trajectories (Annamma, Connor, et al., 2013; Crenshaw, 1989; Waitoller & King-Thorius, 2016). Following is a discussion of this study's limitations and recommendations for practice and policy. Each of these recommendations was premised in DisCrit's Tenet Seven, which called for multiple means of emancipatory activism and resistance, grounded in community voices and interests, whether they be academic, theoretical, pedagogical, or activist (Annamma, Connor, et al., 2013). Additionally, each of these recommendations also supported a future population health reframing of special education disproportionality. All recommendations advocated for practices and policies to address environmental factors impacting African American learners' health and well-being and explored the potential of digital health technology to efficiently and cost-effectively collect data to guide future interdisciplinary policy decisions (Kindig & Stoddart, 2003).

## **Limitations of the Study**

While the three participants of this study offered valuable insight into the experiences of African American, ED learners this study also included certain limitations, as a result of the chosen methodology and the research design. In acknowledging these limitations, I made my

own subjectivity, or assumptions and bias, transparent to readers. Additionally, I indicated areas of improvement for future studies to be conducted on the issue.

The inclusion and exclusion criteria, specifically the selection of articles from peerreviewed, scholarly journals published between 2000 and 2019, suited the purposes of this study. However, it also eliminated a dearth of literature that should be analyzed for their accounting for health and well-being among African American learners with an ED identification. Not only should more databases be searched in future literature reviews of this topic, but a wider range of literature, such as book chapters and organization reports, should be accounted for. While conducting both the initial search and the ancestral searches there was much literature that would have been included were it not for the inclusion criteria of "peer-reviewed articles", which excluded numerous relevant chapters from books. While worth examining under the lens of this study, the omission of so much rich literature because they were not published in scholarly, peerreviewed publications raised a greater question about the inclusiveness of the academic field itself: Why is so much literature about the persistent issue of special education disproportionality published in non-peer reviewed publications, and not in peer-reviewed, scholarly journals? Rather, are the norms of academia restraining the voices of scholars discussing this topic in innovative ways, and thus, preventing the advancement of the issue itself?

This study was initially designed to recruit five participants. However, due to the occurrence of Covid-19, and subsequent quarantine conditions, recruitment was challenging.

Therefore, only three participants were interviewed, limiting the depth of this study's analysis.

Additionally, participants were comprised of African American learners with a medical diagnosis of one or more chronic health conditions. Given my reliance on a medical diagnosis of one or more chronic health conditions, I did not account for African American learners who may have

had an undiagnosed chronic health condition and lacked the healthcare access to see a medical practitioner for a diagnosis and treatment plan. Instead, these undiagnosed, African American learners may have represented the portion of the African American community that manages their chronic health condition symptoms through emergency rooms visits only when they experience an exacerbation (Bemis et al., 2016).

Finally, in centering the health and well-being of African American learners with ED in this study, I made the disproportionality experiences of other racial/ethnic groups beyond its scope. However, the disproportionality literature recognized that other racial/ethnic groups (e.g., Native Americans) are also at increased risk for special education referrals, and the negative consequences of such referrals (Waitoller et al., 2010). Consequently, future studies should examine the extent to which disproportionality discourse prioritizes health and well-being in their over- or under- representation in specific special education disability categories.

Practice: Utilizing the Whole School, Whole Community, Whole Child Model to Center the Health and Well-being of Learners

Table 5

Participant Perception of Health and Education System Communication

Participant Pseudonym	Chronic Health Condition	Has your health provider (e.g., doctor, nurse) ever spoken to you about how your health impacts your learning in class?	Has your anyone in school ever spoken to you about how your health impacts your learning?
L	Seasonal Allergies	No	No
A.S.	Asthma, Obesity	Unsure	Unsure
Jak	Seasonal Allergies	No	No

The three African American male participants and educational, healthcare, and familial stakeholders prioritized different dimensions of health and well-being. More importantly, in their survey responses, participants could not recall or indicate that education and healthcare stakeholders were speaking to them about the connection between health and learning (see Table 5). While these findings are not generalizable, they have implications for future collaborative efforts between health and education stakeholders. Specifically, how do we ensure these partnerships address the needs of the whole child? Also, how do we center community and learner, rather than institutional, voices, and interests in these collaborations? This study recommended the use of the Whole School, Whole Community, Whole Child Model, which "provides the structure to advance education reform in ways that break down traditional siloes through a coordinated and comprehensive set of services, policies, and programs that focus on the whole child and reduce barriers to learning" (Murray et al., 2015, p. 796).

The Whole School, Whole Community, Whole Child Model (WSCC) was first introduced in 2014 and was an amalgam of 10 components from the coordinated school health model and five Whole Child Tenets (CDC, 2020; Association for Supervision and Curriculum Development [ASCD], 2007). These ten components included health education; physical education and physical activity; nutrition environment and services; health services; counseling, psychological and social services; social and emotional school climate; physical environment; employee wellness; family engagement; and community involvement (Michael et al., 2015). The five tenets were:

- Each student enters school healthy and learns about and practices a healthy lifestyle.
- Each student learns in an environment that is physically and emotionally safe for students and adults.

- Each student is actively engaged in learning and is connected to the school and broader community.
- Each student has access to personalized learning and is supported by qualified, caring adults.
- Each student is challenged academically and prepared for success in college or further study and employment and participation in a global environment. (Morse & Allensworth, 2015)

Of note, was the positioning of the WSCC components, with the community on the outer layer, followed by the 10 components, and at the center, 5 Whole Child Tenets. The positioning of the community and child in the WSCC model indicated the centering of the child, and the importance of the community as a partner to successfully implement the model, honoring DisCrit's Tenet Seven (Annamma, Connor, et al., 2013; Lewallen et al., 2015; Morse & Allensworth, 2015).

Murray et al. (2015) proposed that successful implementation of the WSCC would rely on district and school-level coordinators, Whole Child Councils, and the interdisciplinary accountability and data collection. This study advocated for the development and use of the Whole Child Council, particularly because they would be comprised of members that reflected the demographic composition and continuum of views in the community (Murray et al., 2015). The effectiveness of these three components, operating simultaneously to promote a WSCC model, was evident is the case study of Alameda County Health Services Authority (ACHCSA) and Oakland Unified School District (OUSD). The goal of the ACHCSA and OUSD partnership was to create a full-service community school district to address historic inequities that were evident in data disparities, which showed,

compared to a Caucasian child in the affluent Oakland Hills, an African American born in West Oakland is 1.5 times more likely to be born premature or with low birth weight; 7 times more likely to be born into poverty; 4 times less likely to read at grade level; 5 times more likely to be hospitalized for diabetes, and twice as likely to die of heart disease. (Blank, 2015, p. 812)

At OUSD community schools, site managers supported a school site team, comprised of parents, educators, and community partners. These stakeholders were collectively responsible for the community school's leadership, vision, and data collection to improve their work (Blank, 2015). By adhering to the WSCC model's design, which stressed community collaboration for successful implementation, the ACHCSA-OUSD partnership ensured that their activism remained grounded in community voices and interests (Annamma, Connor, et al., 2013).

# Practice: Bridging Interdisciplinary Communication Gaps with Digital Health Technology

The American public school and health system have historically relied on each other to provide essential programs and services to youth and adolescents. Given the compulsory nature of the public school system and its direct contact with 56 million learners, the health system has relied on schools to implement integral health programs during developmentally critical years (CDC, 2019). Despite the interdependence of these two systems to fulfill their individual purpose, and the importance of learner health for educational outcomes, they remained disconnected (Alaimo et al., 2001; Basch, 2010; Bradley & Greene, 2013; Fedewa & Ahn, 2011; Goldman & Smith, 2011). According to Basch (2010), school health has not been a central focus of schools or national strategies to address disparities and inequities in educational opportunities and outcomes.

### Table 6

Digital Health Technology Potential

Participant Pseudonym	Chronic Health Condition	Do you use a mobile phone to manage your health?	Do you use a mobile app to manage your health?	Do you use a wearable digital device to manage your health?
L	Seasonal	No	No	No
. ~	Allergies	••		
A.S.	Asthma, Obesity	Yes	Yes	No
Jak	Seasonal	Yes	Yes	No
	Allergies			

This study recommended that digital health technology be utilized, in conjunction with the WSCC model, to maximize its potential and unify these disparate systems. Digital health technology encourages dynamic communication between stakeholders, personalization of information exchange experiences, and greater autonomy for users operating across systems (see Table 6). Additionally, they support communication networks that were not feasible in the past and were restricted by geographic boundaries or stakeholder schedules. Therefore, they support live-time communication networks, capable of distributing information to a diverse range of stakeholders and promoting collaborative approaches to health management, patient/learner autonomy, and improved academic outcomes (Alaimo et al., 2001; Basch, 2010; Bradley & Greene, 2013; Fedewa & Ahn, 2011; Goldman & Smith, 2011).

Digital health technologies can also bring to fruition often envisioned but rarely realized, unified systems. Given the ubiquity of cellular phones, particularly smartphones, mobile applications' can connect numerous stakeholders to a continuous influx of information, building vast networks of information exchange. Bradley and Greene (2013) found that the exchange from a unified education and health system would benefit children and adolescents. In the ODPHP's (2010) National Action Plan to Improve Health Literacy, the most promising

interagency coaction steps to improve health literacy included creating "a periodic assessment of and report on K-12 students' health literacy skills as defined in the National Health Education Standards" (p. 529). The most promising outcome was "standards of practice for health care professionals who serve children and adolescents, including asking questions about academic achievement (such as grades and attendance) as a routine part of health histories" (p. 529).

Digital health technology may also be the most cost-effective means of building community capacity needed to make the WSCC function efficiently, and realize its potential to address a range of environmental and individual challenges. For example, they can reinforce existing brick and mortar networks, already collaborating to solve problems, improve the services they have access to, and create healthy physical spaces (Chaskin, 1999; Simmons et al., 2011). For example, states like Washington have developed successful brick and mortar networks for community capacity building. The Washington State Family Policy Council established a network of 42 community public health and safety organizations and conducted two studies over ten years, from 1997 to 2007, to determine whether it successfully built capacity. Successful brick and mortar networks such as these can be the model for the digital network for digitally coordinating with the community, with the community well-being more impacted by the collective impact of digital networks than individual efforts (Carpiano, 2007).

## Policy: An ACEs IDEA Category to Shift Focus from the Individual to Structural Contexts

All three participants were labeled as ED, after at least one acute traumatic incident, which either went unacknowledged or untreated by educational and health stakeholders. While these findings from three participants cannot be the basis for policy recommendations, they do raise questions about the problematic nature of existing special education policy, such as IDEA (2004). For example, are trauma manifestations in African American, male bodies, being

conflated with a need for special education services? If so, what recommendations could guide future policy discussions to ensure special education services are not situating deficit in the individual but in systemic barriers?

Borrowing from Watts and Erevelles (2004) work, who argued that addressing school violence required a shift in focus from the individual to the social context in which that violence occurred, this study suggested that future IDEA policy revision consider the addition of an Adverse Childhood Experiences (A.C.E.s) category (Anda et al., 2006). I asserted that addressing special education disproportionality demanded a change in focus from individually manifested behaviors to the structural contexts that contributed to developing those behaviors. While I contented that this was a better labeling option than ED, enabling schools to justify their provision of certain special education services, I also acknowledged it was far from an ideal realization of DisCrit Tenets Three and Five, still leaving African American learners vulnerable to exclusionary labeling that carried negative societal consequences (Annamma, Connor, et al., 2013).

Including A.C.E.s as a new disability category would also move away from the increasingly specific disability classifications of special education, which Turnbull et al. (2007) critiqued for disadvantaging marginalized groups and justifying increasingly discriminatory behavior. The definition of A.C.E.s that would be used to create an ACEs IDEA(2004) category would be inherently inclusive because it accounts for a wide array of concerns such as abuse, neglect, and household challenges, which can be combined to meet the unique social conditions impacting the child. Additionally, because schools receive their funding from federal, state, and local governments, it would hold systems accountable for addressing socio-economic factors impacting student learning. Ecological factors would no longer be something that educational

interventions could choose to exclude when they were being created. Instead, with an A.C.E.s category is included in IDEA (2004), schools would have to consider the needs of their community, the socio-cultural factors impacting student learning, a change that started with the 2004 reauthorization of IDEA. With IDEA (2004), states were held accountable for homeless learners' service needs, and thus, unintentionally acknowledged the role of ecological factors in the development of disabilities (Turnbull et al., 2007).

20 U.S.C. § 1401 (3)(a) lists thirteen disability classifications; autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment (including blindness; IDEA, 2004). This proposed A.C.E.s disability category would be added to this list and include three main categories of A.C.E.s and their subcomponents; (1) abuse and its subcomponents of emotional, physical, and sexual abuse, (2) neglect and its subcomponents of emotional and physical neglect, and (3) household challenges, which includes the subcomponents of a mother treated violently, substance abuse, mental illness, separation/divorce, and incarcerated household member (C.D.C., 1995). The addition of the proposed A.C.E. classification would result in recognition of the social construction of disability, rather than the current disability categories based on the medical model of disability. By basing disability categories mainly on the medical model of disability, IDEA has established a binary relationship between cause and cure. For children with disabilities in most states to receive their right to a publicly funded education appropriate to their needs, they first have to be diagnosed with one of these medically-based classifications. This requires that they show that this classification caused educational deficits and that special education and related services are needed to alleviate this deficit. This was harmful to students who have

already been allowed periods without academic success, and now have to associate deficit with their identity, inhibiting a belief in their ability to improve even with additional special education supports (Dweck, 2010; Eskreis-Winkler et al., 2014).

Currently, students who experienced trauma have not been covered under IDEA (2004), Section 504 (1990), or the American with Disabilities Act (A.D.A.). Instead, if they needed supports and services under special education they had to be classified based on the manifestation of their trauma(s). For example, if their trauma manifested in a behavioral manner that interrupted academic performance, they might be classified as ED, as was the case with the participants of this study. However, this would not guarantee that they would have received trauma-informed placements or teachers, and thus, be supported appropriately in all environments. Instead, they may have received counseling for a set amount of time per week, removed from the learning context. This has become a concern with recognizing the impact trauma has on an individual and the most effective means of intervention.

Thus far, the most prominent effort to create some sort of ACEs classification in the special education process has been legal. In Peters P. et al. v. Compton United School District (CUSD; 2015), students and teachers brought a class-action lawsuit against the school district, in an attempt to hold them accountable for providing services to address the consequences of the complex trauma their children encountered. They argued that high poverty, crime, and homelessness rates have persisted in Compton, California. As a result, the plaintiffs were consistently exposed to toxic stress that negatively impacted their physiological and psychological health and well-being, as well as their academic and professional performance. The plaintiffs (teachers) said that they suffered burnout and secondary traumatic stress from trying to meet the needs of traumatized students, without appropriate training. Students

contended that their academic abilities were negatively impacted as a result of the neurobiological effects of the complex trauma they experienced,. Therefore, they should have qualified for disability services under Section 504 of the Rehabilitation Act (1990) and the Americans With Disabilities Act (A.D.A.; 1990). Furthermore, CUSD had a responsibility to locate all students negatively impacted by complex trauma and inform their parents of CUSD's responsibility to provide them with the means to access Free and Appropriate Public Education (FAPE). Instead, when CUSD observed the neurobiological effects of trauma, or the cognitive and behavioral manifestations, it resulted in "punitive and counter-productive suspensions, expulsions, involuntary transfers, and referrals to law enforcement that push them out of school, off the path to graduation, and into the criminal justice system" (Peters v. Compton Unified School District, 57 U.S. 6). Hence, the plaintiffs filed a complaint that CUSD had (1) violated Section 504 of the Rehabilitation Act, 29 U.S.C. § 794; (2) violated the Department of Education regulations regarding "location and notification," 34 C.F.R. § 104.32; (3) violated the Department of Education regulations regarding "procedural safeguards," 34 C.F.R. § 104.36; (4) violated the Department of Education regulations regarding "free appropriate public education," 34 C.F.R. § 104.33; and (5) violated the A.D.A, 42 U.S.C. § 12101. CUSD, or the defendants, filed a motion to have the complaint dismissed because plaintiffs could not meet the burden of proof for a "physical or mental impairment" as cited under 34 C.F.R. § 104.3(j)(1), (j)(2)(i) or A.D.A. 29 C.F.R. § 1630.2(h). They argued that the plaintiffs were attempting to equate their "zip code" with mental and physical impairment; and associate environmental, cultural, or economic disadvantage (e.g., poverty) with trauma, instead of actual physical or mental impairment. While the court ruled against the plaintiffs, they recognized that they had provided sufficient evidence that trauma significantly impacted multiple areas of their life. Even though

the case was dismissed on a technicality, the ruling was still a validation of trauma's impact on learning, with the court denying their motion for class certification. The court did not recognize the class members that brought the action at the time of certification, noting that the nature of special education identification is that it is highly individualized, and therefore, classes cannot exist, not by legal standards.

### Conclusion

African American overrepresentation in special education services, particularly in the ED category, has been a persistent issue (Artiles, 2008). This has been attributed to biased teacher perception, flaws in the special education identification process, and inconsistent state reporting procedures (Dever et al., 2016). However, there has not been enough focus on sustained interdisciplinary efforts, particularly between education and health fields (Artiles, 2011). Consequently, school-based efforts have not addressed more significant cultural and social contributors to disproportionality (Artiles, 2011). This study centered the voices of African American, ED learners to improve understandings about the overrepresentation of African American, ED learners. Moreover, I hoped their voices could be prioritized in a future population health reframing of special education disproportionality.

It may seem counter-intuitive to draw from a health and well-being field, given the history of oppression associated with the pseudo-science and clinical areas (Annamma, Connor, et al., 2013). However, I contend that resisting oppression has often been most effective when using the oppressor's tools against them, particularly in empowering ways. Reclaiming a field that once committed violent acts against African Americans, and actively worked to diminish their value, is the most radical form of resistance. Audre Lorde (1988) best captured the importance of reclaiming these colonized spaces and ways of being with her explanation of the

political significance of health and well-being, stating, "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare" (p. 131).

The three African American, ED male participants in this study engaged in their own forms of political warfare (Lorde, 1988). For L, this meant leaving the residential treatment facility, getting his high school diploma, and attending college. It was in college that he experienced a level of autonomy he had wanted since high school. For A.S., it meant graduating and attending college to become an educator. He found purpose in his experience with the special education system, realizing that he wanted to be a teacher to help students like himself. Finally, for Jak, this meant returning home to live with his mother. Central to their political warfare was having determination over their own personal, academic, and professional trajectories.

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# Appendix A

### **Recruitment Poster**

# REQUEST FOR RESEARCH PARTICIPANTS

Study Title: Perspectives of African American Learners with Emotional Disturbance Labels on the Impact Chronic Health Conditions have on their Capacity to Learn in the Classroom

### Who is conducting the study and what is this study about?

I'm a doctoral candidate from the University of Kansas' Special Education Department conducting a research study for my dissertation. The purpose of my study is to improve understandings of how chronic health condition(s) and disability labels intersect to impact African American learners, with an Emotional Disturbance label, in the classroom.

#### What will I be asked to do?

As a participant you will be asked to have 3 recorded conversations with me, which will last approximately 45 minutes each. During these conversations we will speak about your chronic health condition(s) symptoms, their impact on different areas of your life, and how you manage your symptoms. Finally, you will be asked to complete a short online survey that describes such things as your race, gender, etc. Compensation will be offered upon completion of each of the three interviews, and the survey, in the form of a gift card.

### Who can join this study?

You can participate in this study if you identify as

- 1. o African-American
- o are between the ages of 13 and 18, and your parents will give you written permission to participate in the study
- 3. o a healthcare provider (e.g., nurse, doctor) has diagnosed you with chronic health condition(s)
- 4. o you have a special education identification of Emotional Disturbance.

### Why should I join this study?

Participating in this study poses minimal risks to you but may help you gain new understandings about how your health impacts you as a learner, and as a result, ways to improve your learning experience in the classroom. Additionally, reflecting about your health management style may lead you to try different approaches to handling your chronic health condition(s) symptoms.

### **Interested? Contact:**

Gayitri K. Indar (Principal Investigator)

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Gindar@ku.edu

(816) 623-0735

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# Appendix B

# **Survey Questions**

Displayed for participants: Impact of Health and Well-being on Learning Experiences of African American Learners w/ Emotional Disability Label

Thank you for participating in my study! Please answer the questions below to the best of your knowledge. All submitted responses will be kept private, by using a pseudonym (code name) instead of your real name.

Please enter the pseudonym (code name) agreed upon by you and the researcher.	

# <u>Age</u>

1) What is your age? \_\_\_\_\_

### **Gender**

- 2) What was your sex at birth?
  - a. Male
  - b. Female
  - c. Intersex
  - d. Prefer not to respond
- 3) Please select the gender identity you most identify with.
  - a. Male/man
  - b. Female/woman
  - c. Transgender male/man
  - d. Transgender female/woman
  - e. Gender queer/non-conforming
  - f. Other
  - g. Prefer not to respond

# **Ethnicity** (Fonseca, 2017)

- 4) Which of the following race/ethnicities do you identify with? Please select all that apply.
  - a. Indigenous (e.g., American Indian or Native American, Aborigine)
  - b. Black (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. Black (African American)
    - ii. Black (Caribbean)
    - iii. Black (African)
    - iv. Black (Hispanic)
    - v. Other
    - vi. Prefer not to respond
  - c. Asian (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. East Indian
    - ii. West Indian (Guyana, Trinidad, Jamaica)
    - iii. Chinese

- iv. Filipino
- v. Japanese
- vi. Korean
- vii. Southeast Asian (Vietnam, Laos, Cambodia)
- viii. Other
- ix. Prefer not to respond
- d. White (QUALTRICS note: If selected, participant will be prompted to specify)
  - i. Non-Hispanic/European
  - ii. Traveler
  - iii. Other
  - iv. Prefer not to respond
- e. Hispanic (QUALTRICS note: If selected, participant will be prompted to specify)
  - i. Cuban
  - ii. Puerto Rican
  - iii. Dominican
  - iv. Mexican
  - v. Central American (Belize, Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama)
  - vi. South American
  - vii. Other
  - viii. Prefer not to respond
- f. Multi-racial
- g. Other
- h. Prefer not to respond

### **Household Characteristics**

- 5) Were you born in the United States of America?
  - a. Citizenship from birth (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. Born in the United States
    - ii. Born outside the United States to U.S. citizen
  - iii. Prefer not to respond
  - b. Citizenship through naturalization
  - c. Unsure
  - d. Prefer not to respond
- 6) What languages are spoken in your home?
  - a. English
  - b. Spanish
  - c. Sign Language (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. American Sign Language (ASL)
    - ii. Pidgin Signed English (PSE)
    - iii. Signing Exact English (SEE)
  - d. Other
  - e. Prefer not to respond
- 7) What is your current housing status?

- a. Stable (QUALTRICS note: If selected, participant will be prompted to specify)
  - i. Apartment
  - ii. House
- iii. Other
- iv. Prefer not to specify
- b. Transient (i.e., Residing for less than 30 days in multiple places)
- c. Homeless (QUALTRICS note: If selected, participant will be prompted to specify)
  - i. Street
  - ii. Homeless shelter
- iii. Transitional housing
- iv. Couch surfing
- v. Other
- vi. Prefer not to specify
- d. Other
- e. Prefer not to respond
- 8) Who currently lives with you? Please select all that apply.
  - a. Parents (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. Biological Mother
    - ii. Biological Father
  - iii. Stepmother
  - iv. Stepfather
  - v. Foster mother
  - vi. Foster father
  - vii. Adoptive mother
  - viii. Adoptive father
  - ix. Prefer not to specify
  - b. Siblings (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. Biological Brother
    - ii. Biological Sister
  - iii. Stepbrother
  - iv. Stepsister
  - v. Foster brother
  - vi. Foster sister
  - vii. Adopted brother
  - viii. Adopted sister
  - ix. Prefer not to specify
  - c. Grandparents
  - d. Other
  - e. Prefer not to specify
- 9) Do you receive free or reduced lunch?
  - a. Yes
  - b. No
  - c. Unsure
  - d. Prefer not to answer

# **Disability Status**

- 10) Have you ever been identified with any of the following disabilities, such as on an Individualize Education Plan (IEP)? Please select any you have been identified with by a professional.
  - a. Yes (QUALTRICS note: If selected, participant will be prompted to specify)
    - i. Autism
    - ii. Deaf-blindness
    - iii. Deafness
    - iv. Emotional Disturbance
    - v. Hearing Impairment
    - vi. Intellectual Disability
    - vii. Multiple Disabilities
    - viii. Orthopedic Impairment
    - ix. Other Health Impairment
    - x. Specific Learning Disability
    - xi. Speech or Language Impairment
    - xii. Traumatic Brain Injury
    - xiii. Impairment (including blindness)
    - xiv. Unsure
    - xv. Prefer not to specify
  - b. No
  - c. Unsure
  - d. Prefer not to respond

### **Chronic Health Condition**

- 11) Have you ever been told by a healthcare provider (e.g., doctor, nurse) that you have any of the following health concerns? (Please select all that apply).
  - a. Asthma
  - b. Diabetes
  - c. Heart Disease
  - d. Cancer
  - e. Sickle Cell Disease
  - f. Other
  - g. Prefer not to respond
- 12) Has your health provider (e.g., doctor, nurse) ever spoken to you about how your health impacts you in school?
  - a. Yes
  - b. No
  - c. Unsure
  - d. Prefer not to respond
- 16) Has your health provider (e.g., doctor, nurse) ever spoken to you about how your health impacts your learning in class?

a. Yesb. Noc. Unsured. Prefer not to respond

# **Health and Classroom Learning**

- 15) Has your anyone in school ever spoken to you about how your health impacts your learning?
  - a. Yes (QUALTRICS note: If selected, participant will be prompted answer)
    - i. Who in your school has spoken to you about how your health impacts your learning?

	_
i.	
ii.	
iii.	
iv.	
V.	

- b. No
- c. Unsure
- d. Prefer not to respond

# **Digital Health Management**

- 17) Do you use a mobile phone to manage your health?
  - a. Yes
  - b. No
  - c. Prefer not to respond
- 18) Do you use a mobile app to manage your health?
  - a. Yes
  - b. No
  - c. Prefer not to respond
- 19) Do you use a wearable digital device to manage your health?
  - a. Yes
  - b. No
  - c. Prefer not to respond

Thank you for your participation!

### Reference

Fonseca, S. (2017, April 24). Designing forms for gender diversity and inclusion. Retrieved from <a href="https://uxdesign.cc/designing-forms-for-gender-diversity-and-inclusion-d8194cf1f51">https://uxdesign.cc/designing-forms-for-gender-diversity-and-inclusion-d8194cf1f51</a>

# Appendix C

### **Interview Protocol**

# Health Conditions and Learning Experiences Interview Protocol<sup>2</sup>

**Setting**: Individual interviews will take place virtually via Zoom.

**Interviewer Intro:** "Hi! My name is Kavita. I'm a doctoral student from the University of Kansas' Special Education Doctoral Program. Thanks for taking the time to speak with me. The purpose of this interview is to share the voices of African American learners with chronic health conditions and an Emotional Disability label with researchers, teacher education programs, and teachers. Specifically, I would like to improve understandings of how chronic health conditions and disability labels intersect to impact the capacity of historically underserved learners to be engaged in the classroom.

There are no right, wrong, or preferred answers. I say this so you feel comfortable speaking freely and openly. Since I'd like to listen attentively during our conversation, I will be recording it, with your permission. This recording will help me accurately remember what we spoke about, and both the recording and my typed transcript of these recordings, will remain confidential. Finally, please remember that you may choose to withdraw from this study at any point during the interview.

Also, if you need a break at any point during our interview please feel free to let me know you're taking a break and I'll pause the recording."

# Seidmans' Three-Interview Series-Modified Health History

- 1) Tell me about the first time you were aware you had a chronic health condition(s
  - o How did it feel physically?
  - How did it affect what you did or said during the time the symptoms lasted?
  - Had anyone told you that you had your chronic health condition(s) before this particular incident? If yes, who?

### **Details of Experiences**

- I. Chronic Health Management Experiences
  - What are the ways that you have been taught to manage your chronic health condition(s)?
    - Who taught you about these different ways to manage your chronic health condition(s)?
  - o Place-based questions:
    - o Describe how you manage the symptoms of your chronic health condition(s) in class.
    - o Describe how you manage the symptoms of your chronic health condition(s) at home.
    - O Describe how you manage the symptoms of your chronic health condition(s) when you're hanging out with friends.
- II. Impact of chronic health condition(s) on Learning Experiences
  - Tell me how your chronic health condition(s) impacts how you PHYSICALLY feel when you're in class.

<sup>&</sup>lt;sup>2</sup>This protocol will be adapted based on iterative data collection and analysis as well as input from participants.

- Tell me how your chronic health condition(s) impacts how you MENTALLY feel when you're in class.
- Tell me how your chronic health condition(s) impacts how you EMOTIONALLY feel when you're in class.
- Describe a classroom experience when you knew your chronic health condition(s) was bothering
  you.
  - Describe your teachers' response in this particular situation.
  - If a nurse, principal, vice principal, or dean got involved describe their response in this particular situation.
- III. Chronic Health Conditions and Special Education
  - O Do you have a meeting every year, with your teacher, parent(s), and other school personnel to discuss your special education needs?
    - Please describe the different ways you are asked to speak about your health during this meeting.
      - Is your health spoken about as something that affected you in the past?
      - Is your health spoken about as something that still affects you now?
  - O What is one question about your health that you have been asked during a special education meeting that you remember?

## Reflection on Meaning

0	"You said earlier that	, can you clarify why this is"	
0	"When	happened, how did you feel? Why do you think you felt this way	y?"
0	"How would you chan	ge to make it a situation that works for you."	

**Interviewer Close:** "Thank you for speaking with me again. Your experiences have helped me understand how your health interacts with your learning in the classroom setting to shape your learning experiences.

- How do you feel the interview process went?
- Do you have any questions for me?

If you're ok with it, I may contact you again to ask any follow-up questions I have about what discussed today."

### Appendix D

### **Adult Participant Consent Form**

# Study Title: Perspectives of African American Learners with Emotional Disability Labels on the Impact Chronic Health Conditions have on their Capacity to Learn in the Classroom

### **KEY INFORMATION**

- This project is studying the perceived impact of chronic health conditions on the capacity of African American learners, with an Emotional Disturbance/Emotional Behavioral Disorder identification, to be an engaged learner in the classroom.
- Your participation in this research project is completely voluntary.
- Your participation will take a total of 2 hours, which will be separated into *two* virtual (e.g., via Facetime) conversations, with each lasting *approximately* 120 minutes.
- You will be asked to do the following procedures:
  - o Complete a short online survey describing yourself (e.g., your race/ethnicity).
  - Speak about your experience living with the symptoms of your chronic health condition(s) when you were in under the age of 18.
  - Speak about the ways in which you managed the symptoms of your chronic health condition(s) when you were under the age of 18, and living in different environments, such as at home, in class, and spending time with friends.
  - Speak about the impact symptoms of your chronic health condition(s) had on your physical, mental, and emotional capabilities, when you were a learner in the K-12 setting.
  - O Speak about the impact your chronic health condition(s) had on your perception of yourself as a learner in a classroom, when you were under the age of 18.

More detailed information on the procedures can be found below

- Your participation in this study does not involve any physical or emotional risk to you beyond that of everyday life
- As a participant in this study, you may learn about their health management style and how that impacts them as a learner.
- Your alternative to participating in this research study is not to participate.

### INTRODUCTION

I am a graduate student in the Department of Special Education at the University of Kansas, Lawrence. The Department of Special Education at the University of Kansas supports the practice of protection for human subjects participating in research. You are being asked to participate in a research study. This form has important information about the reason for doing this study, what we will ask you to do, and the way we would like to use information about you if you choose to be in the study.

The following information is provided for you to decide whether you wish to participate in the present study. You may refuse to sign this form and not participate in this study. You should be aware that even if you agree to participate, you are free to withdraw at any time. If you do withdraw from this study, it will not affect your relationship with this unit, the services it may provide to you, or the University of Kansas.

### PURPOSE OF THE STUDY

You are being asked to participate in a research study about how your chronic health condition(s) impacted your learning experience in the classroom in which you have been identified as having an Emotional Disturbance/Emotional Behavioral Disorder.

The purposes of this study are to understand:

- 1) how the symptoms of your chronic health condition(s) impacted your daily experiences
- 2) how you managed the symptoms of your chronic health condition(s) across different settings (e.g., home, classroom, hanging with friends)
- 3) how the symptoms of your chronic health condition(s) impacted self-perception of your physical, mental, and emotional faculties in the classroom
- 4) how the symptoms of your chronic health condition impacted self-perception of your capacity to be an engaged learner in the classroom

### **PROCEDURES**

Your participation in this research project is completely voluntary. Your participation will take a total of 2 hours, which will be separated into *two* virtual (e.g., via Facetime) conversations, with each lasting *approximately* 60 minutes. During these conversations you will be asked to do the following procedures:

- a. Speak about your experience living with the symptoms of your chronic health condition(s)
- b. Speak about the ways in which you manage the symptoms of your chronic health condition(s) when you are in different environments, such as at home, in class, and hanging with friends.
- c. Speak about the impact the symptoms of your chronic health condition(s) has on your physical, mental, and emotional capabilities
- d. Speak about the impact your chronic health condition(s) has on your perception of yourself as a learner in a classroom
- e. Complete a short online survey describing yourself (e.g., your race/ethnicity)

More detailed information about on the procedures can be found below. If you decide you want to be in my study, I will:

- Provide you with the study description and consent form, and you will be given as much time as needed to review it.
- *Provide you with time to ask me questions about the study.*
- Ensure you are aware that you may withdraw from the study at any point if you would like to.
- \*\*\*Audio taping you as you are being interviewed, to make sure that I accurately remember all the information discussed during our conversations, is necessary for participation in this study. Therefore, if you do not want to be audio recorded, they will not be able to be a part of this study. The researchers will keep these digital audio files for the duration of the study, after which they will be permanently deleted. They will only be used by myself to create a transcript of our conversation.

### RISKS

Your participation in this study does not involve any physical or emotional risk to you beyond that of everyday life. However,

- If you get tired during the interview or survey, you may take a break at any time.
- If you feel emotional or upset at any point in our interview or survey, you may tell the interviewer that you want to take a break or stop the interview.
- If you become uncomfortable during the interview, and no longer wish to share an experience you began discussing, you may tell the interviewer you no longer wish to continue with that particular question and wish to skip to the next question.

### **BENEFITS**

As a participant in this study, you may learn about your health management style and how that impacted you as a learner. Reflection upon the conversation we had may lead you to make choices to improve your future learning experiences, by speaking more openly about your learning needs in the classroom, particularly in relation to your health needs.

### PAYMENT TO PARTICIPANTS

Participants will be paid \$25 for completing the survey, \$25 for Interview 1, \$25 for Interview 2, via an emailed electronic gift card.

### PARTICIPANT CONFIDENTIALITY

Your name will not be associated in any publication or presentation with the information collected about you or with the research findings from this study. Instead, I will use a pseudonym (code name) rather than your real name in my transcripts of our conversations. Your identifiable information will not be shared unless (a) it is required by law or university policy, or (b) you give written permission to share it.

Audio recordings of your interviews will be stored in my personal Jayhawk virtual private network for the duration of the study, after which they will be permanently deleted. Permission granted on this date to use and disclose your information remains in effect indefinitely. By signing this form, you give permission for the use and disclosure of your information, excluding your name, for purposes of this study at any time in the future.

### PRIVATE INFORMATION (DATA)

Your identifiable information will be removed from the data collected during this project, and the de-identified data will be used for future research without additional consent from you.

### REFUSAL TO SIGN CONSENT AND AUTHORIZATION

You are not required to sign this Consent and Authorization form and you may refuse to do so without affecting your right to any services you are receiving or may receive from the University of Kansas or to participate in any programs or events of the University of Kansas. However, if you refuse to sign, you cannot participate in this study.

### CANCELLING THIS CONSENT AND AUTHORIZATION

You may withdraw your consent to participate in this study at any time. You also have the right to cancel your permission to use and disclose further information collected about yourself, in writing, at any time, by sending your emailed request to written request to Gayitri Indar at <a href="mailto:g554i705@ku.edu">g554i705@ku.edu</a> or mailed request to [Gayitri Indar, Department of Special Education, University of Kansas, Lawrence, KS 66045].

If you cancel permission to use your information, the researchers will stop collecting additional information about you. However, the research team may use and disclose information that was gathered before they received your cancellation, as described above.

### **QUESTIONS ABOUT PARTICIPATION**

Questions about procedures should be directed to the researcher listed at the end of this consent form.

# PARTICIPANT CERTIFICATION:

I have read this Consent and Authorization form. I have had the opportunity to ask, and I have received answers to, any questions I had regarding the study. I understand that if I have any additional questions about my rights as a research participant, I may call (785) 864-7429, write to the Human Research Protection Program (HRPP), University of Kansas, 2385 Irving Hill Road, Lawrence, Kansas 66045-7568, or email irb@ku.edu.

I agree to take part in this study as a research participant. By my signature I affirm that I am at least 18 years old and that I have received a copy of this Consent and Authorization form.

Print Your Full Name	Date		
	Your Signature		

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