Inclusion

I'm Trying to Make Myself Happy: Black Students with IDD and Families on Promoting Self-Determination During Transition

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Abstract

Promoting self-determination for students with disabilities has proven to be a critical component of effective transition planning. However, researchers seldom consider race when promoting self-determination for people with disabilities. The purpose of the current phenomenological research investigation was to explore how Black youth with intellectual and developmental disability (IDD) and their families explain transition planning experiences that promote and hinder self-determination. We found that participants in the current study experienced some hurdles during their transition experiences that they perceive are rooted in systemic and structural racism and ableism that prompted advocacy, family engagement, inclusion, building knowledge of rights, and other emergent strategies to promote self-determination. Findings from the current preliminary investigation have implications for transition and self-determination research, as well as improving the quality of services and support for Black youth with IDD and their families.

Keywords: IDD, self-determination, race, disability, transition planning
I’m Trying to Make Myself Happy: Black Students with Disabilities and Families on Promoting Self-Determination During Transition

Adolescent experiences are critical in shaping the lives of youth for years into the future. For youth who have intellectual and developmental disability (IDD), the transition phase prepares them for exiting from school-based supports and sets in motion planning for employment, postsecondary education, and community and adult living. Promoting self-determination throughout the transition phase has been identified as an essential predictor of success in the areas of postsecondary education and employment (Mazzotti et al., 2020). Although self-determination has consistent evidence of cultivating success in transition for students with disabilities (Shogren et al., 2017), additional evidence of how race is used to guide self-determination is necessary to understand its influence on students of color who have disabilities (Burke et al., 2020).

Transition researchers have not consistently addressed how self-determination practices impact different subgroups of students nor considered the relationship between personal characteristics of race and ethnicity and persistent inequities in transition outcomes (Trainor et al., 2020). Addressing the issue is particularly important, as Black youth with disabilities are less likely than White or Asian youth with disabilities to receive proper preparation for post-high school transitions. (Lipscomb et al., 2017). Additionally, research showed that gaps in transition outcomes, such as postsecondary education and employment, are even greater for Black students with disabilities (Thoma et al., 2016) who often experience structural and systemic barriers, including racism and discrimination that impedes educational equities (Sanford et al., 2011). Currently, Black youth are: (a) the second-largest population of the nearly seven million youth who receive services under the Individuals with Disabilities Education Act (IDEA, 2004); (b)
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have the second highest dropout rate; and (c) are consistently in the lowest percentage of youth receiving high school diplomas (Hussar et al., 2020). When considering employment outcomes and job support for youth, significant discrepancies persist. Black working-age adults with disabilities have the highest unemployment rate among persons with a disability (U.S. Department of Labor, 2020). Yet, White transition-aged youth are most often found eligible for critical vocational rehabilitation (VR) services, which are generally associated with obtaining successful employment (Honeycutt et al., 2017). The dissonance between Black and White transition-aged youth is evidence of the urgency to address racist and discriminatory practices tied to the education and transition process, and understanding culturally responsive practices that promote improved transition outcomes for students with disabilities, particularly Black youth with IDD.

Self-Determination in Transition Planning

Researchers have confirmed self-determination as a critical component of effective transition services, with greater positive outcomes for self-determined students when compared to less self-determined students (Shogren et al., 2015). With respect to student self-advocacy, research has shown a strong correlation between both parent and student engagement, along with student participation and leadership of the transition planning process (Griffin, 2011; Martin & Williams-Diehm, 2013). Providing youth opportunities for self-determination is deemed necessary for successful career and vocational development (Shogren & Ward, 2018; Trainor et al., 2012), transition to higher education (Getzel, 2013), and as a strong predictor of successful postschool outcomes (Shogren et al., 2017). Wehmeyer (1997) defined self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (p. 177) and includes
such skills as goal-setting, decision-making, problem-solving, and self-advocacy. Yet the effects of self-determination, and its role on post-high school outcomes, has not been sufficiently examined with respect to cultural factors (Griffin, 2011; Shogren, 2011). While self-determination is often considered a universal construct, it may be expressed differently in various cultures (Wehmeyer et al., 2011). Questions exist concerning the impact of self-determination interventions and research for students from diverse racial/ethnic minoritized backgrounds, while highlighting the need for increased diversity in study participants and research methodology (Burke et al., 2020). Thus, efforts to foster self-determination should be culturally relevant and reflect the values, beliefs, and practices of the culture of the individual (Wehmeyer & Webb, 2011).

Historically, most self-determination and intervention studies have not included participant demographic characteristics (Burke et al., 2020; Trainor & Bal, 2014). However, in emerging studies, researchers have suggested that race and ethnicity status may in fact moderate differences in self-determination scores, with the greatest impacts on Black and Latinx students who have IDD (Shogren, Shaw et al., 2018; Thoma et. al., 2016). Black and Latinx students with IDD also scored lower than White students with even greater effects when considering socioeconomic status. Shogren, Shaw, et al. (2018) cited the need for understanding the relationship between personal factors and their possible influence on self-determination while advocating for culturally sensitive assessment tools. Shogren et al. (2020) furthered the discussion in more recent research, noting race and ethnicity as an influence between student and teacher assessment responses on the Self-Determination Inventory. While these studies are used to further sustain the need to explore race/ethnicity and self-determination, the issue itself continues to be under investigated (Trainor et al., 2020), especially with Black youth with IDD.
Additionally, the literature on the topic of self-determination is overwhelmingly quantitative in nature (e.g., Burke et al., 2020; Shogren, 2011), and research specific to self-determination and Black students with disabilities is mostly non-empirical. Literature reviews, theoretical, and conceptual research (e.g., Thoma et al., 2016) support the need for empirical research that is used to explore race and self-determination. Thus, the purpose of the current study was to build on the quantitative findings in the contemporary literature and extend understanding through qualitative data that examines the transition experiences of Black students and families, particularly regarding how they promote self-determination.

**Theoretical Framework**

We used dis/ability critical race studies (DisCrit) to provide framing and language for the current study. DisCrit is a theoretical framework that engages both critical race theory (CRT) and disability studies to interrogate how racism and ableism form interlocking systems of oppression that marginalize groups within society and in special education in particular (Annamma et al., 2013; Connor et al., 2016). According to the DisCrit theory, race and dis/ability are constructs that root dominant narratives of normalcy in Whiteness and ableism, thus viewing students of color and students with disabilities through a deficit lens and responding with embodied practices that limit opportunities and outcomes for them (Annamma et al., 2018). At the same time, DisCrit theorists recognize the “material and psychological impacts of being labeled as raced or dis/abled” (Annamma et al., 2013; p. 11), thus making it a powerful way to examine self-determination of students. Annamma et al. (2013) proposed seven key tenets of DisCrit that describe how racism and ableism intersect with multidimensional identities, as well as how activism can operate within research to privilege voices of marginalized populations. The tenets
will be discussed in more detail in the text, in terms of their alignment with emergent themes introduced by participants.

DisCrit was used to inform the current investigation by allowing us to examine how Black youth with disabilities and their families promote self-determination with respect to power dynamics and historicity. DisCrit was also used to provide opportunities to elevate and listen to the voices of Black students and families in research. Previous researchers have used DisCrit theory to critically examine how racism and ableism disrupt student self-determination in several aspects of education, such as special education placement in high school (Banks, 2017) and in the critical interrogation of inclusive mathematics instructional practices (Padilla & Tan, 2019). Further, Tabatabai (2020) used DisCrit to note how normative ideologies place an emphasis on self-sufficiency and independence that is often incongruent with the self-described role of mothers of children with disabilities. Similarly, Francis et al. (2020) called for further research that used DisCrit and CRT to inform critical studies of the transition experiences of Black students and families.

Despite emerging research applying DisCrit to interrogate racism and ableism in many aspects of education, little empirical research has been conducted to date using DisCrit to analyze the self-determination of Black youth with disabilities in the transition from school to adulthood. The aim of the current study was to center the voices of Black youth with disabilities and their family members in describing their own experiences in promoting self-determination within a school context during the transition process. The following research questions were formulated to guide the current study:

**Research Question 1**: How do Black youth with IDD and their parents explain transition planning needs and experiences that promote or hinder self-determination?
Research Question 2: How do Black youth with IDD and families work to promote self-determination?

Method

The current qualitative study used an empirical phenomenological research approach (Moustakas, 1994; Seidman, 2019) to gain an understanding of the lived experiences of Black youth with IDD and their parents as they navigated the transition from school to adulthood. Information about their experiences was collected through a series of interviews conducted by phone. The interviews were recorded and then transcribed. Interviews were conducted in youth/parent pairs using a semi structured interview protocol (Creswell & Poth, 2018), which assured that common information was collected from each participant. It also allowed the interviewer to ask follow-up questions for clarification, address novel responses, and enable participants to provide as much detail as possible (Seidman, 2019). Separate interview questions were developed for the parents and youths who agreed to participate, developed from the literature about self-determination (see Table 1).

Participants

We used a purposeful criterion sampling process (Creswell & Poth, 2018) and a snowball sampling method (Lincoln & Guba, 1985). The criterion sampling process ensured that participants of the study had similar experiences; in this case, experiences in going through the transition from school to adult life along with the lived experience of being Black. Adding the snowball sampling method provided the opportunity to expand the pool of possible participants beyond individuals reached using the initial recruitment process. The research team worked with the Association of University Centers on Disabilities (AUCD) partner and their family support team to recruit participants for their study using email communications, flyers, and social media.
posts. The recruitment strategies resulted in the identification of 10 pair of youth/parent pair participants from one state in the southeast region of the United States who met the inclusion criteria. The participant pool met the recommendations for sample size in qualitative studies, ranging from one to 10 (Huber & Whelan, 1999) to develop a collective story. Five pair of youth/parent participants ultimately agreed to participate in the study. The five youth participants were all young Black men with IDD between the ages of 18 and 23. In all cases the parent was the mother who also identified as Black. Pseudonyms were used for the participants’ names to protect their confidentiality. Table 2 shows basic demographic information about the Black youth participants, the transition and educational supports they received, and information about individuals who were considered to be supportive advocates identified as helpful in the transition process for each youth participant. As stated earlier, the parent participants all identified themselves as the mother of one of our Black youth participants. Mothers all worked full-time, outside of the educational field but described themselves as actively involved in their son’s education and community experiences. Four of the five parents participated in some kind of parent support group developed to help parents understand their rights and responsibilities as educational advocates for their sons with disabilities; two participated in a statewide conference focused on promoting self-determination of Black males with IDD during the transition planning period.

Interviewers used a screening tool developed to ensure that youth participants understood the study, were able to consent to participate, and knew they had the right to end their participation at any point without fear of retribution. All study procedures were approved by the university’s institutional review board, the members of which review all research protocols.
involving human participants prior to beginning the recruitment process and other steps of the research study.

**Data Collection**

Participants were given the opportunity to participate in the interviews by phone or Zoom video conferencing. All individuals agreed to participate by phone from their homes. Interviews with the youth were completed first. Each youth could have a parent in the room if they wished. Once the interview was completed with the youth, the interview with the parent was initiated. Interviews were recorded and later transcribed by a member of the research team. Each interview pair lasted approximately 60 to 90 min. Fidelity was established using notetakers and by summarizing the discussion.

Transcripts were uploaded to Google Drive to assist with the written transcript process. Once transcribed, the transcripts were then checked for accuracy, and identifying information was redacted or pseudonyms used. Transcripts were uploaded to a secure drive that only members of the research team could access. Audio recordings were destroyed after they were transcribed.

**Data Analysis**

We used In Vivo Coding to analyze the qualitative data collected from the interviews (Saldaña, 2016). The coding method used words or phrases from the participants themselves to create codes and is particularly useful for studies designed to utilize voices of marginalized individuals, especially youth and others not traditionally acknowledged in research—one of the cornerstones of DisCrit (Annamma et al., 2013; Saldaña, 2016). Three cycles of coding were used to fully exhaust themes during the review. During the first cycle of coding, we developed a broad set of descriptive codes based on our individual reviews of transcripts and the DisCrit
theory. The first round of coding was completed with hand-coding using in-vivo quotes by multiple members of the research team individually. Once the initial coding was completed, the members of the research team met to discuss their codes and to group the codes into themes for each of the two research questions as part of a second round of coding, or focused coding (Saldaña, 2016).

A third round of coding, axial coding (Saldaña, 2016), was then completed individually by the members of the research team. The purpose of axial coding was to “determine which codes in the research are the dominant ones and which are the less important ones….and to reorganize the data set: synonyms are crossed out, redundant codes are removed, and the best representative codes are selected” (Boeije, 2010, p. 109). After team members completed this individually, the team met to discuss and reach consensus on the most relevant axial codes. The discussion focused on the codes that seemed to be common across both research questions to determine if both were needed because they addressed different components, or whether they could be consolidated into one. The consolidation happened for codes such as parent advocacy, community resources, and family values (see Figure 1). By the end of the meeting, consensus was reached. Following the initial inductive process of in vivo coding, the tenets of DisCrit were again considered to inform a subsequent deductive coding process during which previously identified codes were compared to the overarching theory. Robust discussions about relevant tenets informed team decisions to add, contradict, or reshape codes to ensure alignment with participants’ responses. In this way, the DisCrit framework served as a lens to inform tensions between participants’ experiences, perceptions, and identities and constructions of race and dis/ability within the systems they navigated in the transition process (Annamma et al., 2013).

**Trustworthiness and Credibility**
The process of having multiple coders each working independently provided triangulation during each of the three rounds of coding (Creswell & Poth, 2018). Many of the research team members were doctoral students in special education in a large public university in the southeastern part of the United States. Two of the members were also currently practicing transition professionals. Four of the authors held a doctoral degree and were faculty members in higher education (although one author began working on the current study during her doctoral program). All the researchers had experience with postsecondary transition-related topics and were interested in racial disparities in special education, although with various degrees of experience in conducting research used to examine racial disparities. The research team was diverse, with three members who are Black and four members who are White. The team had varying degrees of knowledge related to self-determination, culturally responsive practices, the DisCrit framework, and qualitative research. The diversity of knowledge and skills was used to add further credibility to the findings of the study, because the research team members did not hold similar world-views or experiences.

Lastly, the research team members met to revisit the themes and discuss how key tenets of DisCrit (Annamma et al., 2013) might further inform themes related to the self-determination experiences of Black youth in transition. Throughout the process of coding, the research team also kept a journal in which they identified early themes and reflected on the interview answers, particularly how the comments might be understood in light of the themes and key tenets of DisCrit. Discussions during the full group meetings addressed these topics, as well as the experiences of these Black males and their mothers. We discussed the implications of the experiences of the youth and their families and how they intersected (or did not intersect), with each of the seven DisCrit tenets. For example, the team members discussed how participants
related experiences that illustrated the “neutralized and invisible ways” racism and ableism “uphold notions of normalcy” (Annamma et al., 2013; p. 11). Together, the procedures were used to ensure that our interviews resulted in high-quality data to inform our research questions to address the unique needs of Black students (Brantlinger et al., 2005) and to understand the impact of self-determination during the transition from school to adult life for Black youth with IDD. By the end of these discussions, consensus was reached to create a shared understanding of the experiences as they related to self-determination as well as possible links to racist and ableist interpretations and/or implications.

Lastly, member checks were completed by sharing transcripts with both Black youth participants and their mothers so they could be sure that we accurately captured their words and meanings. This last step of the process before coding additionally provided participants with an opportunity to add any further information or clarify their comments so they accurately portrayed their experiences. Although we shared these transcripts with participants, none of them asked to have any additions or corrections to the transcripts.

**Findings**

**Research Question 1**: How do Black youth with IDD and their parents explain transition planning needs and experiences that promote or hinder self-determination?

Youth and parent perceptions and descriptions of transition practices and services revealed how race and background interacted to promote or hinder self-determination. The participants described (a) need for early transition planning, (b) a need for more transition resources, (c) a need for more youth experiences in the transition process, and (d) a need for trusting family and school relationships.

**Need for Early Transition Planning**: “We didn’t focus on transition until later.”
Parents reported a need to begin transition planning early, indicating it was a critical factor needed to ensure success for their child. The critical need was reflected in the interview with several parents, including Langston’s mother, who explained that she strongly pressed and advocated for her son’s access to the general education curriculum in elementary school. She recalled that advocating for Langston’s inclusion in general education courses was her first critical form of activism she felt was connected to the transition planning process. To make Langston successful later in life and with his transition, she wanted him to “learn what everyone else [general education students] was expected to learn…..because as a Black male I knew he would be at a disadvantage in schools.” Langston’s mother explained that she recognized the need to start transition planning early, and she became concerned early on in Langston’s schooling when “the preparation for transition didn’t happen when it was supposed to.” In discussing why she wanted transition planning to begin early, she stated: “The school didn’t hear my concerns as a Black mother [my concerns with early transition planning]; they thought that learning “all [in settings with students without disabilities]” was stressful for Langston. So, we didn’t focus on transition until later.”

Similarly, Nate’s mother described advocating to ensure transition planning occurred earlier. She described personally identifying jobs and apprenticeships, and presenting these options to the teacher, and as she said, “I’ve done all that work.” She went on to state:

I would think that the transition planning would start from the very beginning. Like as soon as you start high school, in ninth grade. I think having that conversation with the student and having that conversation with the parent about what does...adult life look for you? Where do you, what are your plans after school? You want to go to college? Are you looking to just start a career? What are those goals and then the plan is developed
based on what those goals are. So if your goal is to go to college and you've got a significant learning disability, well then I think that, you know, you've got four years of real work ahead of you to help prepare that person to do all of the things that they have to.”

Both mothers expressed sentiments of frustration with the lack of early transition planning, specifically because they thought that not planning early would negatively impede their child's progress. Their words highlighted Tenet 7 of DisCrit theory which supports activism and diverse forms of resistance (Annama et al., 2013). These examples serve to illustrate the mothers’ responses as expressions of activism showing their resistance toward not being heard or presented with acceptable solutions.

**Need for Resources: “When they gave you the information, it would be too late.”**

Several mothers expressed a need for resources and information regarding transition planning. In turn, the need may have also impacted families’ abilities to engage in and encourage self-determined behaviors, because they simply did not know or have transition information. Charles recalled not receiving the information he needed to pursue an important course he had hoped to explore as he considered his future career. He remembered, “When they gave you the information, it would be too late.” Charles’ mother expressed how the school officials failed to provide information in a timely manner, or at all. In turn, Charles’ mother felt that the school officials did not want to share important and relevant transition information. She echoed her son’s sentiments:

The unfortunate part was that we never got that [transition] information… I would find out after the fact, … so he never got to do [3D Art] because no one ever gave me the information… It was either we found out about it too late or we didn’t get it, or when we
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got it, it happened yesterday or it’s happening tomorrow, so you don’t really have time to prepare. So that was one of things that I didn’t like. They [schools] wouldn’t share the information.

As a result, feelings of frustration seemed to again incite parental activism and showed the tenacity of Black mothers to acquire the cultural capital needed to leverage transition outcomes for their sons. Trey’s mother described the challenges of having to “track things down” on her own with the help of her sister. She remembered:

Like I said, the transition from high school into adulthood was a challenge.

Resources?.....Literally my sister and myself had to track things down, you know, it wasn't noted…I feel like the system is broken for Black children and families so I had to just do things myself.

Nate’s mother also shared the same sentiment and described her role in her son’s transition.

Nate’s mother said, “The transition that he had into the adult world was from me helping him.”

The mothers once again exemplified Tenet 7 and shed light on the activist strategies they used to (re)position their sons favorably within the transition process by exerting their own expertise and resources out of necessity (Annama et al., 2013).

Need for Diverse Youth Experiences: “...as many opportunities as he could.”

Another theme that emerged, promoting or hindering self-determination in Black youth with IDD, was the need for diverse youth experiences while in school, including work experiences, extracurricular activities, participation in the IEP, and inclusion with general education peers.
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Trey described his personal experiences with work experiences that did not align with what he wanted to do. Trey explained he wanted to go into the videography/photography industry, yet, described the following experience in high school.

After it [class] was over they wanted me to clean the cafeteria tables, and I truly didn't like that at all, because basically saying, ‘Okay, you're only good for this [cleaning tables].’ Well, I'm] good for other things other than cleaning tables. So I honestly didn't like [it], I mean, I understand what they was coming from but there has to be a better way of having kids like us [Black males] having jobs, but it has to be something that they like.

When asked about opportunities he would have liked to have, Trey also shared his regret of not participating in theater and drama, classes that he wished he had requested and taken. Instead, he hesitated to share his hope with his Individualized Education Program (IEP) team, anticipating their negative response based on his challenges with reading. Trey shared, “I'm pretty sure they will have some not positive feedback...How would you read a paper? How would you do this?...So to make me not want to, you know, do the class.” In this way, Trey’s insight illustrates Tenet 4 of DisCrit theory ((Annama et al., 2013) and supports efforts to privilege the voices of marginalized populations. Trey’s response provides a stark counternarrative to the silence he experienced when reflecting on his previous decision to not request a class. Whereas previously and perhaps figuratively, Tre’s voice was suppressed due to the anticipated negative responses he imagined from his teachers, his present voice, in contrast, exhibits confidence in sharing this story.

Langston’s mother initially explained, “We [Black families] don’t have opportunities…for one it’s not as populated…it’s [their hometown] kind of rural/industrial, so
work options are pretty limited.” But then she described a time Langston got to work on job
skills aligned with his goals when she stated:

   They actually do real work...they do all the graphics for school systems, programs, and
banners.... He can do the work independently, too... He put a lot of time and effort into
learning the work, but would he get offered a job doing that? Probably not.

While Trey and Langston were presented opportunities for job development, Bryce’s
mother described a time they were told no regarding job development. She explained teachers
were aware of what Bryce wanted, but only identified his academic and transition goals without
considering their input. Bryce’s mother stated:

   [I] was told no, they can’t get him into the technical center because he’s got an IEP,
nobody’s going to go in there and be with him...[we] know that’s what you want to do
and we don’t have the capacity to help with that....I feel like sometimes because my child
is Black and his lack of experience put him at a disadvantage later in life.

The input made Bryce’s mother feel that “they [teachers, case managers, and transition
specialists] didn’t go the extra mile” and caused Bryce to miss out on “the social pieces that he
should have gotten, in high school.”

Inclusion in IEP meetings was another experience described by the parents. Trey’s
mother stated, “They [school counselors] would ask him to participate in, vocalize...but at that
time he was a recluse...he didn’t really come into himself until he graduated.” Langston’s mom
described Langston’s involvement in his IEP meetings by stating, “I think it has given him pride
in doing things that grownups do...he is extremely proud to contribute.” Yet, parents also
described their need to advocate. Langston’s mother described how she wanted him to have “as
many opportunities as he could.” She stated: “I didn't want him to just sit there and not have been
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exposed to the regular curriculum, because I knew that if he didn't there's no way he would have that option [to go to college]…..as a Black man with a disability.”

Lastly, Trey highlighted the need for self-advocacy and finding ways to reach his goals. Trey stated: “…is not to give up and talk to your parents and talk to your case manager, because I know there is a way for everything.... You just got to talk to the right person and know those ways.”

Need for Trusting Family and School Relationships: “I really like teachers who understand.”

Another theme focused on the complexity of family school relationships within the intersection of race and disability. Nate’s mother explained that she anticipated “an uphill battle” for students like her son who are Black and have a disability. She stated, “But I think in general it's hard for, um, Black people overall, to, you know, overcome barriers to success. And I think if you throw in a learning disability, then you're going to have an uphill battle.” Nate’s mother echoed similar sentiments when describing how her son would have had different experiences in school had he been White. Nate’s mother said, “I feel like even if he was a White male, I think that things would have ended differently for him.” The mothers’ reflections showed the complex and layered nuances that their views about the influence of race would serve to inform their sons’ experiences. Tenet 2 of DisCrit (Annama et al., 2013) values multidimensional identities such as race and disability as Nate’s mother illustrated by acknowledging the compounded barriers that exist for Black students with disabilities.

Another such view was used to highlight the adverse experiences between the families and school officials often leading to feelings of disconnect and hopelessness for the mothers. For example, Nate’s mother confirmed a lack of accord along with her struggles, when she lamented:
So he's just kind of been floundering around in school with his mom, you know, fighting and screaming and complaining and nothing ever getting done. Um, I don't think he's any more equipped for the world from a school perspective than when he went in there four years ago.

Nate’s mother also spoke about not feeling included during the decision-making process regarding her son’s course planning and scheduling progress. Nate’s mother said:

I don't feel that we were ever really included in those decisions. Granted, most of the classes that he had to take were classes that he needed, but it was just kind of like, ‘Oh here, you know, this is your schedule, this is what you're going to do.’ I don't think that he was really included in that, nor did I really feel included in that process at his school.

She continued with a poignant statement about the lack of the school officials’ support and its lingering impact on her son’s future:

You know, he thinks the sky's the limit [inaudible], you know, and it should be, but the school should help you be able to get to that point. And unfortunately, and I hope that this doesn't sound harsh, but, honestly no, that, right now the sky isn't the limit for him….his teachers and others failed him and as a Black boy with a disability this worries me.

While some mothers talked about the lack of engagement on behalf of school professionals, one mother expressed what she needed in her relationships with school professionals, which included an openness or willingness to “think outside the box,” as with Charles’ mother, who wanted more collaboration when it came to her son’s educational experiences. Charles’ mother stated:

Experiences. That’s what I want to say. And, and I guess overall making joint decisions and everyone having an open mind about it and not reaching it before we even get
started, assuming you know, just because we have a disability… Think outside the box, you know, creative. Allow them to be more creative. Let them be involved in other things, you know, be, you know, inclusive.

Charles’ mother shared that her growth in advocacy became imperative after years of frustrating experiences with school professionals. She recounted:

When I got to last year, it was probably the first year that I didn’t cry in an IEP. It has grown over time, because we have to, unfortunately, we’ve had to stand up for ourselves and not just allow what happens to just happen.

Her son’s words further illustrated the need and desire for positive and trusting relationships. Charles complimented his interviewer and shared, “I really enjoyed talking with you…I really like teachers who really, who understand my current situation in a school year”.

**Research Question 2:** How do Black youth with IDD and their families work to promote self-determination?

Parents and students described experiences and actions that are most useful for promoting self-determination. They felt that family engagement was important, along with advocating for inclusion with other peers, supporting student preferences, and building their own knowledge. These factors strongly correlated with promoting self-determination. The findings are discussed in more detail in the following sections.

**Family Engagement: “We started to meet other people.”**

The families’ access to different activities and services were important to the students, and family members who supported the students with their endeavors. For example, Trey acknowledged the role his family had in his experiences. Trey stated, “[My] aunt and my mom, you know, they’ve been a big help for you know, helping me find jobs and finding what I like
and don't like, so I think they [are] very big supporters.” Langston’s mother echoed the same sentiment of support. She stated, “My purpose at that time was to make sure that he had as many opportunities as he could.”

Carl’s mother thought that attending conferences and being active in postsecondary education activities were important, stating:

As we began to go to these [conferences], we started to meet other people, see different things, the campus, the atmosphere, you know, how the dorms are set up, and, you know, it sparked an interest in him, and you know, from then on, he was like, well this is what I want to do. Um, and so we just try to foster that.

The mothers believed that having family involvement promoted self-determination behaviors. Nate’s mother felt that being an “involved parent” meant ensuring that Nate was able to have access to opportunities, and it required support from family members. Nate’s mother said:

A lot of it has to do with guidance from both me and my dad [the mother’s father] trying to, uh, helping him [Nate] to make the right decisions and figure out what he wants to do with his life, so as far as like, um, tech class, things like that….this type of, uh, involvement is important with Black families. As a Black mother I like to be involved. She went on to explain that all of Nate’s decisions were about trying to put himself in the best position, where he could have a career that would help him live on his own when he got out of school. While in these examples, there is no specific alignment to DisCrit Theory, the families’ voices were compelling enough to include in the findings and highlight the role that families play in promoting self-determination.

**Advocating Inclusion with Peers and Individual Expectations:** “They pigeonholed him.”
Parents and the participating youth felt that inclusion with their peers, along with the maintenance of high expectations, was a necessary tool for promoting self-determination, which was expressed by parents in multiple ways. Langston’s mother shared:

It was important for him to have opportunities to be in classes and experiences with other children that was not disabled, but also with children that looked like him [other Black males] because it would give him something to look up to and get along with. I can’t say that this always happened. But I also can’t say that the school cared about him being with other successful Black children and teachers that looked like him that could be role models.

Some parents offered comparisons between schools and teachers that held students in high regard, understood them as individuals, and supported their agency with individuals that removed them into isolated environments with little opportunity to engage in meaningful learning. Parents felt that this dissonance existed in inclusion and separation existed and they wanted to protect their child as much as possible in these situations. Charles mother stated:

there are some teachers that just want kids in a classroom where they all look alike [all Black males in special education]…I’ve seen classes like this that Charles was in…nothing against the kids but I just feel like that’s how the system is set up for the Black kids so they don’t get nothing outside of those classes.

Separation was mentioned by multiple parents as a factor that they felt had a significant impact on their child’s education and opportunity to succeed and become more self-determined. Not only did the separation from the general education learning environment affect the self-determination of students, but parents also expressed that school staff members often restricted parents’ agencies to educational decisions. One mother expressed, “Sometimes the professional
would steer it a way that we didn't think was best. Like they didn't think it was a good idea for him to come back and do his standard diploma.” Parental frustration with the lack of high expectations and understanding the individualism of students was expressed several times. One mother said, “They pigeonholed him,” when referring to how the IEP team determined that her son was not capable of learning in general education classes. The responses shared reflect Tenet 3 of DisCrit theory and made visible the social construction of race and disability and suggest the historical impact of both in justifying the segregation of Black students and its significance with respect to transition experiences (Annnamma et al., 2013).

Another mother felt that the way the staff members underestimated her son’s abilities were connected with his not being seen as an individual when she stated that teachers placed “limitations on his capabilities.” She stated, “I think individually they did not sit down and observe what he is capable of.” Parents reported pushing back against the segregation and limitation of expectation in ways that involved reasserting their agency and pushing back against what was offered by school staff members. In many cases, mothers shared that they felt that certain teachers and staff members could have done a better job of understanding their Black male sons, been more supportive of them, and more effectively promoting self-determination through goal setting and decision-making, but that it required significant effort and resources on the part of the parent to identify school officials who provided more opportunity for students and were more inclusive of students.

Supporting Student Preferences: “That’s a choice I made.”

Parents’ and students’ direct involvement in determining wants and needs and recognizing opportunities to help students identify and communicate their preferences was a strategy identified with promoting self-determination. The strategy was found to align with our
study’s theoretical framework, which posited that we (a) must include the voices of people with dis/abilities when providing accounts for their life and experiences (tenet four); and (b) engage in diverse expressions of resistance to educational inequities (tenet seven). Specifically, the students and their family members in our study recognized the need to insert their voices and perspectives directly into conversations impacting the students’ lives in resistance to the cultural and political barriers “disabling” the students.

The students contributed directly to their lives when they made their own choices, problem-solved, and voiced their wants and needs—when they were self-determined. For example, Charles stated, “That’s a choice I made,” when referencing his desire to play basketball as one of his extracurricular activities. Charles, Trey, and Carl all described how playing basketball was a choice each one made. Trey additionally chose to be a member of the “Distinguished Gentlemen” club at his high school, and Nate discussed how he chose his own academic classes, with support from his school counselor.

Students also expressed their wants, preferences, and interests, which required them to know themselves and their needs. For instance, Carl said, “I want to be resourceful and trying to see more possibilities and trying to find other ways to be successful.” For Charles, going to college was something he wanted to do after high school, whereas Langston wanted to seek employment at a local hospital. Charles further balanced the weight of wanting to make others proud and himself happy, stating:

I want to make them [his family] proud….but I’m trying to make myself happy, too, because I’m trying to figure out things on my own, trying to take care of myself and take care of my people around me at the same time.
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In addition to the students, the mothers recognized when and how their children contributed to the decision-making process, and as parents, this allowed an opportunity for them to listen and to then serve as co-advocates on behalf of their child. For example, Charles’ mother reported “He [Charles] kind of…advocated,” after observing her child communicate to his teacher about a situation, so the teacher could accommodate his needs. Conversely, Langston’s mother found that her son, “Put a lot of time and effort into…” learning to “operate the machine that transfers prints onto the shirts or onto the mugs,” although she doubted her son would get offered a job doing that skill. In these efforts, mothers recognized the importance of uplifting the voice of their sons and supported their initiatives by communicating with educators what their son’s desires were. Carl’s mother stated, “When I see that he is advocating for himself, my role then is to support….you know, be like a co advocate”.

Building Knowledge of Rights and Advocacy: “We had a voice.”

The mothers recognized the importance of understanding family and student rights, and how the information could lead to having a voice in the educational transition process. As an example, Charles’ mother stated, “We had a voice” when realizing “what our options were and that we had a voice as well to start fighting for [their child] to get what he really wanted.” The realization came after attending a conference designed to promote self-determination for youth with disabilities. From their conference experience, Charles’ mother realized her son’s current educational placement was not meant for him. She stated, “Being in a classroom with one teacher for almost the whole day wasn’t the answer.” Bryce’s mother also discussed how her voice was needed as the result of several experienced barriers (e.g., mismatched goals not based on student’s wants or needs; low expectations set by educators) that prevented her son from
VOICES FROM BLACK STUDENTS WITH DISABILITIES

achieving his goals. “I was pushing,” Bryce’s mother stated, “so I [can’t] imagine somebody who wasn’t pushing.”

According to Trey’s mother, “You have to become knowledgeable about the system so that you can advocate even more so [because of the child’s race]...You have to speak up, they have to speak up because otherwise it's the status quo.” Overall, it was observed across interviews that the mothers wanted more than the “status quo” for their sons. In fact, they expressed having to frequently “change the course of the conversation [from] settling because of [their child’s] race and disability.” According to Nate’s mother, if her son, “didn't have involved parents, you know involved parents and grandparents….. I'm not sure where he would be. I think he would just give up.” Throughout, Tenet 7 (Annamma et al., 2013) illustrates the level of activism and resistance conveyed by students and families alike. The mothers’ experiences detail their fierce determination to fight for their sons’ rights in the face of multiple barriers experienced.

**Discussion**

The purpose of the current study was to document experiences of Black youth with IDD and parents in promoting self-determination within a school context during the transition process. Cultivating self-determination for Black youth with disabilities will require a collective understanding of Black youth and parents’ experiences, thus leading to a mutual understanding of how school personnel (e.g., special education teachers) should be educated and trained to support them. Parents presented a range of experiences that influenced their perception and role in increasing self-determination. The role was often described as an advocate/co-advocate for promoting educational and community-based opportunity for their child. The youth presented a more discreet experience to achieving self-determination, often describing experiences where
choice-making, decision-making, self-advocacy, and problem-solving moderated self-determination. For both youth and parents, they described experiences that promoted or hindered self-determination. The phenomenon was apparent in two ways. First, mothers and youth described education and transition disparities rooted in racist and ableist structures that hindered self-determination. These hindrances activated their need to respond as advocates during the transition process. Second, and one bright spot of the study, is that mothers and youth highlighted how elements of community life (e.g., personal connections within the community outside of schools, social/cultural capital) improved skills that promoted self-determination.

Consistent with past research (Banks, 2017), mothers and youth described experiences where race and disability intersect and influenced how they promoted self-determination. For example, in building trusting family and school relationships (Nate’s and Trey’s mothers), and advocating for knowledge and inclusion with peers (Charles’ and Trey’s mothers), all felt that racist and ableist systems were central factors that restricted self-determination skill and knowledge development, and limited possibility to collaborate with school transition personnel. These structures were barriers for Black youth and parents that hindered promoting self-determination in instructional settings, environmental opportunities, and in other forms of experiences where youth and families can practice and promote self-determination where cultural and background variables can be respected. This finding was consistent with researchers who suggested that transition services and self-determination instruction in modern schools may not reflect the values of culturally and linguistically diverse families (Achola & Greene, 2016).

**Self-Determination and DisCrit**

Consistent with DisCrit theory (Annamma, et al., 2013; Annamma et al., 2018), our preliminary investigation showed various nuanced ways that race and disability intersected in
transition planning experiences for youth and parents and influenced self-determination outcomes. For example, researchers have documented the role of cultural capital, highlighting its influence on power hierarchies in educational settings often leading to inequities for Black families and students with disabilities (Trainor, 2008; Wilt & Morningstar, 2018). Thus, without access to necessary and mandated information about effective transition planning, the mothers expressed challenges and tensions with education professionals, and felt that these professionals not sharing critical information was rooted in a system (transition process) that marginalized Black youth, and limited their outcomes. Parents were forced into activism because they felt oppressed during the transition planning process. Similarly, how the mothers see themselves as advocates to generate creative thinking to problem-solve challenges with opportunities for their sons in the current study showed choice-making opportunities that empowered them despite the feeling that school system officials did not always hold their best interests in mind. This aligns with the DisCrit framework, particularly tenet seven, which requires activism and supports all forms of resistance (Annamma et al., 2018).

Researchers have suggested the need for family-centered transition planning and culturally relevant transition practices for culturally and linguistically diverse families, including Black families, especially regarding self-determination (Achola & Greene, 2016; Fenton et al., 2017; Thoma et al., 2016). Although DisCrit theorists value multidimensional identities, the Black mothers in our study recognized how racist and ableist practices contribute to their child’s personal experiences. Self-determination was found to be a factor of student success, which we defined as “students exhibiting self-determination (e.g., choice-making, decision-making, self-advocacy, being self-directed), or their parents recognizing self-determination in their child’s activities, to enable more holistic experiences for direct involvement in determining their wants
and needs.” Our definition aligns with DisCrit theorists who posited that we (a) must include the voices of people with dis/abilities when providing accounts for their life and experiences (tenet four); and (b) engage in diverse expressions of resistance to educational inequities (tenet seven). Such advocacy was the consequence of fighting against oppressive educational systems that often viewed their children as “problems,” which aligns with tenet seven of our theoretical framework (Annamma et al., 2018). Overall, it was observed across interviews that youth and mothers wanted more than the “status quo” for their children. In fact, they expressed having to frequently “change the course of the conversation [from] settling because of [their child’s] race/disability.” Their expression was consistent with tenet three of DisCrit, which posited that disability (and race) set people “outside of the Western cultural norms” (Annamma et al., 2018, p 57).

Limitations

First, our sample included five pairs of Black male youth and their mothers. Thus, our findings cannot be generalized. We included youth and parents from different school districts exclusive to one area in the southeast region of the United States, with youth who were between the ages of 18 and 23. Therefore, experiences can differ based on districts, gender, and youth ages. Furthermore, our investigation was used to capture experiences of youth and parents at a single time point, and although parents described past knowledge, they may have been unable to capture observations, interactions, and other perspectives that offers a full range of information regarding transition planning experiences that hindered and promoted self-determination. Moreover, while there was some cohesion between participants’ perceptions, we also acknowledged that some differences existed, including how one mother noted that socioeconomic status (not conflating with race), moderated a portion of the transition planning
experience. Consequently, we were unable to compare/contrast differences in experiences when background knowledge of parents, school district resources, and youth differences are aggregated.

**Implications for Future Research, Practice, and Inclusion**

Within the context of transition planning experiences that are used to promote self-determination, it is critical that school personnel address the failure to provide meaningful culturally relevant self-determination supports and instruction to Black youth with disabilities. Our findings point toward a need to elevate the voice of Black youth and parents to truly understand and promote inclusive and culturally relevant self-determination. Often presented in the literature on transition for Black youth is that postschool transition outcomes are persistently below other racial/disability groups (Lipscomb et al., 2017); however, practitioners and researchers have largely ignored the systemic and structural issues behind these outcomes, and this includes the lack of engaging Black youth and families in promoting culturally and linguistically diverse measures during transition planning to promote better outcomes, including the development of processes and tools to promote self-determination for Black youth. It is apparent there is a need to eradicate racist and ableist systems that exist for Black youth and families in schools, specifically during the transition process. This includes examining instructional and assessments tools and procedures for engaging Black youth in special education. For example, a growing body of researchers continue to support the Self-Determined Learning Model of Instruction (SDLMI) as an evidence-based practice (Hagiwara et al., 2017; National Technical Assistance Center on Transition, 2017; Shogren et al., 2019). Despite the success of the model, we are calling for further implementation to include building from the voices of Black youth and parents in informing changes to the model, and for future researchers
to include a more robust sample of youth and parents from diverse culturally and linguistically diverse backgrounds, specifically Black youth and parents. We gleaned that without additional insight from Black youth and parents in instructional methods and assessments to promote self-determination, existing measures could potentially be culturally deconstructive, as they center Whiteness and disregard the voices of marginalized people, a concern raised when emphasizing a DisCrit agenda (Annamma et al., 2018).

In the current study, Black youth and parents discussed school, family, and community-level options as important moderators for promoting self-determination. For example, Carl and his mother discussed participation in state-wide self-determination programs. The use of these programs to promote self-determination for Black youth should be investigated as a potential source and strategy, as well as determining what level of change for the youth occurs because of their participation. Similarly, as social capital was expressed throughout parents’ narratives in the current study, information on who receives access and holds school officials accountable for parents of color receiving the state and community-level resources is necessary. Parents and youth were direct about the need to advocate for social capital, resources, and other activities in the transition process. Therefore, a closer look at the parents’ roles as co-advocates as a phenomenon for promoting self-determination for Black youth is encouraged.

Conclusion

To address the persistent postschool transition outcomes for Black youth with IDD, practitioners and researchers must understand transition planning experiences that hinder and promote self-determination. We must understand the role racially and linguistically diverse families have and identify opportunities within instruction and system-level supports and resources that are meaningful in informing their preferences for self-determination. Our findings
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were used to expose dissonance between Black mothers and youth, and the experiences during transition planning that influence their roles and actions when they are faced with systemic disparities in the process. Thus, to make certain that Black youth are involved in instruction and practice that promotes opportunities to become more self-determined, additional considerations of parents’ perspectives and practical approaches to meet the needs of this diverse group of students are necessary.
References


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VOICES FROM BLACK STUDENTS WITH DISABILITIES


https://doi.org/10.1080/09362835.2011.537225

Figure 1

Data Analysis

Sample Open Coding
My sister and myself had to track things down; Nobody talked to us; Limited guidance from case manager

Transition needs to start in middle school; Planning needs to start before they get to high school; Early and often

You're going to have an uphill battle; I've felt like certainly that if he but not a black male probably would have been handled differently; They pigeon-holed him

One of my teachers tells me that; Byron had his own mind; i totally am a hard worker

That's a choice I made to play baseball; He wanted the staff there; He kind of... advocated

Exposed to the curriculum; We kept pushing and pushing; Helping him with decision making

We're trying to lead him to being a little bit more realistic; Make sure that he had as many opportunities as he could

It depends on the community; It's all about information and you knowing where it is; It was more about what's available

Axial Codes
Community differences
School services

Parent expectations
Family values
Need for resources
Parent attitude towards school

Youth identity
Student attitude
Student expectations
Youth experiences

Selective Codes: Categories
Need for resources
Early Transition Planning

Transition Planning Experiences

Advocacy and knowledge
Student success/student self-determination

Inclusion ideologies & expectations

Family-led activities
Activities and services

Environmental activities
Community differences

Family SD Promotion
### Table 1

**Sample Interview Questions with Citations to Support Their Inclusion**

<table>
<thead>
<tr>
<th>Question Category</th>
<th>Youth Interview</th>
<th>Parent Interview</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Background</strong></td>
<td>Could you tell me how your background impacts your efforts to accomplish what you want to do?</td>
<td>How does [youth’s name] background-race, family values, culture impact his efforts to accomplish what he wants to achieve?</td>
</tr>
<tr>
<td>(Achola &amp; Greene, 2016; Banks, 2017; Ford, 2012; Shogren, 2011; Thoma et al., 2016)</td>
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<tr>
<td><strong>Problem Solving</strong></td>
<td>Could you tell me about a challenge that you’ve had in school or a problem with a friend, or any issue that you may have had recently?</td>
<td>Could you tell me how [youth’s name] solves problems that may come up at school? Like what factors impact his course of action when a problem arises?</td>
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<tr>
<td>(NTACT, 2017; Shogren, 2011; Thoma et al., 2016; Wehmeyer, 2017)</td>
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<tr>
<td><strong>Decision-making</strong></td>
<td>What factors do you take into consideration when making decisions about your future? What influences you?</td>
<td>What factors does [youth’s name] take into consideration when making decisions about their future? What influences their decision?</td>
</tr>
<tr>
<td>(NTACT, 2017; Shogren, 2011; Thoma et al., 2016; Wehmeyer, 2017)</td>
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<tr>
<td><strong>Race &amp; Opportunities</strong></td>
<td>Do you think that your race/color makes a difference in the opportunities you have while in school? Do you think that your race/color makes a difference in the opportunities you will have in the future?</td>
<td>Do you think that your race/color makes a difference in the opportunities [youth’s name] will have in the future?</td>
</tr>
<tr>
<td>(Achola &amp; Greene, 2016; Banks, 2017; Griffin, 2011; Mazzotti et al., 2016; Shogren, Shaw et al., 2018)</td>
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<tr>
<td><strong>Activities</strong></td>
<td>Tell me about your high school experiences. How did you choose classes and extracurricular activities? What influenced your decisions about classes and/or participation in extracurricular activities?</td>
<td>Does [youth’s name] make decisions about high school courses and activities? If so, what factors does your child take into consideration when making decisions about their high school courses and activities, what influences them? If not, why not?</td>
</tr>
<tr>
<td>(Achola &amp; Greene, 2016; Griffin, 2011; Martin &amp; Williams-Diehm, 2013; NTACT, 2017; Shogren, 2011; Thoma et al., 2016; Shogren &amp; Ward, 2018; Wehmeyer, 2017; Wehmeyer &amp; Webb, 2011)</td>
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<tr>
<td><strong>Barriers</strong></td>
<td>Do you see any barriers to getting what you want for your adult life? What are they? Are there things you can think of to do to overcome those barriers?</td>
<td>Are there specific barriers that stand in the way of your son/daughter meeting his/her plans for an adult life? What are they? How could those barriers be removed?</td>
</tr>
<tr>
<td>(Ford, 2012; Griffin, 2011; Shogren, 2011; Thoma et al., 2016; Trainor et al., 2020; Trainor et al., 2012)</td>
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</tr>
<tr>
<td>Name</td>
<td>Age</td>
<td>Career Goal</td>
</tr>
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<td>------------------------</td>
</tr>
<tr>
<td>Nate</td>
<td>18</td>
<td>Manufacturing, auto mechanics</td>
</tr>
<tr>
<td>Carl</td>
<td>19</td>
<td>Not sure, but wants to go to college</td>
</tr>
<tr>
<td>Bryce</td>
<td>20</td>
<td>Music or Technology</td>
</tr>
<tr>
<td>Trey</td>
<td>23</td>
<td>Film or Photography</td>
</tr>
<tr>
<td>Langston</td>
<td>21</td>
<td>Food Industry, Graphic Arts</td>
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</tbody>
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