# DISRUPTING THE TRANSITION PARADIGM: REDEFINING TRANSITION TO ADULTHOOD FOR SOUTH ASIAN FAMILIES OF CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

# A Dissertation

by

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# DOCTOR OF PHILOSOPHY

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# **ABSTRACT**

The transition to adulthood is a significant step in every individual's life. Specifically, for individuals with disabilities, the transition process requires targeted planning for specific adulthood outcomes (e.g., employment, higher education, living skills, social skills, and community preferences). As such, parent and professional voices and experiences guide the transition planning process to support youth in achieving meaningful adulthood outcomes. However, racially minoritized families often do not have agency in this process or equitable access to transition planning resources. Thus, my three dissertation studies center on the voices of South Asian families and their racialized experiences in redefining, reexamining, and reshaping the transition to adulthood for South Asian parents of children with intellectual and developmental disabilities. The first study used a mixed methods design to explore the strengths and resilience of 48 South Asian parents as they navigated systemic adversities in the transition planning process. The second study scoped 54 studies across four decades of peer review and gray literature to explore the state of parent education interventions for parents of adolescents with autism in the United States. Together, the two studies informed the development, implementation, and efficacy of SAATHI, a pilot transition-focused parent education intervention for 31 South Asian families of children with intellectual and developmental disabilities.

# **DEDICATION**

I would like to dedicate this dissertation to individuals with disabilities, their families, community members, and professionals who are breaking barriers, transforming norms, and redefining meaningful outcomes for all. I would also like to dedicate this work to racially minoritized and underrepresented scholars who are pushing the boundaries of traditional academia to center social justice in their work and offer agency to underrepresented and minoritized voices. Together, our work will continue to shape services for minoritized communities worldwide.

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# CONTRIBUTORS AND FUNDING SOURCES

# **Contributors**

This work was supervised by a dissertation committee consisting of Drs. Gilson, Ganz, and Thompson of the Department of Educational Psychology, and Dr. Viruru of the Department of Teaching, Learning, and Culture at Texas A&M University. It was also supervised by Dr. Singh of the Department of Occupational, Workforce, and Leadership Studies at Texas State University.

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# **NOMENCLATURE**

ASD Autism Spectrum Disorder

CCW Community Cultural Wealth

CLD Culturally and Linguistically Diverse

IDEA Individuals with Disabilities Education Act (2004)

IDD Intellectual and/or Developmental Disabilities

IEP Individualized Education Program

IRR Inter-Rater Reliability

NLTS National Longitudinal Transition Study of Special Education

Students

PET Parent Education and Training

PRISMA-ScR Preferred Reporting Items for Systematic Reviews and Meta-

Analyses extension for Scoping Reviews

RCT Randomized Controlled Trial

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# 1. INTRODUCTION

Transition to adulthood has been an ongoing concern in special education. Early research on postschool outcomes of young adults who had completed schooling under the Education for All Handicapped Children Act, later renamed as Individuals with Disabilities Education Act (IDEA), prompted discussions about adulthood outcomes for young adults exiting special education. In the early 1980's and 1990's, emerging research on post high school outcomes argued for more emphasis on vocational training and employment preparation in school by reporting the dire outcomes related to employment of individuals who had exited high school (Edgar, 1987; Hasazi et al., 1985). Shalock and colleagues (1986) conducted a five-year longitudinal study of 108 students who had graduated between 1979 and 1983 from special education services in high school. The researchers reported that family involvement was a strong predictor of employment outcomes, in addition to vocational preparation at school. Additionally, the researchers also found that over 78% of the adults surveyed were living in supervised environments, either home or an institution, and called to action a need to focus on daily living skills in special education.

Similarly, Wagner and Blackorby (1996) reported findings from the first National Longitudinal Transition Study of Special Education Students (NLTS), which was conducted in 1987 and again in 1990 with students between the ages of 15-21. The researchers found that 30% of students with disabilities had dropped out of high school, 37% of high school graduates had attended a higher education institution, and youth with learning or speech impairments were the only ones in the workforce (Wagner & Blackorby, 1996). The authors also concluded that youth from lower income households fared much worse than those from higher income households,

leading those from lower income households into poverty and financial dependence after high school. Thus, emerging research in transition literature used postsecondary schooling, employment outcomes, and living environments to understand adulthood outcomes, thereby developing parameters that would later define and inform transition outcomes for the field.

Informed by the research and practices related to the post school outcomes of young adults with disabilities, IDEA added transition services for students with disabilities in special education in 1990. IDEA was reauthorized in 2004 to include specific mandates regarding the definition of transition planning services, such as starting services at the age of 16, and established transition planning as an integral component of a child's Individual Education Program (IEP) to effectively plan for their postschool outcomes (IDEA, 20 U.S.C. 1401(34)).

Using the legal definition of transition planning and research with stakeholders (e.g., families, professionals and service systems), researchers have carved a roadmap of what transition planning could look like to increase postschool outcomes of young adults with disabilities. This includes the creation of a transition taxonomy (Koehler et al., 2016), identifying predictors of post school outcomes (Mazzotti et al., 2021), and consolidating evidence-based practices in transition planning (Test et al., 2009). Over the last two decades, the field has strengthened practices to support the development of young adults with disabilities toward personal, professional, and community endeavors related to adulthood.

# 1.1. Defining Transition Planning for Racially Minoritized Families

Alongside the promise and progress of transition planning in the last two decades, scholars in the field should also consider and interrogate the imposed narrative of transition planning. Atwood and López (2014) argue to critically read the racial and systemic undertones

that guide how a particular system functions and who it serves. We must address the silent parts out loud in order to advance towards social justice and equity in the field.

The transition planning process, including goals and outcomes, has been predominantly informed by research with white, middle class, and western populations, which also includes the participants, educators, lawmakers, and the researchers themselves. Blanchett (2006) argues that special education revolves around a master script (Swartz, 1992), where the curriculum and the pedagogical tools to teach it are derived from white, able-bodied, middle-class individuals. The master script of what an ideal transition plan and transition outcomes should look like continues to dominate the field of future planning. As such, the current narratives around transition planning do not serve racially minoritized students and their families, who are currently the largest group of students who are enrolled in and benefit from special education services (U.S. Department of Education, 2020).

Racially minoritized students and their families have been disenfranchised in the transition planning process and thus, have experienced lower postschool outcomes than their white counterparts (Shikarpurya et al., under review). Adulthood outcomes that were characterized by white-dominant narratives are currently being applied to families for whom those narratives are not a reality. For instance, Latino mothers of young adults with developmental disabilities indicated that for them, adulthood for the youth was defined by living independently from home only after they get married (Rueda, 2005).

However, a common measure of assessing independent living skills in transition literature, as indicated by the National Longitudinal Transition Study 2, is the youth's transition away from home after graduating from high school (Shogren & Plotner, 2012). The differences in these perspectives indicate that the current models and definitions of transition outcomes are

not created for nor applicable for racially minoritized families. Definitions change based on the race and racialized experiences of the families and those factors should be taken into consideration when framing transition planning. Instead of not seeing race, I argue that we see individuals and their families as their whole selves, including their racialized experiences, strengths, and adversities to be better equipped to appropriately support them as they transition toward adulthood.

Centering the experiences of racially minoritized families could shape the narratives that define transition planning for disaggregated racial groups. Currently, the majority of transition literature uses the broader categories of culturally and linguistically diverse (CLD) to inform the field about transition experiences of this monolithic group (Greene, 2011; Suk et al., 2019). The CLD label, or the "people of color" label, assumes that all individuals who do not identify as white seek the same services and encounter similar challenges. This grouping erases the identities of these racial groups and binds them into a singular experience. Hence, there is no mention of transition planning for "white students" anywhere in the literature because transition planning practices were designed for and with their needs and experiences in mind. For racially minoritized families, this is simply not the case.

Vast differences exist in how specific racially minoritized families view and experience transition to adulthood. For instance, Black students with intellectual and developmental disabilities (IDD) and their families experienced racism in the transition planning process by stakeholders (Banks, 2017) and are held to much lower expectations than their skills and abilities showed (Scott et al., 2021). Latinx families have encountered challenges with services for translations, access to inclusive education, and they expected family-based decision making

when planning for their child's future (Shogren, 2012; Rios et al., 2021; Skillern & Carter, 2021).

Korean families have expressed desires for their young adult to maintain strong social relationships with their community after high school and for the adult child to live at home with the family across lifespan (Kim & Dabanah, 2021). Lastly, Chinese, and Vietnamese families indicated challenges with navigating the complex legal language of transition services and expressed a greater desire for more community-based services and a stronger focus on daily living skills for their young adults with IDD (Lo & Bui, 2020). Although these experiences do not speak for all individuals that identify with those racial groups, they provide a foundation for how adulthood outcomes could be defined for that population. Having this foundational knowledge could shift the dialogue away from standard transition outcomes toward more individualized and flexible models that are reflective of the unique racialized experiences of racially minoritized families and their young adults with IDD.

# 1.1.1. Gaps in Representation of South Asian Voices in Transition Planning Literature

South Asian Americans represent over six million individuals from countries such as India, Pakistan, Nepal, Bhutan, Indonesia, Malaysia, Sri Lanka, and Burma, (United Nations Statistics Division, 1999). Specifically, Indian Americans account for 21% of the total Asian population within the United States (Budiman & Ruiz, 2021). Yet, there are no transition-focused studies that exclusively document the transition to adulthood experiences of South Asian families of children with IDD. Although prior literature has noted that South Asian parents experience higher stress related to future planning for their children (John et al., 2016) and have limited knowledge of future planning (Zechella and Raval, 2016), no research to-date has strengthened these findings by exploring the transition experiences of exclusively South Asian

families of children with IDD living in the United States. In addition, South Asian families have been singularly defined under the "Asian" category which dilutes their unique experiences, oppressions, and challenges as they understand and navigate the transition to adulthood process for their children with IDD (Yang et al., 1996).

Limited engagement with South Asian families in transition literature has resulted in their individualized experiences being viewed through the lens of an Asian label. As a result, the field has less familiarity with best practices to increase the postschool outcomes of young adults with IDD who identify as South Asian and even less knowledge about supporting families who are navigating the complexities of transition to adulthood. For instance, as a South Asian researcher and a sibling of an individual with autism, the transition process was not meant for my family. The outcomes defined by the transition team did not resonate with my family, and we, including my sibling, were rarely included in the conversations that determined their future outcomes. Power dynamics, racism, unfamiliarity with the legal language of special education, and expectations of western notions of advocacy plagued my family and I as we navigated this journey. Therefore, my identity as a researcher, a member of the South Asian community, and a family member, is deeply integrated into my research. This dissertation was conceptualized based on a premise of self-relevant research, where the researcher explores concepts that are significantly personal to the researcher and are a salient part of their self-identity (Amabile & Hall, 2021).

# 1.2. Present Dissertation

The three studies I pursued for my dissertation advance the field of transition by examining the transition planning process for South Asian families and reducing systemic barriers through culturally competent parent training. The first study used a mixed methods

approach to define and reframe transition to adulthood using a strengths-based perspective. This study aimed to strengthen the field's understanding of the transition experiences of South Asian families of children with IDD. This seminal study extends previous research with Asian families to include the voices of South Asian families. It also offers a strengths-based narrative to move the field forward in capturing the resilience of South Asian families to overcome racialized adversities in the transition planning process. The second study is a scoping review to map the state of parent education training for parents of children with autism. Findings from the review contribute to examining gaps in the literature regarding availability of parent training for racially minoritized families of adolescents with autism, particularly related to transition to adulthood outcomes. It also lays the foundation for defining various terminology used to conduct and report parent training (i.e., parent training, parent education training, parent-mediated training, parent education, etc.), thereby strengthening future research related to parent training interventions.

Together, both studies have informed the culturally informed development of a parent education transition training for South Asian families of children with IDD. South Asians Accessing and Advocating for Transition and Higher Education Inclusion, SAATHI, is the first transition-focused parent education training program in the literature for South Asian families of children with IDD. SAATHI advances the field by expanding the breadth of transition focused interventions and reach racially minoritized families that have been previously underrepresented in literature. It also demonstrates the effectiveness, feasibility, and social validity of this novel intervention to further adapt for other racially minoritized groups. Combined, the three studies introduce the experiences of South Asian families into the field of transition, strengthen knowledge and terminology regarding parent education interventions, and increase young adults'

post school outcomes by equipping families with culturally competent transition training to prepare for the transition planning process.

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# 2. RESISTING LEGACIES OF RACIAL DISPARITIES: COUNTERSTORIES OF STRENGTH AND RESILIENCE AMONG SOUTH ASIAN FAMILIES OF CHILDREN WITH DISABILITIES NAVIGATING TRANSITION PLANNING\*

Due to the collaborative nature of the transition process, families play a critical role in the success of transition planning for individuals with disabilities. Over the past twenty years, research has demonstrated that family involvement in the transition planning process is one of the key predictors of successful postschool opportunities for young adults with disabilities (Mazzotti et al., 2021; Test et al., 2009). For instance, Test and colleagues (2009) conducted a systematic review of predictors of secondary transition outcomes. The researchers found that across 16 predictors, parent involvement was one of the key predictors of successful employment outcomes for youth with disabilities.

Research demonstrates that parent involvement has contributed to successful postsecondary education outcomes (Mazzotti et al., 2016), outcomes related to student wellness and achievement in college (Francis et al., 2018), and increased self-determination and employment outcomes (Lindstrom et al., 2007). For instance, examples of parent involvement include advocating for the needs and interests of their child, holding high expectations, and taking deliberate steps to maximize their child's independent skills (Rossetti et al., 2016). As such, Hirano and colleagues (2016) have summarized measures of parental involvement as: (a) optimal organizational conditions related to school values and beliefs, such as school leadership

<sup>\*</sup> Please Note: This study is currently under review for a special issue in *Career Development and Transition for Exceptional Individuals*.

and teacher beliefs, (b) school interventions for parents, including parental knowledge, expectations, efficacy, and role construction, (c) active role of parents within the transition process, such as an evaluator, advocate, instructor, and collaborator, and (d) increased involvement within secondary education and beyond, such as within the community, school, and home settings.

However, perceptions regarding parent involvement vary widely across the transition planning process, especially regarding the engagement of racially minoritized families. Often, racially minoritized parents are blamed for the academic and functional achievement of their child and seen from a deficit perspective (Harry, 2008). Specifically, Harry and colleagues (2008) identified definitions of family collaborations since the beginning of IDEA and found that racially minoritized parents were viewed using deficit language (e.g., risk factors, racial stereotypes, and generalizations) as compared to their white peers. The discourse of parental involvement has historically been derived from the language used in IDEA (IDEA, 2004), which broadly advocates for parents to attend IEP meetings and for them to be informed of meetings. However, the role of parent as an advocate requires knowledge of white, middle-class attributes of advocacy (e.g., speaking up or calling school districts), which may not consider the collective nature of shared partnerships and decision-making (Kozleski et al., 2008).

Lai and Vadeboncoeur (2012) argue that racially minoritized parents are seen by educators as less knowledgeable, and often balance the perceptions of being over involved or uninvolved, which they deem could negatively impact their child's outcomes. Parents navigate the delicate balance of being subordinate and polite enough to get their views across without disturbing the status quo, with fears of being othered in educational spaces (Lai & Vadeboncoeur, 2012). Lee and Bowen (2006) affirm that when parents come from Eurocentric

norms, values, and social systems, they automatically obtain more social capital, such as knowledge of parent meetings, laws and policies, and parent networks that contribute to their child's success. However, when those social norms and values do not align to Eurocentric orientations, their agency and capacity to impact their child's outcomes decreases (Gonzalez & Gabel, 2017).

# 2.1. Racially Minoritized Families in Transition

Almost 40% of individuals living in the United States identify as racially or ethnically diverse (U.S. Census Bureau, 2020). These racial and ethnic categories include 18.5% of individuals who identify as Hispanic, 12.2% identify as Black, 5.6% identify as Asian, 2.8% identify as belonging to multiple races, 0.7% identify as American Indian/Alaska Native, and 0.2% identify as Native Hawaiian/Other Pacific Islander (U.S. Census Bureau, 2020). It is predicted that by 2045, less than 49% of individuals will identify as white (Jonathan et al., 2020).

As the United States becomes increasingly more diverse with a minority-majority landscape, it's essential to understand how racially minoritized families are currently engaged within the transition planning process. Although parent involvement is one of the largest predictors of successful postschool outcomes (Mazzotti et al., 2021; Test et al., 2009), racially minoritized families often face multiple challenges during this process. Wilt and Morningstar (2018) reviewed transition literature to expand on the field's understanding of the experiences of racially minoritized families. The researchers found that across seven studies with 115 participants, families noted the following barriers to being meaningfully engaged in the transition planning process: limited communication and access to transition-related information, negative assumptions about families from professionals, negative past experiences and ongoing mistrust, and limited availability of community supports (Wilt & Morningstar, 2018). These systemic

barriers point to disparities in the systems within which American schools operate. This review elucidates the necessity of examining systemic structures that impact parental involvement rather than using parents as scapegoats to blame for their child's outcomes.

Similarly, using a qualitative meta synthesis, Hirano and colleagues (2018) noted that across 22 studies with 405 participants, racially minoritized families reported having limited access to transition services, narrated accounts of racism and microaggressions targeted towards the child and family, discussed teacher-directed services that were not based on parental input, and reported that they did not feel that they were active stakeholders in the transition planning process.

Disaggregated findings for specific subgroups of racially minoritized families also reveal how families experience challenges that are unique to their own population. Specifically, when interviewing Korean families, Kim and Morningstar (2020) found that 24.4% of parents thought transition planning was not useful for them, perhaps due to limited resources offered by schools and limited knowledge of transition planning services. Similarly, Lo & Bui (2020) also reported that Korean and Vietnamese parents were seldom offered interpreters during transition planning meetings, and the schools carried lower expectations for the child, resulting in perceived lower involvement from parents. Prior research with Latinx parents also indicates that families did not trust the school system because they felt disempowered, ignored, and unwelcomed by the school professionals (Povenmire-Kirk et al., 2010). Although emerging research posits a stronger emphasis on partnerships between schools and families, systemic barriers, such as racism, ableism, and other intersectional identities continue to marginalize racially minoritized families as they navigate the transition planning process.

# 2.1.1. South Asian Families in Transition

Despite the emerging literature on parental involvement of Asian families, only a handful of studies have exclusively explored the experiences of South Asian families of children with disabilities living in the United States. Most of the research conducted with South Asian families reflects younger children and broader notions of what disability and services may mean for families (Jegatheesan et al. 2010; Ravindran & Myers, 2013). Additionally, while emerging research in transition has explored the experiences of Chinese, Korean, and Vietnamese families (Kim & Morningstar, 2007; Lo & Bui, 2020), scant research has been conducted to expand the field's understanding of how South Asian families navigate adulthood outcomes for their children with disabilities.

Only two available studies to date have specifically focused on future planning or postschool outcomes of South Asian youth with disabilities. Zechella and Raval (2016) interviewed fifteen South Asian families of children with intellectual and developmental disabilities (IDD) and reported that most families faced multiple challenges when accessing services for their child. The researchers also found that families had very limited knowledge of the future outcomes of their child. However, the parents did note that they wished for their child to learn independent skills more than academic skills.

Additionally, John and colleagues (2016) used three measures of support and stress, including the Family Stress and Coping Questionnaire, to identify stressors among 33 Indian immigrant parents of children with developmental disabilities living in the United States. The authors found that parents' largest sources of stress were regarding long term/future planning for the child and finding social opportunities for their child (John et al., 2016). Parents' perspectives of their child's future are telling of the need to specifically expand transition services to this

population. South Asians account for over four million of the entire Asian population in the United States (U.S. Census Bureau, 2020), however, the field of special education, particularly transition, knows very little about how to better prepare and support these families.

Disaggregated transition knowledge from the larger Asian collective toward specific groups, such as South Asians, would lead to more precise support services for South Asian families, strengthen educator knowledge about the specific needs of this population, and would offer greater accountability in the creation of policies directed toward South Asian families. Specific racially minoritized populations become invisible under the larger racial labels, and therefore, do not get access to individualized services that better meet their unique needs. With over 60,000 Asian students exiting high school from special education services each year (U.S Department of Education, 2020), it's critical to understand how to competently prepare South Asian families for transition services.

# 2.1.2. Family Resilience

Racially minoritized families often face multiple systemic adversities within the transition planning process. However, they also carry multiple strengths to face, challenge, and navigate those adverse experiences. The framework of family resilience argues that families strengthen their knowledge and resources when faced with adversities (Walsh, 2012). Resilience is a process in which families evolve over time, building multiple frameworks of strengths as they grow. Walsh (2015) proposed three dynamic processes of understanding and building family resilience: (a) belief systems (e.g., meaning making, positive outlook, and transcendence/spirituality), (b) organizational processes (e.g., flexibility to adapt, connectedness, and family, social, and economic resources, and (c) communication processes (e.g., clarity of information, emotional sharing, collaborative problem solving).

Henry and colleagues (2015) further add that family resilience serves as a protective mechanism against adversities, whereby families develop protective strategies to prepare against future risk. Windle (2011, p. 163) summarized family resilience as "the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity." Family resilience is not a static process; resilience exists within broader macro and mesosystems that further challenge and refine families' inherent and developed strengths.

Family resilience is an emerging framework within special education literature. Bayat (2007) conducted a study with 175 parents of children with autism to understand family resilience. They found that parents built resilience by engaging in multiple forms of advocacy, being connected to formal and informal networks, and changing their worldview regarding disability. Additionally, Caldwell and colleagues (2018) surveyed 56 family members of adults with IDD who had exited a state institution and found a strong relationship between family empowerment, family resilience, and family adaptation, noting the interconnectedness of multiple factors when exploring resilience. The authors also noted that decision-making was a strong component of building family resilience. Lastly, Park and colleagues (2018) used the Connor-Davidson Resilience Scale (CD-RISC) to understand family resilience among 172 South Korean caregivers of transition aged youth with IDD and noted that caregiver resilience mitigated their stress, anxiety, and depression. The authors indicated that caregivers who reported higher perceptions of resilience could be more equipped to navigate adversities. Family resilience is in its infancy, particularly in transition, and demands further research on family strengths to better understand how families overcome adversity.

# 2.1.3. Theoretical Framework

Community Cultural Wealth (CCW) is a framework used to explore asset-based approaches toward understanding marginalized communities (Yosso, 2005). The framework of CCW draws from critical race theory (Crenshaw, 2002) to challenge the notions that only white, middle class populations carry valuable capital (Bourdieu & Passeron, 1977). In schools, this translates to assumptions about marginalized populations who are seen as disadvantaged, including perceptions of students of color "catching up" to the dominant group. In research, this notion is often represented when marginalized populations are compared against a dominant, white group to explore discrepancies in outcomes. CCW is a framework that challenges racialized deficit thinking often associated with students of color by offering strengths-based counterstories about cultural wealth of communities of color. For instance, a recent review of future planning among families of children with IDD noted that across 43 international studies with 3,221 participants, 87.20% of the studies included respondents who identified as white (Lee & Burke, 2020). This indicates that perspectives regarding transition are sought and derived from white populations. CCW aims to include the perspectives of racially minoritized communities to reframe the transition planning process that is more reflective of all populations.

The framework of CCW centers the voices of racially minoritized families and offers a strength-based perspective based on six forms of capital that families carry: (a) *aspirational capital* (ability to maintain hope in face of adversity, e.g., expectations of a child to graduate from a four year college), (b) *navigational capital* (navigating educational structures that are not designed for marginalized communities, e.g., navigating complex financial waivers such as Medicaid program), (c) *social capital* (social networks that are culturally reflective of the communities, e.g., religious communities or online parent groups), (d) *familial capital* 

(knowledge that is shared and nurtured in the family, e.g., extended family support in decision-making), (e) *resistant capital* (behavior that challenges inequity, e.g., asking for due process or hiring an advocate), and (f) *linguistic capital* (ability to communicate in multiple languages as communities navigate educational structures, e.g., using multiple languages to seek support or services). For example, in transition, aspirational capital could be evident in the families when they expect their child to graduate from college while having limited knowledge of college options, limited financial resources, and resistance from transition planning personnel.

Community cultural wealth has been used to explore multiple facets of inequities and strengths among racially minoritized communities in educational literature. For instance, DeNicolo et al. (2015) used testimonios to explore the community cultural wealth of Latina/o students to challenge the deficit perspectives of Latina/o students. Additionally, Valdez and Lugg (2010) used the framework of CCW to examine knowledge that Chicano/a students bring to schools and offer culturally appropriate strategies to serve this unique population. This framework has also been used to understand how racially minoritized faculty members draw from their community cultural wealth when encountering racism in academia (Martinez et al., 2016). Within special education, and specifically transition, Wilt et al. (2021) conducted a scoping review of culturally sustaining practices within transition planning to understand barriers families face and the ways in which schools use culturally sustaining practices to support them. The researchers found that marginalized families relied on resistant capital, aspirational capital, familial capital, and social capital when navigating transition to adulthood. For example, the authors found that families drew upon their social capital by working with informal networks to prepare their child for employment opportunities (Wilt et al., 2021). Prior to this study, the CCW

framework had not been used within transition planning endeavors, and familial strength was not contextualized using strengths-based perspectives.

In addition to the CCW framework, I chose to present the findings as *counterstories*. Solórzano and Yosso (2002, p. 32) define counterstories as a method of re(presenting) stories of marginalized populations and as a vehicle "for exposing, analyzing, and challenging the majoritarian stories of racial privilege." I employed the framework of counterstories to empower and strengthen the experiences of South Asian families as a counternarrative to the deficit-based perspective often associated with marginalized communities of color. The field demands a shift in the paradigm of parental involvement using strengths-based approaches. Thus, this study contributes to the literature by using strengths-based frameworks to redefine and reframe the parameters within which South Asian parents navigate the transition to adulthood process.

## 2.1.4. Purpose of the Study

The purpose of this mixed methods study is to center the voices of South Asian families to better understand their experiences with transition planning. I led a team to conduct a multi-state survey to examine the adversities families faced when accessing transition-related services and interviewed families to explore their strengths when navigating transition planning. I used the framework of community cultural wealth to offer a strengths-based narrative and provide a counterstory to the deficit-based lens often associated with racially minoritized families. I used a sequential, transformative, explanatory, mixed methods design with equal priority to answer the following questions:

1. (Quantitative): How often do South Asian families encounter adversities when accessing transition planning services?

- 2. (Quantitative): What is the relationship between parent demographics and how often parents encounter adversities when accessing transition planning services?
- 3. (Qualitative): What types of community cultural wealth do South Asian families draw upon when navigating the transition planning process?
- 4. (Mixing): How do South Asian parents leverage their community cultural wealth to overcome adversities when navigating the transition planning process?

#### 2.2. Method

A mixed methods design is used in research to collect and analyze both quantitative and qualitative data by mixing or integrating both methods to understand a larger "mixed" research question (Creswell, 2003). Mixed methods research is typically conducted when both forms of data are necessary to answer the research questions, thereby allowing for a more robust inquiry. I used a sequential, transformative explanatory mixed methods research design with equal priority to examine how South Asian parents leverage their community cultural wealth to overcome adversities in the transition planning process.

A sequential explanatory design is conducted in two phases (Creswell et al., 2003; Tashakkori and Teddlie 1998). First, quantitative data is collected and analyzed (e.g., research questions 1 and 2). Second, qualitative data is collected to further expand on and explain the quantitative findings by using participant voices to strengthen the research inquiry (e.g., research question 3). I chose a sequential explanatory design to explore adversities South Asians face using survey data and then re(present) their voices using interviews to understand how parents use their community capital wealth as strengths to navigate the transition planning process, despite the racialized adversities they encounter. By mixing both quantitative and qualitative data sequentially to explain and complement one another, I aim to shift the perspective from a deficit-

based lens of racially minoritized families toward one that highlights their strengths and resilience using the framework of community cultural wealth (e.g., research question 4). For instance, just highlighting the adversities parents face would further perpetuate the notion that these families face challenges and that is simply why their transition outcomes look differently. Contextualizing their racialized adversities within the community cultural wealth they carry moves the field toward a strengths-based orientation that could better explain parental involvement and further individualize the transition planning process for this population.

In a mixed methods study, priority is typically given to either the quantitative or qualitative or equal priority to both methods when collecting, analyzing, and reporting the findings (Creswell. 2003). Typically, in a sequential explanatory design, quantitative methods are given priority because it is often the first method of collecting data and thereby deemed more important. However, prior researchers have given priority to qualitative methods (Ivankova et al., 2006) or equal to both methods (Catallo et al., 2013) based on their research questions. I chose to establish an equal priority for both the quantitative and qualitative methods to: (a) highlight the complementarity of both methods in exploring the larger phenomenon of South Asian parents' experiences navigating the transition planning process, (b) to uniquely contribute to the field's understanding of both findings (i.e., racialized adversities and parent strengths), and (c) to use equally weighted rigorous quantitative and qualitative approaches to explore future transition-related supports and interventions for South Asian families. Specifically, equal priority was reflected in the research questions, in the analysis of quantitative and qualitative methods, in the interpretation of results, and in the mixing procedures.

I chose a mixed methods design to (a) offer a deeper understanding of South Asian parents' transition experiences using the complementarity elements of quantitative and

qualitative methods, (b) integrate the strengths of quantitative findings with qualitative interviews to draw conclusions and examine the complexities of navigating transition planning, and (c) expand mixed methods research design within the realm of special education, particularly in the field of transition studies (Creamer, 2018). A mixed methods design uses the strengths of each method to understand the experiences of South Asian parents intimately and comprehensively in the transition planning process. Thus, a mixed methods approach would provide a better understanding of South Asian parents' experiences than simply one method alone.

I first collected quantitative data (survey) and used the findings to inform the qualitative method (interviews). Mixing was fully integrated using four distinct steps: linked research questions, nested sampling, including sequential data collection and analysis, combining quantitative and qualitative results using blended analysis, and using the blended variables to inform meta-inferences (Table 1). First, I linked the research questions to ensure that both methods were reflected in the research questions prior to beginning the study. There are typically three ways to link the research questions: (1) blended into a single sentence (this is where both methods are reflected in one sentence without explicit labels; Plano Clark et al., 2010), (2) separate but linked questions (e.g., each question reflects the method chosen to answer the question without labels of the methods; Elliott et al., 2014), and (3) explicitly labeled separate questions (e.g., each question is labeled QUANT, QUAL, or MIXED to reflect the nature of the methods used to answer it; Creamer & Ghoston, 2013). I chose to ask explicit labeled separate questions to offer transparency and clarity of each research question and the methodology used to answer it.

Second, integrating both quantitative and qualitative methods requires intentional mixing during sampling. Timing is used as an indication of when the mixing will occur (e.g., concurrent or sequentially) and the characteristics of the sample (e.g., nested, overlapping, or identical; Creamer, 2018). I chose a sequential design because this study occurred in two stages (quantitative first then qualitative), and the data were also collected and analyzed sequentially. For instance, the participants who participated in the interviews were a nested subset of those who participated in the survey (the individuals who completed the survey were then offered an opportunity to be interviewed).

Third, I mixed the two methodological approaches during the data analysis process using blended variables (Table 1). Blending occurs when quantitative and qualitative findings are combined or integrated to generate a new variable or theme, namely a blended variable (Creamer, 2018). Although there are no set of standard procedures for mixing during analysis, the purpose of mixing at this stage is to consolidate findings into thematic categories or variables using multiple sources to deepen the findings of both methods. For instance, themes generated from quantitative findings (i.e., survey results) would be integrated with themes from qualitative findings (i.e., interviews) to result in a singular blended variable that would explain and consolidate the findings from both approaches. I analyzed the findings using blended analysis to generate blended variables that would support in examining how South Asian parents overcome racialized adversities using their cultural community wealth to navigate the transition planning process.

Lastly, I used the blended variables generated from blended analysis to develop a metainference about how South Asian parents overcome their racialized adversities using their community cultural wealth to navigate the transition planning process. A meta-inference is a final point of examination that integrates the conclusions formed during blended analysis to answer the final research question (Creamer, 2018). While a blended analysis combines the findings from both methodological approaches, a meta-inference is the sum that reveals an understanding of the larger phenomenon being explored in the study. A meaningful meta-inference is derived from intentional mixing at each juncture (e.g., research questions, sampling, data collection, and data analysis) to examine a complex research inquiry. I aimed to report a meta-inference that is transparent, meaning it indicates clearly where the findings emerged from, thereby improving the efficacy of the mixed methods procedures.

Mixed methods research uses philosophical transparency to indicate philosophical underpinnings of the research process (Creamer, 2018). I viewed the entire research process from a transformative paradigm, which includes active recognition, acknowledgement, and reflection towards systems of power and oppression that are reflected within research practices (Mertens, 2007). A transformative paradigm explores the role of inequity and power within the research inquiry and seeks to address social justice. For instance, I recruited participants from diverse organizations and informal networks, established trust and ongoing partnership among research participants and researchers, and used a mixed methods approach to strengthen voices across multiple formats. A transformative paradigm critically engages with how communities of color are represented and advocates for social justice and advancing human rights.

# 2.2.1. Survey Recruitment

Recruitment procedures mirrored those explained in Shikarpurya et. al. (under review). I led a team to collect survey data using an online questionnaire which was available from May 2020 to April 2021. I aimed to recruit participants that were racially, ethnically, and linguistically diverse to better understand their experiences with navigating transition planning. I

recruited participants virtually because recruitment took place during a global pandemic in which in-person gatherings and services were limited. I sent an email to each organization, which included a description about the survey, an online link to complete the survey, and flyers in English, Hindi, and Spanish to be distributed to the constituents. In the email, I specified that the survey could be completed in English, Hindi, and Spanish, and it could also be completed with a research team member on the phone. Parents could complete the survey either online via a Qualtrics link or on the phone with me because I am fluent in English, Hindi, and Urdu. The full survey took approximately 20-30 minutes to complete. Parents who indicated they would like to be entered in a drawing received one of four Amazon gift cards for \$10 in appreciation of their time.

"I partnered with 295 family-based organizations, clinics and therapy services, inclusive higher education programs, faith-based organizations, and parent groups located primarily in Texas and some across the country, to recruit participants. These included 44 faith-based organizations (e.g., churches, mosques, synagogues, temples, and faith-oriented special-needs programs), 59 parent/caregiver support groups, 20 school districts, 85 local and national advocacy organizations, 20 sports and summer camp programs, 10 therapy centers, 10 inclusive postsecondary education programs, 11 libraries, 32 social media groups (e.g., Facebook and Twitter), and four social media groups run by self-advocates. Additionally, I also advertised the study on radio shows, posted flyers in local community centers, and used word of mouth communication among racially diverse stakeholders to increase awareness about the study. Organizations recruited participants by sharing the survey link and the appropriate flyer (either in English, Hindi, or Spanish) using a listsery or personal emails" (Shikarpurya et al., under review, p. 8).

Specifically, for recruiting South Asian parents, I distributed flyers in English and Hindi to reach multilingual South Asian families. I contacted 56 South Asian organizations across the United States for a more purposeful sample. These organizations included *Muhsen, Olive Branch, Daya, NAMI, South Asian Council for Social Services, Enabled Muslims, CHETNA, Adhikar*, and many others. Additionally, I employed snowball sampling by asking parents to indicate if there are additional organizations I could partner with to distribute the survey (Onwuegbuzie & Collins, 2007).

## 2.2.2. Participants

This study was part of a larger, multi-state survey project to understand transition experiences of families of children with disabilities (Shikarpurya et al., under review). Inclusion criteria for the present study included participants who were (a) parents or caregivers of a child with any type of self-reported disability, (b) identified as South Asian, (c) could speak and/or read in English or Hindi, and (d) reside in the United States. South Asians are individuals who trace their ancestry or origins from Afghanistan, Bangladesh, Bhutan, India, Maldives, Pakistan, Nepal, Sri Lanka, and Burma (United Nations Statistics Division, 1999). Participants completed a demographic question that asked to indicate their racial identity on the survey, and they were also asked to provide their country of birth. For example, if a participant identified as "Asian" but reported that they were born in India, I counted them as a South Asian participant.

Participants were excluded if they were not a South Asian parent or a caregiver of a child with a disability.

A total of 797 parents of children with disabilities responded to the larger survey, of which 419 identified as racially minoritized. From the larger study, I identified 48 South Asian parents who responded to the survey. Majority of the South Asian participants resided in Texas

(n = 26), while others were from California (n = 2), Florida (n = 1), Illinois (n = 1), Utah (n = 1), and Ohio (n = 1). Additionally, 37 respondents identified as mothers, seven identified as fathers, and two respondents identified as a sibling and an uncle (Table 2). All respondents will be referred to as parents from here onwards because over 80% identified as a parent. Thirty-five parents had a child who was between birth to 21 years old, while 13 parents had adult children over the age of 22. Of the parents who responded to the specific ages of their child, 19 parents had a transition-aged child between the ages of 14 to 22. Child ages ranged between 4-42, with the average age of 16.90. Additionally, 5 parents had a child between the ages of 12 and 13, just a few years away from when transition planning begins in schools. I included parents who did not have a child within the traditional transition planning age (e.g., 14-22) to explore their challenges related to adulthood outcomes that go beyond transition planning within schools. For instance, connection to adult service providers should be emphasized across the lifespan rather than just within the traditional transition age.

Parents were asked to indicate their child's primary diagnosis based on the 13 categories of IDEA; however, they could select multiple diagnoses. Most parents (39%) indicated a primary diagnosis of autism, followed by intellectual disabilities (20.31%), and speech or language impairment (4.69%; see table 2 for additional information). Half of the parents had lived in the United States for over 20 years, while over 32% of parents had been living in the United States between 10-20 years. Almost half (44.9%) of parents indicated they were fluent in English, 16.3% stated they were comfortable with speaking English, 6.1% were still learning English, and 2% indicated very little comfort with speaking English. Three parents completed the survey on the phone with me in Hindi. Additionally, 30% of parents spoke English at home, followed by Urdu (12.2%), Hindi (8.2%), and Gujrati (4.1%). Parents also wrote in other languages they

spoke, including Bengali, Tamil, Mathali, Nepali, and Telugu. Some of parents had less than a 4-year college degree (22.5%), 14.3% had a 4-year college education, and 32.7% had an advanced degree. Finally, 14.2% of parents indicated an annual household income of less than \$50,000, 22.4% reported an income between \$50,000 to \$100,000 and 26.6% reported an income above \$100,000.

I selected the same participants who responded to the survey to participate in the interviews using nested sampling (Creamer, 2018). The survey asked participants if they would like to participate in additional research regarding transition planning, and if they were interested, they were asked to provide an email address. Twenty-six South Asian parents initially indicated an interest for participating in additional studies on the survey, however upon sending them a follow-up email regarding interviews, eight parents indicated their interest. A year after the surveys were administered, I conducted follow up interviews with those eight parents, including six mothers and two fathers. All children had a diagnosis of autism, along with other multiple disabilities. The ages of their children ranged from six years old to 22 years old. Specifically, six parents had transition-aged children (between the ages of 14 and 22), while one parent had a child who was six years old and another who had a child who was eight. Parents spoke the following languages: English (n = 5), Urdu (n = 1), Nepali (n = 1), and Mathali (n = 1). A small number of parents had no religious affiliation (n = 3), while others included Islam (n =2) and Hinduism (n=3). Parents' professions ranged from homemaker (n=2), physician (n=2), professor (n = 1), educator (n = 1), and massage therapist (n = 1).

#### 2.2.3. Data Collection

#### 2.2.3.1. Quantitative

The full survey consisted of four sections with 35 total questions (Shikarpurya et. al., under review). The full survey development process could be made available from (Shikarpurya et al., under review).

## 2.2.3.1.1. Survey Instrument

I conducted a culturally adapted replication of the transition survey created by Blustein and colleagues (2016) to explore the experiences of minoritized families navigating transition planning. The full adapted survey that was administered to participants included seven sections with 35 questions related to (a) knowledge of school-based transition topics, (b) parent involvement in transition planning, (c) knowledge of community-based transition resources, (d) knowledge of adult service systems, (e) parent needs, (f) parent expectations, and (g) parent challenges or adversities. I also asked survey questions related to parent and child demographics. This study only explored the survey section related to parent adversities.

I culturally adapted the transition survey in three phases. First, I reviewed the original survey questions and reexamined its relevance for minoritized families. For instance, I added more questions about independent living skills when living at home, volunteer opportunities in the community, and faith-based community support to offer more culturally relevant options. Second, I simplified the language used from the original survey instrument by replacing "transition planning" with "future planning/planning for the future." I decided to reduce academic jargon to better capture the realities of parents navigating transition planning.

Third, I translated the survey from English to Hindi. I also asked three South Asian parent advocates who were fluent in Hindi to review the survey for consistency and clarity. The

parent advocates identified as a parent of a child with a disability and knew the researchers through personal and professional connections. They suggested linguistic changes to add further clarity for families. Upon revisions, I piloted the survey with three additional South Asian parents who expressed satisfaction with completing the survey. The complete online survey was available in English and Hindi. I also offered an incentive of a \$10 Amazon gift card to four parents in a randomly selected drawing upon the completion of the survey. The parents could indicate at the end of the survey if they wished to participate in the drawing by providing an email address.

## 2.2.3.1.2. Parent Demographics

I asked parents to indicate their demographics like their age, sex, household income, marital status, occupation, level of education, and their race. I also asked culturally responsive demographic questions such as their country of birth, the amount of time they have lived in the United States (e.g., ranging from under one year to living in the U.S to their entire lives), their level of comfort with speaking English (e.g., ranging from none to extremely comfortable), the language they speak most often at home, and their religious affiliation. I also asked parents to provide their zip code to understand the national diversity of participants. Parents also had the opportunity to recommend an organization that we could contact for the survey.

#### 2.2.3.1.3. Parent Adversities

Although the survey had multiple sections, the analysis for the present study focuses specifically on the section related to parent adversities. Parents rated 14 items on a five point Likert-type scale (1= 0% never, 2 = rarely, less than 10% of the time, 3 = sometimes, around 50% of the time, 4 =usually, over 70% of the time, 5 = every time, 100%) to indicate how often they experienced adversities or challenges when navigating services of their children (Table 2).

Survey items ranged widely, including knowledge-based adversities (e.g., little knowledge of employment opportunities), personal or societal adversities (e.g., financial, little support from family members, stigma or taboo), and advocacy related adversities (e.g., my voice not being heard or difference between home and school values). Cronbach's alpha for this survey item was  $\alpha = 0.88$ , which indicated strong internal consistency among the items in this section.

#### 2.2.3.2. Qualitative

I used nested sampling to recruit interview participants (Creamer, 2018). I contacted 23 parents who indicated on the survey that they are interested in being contacted for additional research opportunities related to this study. Of the 23 parents, eight agreed to participate in the interviews. I conducted semi-structured interviews on Zoom for an hour and transcribed the interviews using the Trint software (https://trint.com/). All the interviews were conducted in English, except one which was conducted in both English and Hindi. I developed the interview protocol using the framework of motivational interviewing (Rollnick & Miller, 1995) as a strengths-based approach to interviewing. The interview protocol included two sections, including the first section asking questions about the child (e.g., what are some services your child receives in school related to planning for their future after high school?) and the second about the parent experiences (e.g., what has been your experience with navigating future planning services for your child?). The protocol included a total of 10 questions. I also translated responses that were in Hindi into English for transcription. All interview participants received a \$15 Amazon gift card in appreciation of their time

# 2.2.4. Data Analysis

#### 2.2.4.1. Quantitative Data Analysis

I exported survey responses into IBM SPSS for analysis. I used the SPSS software because of its ease of use and clarity of results. I calculated descriptive statistics to determine the characteristics of the challenges experienced by parents to answer the first research question. Descriptive characteristics included the means, standard deviation, and frequencies (Table 3). Descriptive characteristics provided information about the participants, including their demographics and how they responded to each item. I also measured correlations to examine the strength of the relationship between parent demographic characteristics and the challenges parents experience when navigating transition services for their children (Table 3). I dichotomized the following variables for ease of calculations: religious affiliation (0 = no religious affiliation, 1 = various religious affiliations), primary language spoken at home (1 = English, 2= any other languages besides English), and marital status (0= various relationship status, 1 = married).

I used Spearman rank correlation coefficient to measure the strength of the relationship among the ordinal survey items (Glasser et al., 1961). These items included the adversities experienced by parents and the following demographic items: parents' age, years they have lived in the United States, their comfort levels with speaking English, and their income. I also used a rank biserial correlation to calculate the strength of the relationship between dichotomous and ordinal variables (Wilson, 1976). I used the following demographic items to measure the strength of the relationship between parents' demographic characteristics and the frequency of adversities they have experienced: parents' sex, marital status, religious affiliation, and the primary language spoken at home. I measured the magnitude of the strength of the relationship using

guidelines provided by Cohen (1988), where in psychology and educational research, 0.1 is considered a weak relationship, 0.3 is considered a moderately strong relationship, and 0.5 is considered a strong relationship. I formed the following three hypotheses:

<u>Hypothesis 1</u>: I expect that all parents have faced all of the challenges listed in the survey items over 10% or more of the time.

Hypothesis 1: I expect a negative relationship between parents' level of education and the frequency of challenges they experienced related to the four domains of transition-planning knowledge. For instance, as parents' level of education increases, the frequency of challenges they face related to knowledge of transition planning, employment, college, and knowledge of special education would decrease.

Hypothesis 2: I expect a negative relationship between parents' comfort with English and (a) the frequency of linguistic challenges they experience and (b) the frequency of times others help them access services. For example, as parents' comfort with English decreases, the frequency of challenges related to linguistic barriers and having others help them navigate services would increase.

Hypothesis 3: I expect a negative relationship between parents who speak a language other than English at home and (1) the frequency of knowledge-related challenges they encounter and the (2) frequency of challenges they experience related to the difference between home and school values.

### 2.2.4.2. Qualitative Data Analysis

I used a deductive approach to analyze the interview responses using pre-existing themes from the framework of community cultural wealth (Gale et al., 2013). I chose a deductive approach to expand the field's understanding of strengths-based capital South Asian parents

carry and offer a *counterstory* to the deficit-based perspectives typically associated with racialized families. Deductive analysis is typically used to match codes derived from interviews to a theory or framework to examine practical or realistic implications (Braun & Clarke, 2006). I followed the guidelines of deductive analysis by Pearse (2019) to analyze the interviews using the CCW framework. The steps included: (1) forming a conceptual framework (e.g., CCW), (2) developing propositions, or hypotheses based on the theoretical framework to understand one's own biases and knowledge of the context (e.g., I proposed that the parents would use their linguistic and familial capital to navigate services), (3) establishing a codebook, including labels, definitions, descriptions, inclusion, and exclusion criteria (e.g., my codebook included all six forms of capital), (4) developing question matrix to match questions with the theories for alignment (e.g., I matched each question to whether or not it related to strengths and forms of capital), (5) collecting data (e.g., interviews), and (6) analyzing the data (e.g., using the codebook to match responses and revise as needed). The coding team included me and two additional doctoral students in special education. Once I created the propositions, the codebook, and the question matrix, I trained the coding team on the CCW framework. I used Dedoose to code our transcripts (Dedoose, 2008).

First, the coding team coded the first transcript together to categorize the interview responses and pair the codes to the CCW framework. I also established a category for emerging or new codes found in the interviews that did not exist within the theoretical framework. Next, the coding team members coded the second transcript independently and met for consensus. The coding team coded two additional randomized transcripts independently and met for consensus each week until all eight transcripts were coded. The coding team discussed discrepancies by explaining the codes and negotiating where each code fit within the transcript. If consensus could

not be reached among all the members of the coding team, I made the final decision. I established trustworthiness through data triangulation among multiple coding team members and by conducting member checks with participants (Corbin & Strauss, 2015).

For the member checks, I developed a table of the parent strengths derived from the interviews and emailed it to all the participants. In the email, I asked the participants to share their thoughts on the extent to which the findings reflected their experiences based on the consistency of the findings, its clarity, cohesion, and comprehensiveness. All these terms were defined for the participants, and they were asked to indicate their feedback on an online survey. Participants were also asked to indicate on the member checks survey if they were aware of these strengths prior to reviewing the findings. I also included a question to ask if they identified as racially minoritized. The definition of racially minoritized was offered to the parents in the form, and they were asked to indicate if they felt they fit that category (e.g., As a South Asian, do you identify as someone who belongs to a racially minoritized group or identifies as racially minoritized? Racially minoritized means belonging to a racial group that has been systematically held as "lesser' than or subordinate to the dominant group in society, either by societal rules, systemic structures, or the behavior of individuals.) This question was asked to capture whether the participants saw themselves as racially minoritized to inform how they were identified in the study. I asked this during member checks to learn more about how the parents identified themselves, without adding a predetermined label to their voices and experiences.

Parents had two weeks to respond to the member checks form, and half of the parents responded with their feedback. All the parents who responded indicated their satisfaction with the findings and did not provide any additional feedback regarding the findings. All the parents also identified as racially minoritized on the member check survey. In addition to the member

checks, I also established trustworthiness by keeping a journal of my experiences, and noted my interpretations, biases, and hypotheses throughout the data analysis process. I also maintained a journal with information about the coding process and documented the data analysis discussions for future replicability.

## 2.2.4.3. Blended Analysis

I integrated quantitative and qualitative data using blended analysis (Creamer, 2018). Specifically, I combined the descriptive and correlational statistics, such as the means, standard deviations, and magnitude of relationship strength, with the themes generated during the interview phase. This process occurred in three stages. The first stage included capturing the data side by side to identify themes and trends among the two phases. The second stage involved consolidating the adversities experienced by parents into three overarching categories and identifying the strengths parents leveraged to overcome the adversity for each challenge item. For instance, the survey items related to stigma or taboo, family support, religious/faith-based support, and financial challenges was categorized as "limited capacities of internal and external supports." For this theme, strengths were identified along with the counterstories (i.e., quotes) of parents. In the third stage, I mixed the quantitative and qualitative findings to form a blended variable/theme that combined the findings from the prior stages into a meaningful point of analysis. Lastly, in the fourth stage, I combined the blended findings from the previous stage to develop a meta-inference to inform how South Asian parents leverage their community cultural wealth to overcome adversities within the transition planning process (Tashakkori & Teddlie, 2008).

#### 2.3. Results

#### 2.3.1. Quantitative Findings

How Often do South Asian Families Encounter Adversities When Accessing Transition

Planning Services?

I calculated descriptive statistics (i.e., mean, and standard deviations) using the SPSS software to answer the first quantitative research question (Table 3). While all parents experienced some adversities, the frequency of such occurrences varied. On a scale of 1-5 (1 = never, 0% of the time, 5 = every time, 100%), parents reported that they most often faced the challenge of not knowing what their child will do once they are no longer there to care for them (Table 3; M = 3.86). Specifically, 51.1% of parents indicated that they experienced this challenge more than 70% of the time. In addition, parents also reported that they often faced adversities related to receiving little support from religious or community services (M = 3.30).

I found parents most often experienced adversities that were related to both knowledge and advocacy. Parents most often faced the following knowledge-based challenges: little knowledge of future planning (M = 3.03, SD = 1.36)), little knowledge of college or higher education opportunities (M = 3.01, SD = 1.48), little knowledge of employment opportunities (M = 2.97, SD = 1.48), and little knowledge of the special education system (M = 2.82, SD = 1.40). Additionally, 46.9% of parents reported that they were not being heard by the school, administrators, or other support personnel 50% or more of the time (M = 3.01, SD = 1.26).

Parents reported that they experienced linguistic challenges the least often among all the survey items (M = 2.09). However, it is important to note that parents still experienced this adversity around 10% or more of the time when navigating services for their child. About one-third (33%) of parents also indicated that other individuals help them access services over 50%

of the time (M = 2.57). Using written responses, parents reported that these individuals include older children, friends, social networks, agencies, and other community members. Parents were also offered an opportunity to write other challenges not provided on the survey. Parents indicated a multitude of additional adversities, including access to respite services or care, navigating the realms of finding a job for their young adult, and being stereotyped by physicians and other professionals using archaic information.

What Is the Relationship Between Parent Demographics and How Often They Encounter

Adversities When Accessing Transition Planning Services?

I calculated Spearman's correlation and rank biserial correlation using the SPSS software to measure a linear relationship between parent demographics and the frequency of adversities they experienced (Table 3). If a relationship was found, I calculated the magnitude of that relationship using the following guidelines for r (0.1 = small effect, 0.3 = moderate effect, 0.5 = large effect; Cohen, 1988).

#### Hypothesis 1:

According to Spearman's rank correlation, as parents' level of education increases, parent challenges related to knowledge of future planning (r(30) = -.580, p < .05) decreases. The relationship was negative, strong, and statistically significant. Additionally, as parents' level of education increases, parent challenges related to knowledge of special education systems (r(31) = -.429, p < .05) decreases. The relationship was negative, moderately strong, and statistically significant. I also found that as parents' level of education increases, parent challenges related to language barriers (r(31) = -.613, p < .05) decreases. The relationship was negative, strong, and statistically significant. There was no significant relationship found between parents' level of

education and adversities related to knowledge of employment opportunities and knowledge of college or higher education opportunities.

Additionally, I also found statistically significant relationships between parents' income and the frequency of adversities they encountered. Based on the calculations using Spearman's rank correlation, there is a strong negative relationship between parents' income and the financial adversities they encountered (r(29) = -.574, p < .05), and with receiving little support from family members (r(29) = -.551, p < .05). As parents' income increases, their financial challenges and the support from family members decreases.

Spearman's rank correlations also identified key relationships between demographic characteristics such as parents' comfort with English, their income, and their educational attainment with the adversity of differences between home and school values. Specifically, there was a negative, moderately strong relationship between parents' comfort with English and how often they experienced differences between home and school values (r(31) = -.381, p < .05). There was also a negative, moderately strong relationship between parents' income and the adversities related to differences between home and school values. Lastly, there was a strong, negative relationship between parents' level of education and the extent to which they faced differences between home and school values.

## Hypothesis 2:

According to Spearman's rank correlation, as parents' comfort with English decreases, parent challenges related to language barriers (r(31) = -.523, p < .05) increases. The relationship was negative, strong, and statistically significant. Furthermore, as parents' comfort with English decreases, parents' reliance on the support of others to navigate services increases (r(27) = -.414, p < .05). The relationship was negative, moderately strong, and statistically significant.

Additionally, I found that as parents' comfort with English decreases, the frequency of their challenges with knowledge about future planning (r(30) = -.534, p < .05) and knowledge about the special education systems (r(31) = -.400, p < .05) increases. Both relationships are negative, moderate to strong, and statistically significant. There was also a negative, moderately strong relationship between parents' comfort with English and the adversities they faced related to financial barriers (r(31) = -.405, p < .05) and family support. (r(31) = -.461, p < .05). Hypothesis 3:

According to the rank biserial correlation, there is a strong negative relationship between parents who speak a language other than English at home and the frequency of challenges they encounter with having little knowledge of future planning (r(30) = -.549, p < .05). There was no relationship found between parents who speak a language other than English at home and the challenges they experience related to the difference between home and school values. Rank biserial correlation also identified a moderately strong, negative relationship between parents' marital status and financial barriers (r(31) = -.415, p < .05).

While the above results indicate significant correlations among parents' demographic characteristics and the frequency of adversities they experienced, the following key non-significant correlations also reveal important findings. First, while parents reported that two of their most frequent adversities include not knowing what their child will do after they are no longer there and not having a voice, those items were not correlated with any parent demographics. Second, although over 65% of parents indicated a religious affiliation, it was not significantly correlated with adversities related to religious support. Lastly, despite parents reporting high frequency of experiencing stigma or taboo (M = 2.83), these findings were not

correlated with any demographic characteristics. The reasons for non-significant findings could be twofold, including a smaller sample size and the presence of no real effect.

#### 2.3.2. Qualitative Findings

What Types of Community Cultural Wealth Do South Asian Families Draw Upon When Navigating the Transition Planning Process?

I used the framework of CCW to deductively analyze the interview transcripts. Two graduate students and I coded all transcripts using the definitions of the original six categories of CCW: Navigational capital (e.g., navigational capital refers to skills of maneuvering through social institutions. Historically, this infers the ability to maneuver through institutions not created with communities of color in mind), aspirational capital (e.g., the ability to maintain hopes and dreams for the future, even in the face of real and perceived barriers), resistant capital (e.g., knowledge and skills fostered through oppositional behavior that challenges inequality), social capital (networks of people and community resources that can provide both instrumental and emotional support to navigate through society's institutions), familial capital (cultural knowledges nurtured among family (kin) that carry a sense of community history, memory and cultural intuitions), and linguistic capital (the intellectual and social skills attained through communication experiences in more than one language and/or style). I further extended the original six categories of CCW into additional sub-categories based on the analysis of parent interviews. All parent voices have been provided a pseudonym to protect their identities.

# 2.3.2.1. Navigational Capital

Navigational capital was defined as the strength of parents to navigate or maneuver through special education organizations, agencies, laws, and systems. Navigational capital was the most often reported among South Asian parents when discussing their experiences with

transition planning. Parents reported various strengths within this domain, such as: (a) familiarity with language (e.g., knowing or accessing the language or jargon related to special education; occurred 62 times in transcripts), (b) navigating formal structures (i.e., IEP meetings, service systems, therapy clinics, etc.; occurred 54 times in transcripts), (c) navigating informal structures (i.e., online parent groups, informal organizations, parent trainings, etc.; occurred six times in transcripts), and (d) research avenues (navigating the realm of research to understand and access services; occurred 19 times in transcripts).

While discussing their experiences with navigating transition to adulthood, parents articulated specific words and phrases related to special education system while acknowledging that they didn't know enough about navigating this process. We identified their knowledge of these terms, such as IEP, due process, transition services, day programs, vocational training, IEP goals, and self-contained classes as sources of strength that accompanied their navigational capital. While interviewing parents, I also noted that they extensively described how they navigated online research to distill information that furthered their understanding of specific services for their child. For instance, Saima, a mother stated, "I always wanted my daughter to have [Applied Behavioral Analysis] therapy. Since we were not citizens when she was younger, ABA was not covered by insurance. So, I became very active in researching and finding services for her online. I had to find a way."

Parents described various ways in which they navigated the rules and structures related to both formal and informal organizations. This was not commonly available knowledge, but something they had learned from their interactions with these organizations. I identified the use of this hidden curriculum to be a source of strength that the parents developed. For instance, Puja recounted the manner in which she communicated with the IEP team and the processes involved

by sharing, "I could pick up the phone or I could email [the IEP team] and they would answer my questions. At the pre-IEP meeting, they would give me a rough draft of whatever was proposed for him, so I knew what was coming." In another instance, Sameer, a father, shared their struggles with finding services for their child when the school disagreed with their goals by stating, "My son needed more services. Instead of going into battle with [the school] we just spent a lot of time ourselves and figured out when services were available how to get it. It was financially really hard because insurance wouldn't cover it. But you know if it is possible, that's what you need to do."

## 2.3.2.2. Aspirational Capital

I defined aspirational capital as the parents' ability to articulate their hopes, dreams, and visions for the future, even in the face of systemic adversities. All parents described having aspirational capital. Parents discussed aspirational capital in two ways: aspirations for themselves and aspirations for their children. Parents described aspirations for themselves that were related to their personal development, such as increasing their financial stability, gaining more knowledge, staying on top of the current research, and advocating for their child. All parents discussed in great detail about their desire to get additional training for supporting their child's transition to adulthood. For instance, Urvi stated, "I do not know a lot of details about ADA, so now I have to know more about that. I took the basic trainings, but I need to go get that specific information. That way, he [the son] will know what to advocate for and if he's working, what kind of accommodation he can have. That is my next goal: to learn, and then teach him."

The parent desired to learn more information for personal development to then be able to support their child once he ages out of the school system. In addition, parents also described maintaining aspirations for external development, which was related to educating their

community, sharing their knowledge with others, and expanding their resources to support other families. For example, Aisha shared her vision of creating a South Asian focused community center for adults with disabilities to help them thrive after high school. She stated, "My whole goal is to create a community for our kids. We need a space where they can live independently and receive support that understands their culture." Despite encountering multiple adversities, parents maintained their visions of not just furthering their own personal development, but also expanding their resources to support the larger communities to which they belong.

Parents widely discussed their hopes and dreams for their children. I found multiple sub categories in parents' visions for their children, including (a) the desires for their child to be actively participating in meaningful activities and not being idle at home, (b) having a secure place for their adult child to live and thrive regardless of it being with the family, (c) hopes for the child to have a sense of belonging in the community, in the family, or through relationships (i.e., marriage or children), and (d) high hopes of their child's overall well-being, including their happiness, being loved by others outside the family, and feeling that they are contributing towards society. Parents also shared that while they maintained high hopes for their child, the path towards achieving those dreams was extremely complex, unpredictable, and unpaved. For instance, Saima described the complex relationship of maintain high hopes and living with the realities of today by stating, "My goal is to teach her [the daughter] enough self-help skills that once I'm not here, she's at least capable of taking care of herself, so she's not a burden on the family. But I know she cannot hold a job. I am still figuring it out. I'm preparing myself for when she will stay home. If I myself am mentally ready for her to be home and finding ways to not exhaust myself."

### 2.3.2.3. Resistant Capital

Resistant capital describes forms of advocacy that challenge the status quo, including behaviors that show resistance to structures/organizations to fight for more equitable and just outcomes for their children. Parents specifically discussed two types of resistant capital, notably resistance towards personal factors (e.g., cultural values, upbringing, going against what you once believed) and towards organizational structures (e.g., schools, organizations, communities, etc.). Parents shared that while navigating service systems for their children, they had to resist or let go of the beliefs they had come into the country with to be better advocates for their children. For instance, Alina explained, "I had the mindset, the typical "desi" [refers to individuals from India/Pakistan] mindset that he [the son] is in American schools, everything will be okay. It will be better than India or Pakistan." The parent resisted their own personal beliefs regarding the ideal of the American school system to achieve equitable opportunities for her son. This parent also discussed shifting her mindset towards playing a more active role as a parent (e.g., saying what she wanted rather than expecting the teacher to bring it up). In another instance, Puja described her personal resistance with grappling with their child's diagnosis and the special education label. She stated, "Well, you have to understand that we come from zero knowledge of all of this, right? I mean, when you grow up in a South Asian community, most of those special needs kids are hidden away. You've never seen anyone. They don't ever go to school. When we were in school, we literally had no special needs kids there." Her moments of personal resistance meant deviating from the negative attitudes regarding disability and moving towards redefining what that experience was like for her.

Parents also displayed acts of resistance when interacting with organizations, such as schools, clinics, university centers, and the adult service system. However, it was clear from the

interviews that most parents learned to resist along the way based on how they were treated by the special education structures. For instance, Sameer stated, "Scheduling IEP meeting to me is my right. I look at it as my right to be for them [the IEP team] to reach out to me, to ask about my availability to schedule these meetings. Sometimes that doesn't happen. If a right is taken away from you enough, then eventually you become more able to speak up." This parent also described his dilemma of choosing his acts of resistance, as to not negatively affect the support his child is receiving.

#### 2.3.2.4. Social Capital

Social capital was defined as networks of people, including friends, community members, and other peers who served as sources of support for parents. I found that all parents identified at least one social support, with one parent describing over eight different sources of social capital. Parents found strength and support from disability-specific organizations (e.g., Down syndrome association, autism associations). local or community-based organizations (e.g., Family to family in Texas), faith-based organizations, when connecting with other parents during trainings or workshops led by community organizations, friendships through social activities their children engaged in (e.g., all the children played baseball together or competed in dance), by joining online parent groups on social media, and among their co-workers or colleagues. Parents also described a domino effect of increasing their social capital, as one community member may connect them with another and so on. Once they took the leap to join an organization or a group, their social capital continued to expand.

Furthermore, one parent had taken the initiative to create her own parent support group for families who identified as South Asian living in Houston, Texas. She had met these parents through multiple trainings and had decided to create a space for them to share information,

resources, and stay connected. Parents had not only found various avenues of social support, but they also continued to develop more opportunities for others in the community to remain connected. For instance, Rima shared the importance of staying connected with a social community, stating, "Even if there is just one person who can give you a little bit of advice or a little bit of understanding, it matters a lot." Overall, parents had developed strong social capital in their communities to better help them navigate their individual and collective journeys.

## 2.3.2.5. Familial and linguistic Capital

The last two areas of strength, familial and linguistic capital, were the least discussed by parents. Familial capital was defined as being connected with immediate or extended family, shared knowledge passed down by family, having support from family members, or describing the role of families in their lives. Only half of the parents described instances related to family strength or family presence. For instance, Sarah shared that while her family didn't actively support her, they did not encourage her either to seek services for her daughter. She stated, "Family was never in my way. They were always supportive. But there were moments here and there that I had to convince everyone to get on board and make them understand that fighting for ABA services was worth it. They were okay with giving me my space. I would say they were not involved in it." Another parent mentioned that one of her cousins also had a child with a disability, so connecting with her on a familial and social level was important for her. Other parents mentioned the role of older siblings in serving as sources of support for them and relying on their spouses for familial support. However, parents did not mention any immediate or direct support provided by family members.

Linguistic capital was defined as skills attained by family members by communicating in a language other than English. This included seeking translators, developing strong relationships

with others who are multilingual, and seeking services in multiple languages. This form of strength was discussed the least by parents. One parent mentioned the gift of teaching their child in two languages (e.g., English and Urdu), while also acknowledging the challenges associated with receiving speech therapy in both. Another parent reported that she spoke three languages, which I noted as a sign of strength.

## 2.3.3. Blended Findings and Meta-Inferences

How Do South Asian Parents Leverage Their Community Cultural Wealth to Overcome

Adversities When Navigating the Transition Planning Process?

I combined the quantitative findings (survey) with the qualitative findings (interviews) using blended analysis to form a meta-inference. The mixed findings resulted in three blended variables (Table 4; Figure 1). First, I found that although parents faced adversities related to knowledge of transition planning and access to transition planning resources, they relied on their strengths to seek information from resources outside of the school and maintained high aspirations for themselves. Although parents indicated they experienced multiple challenges with key aspects of transition planning (e.g., employment, higher education, linguistic challenges, etc.), they used their aspirational capital, social capital, and navigational capital as armors of resilience when facing systemic adversities.

Second, parents used their resistant and navigational capital to provide equitable opportunities for their child despite facing adversities with being heard by service providers, schools, practitioners, and other stakeholders. Parents expressed that they did not have a voice when speaking with stakeholders or making decisions for their child, yet they leveraged their strengths to continue fight the system, in whichever manner they could. I also noted that regardless of being immigrants or being born in the United States, the special education system,

including knowledge of parent rights, was a novel system for them. While parents advocated by resisting and navigating the system using special education terminology, they did not know what to advocate for and the path towards getting their voices heard.

Third, while parents indicated limited capacities of internal and external support, they leveraged multiple areas of strengths, including social capital and resistant capital, to create and nurture support systems around them. Specifically, parents indicated that they faced adversities related to receiving familial support, support from religious organizations/community members, finances, and encounter stigma/taboo when navigating services. As a result, parents created their own *chosen* families using their social capital and expanded their support systems. Parents also used their resistant capital and social capital to offer resources to other families, thereby not only expanding their own supports but ensuring that others within their communities are also well supported.

I combined the three blended variables to create a meta-inference (Figure 1). First, parents used outside resources to gain knowledge and maintain high hopes despite facing adversities. Second, parents are empowered, and they know how to advocate, however they don't know what to advocate for. The system is an unfamiliar territory. Third, parents have developed chosen families and lookout for one another. As a result, the meta-inference concludes: Parents have developed community cultural wealth to get in the door to manage systemic adversities, but not enough to overcome overall adversities. A parent-professional partnership built on equity, parent strengths, and culturally affirming practices is needed to support parents in overcoming systemic adversities (Table 4).

#### 2.4. Discussion

The purpose of this study was to (a) explore systemic adversities South Asian families face in the transition planning process, (b) identify types of CCW they draw upon, and (c) examine how they overcome systemic adversities using their CCW when navigating transition to adulthood. Overall, this study presents a novel application of mixed methods to reframe and redefine the prevailing narrative that portrays racially minoritized families only in context of the challenges they experience and systemic oppression they overcome. As such, my findings offer several significant insights to strengthen the transition planning process for South Asian parents as well as for other racially minoritized families of children with disabilities.

### 2.4.1. Reframing Parent Narratives

First, my findings add the specific experiences of South Asian families to the growing transition literature on systemic adversities racially minoritized parent face when navigating the transition planning process (Lo & Bui, 2021; Wilt & Morningstar, 2018). Additionally, my blended findings extend the literature toward identifying strengths, particularly resistant, social, navigational, and aspirational strengths, that South Asian parents leverage to navigate the complexities of transition planning. I posit that parent challenges should be reframed within the context of parent strengths to fully examine the complexities of navigating the transition planning process. Additionally, intentional reframing of parent narratives using strengths-based frameworks advances the language used to explore paradigms related to parent involvement, parent advocacy, and parent partnerships. Specifically, research that continues to reframe the experiences of racially minoritized families of students with disabilities through counterstories of strength and resilience will ultimately expand the narrow scope of parent engagement that currently prevails within special education.

### 2.4.2. Redefining Parent Agency

Second, my findings offer important insights regarding the power and potential of parent voices in the transition process. The quantitative findings emphasized systemic and racialized barriers to advocacy for South Asian parents, which aligns with the experiences of Black (Scott et al., 2021), Latino/a/x (Povenmire-Kirk et al., 2010), and Chinese and Vietnamese parents examined in prior transition literature (Lo & Bui, 2020). However, my blended findings differed from prior literature on advocacy (Burke et al., 2018) by shifting the burden of advocacy from parents to the system. Shifting the dialogue from advocacy to agency emphasizes systemic adversities that govern the extent to which parents are able to voice their concerns. I found that South Asian parents do advocate using their resistant and navigational capital; however, they have less agency due to structural racism and limited knowledge of the culture of advocacy in special education, which is particularly derived from a white, middle-class, individualistic oriented culture. My findings indicate that South Asian parents continue to advocate within the context of their own cultural norms and values, however, their advocacy goes unseen. These experiences emphasize a need to shift away from traditional, white, western-oriented standards of advocacy toward redefining agency and advocacy for South Asian families and students to promote transition planning that align with the student and family's desires, goals, and cultural values.

# 2.4.3. Reshaping Parent Supports

Third, my findings revealed limited capacities of internal and external support systems for South Asian parents of students with disabilities in transition, thereby affirming prior literature on limited faith-based supports (Shikarpurya & Singh, 2021) and ongoing stigma from families among South Asian parents (John et al., 2016). However, my blended findings found

that South Asian parents developed *chosen* families to navigate the complex and uncharted territory of transition to adulthood. Notably, immigrant families build strong social communities outside of their immediate families as pillars of "familial," chosen support systems (Gates, 2017). Additionally, my findings affirmed parents' resilience in expanding their organizational processes toward strengthening their familial supports using chosen families (Walsh, 2015). Thus, I interpret chosen families as a strength, and posit that parent supports should reflect chosen families as part of their systems of support.

#### 2.4.4. Limitations and Implications for Future Research

Although the blended findings offer promising insight to reshape the transition planning experiences of South Asian parents using a strengths-based lens, there are several limitations that present opportunities for future research. First, the findings from this study may not be representative of the experiences of a broader sample of South Asian families of students with disabilities. Specifically, my sample size was modest for both the quantitative (N = 48) and qualitative (N = 8) strands. Additionally, while I aimed to recruit parents across a diverse range of demographic characteristics, most of the parents in this study were homogenous. For instance, they largely held college degrees, had higher incomes than the national average, and primarily communicated in English. Future researchers could aim to conduct broader recruitment across the country to capture a more varied sample.

Second, future research could benefit from further disaggregating racial/ethnic collective labels (i.e., South Asian). For instance, the transition planning experiences among immigrant and non-immigrant South Asian parents could offer further insight to their unique challenges and strengths. Although this study centered on the experiences of parents, youth perspectives are also crucial to improving their adulthood outcomes. Future research could integrate multiple

perspectives, including those of the parents, young adults with disabilities, their chosen families, and community members to capture the systemic adversities they face and the capital they use to navigate those barriers.

Third, since the survey questions related to systemic challenges were already pre-defined, parents could have experienced additional challenges that were beyond the scope of this study. Similarly, parent strengths were also defined within the context of the CCW framework, limiting parents' own expression of their strengths. Future researchers could conduct additional qualitative studies that offer parents the agency to define their challenges and strengths without a prior framework or guidelines. Particularly, their defined strengths could also lead to the development of an additional strengths-based framework for various disaggregated populations or an expansion the current CCW framework.

## 2.4.5. Implications for Practice

This study also offers significant insights for transition practitioners and other key stakeholders to advance the adulthood outcomes of South Asian youth with disabilities and their families. First, teachers and transition specialists could recognize the strengths identified in this study (e.g., navigational capital, resistant capital, social capital) within their transition assessments, transition plans, and within the language they use when communicating with parents. For example, parents' navigational capital could be affirmed by educators when beginning the transition planning meeting (e.g., "I applaud how you have navigated the complex transition planning process so far"). Second, parent training centers, national organizations, and other community stakeholders who inform and train parents could also integrate parents' strengths when connecting them with adult service systems and offering to show them what the next steps may look like. This study highlighted a need to not just increase their knowledge but

to also equip parents with the tools to navigate the adult service system. For instance, these stakeholders could provide a list of questions to ask when speaking to a coordinator at vocational rehabilitation or conduct a mock meeting where parents could practice their advocacy skills.

Third, the findings of this study underscore the vast social connections parents rely upon to navigate transition to adulthood. Therefore, adult service agencies could offer parents more opportunities to connect with affinity groups (e.g., parents from the same culture or with shared experiences) and strengthen parent mentoring relationships to reduce systemic challenges within the transition planning process. Fourth, parents voiced a strong concern for not being heard by professionals. All practioners could increase equity-based partnerships between themselves and the parents by co-planning and using family centered approaches in the transition process.

Finally, racially minoritized youth and their families could apply the findings of this study toward reframing their involvement and outcomes using language that recognizes their strengths and resilience, particularly when navigating the transition process and adult service system. Additionally, parents' strengths could inform partnerships with researchers and practioners to expand community-driven, strengths-based opportunities to advance adulthood outcomes for this population.

#### 2.5. Conclusion

This study used a mixed methods design to examine the systemic adversities South Asian parents faced and the strengths they leveraged to navigate the transition planning process. I found that parents experienced multiple systemic adversities as they navigate the transition planning process. However, they also developed significant strength and resilience to navigate those adversities. Using a meta-inference, I concluded that a parent-professional partnership using equity and community-driven practices is necessary to support parents and increase their

inherent and developed strengths for a successful transition to adulthood. My findings identify, affirm, and promote the strength and resilience of South Asian parents and seek to advance strengths-based and equity-driven parent-professional partnerships in transition

# 2.6. Tables

**Table 1. Explanatory Sequential Design Mixing Procedures** 

Procedure: Interview questions were developed and piloted.  Product: A list of interview questions.
were developed and piloted.  Product: A list of interview
and piloted.  Product: A list of interview
interview
interview
Procedure:
Interviewed
participants from those who
completed the
online survey.
<b>Product</b> : 8 participants were interviewed.
<b>Procedure</b> :
Interviews were
transcribed and
analyzed using a
deductive
approach.
Product:
Community
Cultural Wealth
framework was
used to code the transcripts.

 Table 1. Continued.

Step	<b>Quantitative Strand</b>	Mixing Strand	<b>Qualitative Strand</b>
Results	Procedure: Identified	Procedure: Blended findings	Procedure:
	frequency of challenges	were further distilled to	Identified
	and the strength of correlation with	capture the larger findings.	community cultural wealth of South
	demographic factors.	<b>Product</b> : Meta-inferences were formed using the blended	Asian parents.
	<b>Product</b> : Descriptive and correlation statistics was used to answer the research questions.	findings.	<b>Product</b> : Findings resulted in multiple capital parents use to navigate systemic challenges.

**Table 2. Parent and Child Demographics** 

Parent and Child Characteristics	N	%
Parent		
Age		
18-34	4	8.2
35-54	24	48.9
55-84	5	10.1
Relationship to child		
Mother	37	75.5
Father	7	14.3
Other Relative	2	4.1
Years lived in US	34	2.500
Over 20 years	16	32.7
15-20 years	7	14.3
10-15 years	5	10.2
1-5 years	1	2.0
I have lived in the US my whole life	5	10.2
Comfort with English		
Extremely comfortable- I am fluent	22	44.9
I am very comfortable	8	16.3
I am still learning English, so I am somewhat comfortable	3	6.1
Very little comfortable	1	2.0
Primary language spoken at home		
English	15	30.6
Urdu	6	12.2
Hindi	4	8.2
Gujrati	2	4.1
Other	7	14.3
Marital status		
Married	30	61.2
Widowed	3	6.1
Never Married	1	2.0
Level of education	34	4.971
High School Graduate	4	8.2
Some College	2	4.1
2-year college degree	5	10.2
4-year college degree	7	14.3
Professional degree	12	24.5
Doctorate	4	8.2

Table 2. Continued.

Parent and Child Characteristics	N	%
Income		
Less than \$50,000	7	14.2
\$50,000-\$79,000	8	15.3
\$80,000-\$99,000	7	14.3
\$100,000-\$149,000	9	18.4
More than \$150,000	34	33.5
Religious affiliation		
Christianity	2	4.1
Islam	16	32.7
Hinduism	10	20.4
Buddhism	1	2.0
Catholicism	2	4.1
No religious affiliation	2	4.1
Other	1	2.0
Child	40	1 271
Age	48	1.271
Birth-21 22 or older	35	71.4
Sex	13	26.5
Male	29	59.2
Female	17	34.7
Child diagnosis (%)	1 /	34.7
Autism (39.7)		
Deaf Blindness (1.6)		
Deafness (1.6)		
Developmental Delay (7.9)		
Emotional Disturbance (1.6)		
Functional Delay (3.2)		
Hearing or Visual Impairment (4.8)		
Intellectual Disabilities (20.6)		
Multiple Disabilities (7.9)		
Orthopedic Impairment (1.6)		
Other Health Impairment (1.6)		
Specific Learning Disability (1.6)		
Speech or Language Impairment (4.8)		
1		

Note. Parents could choose multiple diagnoses for the child. N = 48.

Table 3. Frequency Of Adversities Experienced by Parents and Relationships with Demographic Factors.

Parent Adversities	Frequency of Adversities (%)					Sı	earman's	Rank Correl	ation	
	Never 0%	Rarely less than 10%	Some times 50%	Usually over 70%	Every time 100%	M(SD)	1	2	3	4
Not knowing what my child will do after I am no longer there.	6.1	8.2	8.2	18.4	32.7	3.86 (1.33)	- 0.085	- 0.103	- 0.042	- 0.039
Little support from religious and/or community services.	0.2	10.2	14.3	14.3	18.4	3.30 (1.43)	- 0.030	- 0.147	- 0.020	- 0.277
Little knowledge of planning for my child's future.	2.2	12.2	18.4	18.3	12.2	3.03 (1.36)	-0.580**	- 0.001	-0.534**	- 0.256
My voice not being heard individuals involved in planning for my child's future.	2.2	8.2	20.4	20.4	6.1	3.0 (1.26)	- 0.089	- 0.262	- 0.133	- 0.067
Little knowledge of college programs/higher education opportunities.	8.4	8.2	8.2	24.5	10.2	3.0 (1.48)	- 0.299	- 0.046	- 0.282	- 0.277
Little knowledge of employment opportunities.	6.3	12.2	8.2	26.5	8.2	2.97 (1.48)	- 0.146	- 0.093	- 0.203	- 0.162

 Table 3. Continued.

Parent Adversities	Frequency of Adversities (%)						Sp	earman's	Rank Correla	ation
	Never 0%	Rarely Less than 10%	Some times 50%	Usually Over 70%	Every Time 100%	M (SD)	1	2	3	4
Stigma or taboo surrounding disabilities in my family.	0.4	10.2	10.2	22.4	8.2	2.83 (1.44)	- 0.195	- 0.198	0.000	- 0.204
Little knowledge of the special education system.	8.4	8.2	20.4	12.2	10.2	2.82 (1.40)	- 0.429*	- 0.069	- 0.400*	- 0.286
Financial challenges.	6.3	14.3	18.4	16.3	6.1	2.74 (1.23)	- 0.266	- 0.183	- 0.405*	- 0.574**
Other individuals help me access services for my child.	0.4	8.2	16.35	10.2	6.1	2.57 (1.34)	- 0.314	- 0.265	- 0.414*	- 0.445*
Little support from family members.	6.5	10.2	14.3	10.2	10.2	2.54 (1.49)	- 0.223	- 0.218	- 0.464**	- 0.551**
Difference between home and school values.	0.4	18.4	18.	6.1	6.1	2.41 (1.26)	-0.516**	- 0.031	- 0.381*	- 0.359*
Language barriers	6.7	12.2	8.2	8.2	6.1	2.09 (1.39)	-0.613**	- 0.266	- 0.523**	- 0.814**

Note. \* = < 0.05, \*\* = < 0.01; 1 = level of education, 2 = years lived in United States, 3 = comfort with English, 4 = income.

# **Quantitative Theme: Parent Adversity**

# **Qualitative Theme: Parent Strengths**

# **Blended Theme/Variable**

- Lack of information and access to future planning resources
- Limited access and pathways towards information

# Survey items:

- Knowledge of special education system (M = 2.82)
- Employment (M = 2.87)
- Higher education (M = 3.00)
- Future planning (M = 3.03)
- Other individuals help to access services (M = 2.57)
- Linguistic Barriers (*M* = 2.09)

# **Aspirational Capital**

• Child

"My goal is to teach her enough self-help skills that once I'm not here. She's at least capable of taking care of herself, so she's not a burden on the family."

# **Aspirational Capital**

Oneself

"My whole goal is to create a community for our kids. That is my goal, my ultimate goal. That way, you know, our culture is different."

# Social Capital

"When he got diagnosed with autism, in the autism report, it's said in the resources [section] there was, family to family network and other resources, and I started calling them. I took lots of training from family-to-family network and partner resources, the teen project and the ARC. And whatever they suggested, I learned how to advocate for him and because he had a medical diagnosis, I have to be on top of what research is saying about that too."

Blended Theme 1: Parents gain information using resources outside of the school and maintain high hopes for themselves and their child despite facing systemic adversities.

Table 4. Continued.

# **Quantitative Theme: Parent Adversity**

# **Qualitative Theme: Parent Strengths**

# Blended Theme/Variable

- No seat at the table
- Silencing by systems

# Survey items:

- Not being heard by schools and professionals (M = 3.00)
- Differences between home and school values (*M*= 2.41)

# Resistant Capital

Organizational

"With this school, I'll partner with them. I will go meet before the IEP meeting and I'll let them know my concern. And it's not easy. It's not easy, like, you know, because they have different views and they do not think he (my son) is capable and other stuff, right? They don't feel that he is capable and they will not push too much. And for that, I have to advocate for him."

Personal

"I wish I had done due process in elementary. I knew I had the rights, but maybe I did not have the courage to do that. I wish I had done that. Now the school knows me. I will not give him. They know I know the laws. So the school will meet my criteria. I wish had to do due process when he was in elementary school."

# Navigational Capital

Research

"I did not know a detail about ADA. now I have to know more details about that. I know the basics, , but I need to go get that information. Because that way, he will know what to advocate for and if he's working, what kind of accommodation he can have on all that stuff, that is my next goal."

• Formal Organizations

Blended Theme 2: Parents feel like they are not heard, yet they continue to fight for their child's rights and opportunities. More importantly, parents don't know what to "fight" for because the American system, including the laws, are novel.

It's not that they do not have advocacy, it's that they do not know what to fight for and what the territory of that fight looks like. They are advocating and are equally empowered, but do not have the

Table 4. Continued.

Quantitative Theme: Parent Adversity					
	"And so if it's taken away from you enough, then eventually that right gets taken away from you to be able to speak up. I need to make sure to assert my right in that particular moment.	knowledge of the cause or the outcomes.			
<ul> <li>Limited capacities of internal and external support</li> <li>Survey items: <ul> <li>Stigma or taboo (M = 2.83)</li> <li>Family support (M = 2.54)</li> </ul> </li> <li>Religious/faith-based support (M = 3.30)</li> <li>Financial challenges (M = 2.74)</li> </ul>	Social Capital  "In the Hindu community in the temple, they don't have much support there. But I think I found one Muslim communities; they have really good support."  "And one of the things that I will tell you is this is[ an online group for mothers] probably the most accepting community of friends I have ever seen. Because these moms don't care what color, creed, religion you are."  Resistant Capital  Personal  "While I was researching and calling and gathering paperwork and running like a headless chicken, my mom was like, it's not going anywhere. Don't you want to stop? That said, no, I don't want to. And I ended up getting it, so then everyone was like, OK, now we see what you're doing."	Blended Theme 3: Parents have developed "chosen" families to navigate the complex adversities of future planning.  Even when pressed for resources, parents have aspiration to ensure that this doesn't happen to others. Protecting themselves and as well as other community members.			

Table 4. Continued.

**Quantitative Theme: Parent Adversity** 

**Qualitative Theme: Parent Strengths** 

Blended Theme/Variable

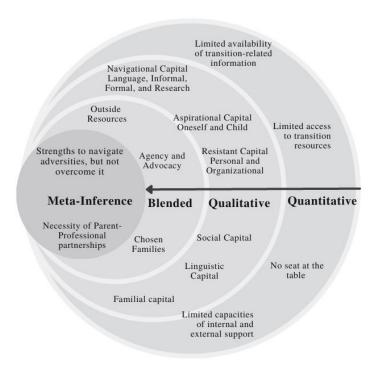
### **Meta-Inference:**

- 1. Parents use outside resources to gain knowledge and maintain high hopes despite facing adversities.
- 2. Parents are empowered and they know how to advocate, however they don't know what to advocate for. The system is an unfamiliar territory.
- 3. Parents have developed chosen families and lookout for one another.

Parents have developed capital to get in the "door" to manage systemic adversities, but not enough to "overcome" it. A parent-professional partnership built on equity, parent strengths, and culturally affirming practices is needed to support parents in overcoming systemic adversities.

# 2.7. Figures

Figure 1. Blended Analysis Findings and Meta-Inference



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# 3. THE STATE OF PARENT EDUCATION INTERVENTIONS FOR PARENTS OF ADOLESCENTS WITH AUTISM: SCOPING THE LITERATURE

Family-centered practices include various approaches to support families of children with disabilities toward successful outcomes. Family-centered practices have been influenced by IDEA part C, which emphasizes parents as key stakeholders in services for children, particularly during early intervention (IDEA, 2004). Additionally, IDEA part B notes the importance of collaboration between schools and families to improve family-centered services for families and children with disabilities. Dunst (2002) defines family centeredness as: (a) an orientation that views families with dignity and respect, (b) keeping families informed and sharing information so they can make informed decisions, (c) individualized services, including access to and availability of services, that are based on family-child needs, (d) development of family-school partnerships, and (e) opportunities for families to make informed choices about mobilization of resources, interventions, and programs. Family-centered practices strengthen the links between school, service providers, and families to benefit the family as well as the child with a disability.

# 3.1. Parent-Centered Practices

The influence of family-centered practices on families and their children with disabilities is well documented in literature. Dunst and colleagues (2007) conducted a meta-analysis of 47 studies to identify the relationship between family centered practices and parents' and the child's functional and behavioral outcomes. The authors found that most studies were conducted with mothers and included children between the ages of 7 and 20 with majority diagnosed with a developmental disability (Dunst et al., 2007). The meta-analysis also revealed that proximal outcomes, which were more closely related to parent/family functioning, were strongly

correlated with family-centered practices. The authors noted that family-centered practices resulted in positive outcomes for the parent and the children, including outcomes related to parenting, well-being, child behavior, social support, self-efficacy, and satisfaction (Dunst et al., 2007). Additionally, Kuhaneck and colleagues (2015) conducted a review of family outcomes for family-centered interventions for parents and their children with autism. The researchers found that across 31 studies, the most common assessment outcomes were related to two categories: (a) parent efficacy, confidence, and competence, and (b) parent stress, family coping and resiliency, and quality of life. The format of family-centered interventions for parents included parent training, parent coaching, and parent-mediated interventions. The authors noted that family-centered interventions were effective for family-related outcomes, such as parental self-efficacy and confidence.

## 3.1.1. Parent Involvement

Parents serve as key stakeholders in shaping the support services the child receives, mediating behavioral interventions, and advocating for their child's needs. One of the ways to increase interventions with children with disabilities is to increase parental involvement in the interventions. Tincani and colleagues (2009) argue that researchers and practitioners must recognize the need to involve families, and therefore, navigate interventions that best serve those families. First, the authors suggest that parental perceptions around disability need to be understood by researchers and practitioners due to cultural influences around labels of disability. Clinical definitions of autism may not necessarily mean the same for parents from diverse cultural backgrounds, and the constructs of stigma may also play a role in how families view autism. Second, the authors recommend learning about specific family concerns and practices before designing interventions. For example, families may prioritize addressing problem

behaviors or increasing academic achievements more than social skills lessons based on their immediate concerns (Fox et al., 2002). Furthermore, in order to increase parental engagement and involvement, parents must have the knowledge of terminology used in schools to provide services, information about special education law and policies, and experiences of how to advocate for services and support for their child with autism.

### 3.1.2. Parent Education Interventions

Parent education interventions serve as an ideal avenue to begin increasing parental knowledge and therefore parental involvement in special education. Parent knowledge is the cornerstone of effective family-centered interventions for families. Various terminology has been used over the years to describe parent education. For instance, Prata et al. (2018) define parent education as teaching parents the skills and information that could improve developmental outcomes of their children with autism. However, Dawson-Squibb et al. (2020) clarify that parent training (also known as parent-mediated) typically refers to interventions where parents are taught about particular skills to then implement with the child (e.g., reduce behavioral problems) while parent education focuses more on delivery of information about autism (Bearss et al., 2015). For instance, Bearss et al. (2015) compared parent training (strategies and skills) with parent education (only-knowledge based- no skills) and found that parent training was more effective in reducing disruptive behaviors.

Recently, Dawson-Squibb and colleagues (2020) coined the term Parent Education and Training (PET) to describe a hybrid approach which includes parent education using a didactic model (role-play, discussions, video guidance) where parents are the only direct participants.

This term combines both the knowledge and the skills associated with parent training and parent education. The authors argue that the PET content "can range from parent and family well-being

(including parent support systems, well-being, self-efficacy and knowledge) to didactics on more child-centered goals including child skill-building and managing of challenging behavior" (Dawson-Squibb et al., 2020, p. 8).

# 3.1.3. Diversity of Parent Education Interventions

Parent education interventions do not share a singular definition and therefore have not been comprehensively captured in literature. Due to the diversity of definitions regarding parent education interventions, it's challenging to measure the effectiveness of interventions and strengthen evidence-based practices for the field. Additionally, lack of a singular definition makes it more difficult for stakeholders such as parents and educators to be informed about what parent education interventions may entail. To date, the largest systematic review of parent education for parents of children with autism was conducted in 2011 (Schulz et al., 2011). The authors used parent training and parent education interchangeably to describe programs or interventions that strictly target increasing parents' knowledge of autism-related information.

The authors found 30 studies on parent education programs spanning from 1987 to 2007.

The authors noted that behavioral and communication skills were targeted most, followed by pivotal response training (PRT) which also included the child in the training. Majority of the participants were mothers, and the average child's age was 3-5 years. The authors found scant interventions for parents of older children, including adolescent-age children. Schultz and colleagues (2011) also found that only 10% of the programs used a curriculum while 42% used a manualized program which was also provided to the parents. Additionally, most programs lasted for 25 hours but varied between 1 week to 1 year. The authors found positive outcomes for all interventions in the studies, resulting in an emerging evidence base of the effectiveness of parent education interventions. The researchers also emphasized that most studies were single-case

designs, outlining a need for larger population samples and increased replication of current interventions.

Suppo and Floyd (2012) extended the literature by exploring parent training based on four settings: home-based services, service-based, home and family based services, or alternative settings. The authors reviewed only peer-reviewed articles and identified 23 interventions that matched their criteria. However, the inclusion of only peer reviewed articles excluded gray literature such as dissertations and thesis that could contain meaningful parent education interventions but were not comprehensively captured in this study. Additionally, due to the broad nature of how parent training was defined, parent training and parent-mediated interventions were blurred, leading to confusion about the characteristics of parent education interventions.

A recent systematic review and meta-analysis of parent training evaluated and compared the effectiveness of parent training interventions for parents of children with autism (Deb et al., 2020). The authors evaluated the effect of the parent training on children's autism symptoms, behaviors associated with core symptoms such as disruptive/challenging behaviors or sleep problems, parent stress, and parents' knowledge of their child's behaviors. The authors found 17 studies that focused on the four strands of interventions: language and communication, joint-attention, behavior skills, and knowledge regarding autism. Limitations of this study included only comparing studies that used a randomized control trial design and had a minimum of ten participants.

Dawson-Squibb and colleagues (2020) recently reviewed PET programs outside of the United States and found 37 studies across 20 countries. Most studies included group discussions, didactic training, home visits, interactive training, handouts, and relaxation techniques, while homework assignments, PowerPoints, and videos were the least used. Additionally, most studies

included psychologists, professionals working in autism clinics, psychiatrists, and special education teachers as trainers. Lastly, the outcomes listed for the studies included: positive behavior support, understanding communication and socialization skills, reducing parental stress, empowering parents, increasing parental knowledge of supports and services, and improving parents' family, school, and personal relationships (Dawson-Squibb et al., 2020). As with prior reviews, the authors found more positive outcomes associated with interventions and only 50% of the studies reported using manuals or curriculums. However, the authors identified more randomized controlled trials (RCT) and more quasi-experimental studies than previous studies. As with prior studies, the authors could not conclude the effectiveness of the interventions and compare them across disciplines due to variability in measurements, curriculum, and tools.

Finally, while emerging reviews have highlighted the necessity of parent education interventions across broad children ages, few studies have explored interventions including older children or adolescents. For instance, Rutherford and colleagues (2019) conducted a systemic review of studies published between 2006 and 2016 of parent interventions for children with autism older than 7 years of age. The review found that most studies were heterogenous, with a strong relationship between parent intervention and their well-being outcomes. However, the studies only included peer-reviewed articles with only parent-wellbeing measures. As such, it is essential to update the review, explore interventions broadly (quantitative and qualitative), and include gray literature to advance knowledge of parent education interventions that include adolescents over the age of 10.

# 3.1.4. Purpose of the Study

Despite recent reviews of parent training interventions, there has been little consensus on how to define, capture, and report parent *education* interventions, particularly in the United

States. While prior reviews have used "parent training" as an umbrella term to identify various interventions for parents (Schulz et al., 2011; Suppo & Floyd, 2012), no review to date has explicitly defined and captured education-focused parent training for parents of adolescents with autism. Thus, the purpose of the current study is to update the current literature using four decades of research on parent education training. Specifically, this review contributes to the field by (a) defining parent education interventions, (b) capturing trends in parent education interventions for parents of adolescents with autism across 40 years of research, and (c) mapping strengths and gaps in the field related to the various characteristics and outcomes of parent education interventions within the United States. I sought to answer the following questions:

- 1. What are the descriptive characteristics of parent education interventions for parents of adolescents with autism living in the United States?
  - A. What are the characteristics of the participants?
  - B. What are the characteristics of the parent education trainings? (e.g., purpose of the intervention, duration and format of training, interventionists, measures, and outcomes)

## 3.2. Methods

I chose to conduct a scoping review to update the field's understanding of emerging literature regarding parent education interventions for parents of adolescents with autism. Specifically, this review aimed to map and visualize the range of interventions conducted in the United States and identify strengths and gaps in the field (Arksey & O'Malley, 2007). I used the five stages outlined by Arksey and O'Malley (2007) to conduct the scoping review, including identifying the research questions, reviewing literature, selecting the studies, charting the data, and finally, summarizing, reporting, and analyzing the findings. As such, I asked broadly defined

research questions to map the literature and charted the findings using specific, pre-defined characteristics to truly grasp the nature of the interventions across four decades of research.

### 3.2.1. Inclusion/Exclusion Criteria

I included studies that met the following inclusion criteria: (a) studies must have been in English, (b) studies must have been conducted in the United States, (c) studies must have included parents of adolescents with autism as one of the participants for the training, who were defined as a parent by the study authors, (e.g., mothers, fathers, legal guardians or primary caregivers), (d) studies must have included an intervention (e.g., experimental studies, single-case studies, pre/post and randomized control trial group studies, and quasi-experimental studies), (e) studies must have included an education component as part of the intervention, and (f) at least one child of a parent enrolled in the intervention must have been 10 years of age or older as reported the authors.

The educational component was defined by integrating the definitions of parent education interventions by Dawson-Squibb et al. (2020) and Bears et al. (2015) as: "An intervention for parents of adolescents with autism to increase their knowledge and directly or indirectly benefit the child." The educational component could include parent-focused goals (e.g., parent wellbeing, stress, coping skills, self-efficacy, advocacy, or knowledge), family-focused goals (e.g., family quality of life, or marital relationships), child-focused goals (e.g., helping a child's communication development, toileting, or feeding) or specific skills training goals (e.g., managing behaviors or social skills). For instance, parents taking care of a dog as an intervention would be excluded due to no educational component.

Additionally, at least one parent in the intervention must identify as a parent of an adolescent with autism who is 10 years of age or older, as reported by the study authors. I chose

the definition of adolescents as individuals between 10-19 years of age, as defined by the World Health Organization ([WHO], 2022). Furthermore, I also included studies with reported mean age of 10 years or older, if specific ages were not provided. I also included studies that reported school grade levels above 5<sup>th</sup> grade if specific age groups were not provided. If the age of the parents' children were not reported, unclear, or reported age ranges rather than specifics, then those studies were excluded from the review.

I chose to select studies only in English because that was the predominant language spoken and written by the research team members. I also selected to limit the studies to the ones conducted in the United States because while a global review was recently published in 2020 (Dawson-Squibb et al., 2020), the last comprehensive review documenting parent education training for parents of children with autism within the United States was published in 2011. Updating the literature exclusively from the United States was an important purpose of the study. Additionally, parent knowledge is typically guided and governed by the special education policies within each country, which in the United States is IDEA. Since parent education interventions differ vastly in their scope and outcomes based on the special education policies guiding their practices, it would be beyond the scope of this review to include studies outside of the United States.

The aim of the review was to explore parent education interventions for parents of children with autism, so I selected studies that included parents who were part of the intervention. I included studies that explicitly stated the autism diagnosis of children, which could have included the following labels: ASD, autism, autistic disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), high-functioning autism (HFA), or Asperger disorder, as reported by the authors. Children could have had multiple diagnoses in

addition to autism, but all children must have had at least a diagnosis of autism to be included in this review. I excluded studies that only listed behavioral challenges but did not explicitly state that children were diagnoses with autism. Additionally, I also excluded studies that listed the children had intellectual and/or developmental disabilities, but did not explicitly state that all children were diagnosed with autism.

I aimed to explore whom parent education interventions included (e.g., parent-only, parent and child, or parents with other caregivers and/or staff) to map the extent of the interventions. Although additional individuals could be part of the intervention, parents must be one of the individuals receiving the intervention to be included in this review. In a previous review, the researchers defined parent education training as only consisting of parents; however, for this review, I decided to include parents as one of the training participants to have a wider scope of the literature on parent education interventions (Dawson-Squibb et al., 2020).

I defined parents based on the definition provided by the authors of each study, which includes mothers, fathers, legal guardians, and primary caregivers. Research with racially minoritized families has also expanded traditional definitions of "family" to include additional caregivers and extended family members as part of the family unit (Gates, 2017). Thus, I chose to have a broader scope of the definition of parents as to not limit the studies to certain recipients and to widely understand parent education interventions under the umbrella term of parents. While the scope was broadly defined, I chose the language of "parents" because parents was the most common term used in studies to define participants that were either parents or family members, rather than the term "families." Finally, I also included peer reviewed articles, doctoral dissertations, and master's thesis in the inclusion criteria to scope the literature. Gray

literature expanded the realm of studies and widened the scope of parent education interventions conducted in the United States.

# 3.2.2. Search Procedures and Screening

I conducted an electronic search in seven online databases using search terms across the following areas to answer my research questions: Diagnoses ("autism spectrum disorders" OR "pervasive developmental disorders" OR autism OR "intellectual disabilit\*"OR "mental retardation" OR "mild intellectual disabilit\*" OR "moderate intellectual disabilit\*" OR "severe intellectual disabilit\*" OR "developmental disabilit\*" OR "OR "severely disabled" OR "severe handicap" OR "severe handicaps" OR "severe handicaps" OR "mental handicaped" OR "mental handicap" OR "mental handicaps" OR "mentally handicapped" OR "mental retard" OR "mentally retarded" OR "mental disability" OR "mental disabilities" OR "mentally disabled"), parent education ("parent\* education" OR "parent training" OR psychoeducation OR "parent\* intervention" OR "parent\* workshops") and participants (mother\* OR father\* OR grandparent\* OR grandmother\* OR grandfather\*). The electronic search was completed in July 2021. I completed the search procedures in four phases (Table 5). Across all the four phases, inter-rater reliability (IRR) was calculated by determining the number of agreements and dividing by the total number of agreements and disagreements. I then multiplied the number by 100%.

In the first phase, I used each individual search term in the title, abstract and descriptions. I then combined them using AND. The initial search resulted in 12,507 studies (Figure 2). After duplicates were removed, the search results included 10,042 articles in the title and abstract phase. I trained two advanced-level doctoral students to code the initial articles using our inclusion criteria. The research team (two trained doctoral students and I) developed inter-rater reliability (IRR) for 50% (n = 5,021) of the studies in the title and abstract phase. I chose to

conduct IRR for 50% studies in the title and abstract phase so that all the coders could become more familiar and comfortable with the scope of this study as they code more studies. The research team had an IRR of 95.79% in the title and abstract screening stage. We identified 729 studies for full-text review.

In the second phase, the coding team developed IRR for 32% (n = 233) of the studies in the full text phase. I chose to reduce the percentage coded from the title and abstract phase to the full text phase because all the coders had established familiarity with the scope of the review, were advanced doctoral students, and expressed confidence in their coding skills. The research team had an IRR of 80% in the full text phase. The IRR was lower for full text studies due to several reasons, including limited clarity of the educational component of the intervention from the articles, unclear demographic characteristics of participants, and unconfirmed diagnosis of autism (e.g., some studies did not clarify if all the children included in the study were diagnosed with autism). Disagreements were resolved by seeking consensus of all the research team members. We identified 300 studies for extraction.

In the third phase, I independently coded the 300 full text studies using the inclusion criteria for adolescent children. According to my inclusion criteria, at least one child of a parent in the intervention must be 10 years of age or older, as reported by the researchers. This criterion was established to explore the breadth of parent education interventions for parents of adolescents with autism in the United States. If the study did not report child ages, or did not clearly state that at least one child was 10 years of age or older, it was excluded.

In the final phase, I identified 52 studies that met the criteria for adolescent children. I conducted forward searches by reviewing articles that cited the 52 studies and hand searches by reviewing key journals in special education, autism research, and dissertation literature. The

forward and hand searches did not result in any additional studies. I also conducted ancestral searches by reviewing references from the 52 identified studies, and from analyzing prior reviews (Dawson-Squibb et al., 2020; Deb et al., 2020; Schultz et al., 2011; Suppo & Floyd, 2012) to identify additional studies. I identified two additional studies from the ancestral search (Figure 2). Finally, I extracted and charted data from 54 identified studies (52 from databases and 2 from ancestral search).

# 3.2.3. Data Charting

Each study included in the review was charted based on the following characteristics: (a) parent and child demographics and (b) intervention characteristics (e.g., recruitment, intervention name and design, objectives, materials, setting, delivery, format, duration, interventionists, outcomes, and implications). Studies that did not report the information used for charting were labeled as not reported. Data were extracted and charted using Covidence (Covidence systematic review software, 2021). Covidence is a web-based collaboration software platform for systematic and other literature reviews. I developed predetermined categories for each charted characteristic and also created open-ended options for data that required multiple or additional responses. The research team calculated reliability for data charting by determining the number of agreements and dividing by the total number of agreements and disagreements. We then multiplied the number by 100%. We calculated reliability for 24% of the studies (n = 13). Each member of the research team charted the data independently, and the team met for consensus weekly. Our agreement was 83%, with the lowest agreements resulting from intervention details (47%), participant characteristics (26%), and intervention outcomes (14%). Disagreements were resolved by seeking consensus from all the members of the research team.

## 3.2.3.1. Parent and Child Characteristics

Parent characteristics included the total number of parents who participated in the study (including parents and/or other stakeholders), sex (e.g., male, female, non-binary/third gender, other, or not reported), age (e.g., 18-35, 36-55, 56-75, 76 and older, other age ranges reported, or not reported) race/ethnicity (e.g., White, African American/Black, Latina/Latina/Latinx, Native American/Alaskan Native, Native Hawaiian or Pacific Islander, Biracial, Multiracial, other, or not reported), and parent's level of education (e.g., less than high school, high school graduate, some college, college graduate, professional degree, other, or not reported). I also charted if parents had any participated in prior interventions as well. Child characteristics included sex (e.g., male, female, non-binary/third gender, prefer not to say, or not reported) age (e.g., 3 years of age or less, 4-9 years, 10-14 years, 15-18 years, 19-21 years, 22 and older, other age ranges, or not reported ), and disability (e.g., autism spectrum disorders, pervasive developmental disorders, Asperger's, and other disabilities). I also charted if the children had participated in any prior training interventions. I predefined these categories to facilitate the charting process.

# 3.2.3.2. Study Recruitment

I charted information about how the participants were recruited to learn more about traditional and novel methods of recruitment. Additionally, since the review was conducted in the midst of a global COVID-19 pandemic, it was important to note how researchers were recruiting participants in both face to face and online formats. The predetermined categories included clinics, school, centers or associations, social media, university centers, other, or not reported.

## 3.2.3.3. Intervention Design and Name

I charted specific details about the intervention to identify patterns and explore emerging methods of conducting parent education training. Specifically, I identified the various types of intervention design used in parent education interventions for parents of adolescents with autism. The predetermined categories included single case, pre/post, randomized control trial, quasi-experimental, qualitative, mixed methods, multimethod, case study, other, or not reported. If a study reported multiple designs (e.g., pre/post design with qualitative findings), then both of the options were documented. Additionally, I also identified the name of the intervention based on the information provided by researchers. If there was no reported name, or the study simply stated, "parent training," then this item was left blank. Identifying the name of the intervention also revealed potential replication of the interventions.

### 3.2.3.4. Intervention Objectives

I identified the objectives of the intervention based on what was reported by the researchers in each study. The objectives were defined as the purpose of the intervention. If the objectives of the intervention were unclear from the study, or the researchers did not report their purpose, it was documented as not reported. Predetermined categories included objectives related to behavioral/ABA, stress, social skills, feeding, communication, transition or future planning, health or wellness, sleep, advocacy or empowerment, other, or not reported.

#### 3.2.3.5. Intervention Materials

Specifically, I identified types of materials used for the training of the parents, as indicated by the researchers. These predetermined categories included a manualized curriculum, toys, handouts/folders/binders, PowerPoints, online materials, other, or not reported. Online materials were defined as any materials offered to participants using email, website, social

media, or other online tools. Additionally, I also documented specific pedagogical components used in the training to map the literature. These categories included lectures, group discussions, role plays/case studies, experiential activities (e.g., playing with toys, wearing a sleep headset, or wearing a Fitbit), writing/journaling, videos, homework, interaction or communication with the child, other, or not reported.

## 3.2.3.6. Intervention Setting, Delivery, and Format

Additionally, I charted the setting of the training to explore how interventions have been delivered to parents and note trends between face to face and online settings. The categories of intervention settings included the homes of participants, clinics, hospitals, library or community centers, online, other, or not reported. I also chose to map how interventions were delivered, particularly because many trainings pivoted towards an online format during the COVID-19 pandemic. These categories included studies that were delivered only face to face, hybrid (both face to face and online), synchronous online, asynchronous online, online regardless of being synchronous or asynchronous, other, or not reported. Lastly, I also charted the format of the training to identify trends across four decades of interventions, which included group trainings, individual trainings, both group and individual trainings, online or self-paced trainings, other, or not reported.

#### 3.2.3.7. Duration of intervention

I identified the duration of the studies to further examine trends in parent education interventions. I identified how long the entire intervention lasted (total duration in weeks) and the exact duration of the intervention (hours). Predetermined categories for the total duration of the intervention included 1 day or less, 2-5 days, 1-3 weeks, 4-5 weeks, 6-7 weeks, 8 and more

weeks, other, or not reported. Categories for the time of the intervention included less than an hour, 1-3 hours, 4-10 hours, 11-17 hours, 18-24 hours, 25 and more hours, other, or not reported.

#### 3.2.3.8. Interventionists

I chose to explore the professional background of the individual(s) delivering the intervention. The categories included trained professionals (e.g., behavior therapists or psychologists), researchers (e.g., first author, research assistants, or doctoral students), teachers or school professionals, parents, community leaders, self-administered, other, or not reported. I did not collect any information on the training experiences of the interventionists.

### 3.2.3.9. Social Validity of Interventions

I also measured whether the intervention reported social validity measures. The predetermined categories included how social validity was measured, such as using surveys, interviews, both surveys and interviews, other, or not reported.

#### 3.2.3.10. Intervention Outcomes

I identified the specific outcomes measured by each study to capture the dependent variables used in each intervention. I aimed to understand how often measures repeated across studies and examine trends. I explored outcomes related to both parents and children. First, I identified whom the outcomes were measured for, including those for children, for only parents, or for both parents and their children. If the parent completed questionnaires or surveys that asked them questions about their child's outcomes (e.g., social skills, sleep habits, etc.) then they were noted as outcomes for child, even if the parents reported them on behalf of their children. Additionally, I documented the names of the measures used in each study, and whether or not it was reported as successful, not successful, or had mixed results. Mixed results were defined as measures that were reported successful for some populations but not others, or successful in

some contexts while not in others. Since I was interested in mapping the interventions, I did not chart specific details related to the intervention, such as effect sizes.

### 3.2.3.11. Intervention Implications

Finally, I was interested in exploring how parent education interventions for parents of adolescents with autism report implications of the interventions. Particularly, I charted if the researchers' reported implications for research, practice, and/or policy. The categories included responses related to yes, no, or other.

#### 3.3. Results

I conducted a scoping review of parent education interventions for parents of adolescents with autism to describe the characteristics of parent education interventions, capture trends in parent education interventions for parents of adolescents with autism, and map strengths and gaps in the field related to the various characteristics and outcomes of parent education interventions within the United States. The results are organized to respond to the research questions, including sub-questions, based on the 54 studies found within literature.

# 3.3.1. What Are the Descriptive Characteristics of Parent Education Interventions for Parents of Adolescents with Autism Living in The United States?

I scoped the literature on parent education interventions and identified 54 studies, including 39 peer-reviewed journal articles, 13 dissertations, and two master's theses (Figure 2). The studies were found across four decades of interventions, ranging from 1978 to 2021.

# 3.3.1.1. What Are the Characteristics of The Participants?

# 3.3.1.1.1. **Parents**

A total of 2,136 participants participated in parent education interventions, including 1,583 parents, 539 children, and 14 other stakeholders (e.g., teachers, grandparents, nurses, or

other individuals; see Figure 3). Of the parents, 14% (n = 225) identified as males, 70% identified as females (n = 1107), and 0.03% identified as non-binary/third gender (n = 6). Seven studies did not report information on parents' sex. 13 parents were between the ages of 18-35, 47 parents were between the ages of 36-55, one parent was between the ages of 56-75, and no parents were older than 76. Some studies also reported their own age ranges, which all differed. These ages ranged from 19-63, with no consensus of how many parents were in each age group. This was difficult to capture because 14 studies only included age ranges with no participant specific details and two studies only included a mean age of parent participants.

Across 54 studies, only 61% of studies captured parents' race (n = 33), while 39% of studies did not report racial characteristics (n = 21; Table 6). Among the studies that reported racial characteristics, 523 parents identified as White, 138 as Latino/a/x, 65 as Asian, 52 as African American/Black, 30 reported as other, 11 as multiracial, five as Native Hawaiian/Pacific Islander, three as Native American/Alaskan American, and two as biracial. No studies reported any Middle Eastern/North African parent participants. In terms of parent education, 266 parents identified as a college graduate (e.g., Bachelors), 155 as having some college education (e.g., Associate's, technical degree), 114 with a professional degree (e.g., Master's, Doctorate, or other professional degree), 62 with a high school degree (e.g., GED, high school diploma), 35 had less than a high school degree, and six had other forms of education. Of the 54 studies, 25 studies did not report parent education characteristics. Finally, 36 studies did not report if parents had any prior training, six reported that parents did not have any prior training, and 12 studies reported that parents had engaged in a prior training opportunity.

#### 3.3.1.1.2. Children/Youth Participants

Children's characteristics were also charted, including their sex, age, disability, and prior training. First, 836 children identified as males and 217 identified as females (Figure 3). Notably, 15 studies did not report these characteristics. Second, across the 54 studies, at least one child in each study was reported to be 10 years of age or older, as defined by the inclusion criteria.

Overall, 180 children were three years of age or younger, 217 were four to nine years of age, 85 children were between 10-14 years of age, and 14 were between 15-18 years of age. In addition to my predetermined categories, 34 studies also reported their unique age ranges. Across those 34 studies, 22 studies reported age ranges (e.g., 3-17 years of age), seven studies reported the mean ages (e.g., 10.8 years), and five studies reported how many children were within each age range (e.g., 16 children between the ages of 12-16; Table 6).

Third, while all children must have had a diagnosis of autism to meet the inclusion criteria of this review, I extracted the specific type of diagnosis reported. Of the 24 studies that specified the diagnoses, 178 children were diagnoses with autism spectrum disorder (ASD), 19 were diagnosed with pervasive developmental disorder-NOSS (PDD), 70 were diagnosed with Asperger's Syndrome (AS), 13 with autism and an intellectual disability, and 38 with autism and other disabilities. 30 studies did not report specificities of the autism diagnosis. Lastly, 44 studies did not report if the child received any prior training, and only four studies indicated that the child received prior training. Six studies reported that the child did not receive any prior training.

## 3.3.1.2. What Are the Characteristics of The Parent Education Trainings?

# 3.3.1.2.1. Study Recruitment

Out of the 54 studies, majority of the studies reported recruitment information (n = 47), while a small number did not report any recruitment information (n = 7). Since multiple

recruitment methods are typically used to recruit participants (see recruitment for study 1), the recruitment categories were not mutually exclusive (e.g., one study could have multiple recruitment methods). Centers or organizations (e.g., ARC of Texas) were used the most often (n = 26), followed by clinics (e.g., autism clinics, therapy centers, occupational therapy clinic; n = 22), schools (n = 11), social media (e.g., Facebook posts; n = 10), and university centers (e.g., university disability centers or other university listservs; n = 7). 15 studies included other categories, such as parent support groups or referrals from other parents (n = 5), autism events (e.g., conferences; n = 2), prior interventions (n = 1), community based outreach (n = 1), university faculty (n = 1), registry at university (n = 1), nonprofit organizations (n = 1), hospital (n = 1), contacts from first author (n = 1), and Qualtrics panels (n = 1).

### 3.3.1.2.2. Intervention Design and Name

All studies reported information related to the research design used in the parent education interventions. While majority of the studies used one design (n = 41), 13 studies used multiple designs within their interventions (See Table 7 and Figure 4). Across studies with a singular design method, 14 studies implemented a pre/post design, 14 studies used a single-case design method, eight studies employed a quasi-experimental design, three studies used a randomized controlled trial, one study used a case study design method, and another used a qualitative design (e.g., only solicited qualitative responses after an intervention). Studies that used multiple design methods, included a pre/post design with mixed methods (n = 1), quasi experimental (n = 7), and randomized control trial (n = 2). Three studies included a single-case design with pre/post methods as well. Additionally, the single-case designs included seven studies with non-concurrent multiple baselines across participants (e.g., Davis et al., 2020; Gould et al., 2018) or across target skills (e.g., Aguilar, 2018), one A-B-A design (e.g., Hampshire et

al., 2011), five multiple baseline designs across participants (e.g., Andrews, 2020; Singh et al., 2014), and five across behaviors or targeted skills (e.g., Chen, 2016; Mitchel et al., 2010).

I also charted the names of reported interventions and whether it was replicated. 35 novel interventions were found, and acceptance and commitment training were the most commonly implemented (n = 3). Novel interventions were defined as those that had not been replicated across the 54 studies. Additionally, the Latino Parent Leadership Support Project (LPLSP) was implemented twice (Table 7). 15 studies did not report the name of their intervention or named it "parent training."

## 3.3.1.2.3. Intervention Objectives

I captured the purpose of each intervention to explore which training objectives were used more/less often in research (Figure 4). Most interventions included behavioral training (e.g., ABA, behavior-related objectives; n = 22), followed by stress-related outcomes (e.g., anxiety, depression, stress reduction; n = 17), health/wellness related objectives (e.g., feeding, exercise; n = 11), social skills related objectives (n = 10), transition/future planning related objectives (e.g., sexuality, adult service systems; n = 8), and advocacy or empowerment related objectives (e.g., increase parent advocacy skills; n = 6). Studies also reported additional purposes of parent education interventions (n = 21), including knowledge of autism related information (n = 5), mindfulness (n = 4), social support and self-efficacy (n = 1), homework skills (n = 2), child's narrative skills (n = 1), teaching parents about evidence-based practices (n = 1), creating parent support groups (n = 1), enhancing parents' quality of life (n = 1), participation of families in activities (n = 1), and sexuality education (n = 1).

#### 3.3.1.2.4. Intervention Materials

Overall, 43 studies reported information related to intervention materials, while 11 studies did not report those details. Studies reported using one type of materials (n = 22), and multiple materials during the intervention (n = 21; Table 7). Materials used included only handouts/folders/binders with information (n = 4) and handouts/folders/binders with information and PowerPoints (n = 1). Additionally, manualized curriculum by itself was used more often (n = 18), and studies also reported using handouts/folders/binders with information (n = 7), videos (n = 2), PowerPoints (n = 4), online materials (n = 5), and toys (n = 2) along with the manualized curriculum. Finally, one study used both toys and online materials.

I also charted pedagogical components used during the parent education interventions. While most studies reported how they conducted the intervention (n = 48), six studies did not report these details. Most studies used a combination of pedagogical tools during the intervention. Group discussions were used most often (n = 18), followed by interaction or communication with the child (n = 16), role play/case studies (n = 16), experiential activities (n = 12), lectures (n = 12), homework (n = 11), videos (n = 10), and writing/journaling (n = 2). Some studies used group discussions (n = 3) and interaction or communication with the child (n = 3) exclusively (i.e., did not combine with other methods). Studies also reported 16 other pedagogies used, including modeling (n = 3), feedback (n = 2), meditation (n = 2), vignettes (n = 2), games (n = 1), phone calls (n = 1), news articles (n = 1), coaching (n = 1), and online discussion boards (n = 1).

# 3.3.1.2.5. Intervention Setting, Delivery, and Format

The parent education interventions took place in various settings. For instance, six interventions occurred in clinic settings, four in participants' homes, and three in online settings,

exclusively. A vast majority of interventions occurred in multiple settings, including participants' home and other settings (e.g., clinics, schools, universities, or communities; n = 8), and online with other locations (e.g., online and at home, clinics and online, and other locations close to participants; n = 6). Other categories of intervention settings included library or community center (n = 2), university or classrooms (n = 2), local centers or autism affiliated centers (n = 2), and the school district office (n = 1).

Interventions were delivered using multiple formats, either face to face only, hybrid, exclusively online, or using other modalities (Table 7). Majority of the interventions captured were delivered using face to face modalities (n = 41), while others were offered using online (n = 6) or hybrid models (n = 4). For studies that reported online modalities, majority were synchronous (n = 3), one was asynchronous (n = 1), and two did not report if the training was delivered asynchronously or synchronously. Additionally, four studies reported using other modalities, including both telehealth and face to face approaches (n = 1), face to face or online in a shared setting (n = 1), face to face or telemedicine (n = 1), and self-paced online training compared with a face to face setting (n = 1).

Lastly, I explored the format of the interventions, such as group trainings, individual trainings, both group and individual trainings, and online trainings. Majority of the trainings were held in groups (n = 29), while others included individual training (n = 20), and both group and individual trainings (n = 3). Only one study identified a completely self-paced format, while another included both face to face and self-paced/online components.

## 3.3.1.2.6. Duration of intervention

I identified how long the entire intervention lasted (total duration in weeks) and the exact duration of the intervention (hours). Among studies where the entire duration was reported ( $n = \frac{1}{2}$ 

44), most interventions lasted eight weeks or more (n = 20), followed by six to seven weeks (n = 8), four to five weeks (n = 7), two to five days (n = 5), one to three weeks (n = 3), and one day or less (n = 1). In terms of the duration of the intervention hours, most studies reported the intervention lasting between four to ten hours (n = 14), followed by 11-17 hours (n = 9), one to three hours (n = 9), 18-24 hours (n = 6), and 25 or more hours (n = 3). 14 studies did not report the duration of the intervention (Table 7).

#### 3.3.1.2.7. Interventionists

I found that majority of the interventions were conducted either by the researchers themselves (e.g., first author, research assistants, university faculty; n = 21) or trained professionals (e.g., psychologists, behavioral therapists; n = 19). Additionally, some studies reported multiple interventionists, including both trained professionals and researchers (n = 5), and trained professionals and community leaders (n = 1). Finally, one study included community leaders exclusively as interventionists (n = 1). Six studies did not report information related to the interventionists.

## 3.3.1.2.8. Social Validity of Interventions

Social validity was recorded for all of the reported studies. Most studies reported conducting surveys for social validity (n = 28), while others included both surveys and interviews (n = 6). A handful of studies used only interviews for social validity (n = 2). One study reported using open-ended responses (n = 1), however it was unclear whether that was from surveys or interviews. 17 studies did not report information related to social validity.

#### 3.3.1.2.9. Intervention Outcomes

Most studies reported outcomes for both the parent and the child (n = 30). Some studies included intervention outcomes for only parents (n = 20), while others only included child

outcomes (n = 4). Many studies reported using multiple outcomes and dependent variables as measures of the success of the intervention (Enav et al., 2019). These outcomes ranged from two to seven measures reported and evaluated. Given the exploratory nature of a scoping review, I defined a successful outcome based on how the authors interpreted the results of their studies. Across the 54 studies, I found 120 successful outcome measures, 43 unsuccessful outcome measures, and 27 outcomes with mixed results or findings.

## 3.3.1.2.10. Intervention Implications

I found that most studies reported implications related to research (n = 51), while a few did not report any research implications (n = 3). However, reporting of implications related to practice were much lower. Specifically, only 22 studies reported practice-oriented implications, while others did not report these implications (n = 32). Finally, across 54 studies, only one study reported implications related to policy, while most did not report policy implications (n = 53).

#### 3.4. Discussion

The purpose of the scoping review was to examine participant and intervention characteristics for parent education interventions for parents of adolescents with autism. I found that most studies included primarily white participants, had a stronger focus on equipping parents of younger children with behavioral-related skills, and supported an increasing trend toward online interventions. Additionally, the findings of the scoping review also showcase vast diversity in parent education interventions, including the purpose, parameters of "education" focused interventions, as well as the varied age ranges of children. As such, the findings reveal several significant trends across four decades of interventions related to reporting of racial characteristics, intervention accessibility, intervention objectives, and implications for policy.

First, across 54 studies identified in this review, I found that only 33 of the studies reported parents' race, while 21 studies did not report any racial characteristics (Table 6). Across racially minoritized participants, Latinx participants were the most represented (n = 138), while Native Americans (n = 5) and Middle Eastern/North African parents (n = 0) were the least represented (Figure 5). Moreover, although there was a steady increase of racially minoritized participants since 1978, white participants far outnumbered this growth each year. For instance, between 2010 to 2021, only 266 racially minoritized participants were identified in this review, as compared to 444 white participants (Figure 6).

While earlier studies did not report racial characteristics of parent participants perhaps due the homogeneity of interventions for primarily white families (Koegal et al., 1978), I found 14 studies within the last 10 years that also did not report racial characteristics (Milgramm et al., 2021; Singh et al., 2021). Prior literature on race reporting in autism interventions has found that most studies that do not report race are single-case studies (Steinbrenner et al., 2022). However, my findings revealed that majority of the studies in this review that did not report racial characteristics were group studies (n = 12) and were also peer-reviewed (n = 16).

Over the last 10 to 20 years, reporting on racial and ethnic characteristics within autism research has determined widening disproportionality of diagnoses, interventions, and supports for racially minoritized populations, namely for Black (Wetherby et al., 2008) and Latinx families (Pierce et al., 2014). Only by identifying and labeling racial characteristics researchers can further examine the intersectionality of race and dis/ability within interventions (see study 1) and develop individualized parent supports to strengthen parent education intervention outcomes. Furthermore, it is imperative to disaggregate racial labels (e.g., Chinese instead of Asian; Chiang et al., 2014) and expand reach to unrepresented racial groups (e.g., Middle Eastern/North African

or Native American) to further offer culturally affirming interventions that are effective and contextualized to that population.

Second, most studies reported only face to face formats for interventions (n = 41). However, I found an increasing trend toward online or hybrid (e.g., both face to face and online components) training formats, particularly between 2020-2021 (Table 7). In March of 2020, the global COVID-19 pandemic shifted the format of trainings and increased reach using virtual formats, thereby resulting in significant increases in virtual training. The online or hybrid interventions differed in their methods, ranging from group studies (n = 8) to single-case studies (n = 5), indicating effectiveness across both methods of parent training. Online or hybrid training formats have now become the norm for increasing access to underrepresented groups and offering additional opportunities to enroll and report racially minoritized participants in parent education interventions. Thus, this model could be effective in increasing representation of Middle Eastern/North African participants, Native American participants, and other disaggregated racial subgroups.

Third, I found that most interventions had multiple objectives, with 22 interventions targeting some aspects of behavioral/ABA skills for either the parent, the child, or both (See Table 7 and Figure 4). My findings affirmed prior reviews that also noted a large focus on behavioral objectives (Schultz et al., 2011). However, the current review extends prior literature in several ways. Notably, I found the following characteristics among 22 studies that included some behavioral objectives: 64% reported both parent and child outcomes, 50% used single-case methodology, and 41% did not report racial characteristics. The increase in group studies is promising, however, there is a pressing need to report racial characteristics in behaviorally focused interventions. Additionally, considering that all these studies included adolescents above

the age of 12, the findings also promote targeting some components of behavioral skills for parents of older adolescents.

In addition to the large presence of behavioral objectives, my findings also highlighted increasing interventions to support parents' overall well-being, particularly for racially minoritized families. Racially minoritized parents experience multiple systemic adversities (see study 1) and require education interventions that are responsive to their intersectional needs. Therefore, the shift towards increasing parental well-being using parent education interventions emphasizes further growth opportunities in this domain for researchers and practioners.

Lastly, only eight studies reported transition-related objectives, pointing to an immediate need in the field (Table 7). This is particularly important as transition to adulthood planning begins in early adolescence (e.g., 12-14 years of age) and it is imperative to inform and prepare parents in this domain. Transition knowledge could also be incorporated within autism-knowledge related goals to ensure parents are equipped with reliable resources prior to middle school.

Fourth, I found that 67% of studies implemented group interventions, with only a small portion focusing on single-case or case study interventions. While prior reviews have identified the use of more single-case studies (Schultz et al., 2011), this study noted an increasing trend toward group studies for parent education interventions. However, across 54 studies, I only found only one study that used mixed methods within a parent education intervention (Pearson et al., 2021), pointing to a need to advance the field in this area. Additionally, I also found that only three studies were replicated (e.g., LPLSP, MBPBS, and Transitioning Together), highlighting gaps in replication or culturally adapted replication of intervention studies (Table 7). Advancing replication practices will offer effectiveness of the studies across participants, formats, and

contexts to better strengthen and support parent education interventions for parents of adolescents with autism.

Fifth, this review highlights a need to advance parent education interventions for older adolescents, particularly during and after high school. Only 43% of the studies included youth 14 years of age or older, however most did not offer specific number of adolescents involved and their age groups (Table 7). Additionally, the age range of children included in the study varied widely, ranging from 2-35 years of age in some instances (Montgomery et al., 2015), which makes it challenging to evaluate the appropriateness and effectiveness of the intervention for exclusively parents of adolescents. However, a few studies only trained parents of older adolescents (DaWalt et al., 2018; Mitchel et al., 2010; Singh et al., 2019) and targeted interventions related to transition planning, mindfulness, and social skills. Emerging trends showcase opportunities to conduct targeted interventions for older adolescents (i.e., above the age of 14) using a combination of objectives to strengthen parent supports.

Finally, my findings also offer opportunities to discuss implications of parent education interventions, particularly for practice and policy. Across the 54 studies, only 41% of studies included implications for practice while one study reported implications for policy (Kuhn et al., 2020). The reporting of implications for practioners could help various practioners (e.g., teachers, behavioral therapists, transition specialist, adult service systems) apply their findings to support parents of adolescents with autism and also reduce the research to practice gap. Historically, special education has evolved into practice from laws and policies in IDEA (2004), pointing to the reciprocal relationship between research and policy. Thus, reporting policy implications of parent education interventions is essential to transforming support systems for parents, particularly for racially minoritized parents.

#### 3.4.1. Limitations and Directions for Future Research

This review offers a current landscape of parent education interventions for parents of adolescents with autism. Thus, its findings should be recognized alongside its limitations. First, I included studies that reported at least one child 10 years of age or older to offer a broader overview of interventions for parents of adolescents. However, due to varied reporting practices (e.g., age range or mean) and large ranges provided by researchers, I could not isolate how many adolescents were served by these interventions, limiting generalization to this population. Future researchers could search within a certain age range (e.g., 14-21) or across studies that only report specifics on adolescent ages (e.g., five adolescents 14 years of age) to target a review for this population.

Second, I adapted the definition of parent education interventions using prior literature (Bears et al., 2015; Dawson-Squibb et al., 2020) and could have omitted literature that did not fit this definition. There could have been additional education interventions that I did not capture due to my own definition of parent education interventions. Future researchers could further explore only the interventions related to educating just the parents to explore parent education interventions more precisely. Researchers could also use my definition of parent education interventions to replicate this review with varied disability diagnoses, age groups, or location. Third, reporting standards varied greatly across participant and intervention characteristics of studies. While I made intentional attempts to capture the literature widely, I could have missed some studies due to consensus among the research team or due to limited reporting.

Fourth, I conducted this review to explore interventions within the United States to update the literature within this country. However, due to this criterion, I could have missed interventions for parents globally. Future researchers could explore interventions outside of the

United States or within their own national contexts to better understand the scope of parent education interventions for parents of adolescents with autism.

Finally, the focus of this review was to explore the state of parent education interventions, and therefore, I did not report effect sizes or explicit measures of effectiveness. I also did not compare the effectiveness of studies because it was beyond the scope of this study. Future researchers could explore the effectiveness of parent education interventions across participants, formats, contexts, and measures in a systematic review.

## 3.4.2. Implications for Practice

This scoping review offers a bird's eye view of parent education interventions for parents of adolescents with autism across four decades of research. Notably, it offers several implications for various practioners (i.e., teachers, service professionals, and higher education professionals). Teachers could use this review as a guide to explore ways in which researchers have explored parent training, offering opportunities to replicate aspects of some interventions for parents within their contexts. Educators and parents are partners in the special education process, and teachers could inform parents of the availability of these interventions or connect them to the researchers for ongoing studies. Additionally, despite the inclusion of older adolescents within this review, many of the interventions are focused on younger adolescents (e.g., 13 years of age or below). It is therefore imperative for educators to continue to offer trainings or additional support to parents of older adolescents, since they are least represented in parent education interventions and may not have support readily available outside of schools.

Service professionals often partner with local agencies to connect parents to adulthood opportunities. Given the increase of virtual interventions found in this review, service professionals could replicate or create those opportunities for parents within their own contexts.

Additionally, they could emphasize their efforts on further supporting racially minoritized parents, as those populations are least represented within parent education interventions. Thus, it is essential to equip those parents with culturally affirming resources.

Finally, higher education professionals could also gain significant insights to apply within their contexts. As indicated by this review, parents of adolescents with autism may have little access to or availability of interventions for transitioning after high school. Thus, higher education stakeholders could conduct information sessions for these parents regarding college opportunities or inclusive postsecondary education programs (IPSE). Higher education professionals could also connect parents to disability services in higher education, as well as other parent affinity groups to increase parent supports and their overall well-being. Lastly, higher education professionals could collaborate with educators in the school system to offer targeted interventions to parents of adolescents with autism prior to strengthen and expand their support systems.

#### 3.5. Conclusion

This scoping review offers a current landscape of parent education interventions for parents of adolescents with autism in the United States. The findings offer important insights, including increased trends in enrolling racially minoritized parents, increased accessibility to participate using virtual training opportunities, and expansion of training objectives towards parental well-being and empowerment. However, there is an ongoing need to expand transition-focused interventions and reporting of racial characteristics to strengthen parent supports for parents of adolescents with autism.

# 3.6. Tables

**Table 5. Search Terms.** 

Disability	Participant	Intervention
Pervasive developmental disorders	• Mother	Psychoeducation
<ul> <li>Autism spectrum disorders/ASD/Autism</li> </ul>	• Father	• Parent education
<ul> <li>Intellectual disability</li> </ul>	<ul> <li>Grandparent</li> </ul>	<ul> <li>Parent training</li> </ul>
<ul> <li>Mental retardation</li> </ul>	• Grandmother	<ul> <li>Parent workshop</li> </ul>
<ul> <li>Mild intellectual disability</li> </ul>	• Grandfather	• Education of parents
<ul> <li>Moderate intellectual disability</li> </ul>	• Nuclear family	
<ul> <li>Severe intellectual disability</li> </ul>	• Extended family	
<ul> <li>Developmental disabilities</li> </ul>	• Single parent family	
<ul> <li>Mental handicap</li> </ul>		
<ul> <li>Asperger's syndrome</li> </ul>		
• Children with disabilities		
Parents of disabled children		

**Table 6. Parent and Child Demographics for ASD Parent Education Interventions** 

Study	<b>Total Number of Participants</b>			Parent Race	Child Age M (Range)	
	Parent	Child	Other			
Most Children 13 year	rs of age or you	ınger				
Aguilar (2017)	3	3	1	3 LAT	NR (7-11)	
Andrews (2020)	4	4		4 WH	8.5 (6-11)	
Brown-Beasley (2020)	14		2	6 WH; 8 BL; 2 OTH	9.8 (3-19)	
Celiberti (1993)	9	9		NR	6.7 (4-10)	
Chen (2014)	3	3		1 WH; 2 LAT	9.3 (8-10)	
Chiang (2014)	9	9		9 AS	NR (3-11)	
Corona et al. (2019)	25	25		39 WH	13.8 (12-17)	
Davis et al. (2020)	2	2		1 WH; 1 LAT	10.5 (6-15)	
DeFreitas (2015)	3	3		NR	10.3 (10-11)	
Dogan et al. (2017)	4	4		3 WH; 1 BL	10.0 (9-12)	
Dunn et al. (2012)	20			17 WH; 1 LAT; 1 MR	6.5 (3-10)	

Table 6. Continued.

Study	Total Numb	<b>Total Number of Participants</b>		Parent Race	Child Age M (Range)
	Parent	Child	Other		
Gattuso (2013)	8		1	6 WH; 1 LAT; 1 PI; 1 BI	13.0 (3-13)
Gould et al. (2018)	3	3		3 WH	7.0 (4-12)
Hahs et al. (2019)	18			12 WH; 3 BL; 1 NA; 2 OTH	8.4 (5-13)
James (2019)	58			37 WH; 3 AS	7.3 (2-16)
Koegel et al. (1978)	4	7		NR	NR (4-13)
Kroodsma (2008)	40			NR	9.8 (3-17)
Kuhlthau et al. (2020)	51			43 WH; 3 BL; 2 LAT; 2 AS; 1 PI; 2 OTH	NR (2-17+); 51% of children were between 2-11
Kuhn et al. (2020)	5	5		5 LAT	13.6 (NR)
Kuravackel et al. (2018)	33	33		NR	8.2 (3-12)
Loupee (2016)	58		1	22 WH; 13 BL; 21 LAT; 3 OTH	NR (0-10+); 90% of children were between 0-9
Malmberg (2007)	6	6		2 WH; 1 LAT; 2 AS; 1 BI	6.9 (4-10)
Matheson et al. (2019)	20	20		6 WH; 7 LAT; 1 NA; 4 AS; 2 PI	9.9 (6-13)

 Table 6. Continued.

Study	Total Numb	er of Part	icipants	Parent Race	Child Age M (Range)	
	Parent	Child	Other			
Milgramm et al. (2021)	270			NR	3.9 (1.4-12)	
Montgomery (2015)	57			35 WH; 5 LAT; 7 AS; 10 OTH	NR (2-32); 75% of children were < 10 years	
Padgett (2020)	32			27 WH; 2 LAT; 1 AS; 1 PI; I MR	7.9 (K5 <sup>th</sup> grade)	
Pearson & Meadan (2021)	9		1	10 BL	7.8 (3-11)	
Pugliese et al. (2020)	84	84		NR	13.1 (9-18)	
Reaven et al. (2009)	33	33		27 WH; 2 BL; 2 LAT; 2 OTH	11.1 (8-14)	
RUPP Autism Network (2007)	17	17		15 WH; 2 BL; 2 LAT; 1 AS; 3 MR	7.7 (4-13)	
Schreibman et al. (1991)	19	19		NR	7.2 (2.8-12.7)	
Schultz et al. (2012)	26	26		25 WH; 1 LAT	12.7 (11-14)	
Singh et al. (2021)	175			NR	12.2 (9-14)	
Solomon et al. (2008)	19	19		NR	8.0 (5-12)	
Stewart et al. (2007)	1		1	NR	10.0 (NR)	

 Table 6. Continued.

Study	Total Number of Participants		icipants	Parent Race	Child Age M (Range)	
	Parent	Child	Other			
Subramaniam et al. (2017)	4	4		NR	7.0 (2-11)	
Tomaino (2011)	6			NR	7.6 (5-10)	
Most Children 14 yea	rs of age or old	er				
Burke et al. (2016)	34		6	40 LAT	8.1 (3-19)	
Burke et al. (2018)	22			22 LAT	8.3 (3-17)	
Cash (2014)	6	6		NR	14.7 (11-18)	
Corona et al. (2016)	8	8		NR	NR (12-16)	
Cruz-Torres et al. (2020)	3	3		3 WH	14.1 (12-17)	
DaWalt et al. (2018)	45	45		38 WH	15.4 (14-17)	
Duncan et al. (2018)	7	7		NR	16.6 (14-18)	
Enav et al. (2019)	68			35 WH; 3 LAT; 21 AS; 7 OTH	9.9 (3-18)	
Hampshire et al. (2011)	1	1	1	NR	Middle School	
Hampshire et al. (2016)	5	5		NR	Grades 6 <sup>th</sup> -8 <sup>th</sup>	

Table 6. Continued.

Study	Total number of Participants			Parent Race	Child Age M (Range)
	Parent	Child	Other		
Kirby et al. (2021)	22	22		18 WH; 2 LAT; 1 ASL 1 MR	15.7 (14-19)
McCabe et al. (2017)	10	10		10 WH	19.0 (15-25)
Mitchell et al. (2010)	3	3		NR	16.6 (15-19)
Singh et al. (2014)	3	3		NR	16.7 (15-19)
Singh et al. (2019)	47	47		NR	15.2 (13-17)
Taylor et al. (2017)	41	41		36 WH; 3 BL; 2 OTH	+/- 2 years high school exit
Ura et al. (2021)	106			52 WH; 7 BL; 15 LAT; 1 NA; 13 AS; 4 MR	NR (2-18)

Note. WH = race is White; LAT = race is Latino/a/x/Hispanic; BL = race is Black/African American; NA = race is Native American/Alaskan Native; AS = race is Asian; PI = race is Native Hawaiian or Pacific Islander; BI = race is biracial; MR = race is multiracial; OTH = race is other.

**Table 7. Intervention Characteristics for ASD Parent Education Interventions** 

Study	Name	Purpose	Design	]	Intervention ]	Duration (Hours)	Outcomes	
				Modality	Materials	Components		
Majority of ch	aildren were 13	years of age or	younger				_	
Aguilar (2017)	BST	Behavioral	SC	F2F	MC; T; HAND; ON	RP;EXP;VID;H W;INT	NR	Parent
*Andrews (2020)	ACT + BPT	Behavioral; Stress	SC	OS	MC; HAND; PPT; ON	GD; EXP;HW	6	Both
*Brown- Beasley (2020)	NR	Evidence- based practice	PP	OS	PPT	LEC	2	Parent
*Celiberti (1993)	NR	Behavioral; Sibling play	SC	F2F	MC; T; HAND	EXP; INT; PH	4	Both
*Chen (2014)	Model-led- test coaching	Behavioral	SC	F2F	MC; HAND; PPT; VC	LEC; EXP; MOD	3	Both
Corona et al. (2019)	PEERS	Stress; Social skills	PP	F2F	MC	GD	NR	Both
Davis et al. (2020)	Remote caregiver training for token systems	Behavioral	SC	0	T; ON	EXP; VID	1-3	Parent

 Table 7. Continued.

Study	Name	Purpose	Design	<b>Intervention Delivery</b>			Duration (Hours)	Outcomes
				Modality	Materials	Components		
*DeFreitas (2015)	ACT	Behavioral	SC; PP	F2F	MC; HAND; VC	RP; EXP; HW; INT	NR	Parent
Dogan et al. (2017)	Behavior skills training of social skills	Behavioral; Social skills	SC	F2F	MC; HAND	RP; INT; MOD; VIG; FB	NR	Both
Dunn et al. (2012)	Contextual intervention	Stress; Family activities participation	PP	F2F	MC	СО	10	Both
*Gattuso (2013)	NR	Stress; Parent support groups	PP	F2F	HAND	GD	12	Parent
Gould et al. (2018)	ACT	Behavioral	SC; PP	F2F	MC; HAND	LEC; GD; RP; MOD	9	Parent
Hahs et al. (2019)	ACT	Behavioral	PP; RCT	F2F	PPT	NR	4	parent
*James (2019)	NR	Autism knowledge	PP; Quasi	F2F	NR	GD; HW	8	Parent
Koegel et al. (1978)	NR	Behavioral	SC	F2F	NR	LEC; EXP; VID	1.5	Both

 Table 7. Continued.

Study	Name	Purpose	Design	]	Intervention 1	Duration (Hours)	Outcomes	
				Modality	Materials	Components		
*Kroodsma (2008)	NR	Behavioral; Stress; social support; health	PP; Quasi	F2F	MC; HAND	GD; HW	15	Parent
Kuhlthau et al. (2020)	SMART-3RP	Stress; health	Quasi	OS	MC; PPT	NR	12	Parent
Kuhn et al. (2020)	JET	Transition	Qual	F2F	MC	GD; VID; News	10	both
Kuravackel et al. (2018)	COMPASS for Hope	Behavior; stress; advocacy	PP; Quasi	F2F + O	MC; HAND	NR	12	Both
*Loupee (2016)	Autism Parent Training Program	Behavior; autism knowledge	PP; Quasi	F2F	NR	NR	8	Parent
*Malmberg (2007)	NR	Behavior	SC	F2F	NR	INT	NR	Both
Matheson et al. (2019)	TEAM UP	Health	PP	F2F	MC	RP;INT	16	Both
Milgramm et al. (2021)	NR	Autism knowledge	PP	F2F	MC	GD; DID	10	Parent
*Montgomery (2015)	ACT	Behavior; stress	PP; Quasi	F2F	MC	GD; HW; VIG	15	Parent

 Table 7. Continued.

Study	Name	Purpose	Design	Intervention Delivery			Duration (Hours)	Outcomes
				Modality	Materials	Components		
*Padgett (2020)	Mindful parenting intervention	Stress; health; mindfulness	PP; RCT	F2F	MC; ON	VID; HW; DB	6	Parent
Pearson & Meadan (2021)	FACES	Advocacy; autism knowledge	PP; MM	F2F	NR	NR	18	Parent
Pugliese et al. (2020)	STAR	Social skills; transition	PP; Quasi	F2F + O	MC; ON	GD; RP; EXP; HW	9	Both
Reaven et al. (2009)	CBT	Behavior; stress; health	Quasi	F2F		GD; RP; EXP; HW	9	
RUPP Autism Network (2007)	NR	Behavior	PP	F2F	MC	GD; VID; INT	17.5	Both
Schreibman et al. (1991)	NR	Behavior	Quasi	F2F	MC	NT	NR	Parent
Schultz et al. (2012)	Social Competence Intervention for Parents	Stress; social skills; health	Quasi	F2F	MC	LEC; HW	20	Both

 Table 7. Continued

Study	Name	Purpose	Design	]	Intervention Delivery			Outcomes
				Modality	Materials	Components		
Singh et al. (2021)	MBPBS	Stress; health; mindfulness	RCT	F2F + O	MC	RP; WRT;MED	NR	Both
Solomon et al. (2008)	PCIT	Behavior; stress; social skills	Quasi	F2F	MC	EXP; VID; INT	NR	Both
Stewart et al. (2007)	BST	Behavior	CS	F2F	MC	INT	13	Both
Subramaniam et al. (2017)	DTI	Behavior	SC	Н	MC; HAND	LEC; RP; INT	1.5	Both
*Tomaino (2011)	Script procedure	Behavior; social skills	SC	Н	HAND	INT; CS	NR	Both
Majority of ch	ildren who wer	e 14 years of a	ge or older	•				
Burke et al. (2016)	LPLSP	Advocacy	Quasi	F2F	MC	NR	36	Parent
Burke et al. (2018)	LPLSP	Advocacy	PP	F2F	MC	GD; EXP; GM	36	Parent
*Cash (2014)	Parent Manual	Social skills	PP	F2F	MC; HAND	GD; RP;INT	NR	Child
Corona et al. (2016)	NR	Transition; Sexuality	PP	F2F	HAND	GD	12	Both

 Table 7. Continued.

Study	Name	Purpose	Design	Intervention Delivery			Duration (Hours)	Outcomes
				Modality	Materials	Components		
Cruz-Torres et al. (2020)	Parent Delivery of Video Prompting	Behavior; Transition	SC	Н	MC; HAND; PPT; ON	RP;VID;INT	15	Both
DaWalt et al. (2018)	Transitioning Together	Transition	RCT	F2F	MC	LEC; RP	14	Both
Duncan et al. (2018)	STRW	Transition; Health	SC	F2F	MC; HAND	VID; HW; FB	18	Both
Enav et al. (2019)	Mentalization Intervention	Health; Mental Health	Quasi	F2F	HAND; PPT	LEC; GD; HW	6	Both
Hampshire et al. (2011)	Homework	NR	SC	F2F	HAND	HW	2	Child
Hampshire et al. (2016)	Homework	NR	SC	F2F	NR	HW	3	Child
Kirby et al. (2021)	MAPSS	Transition	PP	F2F	MC	GD	9	Both
McCabe et al. (2017)	NR	Child's narrative skills	Quasi	F2F	NR	RP	2	Child
Mitchell et al. (2010)	NR	Social skills	SC; PP	F2F	MC; PPT	GD; RP; VID	10	Both

Table 7. Continued

Study	Name	Purpose	Design	Intervention Delivery			Duration (Hours)	Outcomes
				Modality	Materials	Components		
Singh et al. (2014)	MBPBS	Stress; mindfulness	SC	F2F	MC	EXP; INT; MED	NR	Both
Singh et al. (2019)	MBPBS	Stress; health; mindfulness	PP; Quasi	F2F	MC	WRT	NR	Both
Taylor et al. (2017)	VAP-T	Transition	RCT	F2F + O	MC; HAND; PPT	LEC; GD; RP	30	Parent
Ura et al. (2021)	NR	Behavior; social skills	PP	OS	NR	EXP; VID; INT	NR	Both

Note. \* = indicates gray literature; PP = design is pre/post; OS = design is online-synchronous; SC = design is single-case study; Quasi = design is quasi-experimental; RCT = design is a randomized controlled trial; MM = design is mixed methods; CS = design is a case study; F2F = delivery format is face to face, in person; O = delivery format is online, and type is not reported; OA = delivery format is online-asynchronous; OS = delivery format is online-synchronous; H = delivery format is hybrid; MC = materials include a manualized curriculum; PPT = materials include powerpoints; HAND = materials include handouts/folders/binders; T = materials include toys; VC = materials include video cameras; ON = materials include online items; RP = delivery components included videos; INT = delivery components included experiential activities; VID = delivery components included group discussions; LEC = delivery components included lectures; GM = delivery components included games; PH = delivery components included phone calls; MOD = delivery components included modeling; VIG = delivery components included vignettes; FB = delivery components included feedback; CO = delivery components included coaching; NEWS = delivery components included conversation scripts; DB = delivery components included discussion boards; MED = delivery components included meditation practice; WRT = delivery components included writing/journaling; HW = delivery components included homework; NR= not reported.

## 3.7. Figures

Figure 2. PRISMA diagram of Studies Scoped.

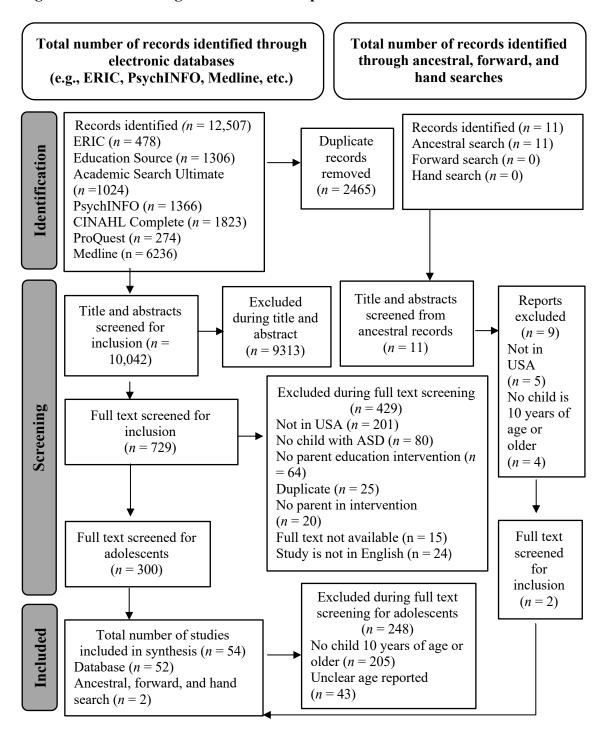


Figure 3. Parent and Child Characteristics



**Figure 4. Overall Studies Characteristics** 

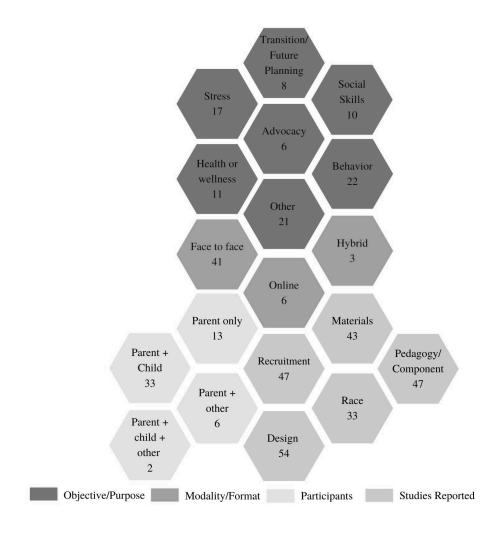


Figure 5. Racially Minoritized Participants in ASD Parent Education Interventions

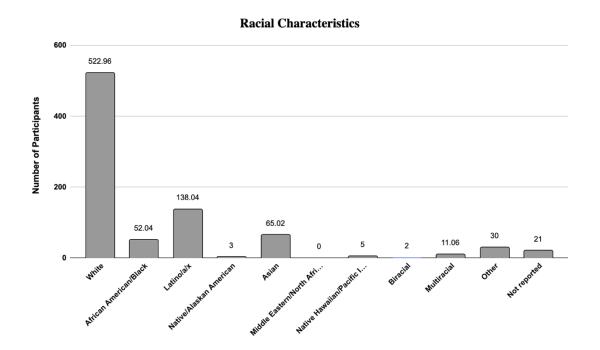
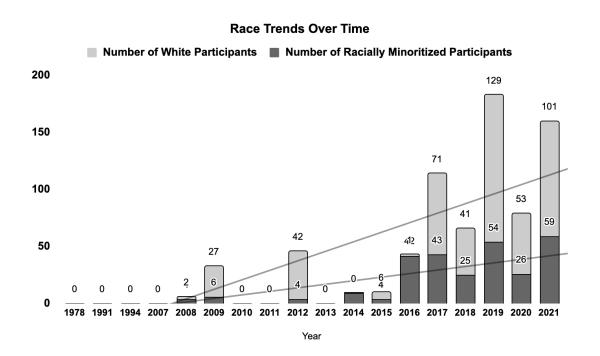


Figure 6. Race Trends Over Time



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# 4. SAATHI: A PARENT EDUCATION TRAINING FOR SOUTH ASIAN PARENTS OF CHILDREN WITH IDD

Transition is an iterative and ongoing process that demands active collaboration among multiple stakeholders, including the individual with a disability, their families, community members, and the school-based transition team. Families are particularly central to this process because they support future planning decisions, such as advocacy efforts and adult service systems, that guide the post school outcomes of their children with disabilities. Notably, in 2015, the American Association of Intellectual and Developmental Disabilities (AAIDD) identified supporting families as one of its primary priorities to advance research and practice in this area (Meadan & Snodgrass, 2018). The researchers recognized the important roles families play in supporting and advancing post school outcomes of their young adults with IDD and identified family members as experts in advocacy, locating resources, and gathering knowledge related to future planning endeavors (Meadan & Snodgrass, 2018).

# 4.1. Building Family Partnerships in Transition

Building positive partnerships with racially minoritized families who are navigating the transition planning process is essential to expanding postschool outcomes of young adults with IDD. Parent and caregiver voices typically guide the field in learning more about how they prefer to be supported. Francis and colleagues (2018) conducted interviews with 12 Hispanic families to understand their experiences with transition planning and identified several strengths the families shared. The families indicated that their positive experiences of transition planning were informed by (1) trusting partnerships between stakeholders and families, (2) availability of and access to knowledge/resources, (3) maintaining connections with community members, and (4)

high expectations from stakeholders regarding the child's skills and outcomes (Francis et al., 2018). Once equipped with the knowledge and advocacy skills, racially minoritized families of children with IDD could successfully navigate the complexities of transition planning and strengthen the postschool outcomes of their child. Thus, stakeholders, including educators and researchers, must develop culturally responsive training to prepare families with the knowledge and advocacy skills to effectively navigate future planning.

Extending the research on family voices, Wilt and colleagues (2018) conducted a scoping review of culturally sustaining practices in transition for racially minoritized families and identified several themes from seven studies across 115 participants. The researchers reported that one of the largest themes they found was effectively communicating to families about transition planning opportunities (Wilt et al., 2018). For instance, families desired additional communication from stakeholders and service providers about navigating adult service systems, advocating, school-based transition opportunities, and family-based transition plans (Greenen et al., 2005; Landmark et al., 2007; Povenmire-Kirk et al., 2010; Rueda et al., 2005; Shapiro et al., 2004). Building family's knowledge of the opportunities that could be available for their son or daughter after high school is essential for forging a path toward equity-driven partnerships between families and transition professionals to advance postschool outcomes of young adults from racially minoritized communities.

# 4.1.1. Parent Training to Support Families

Training parents has been an effective avenue to increase support for families across the lifespan. Parent training equips and supports individuals with IDD and their families across various domains. Parent training typically includes components related to parent support or psychoeducation, parent-mediated training, or a combination of both. Bearss and colleagues

(2015) define parent support or psychoeducation as indirectly benefiting the child, whereas parent-mediated training focuses more on techniques that aim to directly support the child with various skills. For instance, learning about core symptoms of a disability could be a psychoeducational intervention, whereas specifically learning about toileting skills and then applying them directly with coaching support could be a parent-mediated approach.

Parent training goals also vastly differ. For instance, parents of children with IDD have been trained on knowledge specific to special education (Burke & Sandman, 2016), sexuality education (Rooks-Ellis, 2020), social skills (Karst et al., 2015), reducing challenging behaviors (Pillay et al., 2011), and daily living skills (Matsumura et al., 2022). Specifically, parent training related to parent educational outcomes has focused on knowledge of autism core symptoms (Smith et al., 2014), providing parents of children with developmental disabilities and challenging behaviors with coping strategies to reduce parent stress (Jones & Passey, 2004), and increasing parent advocacy and empowerment (Jamison et al., 2017). Furthermore, a recent review of interventions to increase parental involvement in special education found that most parent training interventions that used randomized controlled trials were related to individualized education program (IEP) meetings, particularly teaching parents more about special education law, IEP meetings, and parent advocacy (Goldman & Burke, 2017). The diversity of parent training outcomes emphasizes the need to target specific, individualized skills to further support and equip parents in multiple domains. While knowledge has been a prominent feature of parent training programs, additional components such as parental well-being and advocacy focus on varied skills that help prepare parents to navigate special education systems successfully.

Parent education training with exclusively racially minoritized families is an emerging endeavor in special education, and only a handful of studies have focused on a multitude of goals

for parent training. Prior to these studies, parent education training was derived from and implemented with a white, middle class, and western oriented lens that did not account for the unique and individualized needs of racially minoritized families. Parent education training with diverse racial populations informs the field of the content of knowledge that may be more relevant to the unique needs of families and the outcomes that would better support parents and their children.

Emerging literature has addressed parent training with racially minoritized families. Parent training with African American families of children with IDD has focused on parental advocacy, empowerment, and support (Pearson & Meadan, 2021), and trauma informed advocacy support with accessing services (Kaiser et al., 2022). With Latinx parents, parent training outcomes have included increased advocacy (Burke et al., 2016), increased parent empowerment (Magaña et al., 2015), and increased knowledge of special education law and service systems (Rios et al., 2021). However, no study to date has specifically focused on training exclusively South Asian parents to explore their unique transition outcomes. The development and evaluation of a parent training with various subgroups of racially minoritized families, such as South Asian parents, could strengthen current and future support systems offered to South Asian families. It could also individualize services that are unique to parents' needs, and inform the field about the strengths and challenges this population encounters when navigating the transition planning process.

# 4.1.2. Parent Education Training in Transition

Parent training has been relatively recent in the field of transition, and parent education interventions have slowly grown over the past 20 years. Since transition planning became integrated in the IEP process in 1987, Boone's (1992) study was one of the first to implement a

parent education intervention to increase parents' involvement in the (IEP)/transition conference (now known as person-centered planning). The intervention offered parents an opportunity to learn about the importance of transition planning, provided information on transition opportunities after high school, and provided insight for advocating for your child during the IEP meeting.

DaWalt and colleagues (2018) conducted a parent education intervention, *Transitioning Together*, which included 45 participants who were parents of young adults with autism. The intervention curriculum discussed topics such as knowledge of autism, employment and college planning, family topics, community involvement, and legal issues. The authors concluded parents had reduced depressive symptoms, increased knowledge of transition, and increased problem-solving skills.

Using a computer program, Rowe and Test (2010) developed a single-case study with four parents to increase parental transition knowledge along three categories: postsecondary goals, postsecondary transition service providers, and secondary transition services. The authors concluded a functional relationship between the intervention and increased knowledge of transition planning among all 4 participants. Furthermore, Young and colleagues (2016) attempted to understand which resource (brochure or brochure and training) would result in increased knowledge of transition services among 23 parents. The authors found that brochure plus 30 minutes of training yielded higher retention of knowledge of transition services.

Additionally, the authors also called families six months after the intervention to understand if they had contacted any services, and most of the individuals who participated in the brochure plus training intervention arm had called various transition service providers to learn more.

One of the most recent parent education trainings was conducted by Taylor and colleagues (2017; 2022) called *VAP-T* and *ASSIST*. For the VAP-T, the authors conducted a 12-week randomized controlled trial with 41 families of young adults with autism 2 years prior to their high school exit. The *VAP-T* curriculum included the following categories: person-centered planning, postsecondary education, financial support, employment, Medicaid, future planning, medical services, and advocacy. Parent outcomes included increased knowledge of the adult service system, increased comfort and skills to advocate for services, and increased parental empowerment. Similarly, *ASSIST* (Taylor et al., 2022) was a multi-site 12-week intervention with 91 parents to increase their knowledge of adult service systems. The researchers concluded that parents increased their knowledge, were satisfied with the training, and that the training was feasible and acceptable.

Additionally, a recent review identified three parent education interventions to increase self-determination of young adults with IDD (Dean et al., 2021). The authors found that the three studies used a family-centered framework to teach parents self-determination skills to increase the youth's outcomes. All studies noted an increase in the self-determination outcomes of the young adult, specifically related to decision-making skills (Hagner et al., 2012), goal attainment (Kim & Park, 2012), and task-specific skills (Harr et al., 2011). Due to the small number of interventions found, the authors argue that little attention has been paid to the domain of self-determination outcomes in parent training interventions and call to action a need to increase research in this area.

Although parent education training has grown significantly in recent years, few interventions have been specifically developed and adapted for racially minoritized families to increase their postschool outcomes and access to adult service systems. To date, only one

transition-specific parent training has been developed and adapted for racially minoritized families in the United States. Kuhn and colleagues (2019) culturally adapted *Transitioning Together* (DaWalt et al., 2018) for Latinx families using the ecological validity framework (EVF). The authors conducted interviews to understand parent experiences with the training and found that in addition to the curriculum, family members also desired to learn more about sexuality education, navigating service systems (healthcare, psychiatrists, assisted living), addressing legal issues (immigration, trusts, guardianship), and further knowledge of vocational programs and services.

The paucity of parent education training for transition-related services necessitates an increased focus in this area to increase postschool outcomes of young adults with IDD from racially minoritized backgrounds. Growing interventions related to transition-focused outcomes for young adults with IDD have consisted of primarily white populations (DaWalt et al., 2018; Francis et al., 2013; Rowe & Test, 2010; Taylor et al., 2017; Young et al., 2016) which is not representative of the unique support needs of racially minoritized families. Lack of racial diversity within transition-focused parent training reflects a current orientation that is dominated by a western, white gaze that ultimately has defined transition planning outcomes for all populations, despite their individualized racial differences and racialized experiences. The field demands a shift toward preparing specific, disaggregated racially minoritized populations to (1) increase parent partnerships with adult service systems and transition stakeholders and (2) prepare parents to make culturally affirming and informed decisions for their child when planning for their adulthood outcomes.

#### 4.1.3. South Asian Parents

Within the United States, the South Asian population is growing rapidly. Indian Americans account for 21% of the total Asian population within the United States, represent the largest Asian group in Texas (28%), and Hindi is the second most common language spoken in the country among Asians after Chinese (Budiman & Ruiz, 2021). South Asian individuals, particularly Bangladeshi and Pakistani Americans, doubled in size between 2000 and 2010 (Asian American Center for Advancing Justice, 2011). While a handful of researchers have explored South Asian parents' perceptions related to transition planning (John et al., 2016; Shikarpurya & Singh, 2021; Zechella & Raval, 2016), no study to date has explicitly explored the outcomes of a parent education transition training for South Asian parents of children with IDD living in the United States. In addition to a dearth of research with South Asian populations in transition, outcomes among different ethnic groups within the racial Asian label could differ significantly from one another. For example, research with Asian population with disabilities in Hawaii shows discrepancies between the vocational rehabilitation services perceived to be received by the larger data on Asians and the gaps between certain ethnic groups (Yang et al., 1996). Specifically, for South Asians, an intervention that leverages their strengths (see study 1) and uses culturally competent practices to equip them with transition-focused knowledge would speak to the precise needs of the population.

# 4.1.4. Purpose Of This Study

The purpose of this study is to report the development, effectiveness, acceptability, and feasibility of South Asians Accessing and Advocating for Transition and Higher Education Inclusion ("SAATHI," which in Hindi means companionship or support). SAATHI was a sixweek pilot parent education transition training intervention for South Asian parents of children

with IDD living in the United States. I developed SAATHI to share transition-related resources with parents, offer a South Asian community for parents to engage with, and connect parents with local organizations and stakeholders with the aim of increasing their child's postschool outcomes. Additionally, SAATHI also bridged the gaps identified in study 2 related to limited interventions developed for racially minoritized families, including no interventions for South Asian families, and scant trainings related to transition resources. My research questions were:

- 1. Does participation in SAATHI increase parents' knowledge of transition-related outcomes for their child?
- 2. Does participation in SAATHI increase parents' self, community, and familial mastery?
- 3. Does participation in SAATHI decrease parents' stress?
- 4. Do parents perceive an increased sense of community and belonging after participating in SAATHI?
- 5. Does parent to parent engagement increase after participating in SAATHI?
- 6. Do participants consider SAATHI parent education transition training to be socially valid (feasible and acceptable)?

#### 4.2. Methods

# 4.2.1. Researcher's Positionality

I identify as a South Asian, Muslim female who has extensive experience working with racially minoritized families in special education. My scholarship uses critical frameworks to inform and advance adulthood outcomes of racially minoritized youth with disabilities and their families. I also identify as a sibling of an individual with autism.

# 4.2.1.1. SAATHI: Preparing for Adulthood Parent Education Training

South Asians Accessing and Advocating for Transition and Higher Education Inclusion (SAATHI) was a pilot parent education training program for South Asian parents of children with IDD living in the United States. The purpose of SAATHI was threefold: (a) to prepare parents to successfully navigate post school opportunities for their children with IDD, (b) to foster a sense of community and belonging among parents, and (c) to support their mental well-being. SAATHI was developed to mitigate challenges racially minoritized parents often encounter when navigating transition-related services and to offer strengths-based resources to specifically address transition concerns identified by South Asian parents (See study 1). Informed by prior studies, SAATHI offered transition-focused resources and community supports using strengths-based approaches to prepare parents for post school opportunities. SAATHI was held online for six weeks, 90 minutes per week, using a group training model with two cohorts. SAATHI was evaluated using quantitative and qualitative measures.

# 4.2.1.1.1. Theoretical Frameworks

SAATHI was developed using two theoretical frameworks, including critical race theory (Delgado & Stefancic, 2001) and ecological validity framework (Bernal et al., 1995). Critical race theory has been embedded in educational interventions using the following five tenants: (a) race, racism, and intersectionality of identities is central to educational principles and structures, (b) to challenge dominant, deficit-based narratives, (c) to commit to social justice endeavors, (d) to acknowledge that experiential knowledge of individuals is legitimate and critical to understanding and analyzing systems in education, and (e) commitment to an interdisciplinary perspective to challenge dominant ideologies (Solórzano and Bernal, 2001). Additionally, I have

used the framework of counterstories within critical race theory to re(present) the voices of South Asian families from a strengths-based perspective (Solórzano & Yosso, 2002). Counterstories challenge the dominant myths and stereotypes of a racial or cultural group and serve as a tool to empower voices that are often overlooked or unheard.

Critical race theory informed the development of SAATHI in multiple ways. First, the training resources, including the pre-training resources, weekly content PowerPoints, and additional resources shared after the training, were developed using language that addressed parents' strengths and avoided using deficit-based language. For example, at the beginning of each content session, I used a PowerPoint slide to remind parents that they have a voice and a seat at the table to be able advocate for their children. Specifically, I listed six strengths found in the first study (See study 1) to encourage, voice, and bolster parental strength (e.g., ability to navigate complex systems and organizations; fighting and resisting personal and organizational systems).

Second, after each weekly content session, parents were placed into pre-determined online breakout rooms to discuss the application of the content and develop solutions for the case studies. These discussions affirmed parents' experiential knowledge as legitimate and encouraged parents to integrate content knowledge and their experiential knowledge to make informed decisions regarding transition opportunities. Lastly, the pretest, posttest, and the case studies used during weekly trainings used strengths-based language and culturally competent examples rather than one focused on deficit discourse. For example, the pre/posttest asked the following, "Anita likes to bake and would love to find a job one day in a bakery. Which of the following services could help her find a job? Check all that apply." Similarly, a case-study for breakout room discussions contained the following prompt "As an empowered and a

knowledgeable parent, come up with five questions you can ask group homes or day habilitation programs before you enroll your child. Example: Who will be their peers?"

In addition to applying the framework of critical race theory, I also used the Ecological Validity Framework (EVF) to develop SAATHI using cultural competence. EVF was developed by Bernal and colleagues (1995) as an eight-dimensional framework to improve ecological validity among racially minoritized populations when developing or adapting interventions. The eight dimensions of EVF include: *language* (e.g., using culturally competent language or words participants would be typically familiar with), *persons* (e.g., acknowledging similarities or relationships between trainer and participants), *metaphors* (e.g., symbols or common sayings familiar to participants), *content* (e.g., cultural knowledge), *concepts* (e.g., treatment concepts that resonate with participants), *goals* (e.g., goals that support cultural values and cultural needs of participants), *methods* (e.g., treatment methods that reflect cultural competence), and *contexts* (e.g., training locations that would be culturally appropriate).

Specifically, I embedded the EVF framework in SAATHI by: (1) Sharing key words and phrases in Hindi and/or Urdu as desired by parents, (*language*), (2) serving as a the trainer due to my own positionality as a sibling and a person from South Asia, and I invited guest speakers who also were family members to build parents' trust (*persons*), (3) incorporating language such as "future planning training," and using words such as "desi" to reflect the insider term used by some South Asians to self-identify (*metaphors*), (4) embedding content that discussed planning for parents with various citizenship statuses, religious beliefs, and economic status, as well as including content addressing stigma, navigating challenges, and financial planning as culturally informed content knowledge (*content*), (6) used concepts of community integration, extended families, and social networks to discuss future employment opportunities (*concepts*), (7)

reframed training as a community companionship and partnership by having conversations with parents rather than lecture-style models, modeling breakout room discussions, and offering personal life examples of navigating adult service systems (*methods*), and (8) using accessible format of Zoom so that more parents could participate without transportation concerns (*contexts*).

# 4.2.1.1.2. Community-Driven Partnerships

I also partnered with multiple community stakeholders to guide and inform the development of SAATHI. Prior to and upon determining the content of the training sessions, I consulted with other researchers who have also conducted parent interventions related to parents' knowledge of adult services and advocacy (Burke et al., 2019; Taylor et al., 2017) and those who have conducted interventions with specifically racially minoritized families (Castro-Olivio & Merrell, 2012). Additionally, I partnered with three leaders from partner organizations (*DUS*, *DREAM*, and *Special Stars*) and three South Asian parents of children with disabilities to develop the content for SAATHI. The community partners supported with developing the training and served as an advisory council to ensure cultural competency.

First, I created an outline of the weekly content informed by Study 1 and prior research (Shikarpurya et al., under review) and individually asked each community partner to review it for relevance, need of parents, and accessibility of information based on their individual expertise. Second, I asked each community partner for their feedback on the pretest and posttest measures, parent satisfaction survey, and weekly feedback surveys based on their expertise. I specifically asked for feedback related to ease of completing the surveys, clarity of the questions, and language or academic jargon used in the surveys. Third, I specifically collaborated with the three leaders from partner organizations to determine optimum length, timings, and duration of the

training. For instance, one of the training sessions were held on Wednesday nights at 8pm to ensure most parents could participate after work. I incorporated all of their feedback into the final training documents.

#### 4.2.1.1.3. **Recruitment**

Upon receiving approval from the institutional review board at Texas A&M University, I began to recruit participants for this study. Recruitment occurred in three phases. First, I formed partnerships with three organizations that work largely with South Asian families of children with disabilities in Texas. *Dar Us Sakina* (DUS) is a non-profit organization that supports Muslim families of children with disabilities in the Houston area. I was connected to *Dar Us Sakina* by a parent organization, *Muhsen*, with whom I had worked with previously to recruit South Asian families (Shikarpurya et al., under review).

DREAM is a parent-led organization in Dallas, Texas who I contacted via email to recruit participants. I had met the leadership of DREAM when we were both serving as a panelist for a webinar from AAIDD. Special Stars is a South-Asian parent support group, started by South Asian parents in Houston, Texas to discuss resources and share best practices on a weekly basis. The lead parent of Special Stars had previously completed a survey for a prior study (Shikarpurya et al., under review) and offered to stay connected with me. I reached out to the lead parent of Special Stars to recruit for SAATHI as well. I have been involved with all three of the organizations prior to recruitment for SAATHI and have built strong partnerships with the leadership of these organizations.

Second, I contacted the leaders of the three organizations (e.g., *DUS*, *DREAM*, and *Special Stars*) three months prior to recruiting for SAATHI to share information about the training, discuss the alignment of the needs of the organization with the training objectives, and

develop shared goals. I initially contacted each leader via email. After initial contact, each of the three leaders and I communicated via email, phone, and text messages on a weekly basis to revise the training documents, connect with local stakeholders for additional feedback, and ensure that all the training content is culturally competent and affirming for South Asian families within their organizations. We also discussed ideal timeframe of the training, including length and duration, to overcome Zoom fatigue. Once the three stakeholders and I confirmed the brochures, recruitment timelines, and recruitment modalities, we began the recruitment process.

Third, I recruited participants for two months, from June 2022 to August 2022. I sent an email to each organization that included a brief description of SAATHI transition training, including its benefits and compensation, a flyer in English with details of SAATHI, and my phone number and email address if participants have any questions and would like to speak with me regarding the study. I asked each organization to share the information in the email with their constituents. The organizations sent an email reminder to parents once a month, starting in June 2022. I was also invited by the organizations to share SAATHI recruitment details using WhatsApp messaging service, where I shared the study details, study flyer, and my information.

The organizations continued to remind parents of the training using WhatsApp every two weeks, starting in July 2022. I also created a one-minute video for parents of the three organizations to be shared in the WhatsApp groups and on Facebook Live. The organizations emphasized the importance of sharing training details using multiple avenues that are widely accessed by South Asian parents, such as WhatsApp parent groups and Facebook Live events to increase access. The one-minute recruitment video was shared by the organizations four times during recruitment, starting at the end of July 2022. I expected 20-30 parents to attend and successfully complete the six weeks online training. I chose 20-30 participants as a threshold

because recent studies with racially minoritized families have shown that it is feasible and acceptable to conduct parent education with this sample size (Rios et al., 2021).

## 4.2.2. Participants

#### 4.2.2.1. Inclusion Criteria

Participants in this study completed a six-week training to learn about postschool opportunities for their children after high school, engage with other South Asian parents in the trainings, and develop connections with local stakeholders. Parents were included in the study if they: (a) identified as a South Asian parent, a legal guardian, or the primary caregiver of a child with IDD, (b) could read and write in English and spoke English, Hindi, or Urdu, (c) had a child between the ages of 3 and 25 years old with documented IDD, (d) provided self-reported confirmation of a diagnosis of IDD, (e) were able to attend a six-week, online parent training that occurred once a week, for 90 minutes on Zoom, (f) completed pre and post surveys, and (g) attended at least four of the six weekly training sessions. I also offered an Amazon gift card of \$25 to parents who attended all of the training sessions (six out of six), completed the pre and post surveys, completed weekly feedback surveys, and completed the parent satisfaction survey on week seven.

Parents were defined as a biological parent, a legal guardian, or a primary caregiver. I also included parents who did not identify as South Asian, but were either a spouse of South Asian individuals, identified as a Muslim parent who was recruited from DUS, or indicated strong ties and affiliation with the South Asian community (N = 4). I broadened access to the training for these parents because they expressed a strong desire to complete the training and had shared affinity with the other South Asian parents (e.g., shared faith (N = 3), or deep knowledge of the community via their spouses (N = 1).

Additionally, I did not include parents of children younger than three years old because there are already supports available with early diagnosis. However, I did include parents of children younger than typical transition age (14 or 16 years old) to equip them with transition-related resources earlier so that they are prepared for this next phase and could make informed decisions as their child approaches adulthood. Lastly, while young adults exit special education at the age of 22 years in Texas, prior studies (Shikarpurya et al., under review) have highlighted a need to also equip parents of older adults who have exited special education services to continue to expand their adulthood outcomes. Thus, I chose to broaden the child's age range to 25 years old.

#### 4.2.2.2. Consent

Parents first consented to participating in the study. Once they agreed to participate by signing the consent form, they could proceed to complete the pretest. On the first day of the training, I first introduced the details of the training and reviewed the consent document with the parents. I also asked to see if parents had any questions about the training and/or the consent procedures. Next, parents were asked to complete the pretest, which lasted approximately 30 minutes. Once parents had consented to the study and completed the pretest, I began the training session.

#### 4.2.2.3. **Attrition**

I conducted an a priori power analysis using G\* Power version 3.1.9.7 to determine the minimum sample size required to test the effectiveness of SAATHI (Faul et al., 2007). I estimated the power of matched pairs (e.g., difference between two dependent means) using a power of 0.8 with an effect size of 0.5 (Cohen, 1988). Based on the power analysis, I would need

a minimum sample size of 27 participants to detect a medium effect. Thus, with a sample size of 31 participants, it was adequate to test the effectiveness of SAATHI.

82 parents had shared initial interest in SAATHI, either by contacting me directly via email (N = 23), phone calls (N = 6), and text messages (N = 11), or sharing their interest with their respective organizations (N = 42). From the initial 82 parents who were interested, 49 parents attended the first session and/or completed the pre-test. Although the pretest was administered on the first training session, some parents who could not attend asked to take the pre-test independently prior to the first session. Three parents did not attend any additional sessions after the first session. Of the remaining 46 parents, 13% of the parents attended two of the six sessions (N = 6), 19.6% attended 3 of the six sessions (N = 9), 11% attended four of the six sessions (N = 5), 19.6% attended five of the six sessions (N = 9), and 37% attended all of the six training sessions (N = 17).

Overall, 31 participants, or 67% of parents out of the initial 46 parents, were included in the study because they attended at least four of the six training sessions (Figure 7). I calculated overall attrition by dividing the number of parents who did not attend any additional sessions after completing the pretest (N = 6) by the number of parents who attended the first session and completed the pretest (N = 49) multiplied by 100. I calculated attrition using this method because out of 49 initial participants, only three had dropped out and did not attend any further sessions while 46 participants remained in the study and attended additional sessions. Overall attrition was 6%.

# 4.2.3. Duration and Length of SAATHI

The six-week training sessions occurred once per week, for 90 minutes on Zoom. While prior transition-focused trainings have been 12-weeks or longer (Burke et al., 2016; Taylor et al.,

2017), and findings from study 2 also indicated longer length of parent trainings (e.g., 8 weeks or more), I chose the length of six-weeks for SAATHI based on feedback from community stakeholders. I made this decision due to the following reasons: (a) lower familiarity of South Asian parents with formal trainings, (b) zoom fatigue for online trainings longer than six weeks, and (c) prior experiences of community stakeholders with six-weeks as an ideal length to keep parents engaged in trainings. Additionally, I chose to conduct each session for 90 minutes due to the content of the sessions, guest speaker availability, and input from community stakeholders. Community stakeholders shared their feedback based on their prior experiences with conducting trainings for South Asian families within their respective organizations. Zoom fatigue was also noticed very often by community stakeholders, and we did not want to lose the attention of parents.

## 4.2.4. **Setting**

SAATHI occurred weekly on zoom using a pre-determined zoom link. I chose to conduct SAATHI virtually because (a) majority of the interested parents shared they would prefer an online training using Zoom due to their familiarity with the platform, (b) we are in the midst of a pandemic and I chose to offer a more accessible training platform for all parents, and (c) scant research exists regarding the effects of online parent training, as determined from study 2. I shared the zoom link with the participants on our shared WhatsApp groups and via email on a weekly basis. The zoom link remained the same for each cohort. I also recorded the trainings each week and shared all the training videos a week after the last session was completed.

#### 4.2.5. Cohort Model and Communication

I placed participants into two cohorts based on their affiliated organization (see details in Recruitment section). While I initially recruited from three organizations, only two participants

attended the training sessions from one of the organizations. Therefore, they were placed with a non-affiliated cohort. The time of the training was decided in consultation with the leaders of the organizations. One cohort met on Zoom for training on Wednesday evenings, while the other cohort met on Sunday afternoons. Parents received the training in two cohorts to provide more time for interaction and engagement during the training sessions. This also ensured that parents were able to ask their questions in a smaller group setting and developed meaningful relationships with their peers.

I also assigned each cohort of parents (e.g., Wednesday and Sunday groups) to a WhatsApp group. I used WhatsApp because it is a common form of communication among South Asian parents and the organizations already used their method to communicate with parents, so they were very familiar with it. I communicated all training related information on these two WhatsApp groups.

#### 4.2.6. Materials

I created a physical binder with 30 sheets of resources for parents in the study. These resources were divided by content for each training session, and offered tools for parents to use when planning for their child's adulthood outcomes. For instance, the resources included advocacy tips for transition planning meetings, an email template to schedule a meeting with transition professionals, and a list of questions parents could ask when exploring day habilitation and/or 18+ programs. Two weeks before starting the training, interested parents were asked by their respective organizations to complete an interest form, indicating their interest in receiving these resources either in person or online. I asked parents who preferred a physical binder to pick up the binder from a known, local community location (N = 20), and emailed a PDF copy of the

resources to everyone else. I also emailed a PDF copy of all the PowerPoints used during the training and recordings of all the trainings to the participants who completed the pretest.

## 4.2.7. Overview of Weekly Sessions

Each SAATHI training session began with 10-minutes of parent engagement, where I asked parents about their strengths and challenges from the prior week, any key learnings from prior weeks, and anything else they preferred to share. During this time, parents typically shared their strengths and challenges, and their peers also added on to their stories, or provided advice based on their own experiences. Next, I shared a PowerPoint slide listing their strengths as parents, and introduced the topic of the session using PowerPoint. I discussed the content of the session using conversation-style method, often asking questions and offering personal stories to supplement the content. This discussion lasted for 30-40 minutes each session.

Afterwards, I modeled a case study related to action items parents can take after learning about the content, and placed parents into pre-determined breakout rooms to discuss a new case study. Parents were asked to discuss the case study with their peers in the breakout rooms for 30 minutes. During the last 10-15 minutes, we discussed the outcomes each group came up with, and I asked parents to complete the weekly feedback surveys. I also reminded the parents about the topic for next session and asked if anyone had any questions or concerns they would like to discuss.

The content of the six-week training included: (1) introduction to parent training and transition planning, (2) higher education and living opportunities, (3) financial planning and government benefits with a guest speaker who identified as a sibling of an individual with a disability and worked professionally as a special needs financial planner, (4) financial planning and guardianships with a guest speaker who identified as a parent of a child with a disability and

worked professionally as a special needs lawyer, (5) employment opportunities and navigating challenges with schools/services and (6) choosing reliable community resources. An optional booster session on sexuality education with a guest speaker who identified as an expert on sexuality education for individuals with disabilities was offered to interested parents two months after the training ended.

#### 4.3. Measures

#### 4.3.1. Pretest and Posttest

Parents completed an identical pretest and posttest. The purpose of this measure was to determine if the participant scores have changed from the pretest to the post test since completing SAATHI. The pretest was completed at the first training session, and included a consent form and demographic information. The posttest was completed on the last day of the training session, and did not include a demographic section. Parents did not have a time limit to complete the pretest and posttest, however most parents completed the tests within 30 minutes. Both the pretest and the posttest were administered using Qualtrics, and parents were provided with the Qualtrics link using Zoom chat and their respective WhatsApp groups. I also calculated Cronbach's alpha to measure internal consistency of each scale.

# 4.3.1.1. **Demographic Information**

I developed this section to understand parent characteristics and demographics. Parents were asked to provide their (a) names, (b) email address, and (c) phone numbers to be added to the WhatsApp group. Additionally, parents were asked to complete 20 questions about their own demographic information as well as information about their child (e.g., what is highest level of education? what is your child's diagnosed disability?) This information also ensured that to determine participants' eligibility. Additionally, I also asked if their child currently receives any

future-planning services, if they have ever received any future-planning services, and how important was it for parents to learn about future planning opportunities.

## 4.2.9.3. Parent Stress Scale (PSS): Dependent Variable

I used the 10-item parent stress scale (Cohen, 1983) to explore parents' perceived stress prior to and after completing SAATHI training (e.g., In the past month, how often have you felt that you were unable to control the important things in your life?). For each item, parents responded to five-items on a Likert scale (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often). Scores are calculated by reversing responses (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items and then adding the scores across all subscale items. I chose to use this scale for clarity of language, brevity of the scale, and ease of understanding. Cronbach's alpha was 0.90 at pretest and 0.88 at posttest.

### 4.3.1.2. Multicultural Mastery Scale (MMS): Dependent Variable

The multicultural mastery scale was developed by Fok and colleagues (2012) to explore the multidimensional mastery of culturally competent coping strategies. I used this scale to further explore parents' own sense of control and mastery as well as their perceptions of using familial and community resources when coping with stress and challenges. The three categories of mastery (e.g., own self, family, and community) could be viewed as agents of parental strength and resilience in coping and overcoming difficult circumstances. While this scale has been validated and implemented with indigenous Alaskan youth, Fok and colleagues (2012) encouraged future research with other collectivists cultures, such as South Asians, to adapt this scale.

I adapted the 13-item multicultural mastery scale (MMS) using own expertise and collaborating with community stakeholders. Specifically, the original scale included three

dimensions of mastery: self-mastery, family mastery, and friends-derived mastery. However, for South Asian families, as found in the first study, community is an essential aspect of their sense of belonging, and therefore necessary to explore. I changed the "friends" mastery to community mastery (e.g., working together with my community I can solve many of my problem) and included the following definition of community at the beginning of the scale: "Community refers to your friends, social community, faith community, parent community, or the larger disability community." Parents could respond using a five-point Likert scale (e.g., strongly disagree, disagree, neither agree nor disagree, agree, or strongly agree). There were four-items for community subscale, four-items for family subscale, and five-items for self-subscales.

Cronbach's alpha was 0.81 at pretest (community subscale was 0.86, family subscale was 0.81, and self-subscale was 0.76) and 0.91 at posttest (community subscale was 0.88, family subscale was 0.89, and self-subscale was 0.83).

#### 4.3.1.3. Transition Knowledge: Dependent Variable

I created a 10-item multiple choice transition knowledge scale based on the content of the six-week parent training. Items included questions related to: (a) overall transition planning laws (e.g., In Texas, at what age can you legally start transition planning?), (b) application of advocacy skills (e.g., Ankit and his parents have been working with his ARD/IEP team to make sure he is improving his ARD/IEP goals. However, they feel that he is not making progress, and his ARD/IEP team is not helping him. They want to advocate for him but are unsure where to start. What can his parents do to advocate for his needs?), (c) higher education and employment (e.g., What is an inclusive postsecondary education program?), and financial planning (e.g., At what age can a child begin to receive supplemental security income benefits?). Each question was given one point for a correct response and a 0 for an incorrect response, with a maximum of

ten points awarded. In this study, the Kuder-Richardson coefficient was .50 at pretest and .52 at posttest.

#### 4.3.1.4. Advocacy Scale: Dependent Variable

Parent advocacy has been measured in transition interventions to explore parents' knowledge and comfort with advocating as well as how frequently they use their skills to advocate in adult service systems (Burke et al., 2016; Lee et al., 2022). I adapted the original scales based on my expertise and feedback from community stakeholders to increase cultural competence for South Asian parents. For the knowledge and comfort subscale (Burke et al., 2016) I added items related to parents' comfort with: their rights in special education, sharing information with other parents, using resources outside schools to locate information, experiences with appropriate academic placements, and voicing their concerns with transition stakeholders. Parents could respond using a five-point Likert scale (1 = Not at all, 2 = below average, 3 = average, 4 = good, and 5 = excellent).

I also scaffolded the items on the action subscale (Lee et al., 2022) toward smaller goals that parents could work towards. Specifically, I added attending trainings, asking for support from community members, calling agencies, and asking for translators among other items as actions related to parent advocacy. Parents could respond using a five-point Likert scale (1 = Not at all, 0 times, 5 = very often, six or more times). In this study, there were eight-items related to parents' knowledge and comfort with advocacy, and 10-items regarding frequency of actions they have completed related to advocacy. Cronbach's alpha was 0.92 at pretest (knowledge and comfort subscale was 0.88, and action subscale was 0.89) and 0.92 at posttest (knowledge and comfort subscale was 0.90 and action subscale was 0.90).

### 4.3.2. Weekly Community Engagement

I calculated parents' weekly engagement with their peers in the training using the WhatsApp groups created for each cohort. I defined engagement as parents asking questions, posting information or resources, providing vignettes of their experiences, or seeking advice from other parents on the WhatsApp group. I created a five-point checklist to measure parents' extent of engagement with each other via WhatsApp exchanges (e.g., At least one participant initiated a text regarding resources related to future planning; appendix x). I also noted qualitative data for each weekly measure, including the number of participants who exchanged messages in a week, the number of messages exchanged each week, and the themes that were discussed. Parent engagement was measured from the first week of training until one week after the last training session. I calculated parent engagement on a weekly basis, on the Sunday of each week.

#### 4.3.3. Social Validity

#### 4.3.3.1. Weekly Feedback Surveys

I created a five-item weekly feedback survey for parents to complete via Qualtrics after each weekly training session. The survey asked parents questions about their experience with the week's session (e.g., The information presented today was clear and easy to understand), extent to which they found the session helpful and applicable (e.g., I learned something new from the training session; I can apply what I learned today to help me plan for my child's future), and the extent to which they felt confident with their advocacy skills after the session (e.g., I feel more confident with advocating for my child's future planning needs). Parents responded to the survey items on a five-point Likert scale (1 = strongly disagree, 5 = strongly agree). I also asked an open-ended question about any additional feedback parents may have regarding the training.

Additionally, for sessions with guest speakers (e.g., week 3, week 4, and the booster session), I included an extra question that asked about the speaker (e.g., I would recommend this speaker for future trainings).

## 4.3.3.2. Parent Satisfaction Survey

In addition to the weekly parent feedback surveys, I created a 21-item parent satisfaction survey, which was administered a week after the training ended. The survey was designed to explore (a) parents' overall experiences with the design, instruction, and content of the sessions (e.g., I feel more prepared for navigating transition to adulthood for my child after this training), (b) their perceptions of community engagement and belonging (e.g., I felt a sense of belonging during the SAATHI training), (c) their perceptions of their advocacy skills (e.g., I feel prepared to advocate for my child's transition outcomes after participating in SAATHI), and (d) their recommendations for future trainings (e.g., I would recommend SAATHI to other South Asian parents of children with disabilities). Parents responded to the survey questions using a five-point Likert scale (e.g., 1 = strongly disagree, 5 = strongly agree). I also three open ended questions about additional recommendations they may have, other topics they would like to learn about, and any further feedback or suggestions they have about SAATHI training.

### 4.3.4. Feasibility and Fidelity

I measured feasibility using the social validity measures (e.g., weekly parent surveys and parent satisfaction survey) as well as parents' attendance and attrition rates. After receiving parents' consent, I recorded all of the training sessions to a password protected google Drive account to measure the fidelity of the training. Specifically, I developed an 11-point fidelity checklist that was completed for each training session (one per cohort = 12 total) to measure how true to the manual was each session that was conducted by the trainer and reflected the goals of

the training. Each session could be awarded a maximum of 11 points. The checklist asked questions related to specific goals of the training, including (a) a clear beginning and end (e.g., researcher has introduced the session topic), (b) advocacy portion (e.g., researcher has modeled an advocacy case study before putting people into groups), and parent voice (e.g., researcher has offered space to ask questions during the sessions). I also asked an open-ended question at the end of the fidelity checklist to share any observations related to parental involvement.

Two undergraduate researchers who were naive to the study completed the fidelity checklist. Each researcher completed the twelve checklists independently. I calculated the final percentage of fidelity across all the training sessions for each cohort by measuring the average of the independent scores and multiplying by 100.

## 4.3.5. Data Analysis

I analyzed the quantitative data using the SPSS software. The pre/post survey questions were analyzed in three steps. First, I calculated Cronbach's alpha for the pre and post survey items for the ordinal scales: MMS scale, Advocacy Scale, and the PSS Scale. This was to determine internal consistency of the survey items. I also calculated the Kuder-Richardson Coefficient for the nominal survey items in the transition planning knowledge scale. This was also to determine the extent to which the survey items were reliable and consistent. Second, I calculated the descriptive characteristics of survey items (*M*, *SD*) and checked for missing values. I did not find any missing data. Third, I conducted a paired-t test using responses from all the scales (e.g., MMS, PSS, advocacy scale, and transition knowledge scale) to understand if parent scores had significantly changed from pre to post test. I also checked for three assumptions of normality: Normality using a histogram, checked for outliers in data, and conducted the Shapiro-wilk test to identify if data was normally distributed.

Additionally, I conducted both quantitative and qualitative analyses for the social validity surveys. Specifically, I conducted descriptive statistics (M, SD) for the quantitative responses on the parent satisfaction survey. I also conducted qualitative analyses for the open-ended responses. For instance, three undergraduate researchers and I categorized the qualitative responses and developed consensus on similar themes. Finally, I counted the number of points on the WhatsApp Checklist each week to determine parent engagement. I also thematically organized the open-ended notes I took to understand topics discussed and parent engagement each week.

I formed six hypotheses, one for each research question. First, parents' scores will significantly increase from pre to post test on the following measures: transition knowledge, multicultural mastery, and advocacy. Second, parents' stress scores will significantly decrease from pre to post test. Third, parents will indicate high community engagement on the satisfaction survey administered a week after the training ends. Fourth, parents' engagement will increase across the six weeks, calculated using the WhatsApp checklist. Finally, SAATHI training will have high fidelity and high acceptability, as measured using a fidelity checklist and social validity measures.

#### 4.4. Results

The purpose of this study was to determine the development, effectiveness, acceptability, and feasibility of SAATHI, a novel transition-focused parent education training for South Asian parents of children with IDD. The results are organized by the research questions.

## 4.4.1. Does Participation in SAATHI Increase Parents' Knowledge of Transition-Related Outcomes for Their Child?

I conducted a paired t test to calculate if there were significant differences between pre and post test scores on the transition knowledge scale. All data were distributed normally and there were no missing data. I also did not find any outliers in the responses between pre and posttests. I also used Cohen's d to measure effect sizes, where 0.2 is considered a small effect, 0.5 is considered a moderate effect, and 0.8 is considered a large effect (Cohen, 1998). The results of the paired t test indicated a significant difference between pre (M = 6.94, SD = 1.55) and post (M = 7.87, SD = 1.36) scores on the transition knowledge scale (t(30) = 3.28, p = .003; Table 8). The effect size was 0.59, which I interpreted as a moderately significant effect. The findings confirmed my hypothesis that my parents' scores will significantly increase on the transition knowledge items from pretest to posttest.

# 4.4.2. Does Participation in SAATHI Increase Parents' Multicultural Mastery Across their Community, Family, and Themselves?

I used a paired t test to measure if there were significant differences between pre and post test scores on the MMS. The data were distributed normally and I did not find any missing data. There were no outliers in the responses between pre and posttests. The results of the paired t test indicated a significant difference between pre (M = 3.57, SD = 0.48) and post (M = 3.79, SD = 0.64) scores on the overall MMS (t(30) = 2.93, p = .006). The effect size was 0.53, which I interpreted as a moderately significant effect. The findings confirmed my hypothesis, thereby rejecting the null hypothesis.

I also calculated the difference between pre and post scores on the three subscales of the MMS (Table 8). I did not find any significant differences between pre (M = 3.70, SD = 0.72)

and post (M = 3.91, SD = 0.82) scores on the family subscale (t(30) = 1.94, p = .062). Similarly, there were no significant differences between pre (M = 3.30, SD = 0.64) and post (M = 3.40, SD = 0.71) scores on the self-subscale (t(30) = 1.93, p = .063). However, I found significant differences between pre (M = 3.79, SD = 0.67) and post (M = 4.02, SD = 0.79) scores on the community subscale (t(30) = 2.17, p = .038). The effect size was 0.39, which I interpreted as a small to moderate, significant effect.

## 4.4.3. Does Participation in SAATHI Decrease Parents' Stress?

I found that the data for this scale was distributed normally, including no outliers and no missing data. The paired t test findings did not indicate significant differences between pre (M = 19.87, SD = 6.16) and post (M = 19.74, SD = 5.65) scores on the PSS measure (t(30) = 0.143, p = 0.89). Although the scores decreased from pre to post test, my findings did not align with the hypotheses (Table 8). I failed to reject the null hypothesis that there is no difference between the means.

# 4.4.4. Do Parents Perceive an Increased Sense of Community and Belonging After Participating In SAATHI?

I calculated parents' perceived sense of community and belonging using the results from the parent satisfaction survey, which was administered a week after the training ended (i.e., week seven). Parents were asked to indicate their agreement with five statements related to community engagement. Most parents agreed or strongly agreed with the following: 93.5% indicated they enjoyed interacting with other parents during this training, 80.7% felt their interactions with the other participants increased from the beginning of the training to the end of the training, 93.5% found the WhatsApp group to be helpful in communication with other parents during SAATHI, 93.6% planned to keep in touch with some of the other parents from SAATHI, and 100% felt a

sense of belonging during the SAATHI training (Figure 8). These findings confirmed my hypothesis.

#### 4.4.5. Does Parent to Parent Engagement Increase After Participating In SAATHI?

I calculated parent engagement for each cohort by measuring their weekly scores on the WhatsApp Checklist. The items on the checklist included: (a) parents initiating a text regarding future planning resources, (b) parents initiating a text regarding any resources, (c) parents asking questions related to the transition planning topics, (d) parents asking questions related to the training, and (e) parents responding to my messages and/or comments. For the first cohort (cohort A), the parents' average score was 4.16 ( out of a score of five per week across six weeks), while the average of the second cohort (cohort B) was 3.16 (Figure 12). Both cohorts did not experience linear growth across the six weeks, and their participation on the WhatsApp groups was lower for week 5. These findings did not align with the hypotheses.

Additionally, I also noted the topics shared each week, how many parents, participated in the conversations, and overall observations. I noted three important trends. First, parents across both cohorts communicated using emojis (e.g., thumbs up, heart, and smiley face) more than words. Second, while the same parents typically took initiative to start a conversation, it led to new parents (e.g., parents who had not shared before) to continue the discussion on the WhatsApp group. Finally, both cohorts continued the conversations around the session topic for the week and sought resources from other parents. They also continued to share additional resources with one another beyond the scope of the training content. Across both cohorts, parents discussed the most about sharing resources related to future planning (e.g., community organizations, discussing transition with IEP team, and which transition goals to emphasize during IEP meetings) and asked each other for advice (e.g., advice related to financial planning,

advocacy in schools, and employment outcomes). Additionally, parents also asked for training recordings each week, and asked each other what they had missed if they could attend a particular week.

# 4.4.6. Do Participants Consider SAATHI Parent Education Training to be Socially Valid (Feasible and Acceptable)?

I calculated the social validity of the training using the parent satisfaction survey, weekly parent surveys, and their attendance, attrition rates, and training fidelity. On the parent satisfaction survey, 90.3% of parents agreed or strongly agreed that they felt confident in their skills to start planning for their child's future, and 100% of parents agreed or strongly agreed that SAATHI improved their knowledge of future planning opportunities for their child (See Figures 9 to 11). Additionally, across the six weeks of weekly feedback surveys, parent responses indicated high satisfaction with the training. For instance, 98% of parents agreed or strongly agreed that the training information was clear and easy to understand and 97% agreed or strongly agreed that they learned something new from the training session (See Figures 13 to 18). Overall, 85% of parents attended each session consistently, and attrition was 6%, indicating acceptability of SAATHI. Lastly, I calculated that 85% of the SAATHI sessions were delivered as intended, using a fidelity checklist, indicating high feasibility.

#### 4.5. Discussion

The purpose of this study was to explore the effectiveness, acceptability, and feasibility of SAATHI, a transition-focused parent intervention for South Asian parents of children with IDD living in the United States. While emerging interventions have explored transition-related outcomes for Latino/a/x families (Burke et al., 2017; Taylor et al., 2017; Kuhn et al., 2019), this is the first transition-focused intervention with exclusively South Asian families of children with

IDD. Overall, the findings indicate that SAATHI was effective in increasing parents' transition knowledge, their multicultural mastery, their advocacy skills, and their community engagement. SAATHI also had high feasibility and acceptability, thereby demonstrating high social validity for parents. As such, the findings of this study make three significant contributions to the literature.

First, the findings of this study emphasize the effectiveness of this pilot transitionfocused training for South Asian parents. After participating in SAATHI, parents increased their
transition-related knowledge, their overall sense of control and mastery in coping during difficult
challenges, particularly using their community resources, and their advocacy skills. Parents also
felt a sense a belonging and increased their community engagement after participating in
SAATHI. Additionally, SAATHI was feasible (e.g., 85% fidelity) to conduct and was widely
accepted by parents (e.g., 85% or more attendance weekly). Parents also indicated high
satisfaction with SAATHI and 100% of parents indicated they felt more prepared to navigate
transition planning after attending the training. Additionally, this pilot study also affirms and
adds to the growing literature on the effectiveness of online/virtual parent education
interventions (see study 2).

Second, this pilot study demonstrates how integral community engagement and belonging are to parent education interventions for racially minoritized parents. Prior parent education interventions have also highlighted parents' increased sense of community after the intervention, particularly for Black parents (Pearson & Meadan, 2021) and other racially minoritized families (Gattuso, 2015). However, little is known about whether these goals were intentionally incorporated into the intervention and measured. In this study, I was intentional in creating and promoting community development. For instance, the training included 30 minutes

of break out room sessions for parents to come together and discuss a scenario and I also offered 10 minutes at the beginning and end of each session for parents to share their experiences and ask any questions. Furthermore, I also offered parents a WhatsApp group where they could communicate with each other freely, thereby intentionally integrating and promoting community engagement. As such, I also measured parent engagement in multiple ways, including a WhatsApp checklist to explore weekly engagement and a social validity measure to determine overall community engagement and belonging among parent participants. However, it must be noted that I also interacted back with the parents on the WhatsApp groups (e.g., posting resources, asking questions, and sending reminders about the training) which could have impacted parents' engagement levels and perhaps their comfort with engaging on the WhatsApp platform.

Additionally, it is also important to acknowledge that parents may have already established parent-professional partnerships through their organizations, which could have led to increased sense of community. I intentionally assigned parents into cohorts based on the organization to which they belonged to. Also, two parents were added to a cohort that they did not belong to due to scheduling preferences and their availability. However, I observed that during the trainings and on the WhatsApp chat, while parents could have been from the same organization, they did not know each other well. Perhaps the familiarity with the organization could have brought parents together and attending SAATHI offered them a dedicated space to further their relationships.

Finally, SAATHI offers an opportunity to reframe the development of parent education interventions for racially minoritized parents from a critical, strengths-based framework. I used the frameworks of CRT and EVF to embed parent strengths and recognize parent expertise

across the training, thereby reframing the narrative of "experts" as part of the repertoire of parents. Rather, I did not position myself as the "expert," but offered facilitated discussions and reminded parents of their own expertise and strengths in navigating transition to adulthood. For example, each training session began with a slide outlining parent strengths (see Study 1) to reinforce a strengths-based framework for parent education interventions. The slide reminded parents that their stories and experiences are valuable, and that they too, are experts in the process. Similarly, I also offered parents case studies where they could disseminate knowledge amongst themselves to acknowledge and promote their own lived experiences and expertise. A strengths-based approach could have contributed to increased parent-professional (or community member) relationships and continued satisfaction with SAATHI.

#### 4.5.1. Limitations and Future Research

Although SAATHI was an effective pilot training, it also carries limitations and further opportunities for future research. First, I as the researcher, categorized parents as "South Asians" based on their nationality. Since South Asia encompasses 9 countries and countless languages, it is difficult to explore the effectiveness of the training for various disaggregated groups. Future researchers could consider asking parents how they identify (e.g., Muslim, Indian, Nepali, or South Asian) and use those labels to inform the intervention. Additionally, researchers could also conduct smaller pilots of SAATHI for disaggregated groups based on their affinity to further increase community engagement and the effectiveness of the training. While diversity of parents was a strength of the training, it could have also led to some parents feeling isolated, particularly those who had just immigrated, who did not speak English fluently, or did not belong to the dominant cultural group. Future researchers could also consider a more homogenous sample of participants for strengthened community engagement.

Second, I sought to increase parent well-being by decreasing parent stress. As a Pakistani-American who has lived in the United States for the majority of my life, I had associated parent well-being with stress factors using a western-oriented lens. However, this limited my worldview of parent well-being to only stress, whereas parent well-being could be explored using many social and psychological factors. Future researchers could move toward a model to explore parent well-being using measures such as community engagement, happiness, resilience, and parents' sense of belonging. Moving beyond deficit-oriented measures could further illuminate additional factors associated with parental well-being, particularly for racially minoritized parents living in the United States.

Third, since this was a novel intervention aimed at South Asian parents, I only invited parents (e.g., mother/father or other non-traditional parents) to attend the 6-week training. However, informed by the results of study 1, future researchers could also consider inviting chosen families (e.g., individuals who are not biological but carry significance for families) to parent education interventions. This could create additional systems of support for families and offer more opportunities for community engagement and advocacy across various family units. For example, future researchers could consider inviting neighbors, faith-leaders, siblings, extended families, and other individuals whom the stakeholders consider chosen families. Additionally, while this training was focused on parent outcomes, future researchers could also invite youth with IDD to the training and measure the effectiveness of the training for their transition outcomes.

Fourth, SAATHI was evaluated as single-group study, limiting conclusive evidence that the training was the only factor in increasing parent knowledge, community engagement, self-efficacy, and advocacy. While small pilots are necessary in establishing an evidence base for

interventions, additional studies must be conducted to fully explore the scope and outcomes of SAATHI. Future researchers could conduct a randomized controlled trial of SAATHI to understand if indeed SAATHI was the determining factor in increasing parents' transition, advocacy, and well-being outcomes. Furthermore, future researchers could also explore the effects of in-person and online training on parent outcomes to contribute to transition literature.

Lastly, I established close relationships with SAATHI parents and was often asked to review IEP documents, attend transition meetings, and offer additional resources to parents. This could have impacted parents' perceptions of belonging to a community and parent-to-parent relationships. Future researchers could also consider conducting a quasi-experimental study to explore the effects of SAATHI as-is, or SAATHI with a 30 minute 1-1 consult for each parent per month. This could help future researchers isolate variables that could have contributed to SAATHI's success, particularly relating to community engagement and belonging. Additional research with SAATHI could offer more culturally competent and culturally affirming strategies to develop and implement transition-focused parent education interventions.

### 4.5.2. Implications for Practice and Policy

The success and promise of SAATHI offers several implications for practitioners (e.g., educators, transition stakeholders, and adult service systems) and for policymakers. First, parents were able to learn and discuss more about collaboration with professionals during SAATHI. This could lead to increased partnerships and communication between racially minoritized parents and practitioners across various contexts. Additionally, after attending SAATHI, parents increased their comfort with advocacy and the frequency of advocacy-related actions. Increased advocacy could significantly enhance parent professional partnerships. However, for practitioners, it is also important to offer parents the agency to advocate as well as encourage

their advocacy skills. Furthermore, equipping parents with transition-related resources prior to exiting high school could also reduce the burden on adult service systems to both educate and provide services. Rather, service systems could increase focus on reducing educational disparities and offering families more opportunities to practice their advocacy and self-determination skills.

Second, SAATHI has demonstrated the effectiveness of intentional investments in building community partnerships for racially minoritized parents. Policymakers could integrate community-partnerships as essential components of the transition planning process, particularly when reauthorizing IDEA. Additionally, federal funding could also prioritize community-partnerships in research, particularly in research with racially minoritized communities.

SAATHI's promise also implies a shift away from the larger social labels of racially minoritized toward addressing systemic barriers and disparities faced by disaggregated subgroups. Thus, policymakers could consider research, funding, and family collaborations from a disaggregated lens, reflecting priorities related to subgroups of racially minoritized families.

### 4.6. Conclusion

South Asians Accessing Transition and Higher Education Inclusion (SAATHI) was a 6-week, 90 minute online transition-focused parent education intervention for 31 South Asian parents of children with IDD living in the United States. SAATHI was effective in increasing parents' transition knowledge, their mastery, and their advocacy. SAATHI was a promising intervention to continue to equip, support, and strengthen the transition to adulthood outcomes of youth with IDD and their families. It also offered a model to develop, implement, and adapt for other disaggregated subgroups of racially minoritized parents, with a focus on parents' knowledge, well-being, and community engagement.

## **4.7. Tables**

**Table 8. Pretest and Posttest Results** 

Measure	Pre M (SD)	Post M (SD)	t	p	Cohen's d
Transition Knowledge	6.94 (1.55)	7.87 (1.36)	3.28	0.003**	0.59
Multicultural Mastery	3.57 (0.48)	3.79 (0.64)	2.93	0.006**	0.53
Scale (MMS) Overall					
MMS Subscale:	3.79 (0.67)	4.02(0.79)	2.17	0.038*	0.39
Community					
MMS Subscale: Family	3.70 (0.72)	3.92 (0.82)	1.94	0.062	0.35
MSS Subscale: Self	3.30 (0.64)	3.50 (0.71)	1.93	0.063	0.35
<b>Advocacy Scale Overall</b>	2.58 (0.70)	3.29 (0.69)	7.13	< 0.001***	1.28
Advocacy Subscale:	2.94 (0.76)	3.79 (0.66)	6.12	< 0.001***	1.10
Comfort	, ,	, ,			
Advocacy Subscale:	2.30(0.79)	2.90 (0.86)	4.83	< 0.001***	0.87
Actions	. ,	• •			
Perceived Stress Scale (PSS)	19.87 (6.16)	19.74 (5.65)	0.14	0.897	0.03

Note. \* = significant at < 0.05, \*\* = significant at < 0.01, \*\*\* = significant at < 0.001.

## 4.8. Figures

Figure 7. Participant Recruitment and Attrition

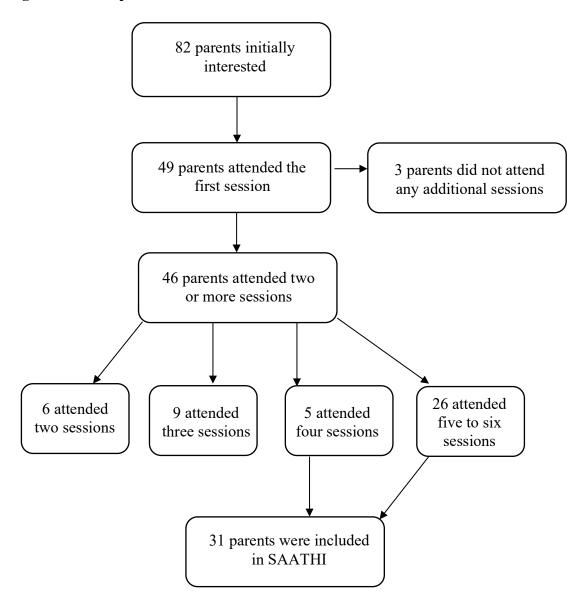


Figure 8. Community Engagement on Week 7 Satisfaction Survey

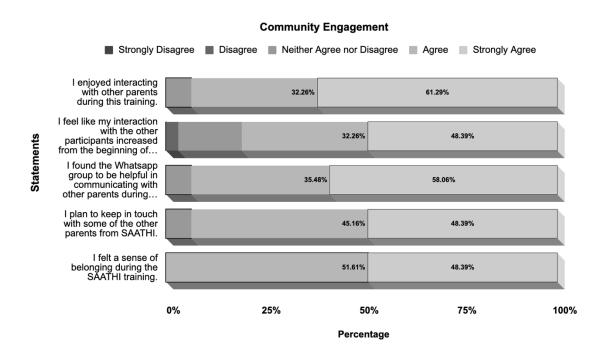


Figure 9. Overall Experiences on Week 7 Satisfaction Survey

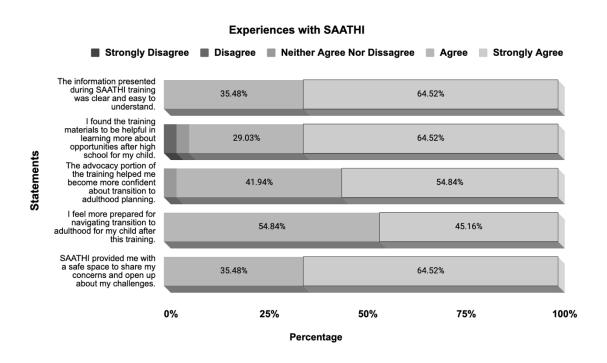


Figure 10. Parent Advocacy and Overall Well-Being on Week 7 Satisfaction Survey

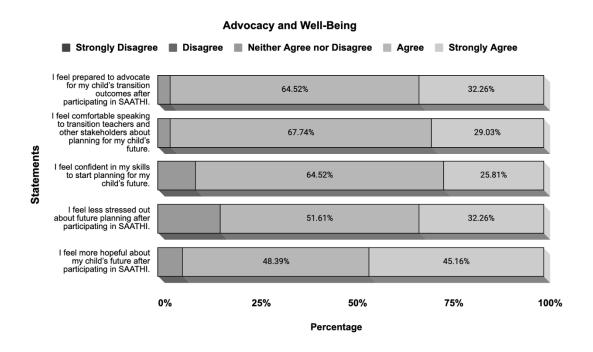


Figure 11. Parent Recommendations for the Future on Week 7 Satisfaction Survey

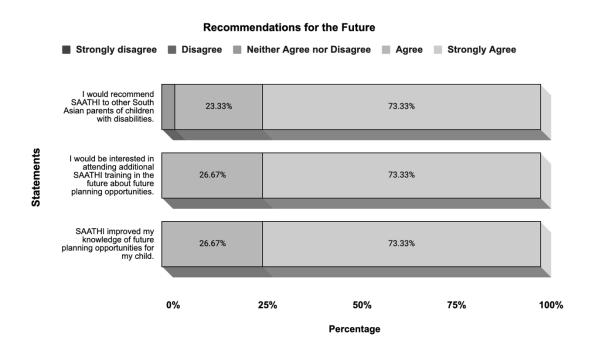


Figure 12. Weekly Parent Engagement on the WhatsApp Checklist

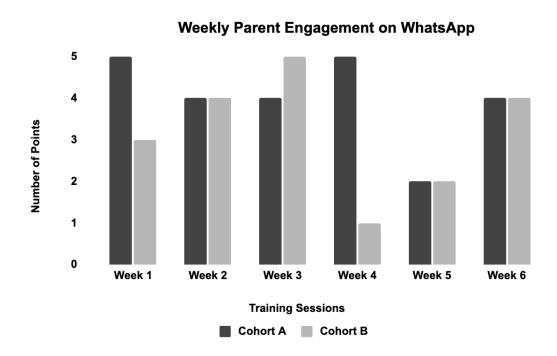


Figure 13. Overall Weekly Feedback

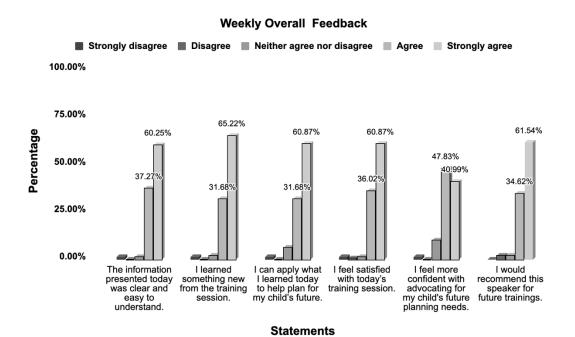


Figure 14. Weekly Feedback: Trends in Information Presented

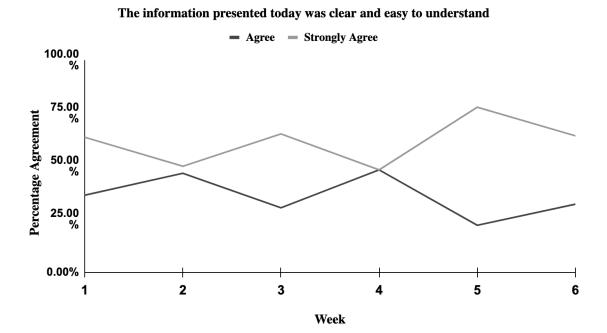


Figure 15. Weekly Feedback: Trends in Information Learned

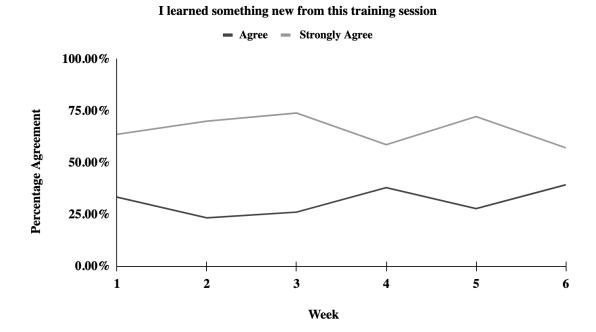


Figure 16. Weekly Feedback: Trends in Application of Learning

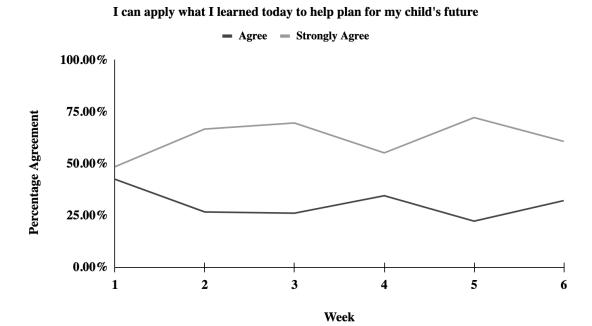


Figure 17. Weekly Feedback: Trends in Parent Satisfaction

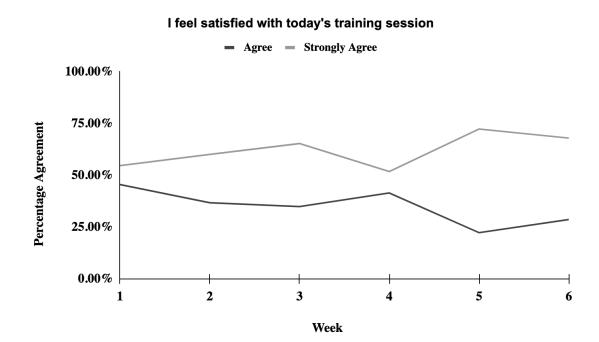
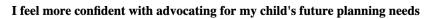
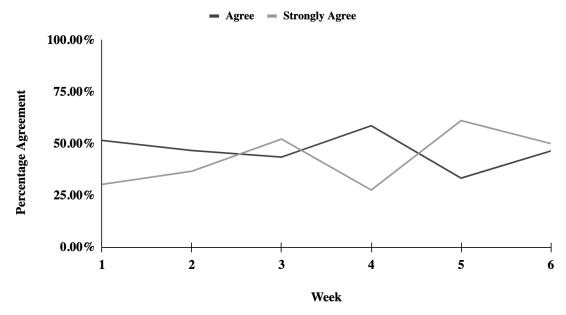


Figure 18. Weekly Feedback: Trends in Confidence in Advocating





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#### 5. CONCLUSIONS

The transition planning process is significant to preparing young adults with disabilities and their families for meaningful postschool outcomes. While transition planning is essential to increasing adulthood outcomes, racially minoritized families do not receive equitable or culturally affirming support in this domain. Thus, my three studies contribute toward redefining, reexamining, and reshaping transition to adulthood for racially minoritized families, particularly South Asian families.

#### 5.1. Redefining Transition to Adulthood

The first study used a mixed methods design to explore ways in which South Asian parents leverage their community cultural wealth to overcome systemic adversities when navigating the transition to adulthood process. The mixed findings demonstrated that parents used their inherent and developed strengths to navigate around the systemic adversities they faced; however, they did not have the agency and capacity to use those strengths to navigate unfamiliar spaces, such as adult service systems. My findings emphasized a need to offer culturally affirming and competent parent-professional partnerships using parent strengths to support parents as they navigate the transition planning process.

This study contributes to the field in several ways. First, this study adds to the emerging literature on using strengths-based approaches to explore transition to adulthood. The study's findings emphasize the use of mixed methods and strengths-based, critical frameworks to explore the extend of parent experiences, particularly as they navigate the complexities of transition to adulthood. Second, this study advocates for disaggregating larger social labels of race in research to deeply examine the racialized experiences of subgroups of racially

minoritized families. As one of the first studies to explore the experiences of South Asian families in transition, this study's findings contribute toward individualizing resources and support for various subgroups of families. Rather than exploring all racially minoritized families as a one-size-fits all model, this study encourages examining the individual strengths and challenges of various subgroups. Finally, the findings of this study highlight the importance of social relationships, particularly the role of chosen families, in facilitating the transition planning process. Parents reported large instances of social capital, and shared that their social networks served as an additional layer of support during this critical time.

#### 5.1.1. Reexamining Interventions for Racially Minoritized Parents

The second study explored the state of parent education interventions for parents of adolescents with autism in the United States. This review identified 54 studies across four decades of research. The review unveiled three areas of parent education interventions that could be further examined, thereby contributing significantly to the field of autism studies and special education.

First, the review found that a large segment of parent education intervention studies did not report racial characteristics of participants, including those conducted within the last 10 years. Notably, among those that did report racial characteristics, most of the participants identified as white. Additionally, studies with older adolescents did not reflect broad diversity, as most studies were with white populations or did not report racial characteristics. The review emphasized a need to increase the development, implementation, evaluation, and reporting of parent education interventions for racially minoritized families of children with autism to further support these underrepresented families.

Second, the review identified a growing trend toward online, group studies to increase parent well-being, particularly for parent participants who identified as racially minoritized. The emerging variety of online structures (e.g., synchronous, asynchronous and hybrid) were evident for interventions with parents of younger and older children, particularly within the last five years. As the COVID-19 pandemic highlighted, virtual interventions could reach broader populations, particularly those who are underserved and under resourced. This review's findings further promote opportunities to reach broader, more diverse populations through online interventions to further expand support to all families across the country.

Third, the scoping review revealed a large focus on behavioral-focused interventions, particularly for younger adolescents (i.e., under the age of 13). While studies with children 13 years of age or younger remained focused on behavioral outcomes for both the parent and the child, those that included racially minoritized participants included some components of parent-well-being outcomes. However, for the studies with children 14 years of age or older, the focus was more on transition skills, social skills, and parent well-being (e.g., advocacy, mental health). Notably, transition starts at the age of 14 in the United States, which adds to the growing interventions focused on transition-related skills for children 14 years of age or older. However, prior studies (see study 1) have emphasized a need to start transition preparation prior to the age of 14 to better equip and prepare families in this domain.

# 5.1.2. Reshaping Transition to Adulthood

The final study of my dissertation combined the findings from the first two studies to inform the development and implementation of a transition-focused parent education intervention for 31 South Asian families of children with IDD. The first study informed of the significance of integrating parent strengths and resilience as a key component of a culturally

competent and affirming parent intervention. The second study highlighted a need to conduct interventions with racially minoritized families that included transition-focused and parent well-being centered components as instrumental domains of the intervention. Together, the two studies informed the development, implementation, and efficacy of SAATHI, contributing to the emerging literature on the effectiveness of parent education interventions to increase the knowledge and well-being of racially minoritized families in the transition to adulthood process. Thus, the final study contributes to the field in several ways.

First, SAATHI was a novel, transition-focused intervention for South Asian parents, a population that has been underserved and unrepresented in transition literature. SAATHI contributed to the effectiveness and promise of increasing the development and evaluation of parent-centered transition interventions, particularly for racially minoritized families. The promise of SAATHI offers opportunities for replication and cultural adaptation for other subgroups of racially minoritized families, thereby creating additional ways to enhance parent-professional partnerships.

Second, SAATHI offered the duality of exploring parent knowledge and increasing parents' community engagement as well as a sense of belonging. Community engagement was an intentional outcome of the training, thereby expanding the realm of traditional intervention outcomes (e.g., stress, overall well-being, parent knowledge). Additionally, as an online training, SAATHI also extends emerging research with transition-focused online interventions for minoritized populations. The success of SAATHI offers opportunities to explore culturally competent and affirming parent interventions as catalysts in reshaping transition to adulthood outcomes of racially minoritized youth and their families. Further replication of SAATHI in diverse contexts, with varied populations, and across both online and face to face contexts could

help isolate specific variables that promote successful and meaningful parent-professional partnerships for South Asian families.

Together, the three studies contribute to the emerging literature in advancing transition to adulthood outcomes of racially minoritized youth and their families. The voices, experiences, and outcomes of South Asian families are celebrated across the three studies, thereby carving a space for them in special education and transition-focused literature.

#### APPENDIX A

#### SAATHI WEEKLY SESSIONS OVERVIEW

# **SAATHI Weekly Sessions Overview**

# Standard Procedures: Weekly sessions held for 1.5 hours via Zoom

- 10 minutes: Parents' share strengths and challenges from the week
- 40 minutes: Trainer reminds parents of their strengths and introduces topic for the week
- 30 minutes: Trainer models a case study (ex. How to use the knowledge to advocate) and parents discuss in breakout rooms
- 10 minutes: Complete feedback survey and answer questions

Week	Торіс	Data
1	Introduction to transition planning Objectives:  1. Introduce the language of transition planning 2. Laws and regulations of transition planning	<ul> <li>Consent forms</li> <li>Pre-test survey</li> <li>Parent feedback form</li> <li>WhatsApp checklist</li> </ul>
2	Opportunities after High School: Higher Education and Living Options Objectives:  1. Inclusive postsecondary education opportunities and Think College 2. Community-based examples of living arrangements	<ul><li>Parent feedback form</li><li>WhatsApp Checklist</li></ul>
3	Financial Planning (Guest Speaker-Special Needs Financial Planner and Sibling)  Objectives:  1. Government benefits after the age of 18  2. Navigating challenges when seeking government benefits (ex. Citizenship, undocumented, language, religion)	<ul> <li>Parent feedback form</li> <li>WhatsApp Checklist</li> </ul>

4	Wills, trusts, and Guardianship (Guest Speaker- Special Needs Lawyer and Parent)  Objectives:  1. Securing a financial future for young adult  2. Navigating challenges when planning for guardianship and special needs trusts (ex. Citizenship, undocumented, language, religion)	<ul> <li>Parent feedback form</li> <li>WhatsApp Checklist</li> </ul>
5	<ul> <li>Employment and Navigating Challenges</li> <li>Objectives:         <ul> <li>Employment training and opportunities within the community</li> <li>Skills to navigate common challenges in the transition planning process and adult service systems</li> </ul> </li> </ul>	<ul><li>Parent feedback form</li><li>WhatsApp Checklist</li></ul>
6	Reliable Resources in the Community Objectives:  • Identifying resources in the community  • Connecting parents with reliable and trusted organizations/groups/community members to navigate transition planning	<ul> <li>Posttest survey</li> <li>Parent feedback form</li> <li>WhatsApp Checklist</li> </ul>
7		Parent Satisfaction     Questionnaire
13	Sexuality/Consent Booster session (guest speaker-Psychologist) Objectives:  • De-stigmatize sexuality education within the community • Community conversations regarding sexuality education, consent, and relationships for young adults	Parent feedback form

#### APPENDIX B

#### **SAATHI PROCEDURES**

# **Timeline of Training**

#### 1.1. PRE-TRAINING

- 1.1.1. The researcher will work with three organizations to recruit participants for the training and offer an introduction session to anyone who may be interested.
- 1.1.2. The researcher will conduct an introduction session to introduce the training and answer any parent questions. This will occur 2 weeks before training is scheduled.
- 1.1.3. Parents who attend the introduction session will be asked to provide their email address so that I can send them consent and assessment documents and information about location/times of training sessions
- 1.1.4. Parents who attend the 1st training session will be advised of the study procedures, consent, etc.
- 1.1.5. Parents who attend the 1st session and who would like to participate in the study will complete the consent forms and pre-assessments.
- 1.1.6. Parents will be advised that we will meet online only for six weeks for the training and we will have a WhatsApp group to get updates, communicate, etc.
- 1.1.7. Parents will be advised that the training will be online via Zoom.

#### 1.2. TRAINING MATERIALS

1.2.1. Parents could pick up a resource binder with information one week before the training or could receive a PDF copy via email.

#### 1.3. SAATHI TRAINING

- 1.3.1. Each training will include a meet and greet (10 mins), followed by training (40 mins), advocacy and role play (30 mins), and closing questions/feedback (10 mins). Each session will be held for 1.5 hours per week, once a week, for 6 weeks.
- 1.3.2. During the last week, parents will be asked to take the POST survey using a Qualtrics link.
- 1.3.3. Week 7, parents will be asked to complete a 20 minute online questionnaire
- 1.3.4. Week 13, an online booster session will be offered to parents.

#### 1.4. POST TRAINING

- 1.4.1. Sehrish will conduct a paired t test to see changes in scores from pre to post test on survey items.
- 1.4.2. Sehrish will examine the extend of community engagement from the following data:
  - 1.4.2.1. Overall satisfaction survey items
  - 1.4.2.2. WhatsApp group engagement: This includes counting the number of messages on WhatsApp from week 1 to week 6, indicating trends in the content of the information, and counting if the same or different people are interacting on the shared group.

#### Compensation

1.5. Parents will be compensated for their time. Parents will receive \$25 for completing all 6 sessions.

#### APPENDIX C

#### SAATHI RECRUITMENT FLYER: DUS



Dar-us-Sakina is inviting all of our special needs parents to sign up to the:

# First training:

special needs parents Wednesday, Aug 10th 8 pm\*

# RANSITIONAL TRAINING FOR SPECIAL NEED PARENTS

# SAATHI PARENT TRAINING

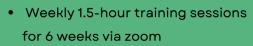


Registration Deadline: August 4th
Register at \*\*\*\*\*\*\*\*\*

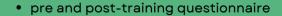
\*\* training will take place at the same time/day each week

Dar-us-Sakina is partnering with Texas A&M's Sehrish Shikarpurya M.E.D. Sehrish is a special sibling who was inspired to create this training to help special needs parents access and advocate for resources that will help their child succeed.

#### 3.5 Month Commitment

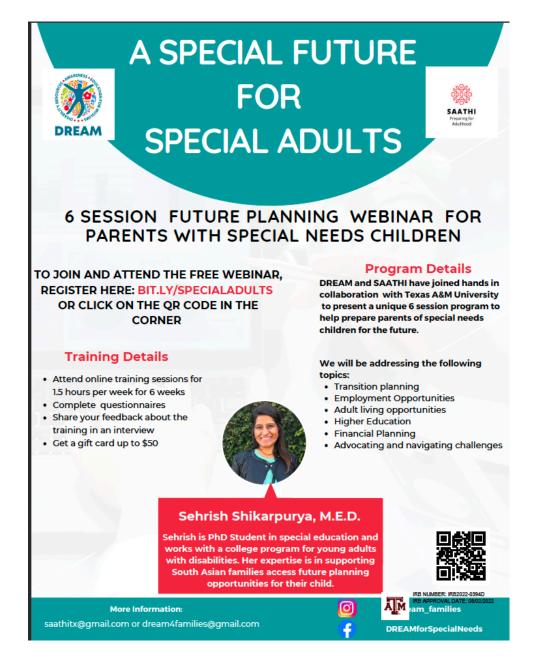






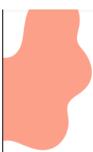
#### APPENDIX D

#### SAATHI RECRUITMENT FLYER: DREAM



#### APPENDIX E

#### SAATHI RECRUITMENT FLYER: SPECIAL STARS



# **SAATHI Parent Training**

# A Future Planning Training For Parents of Children With Disabilities

Researchers at Texas A&M University are conducting a 3-month study to support parents with planning for their child's future.

# **Training Details**

- Attend weekly training sessions for 1.5 hours per week for 6 weeks
- Complete pre and post questionnaires
- Complete a follow up interview after 2-months
- Participants can receive up to \$50
- Respite care may also be offered

# **Potential Benefits Include:**

- Increased knowledge about opportunities for your child after high school.
- Community building with other parents.
- Reduced stress
- Earlier planning = More opportuntiles for your child to succeed.

# **Training Topics**

- Transition planning
- Employment Opportunities
- Adult living opportunities
- Higher Education
- Financial Planning
- Advocating and navigating challenges
- · And many more!



#### Trainer: Sehrish Shikarpurya, M.ED.

sehrish is PhD Student in special education and works with a college program for young adults with disabilities. Her expertise is in supporting South Asian families access future planning opportunities for their child.

IRB NUMBER: IRB2022-0394D IRB APPROVAL DATE: 06/21/2022

Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more ar Interested parents can email us to learn more are Interested p

saathitx@gmail.com

#### APPENDIX F

#### SAATHI CONSENT FORM

HRP-5xx (5/30/2017)

#### **INFORMED Consent Document**

**Title of Research Study:** SAATHI (South Asians Accessing and Advocating for Transition and Higher Education Inclusion) Parent Transition Parent Training

Investigator: Sehrish Shikarpurya and Dr. Birdie Ganz

Funded/Supported By: Texas A&M University Student Research Grant

#### Why are you being invited to take part in a research study?

We are conducting a future planning parent training for parents of children with special needs. We understand that thinking about what your child will do after they graduate is a difficult process. We want to support you in learning more about all the opportunities that could be available for your child after high school so they could be successful in adulthood. We developed this training specifically keeping your needs and challenges in mind to make sure it is culturally and linguistically appropriate for you and your family.

The purpose of this training is to:

- 1. Increase your knowledge of future planning opportunities for your child after high school, such as college options, employment, living arrangements, and financial support.
- 2. Increase your advocacy skills so that you can voice your concerns and partner with the IEP team to develop appropriate goals for your child.
- Support you with developing meaningful relationships with other parents in a small group setting while learning about future planning opportunities.

This training will be held for 1.5 hours per week, for 6 weeks. Training will be held online on Zoom. You will be invited to attend all the training sessions and complete pre and post assessments to assess your progress. In addition, you will be asked to complete a 10-minute survey a week after the training and participate in a 35-45-minute interview 2-months after the training ends. You could earn up to \$50 for participating in this study.

To participate in the training, you must be:

- 1. A parent of a child with a disability.
- 2. Have a child diagnosed with a disability who is between 3-22 years of age.
- 3. You must reside in Texas.
- 4. Have access to Zoom via a computer or a phone.
- 5. Can read and write in English.

#### What should you know about a research study?

Once you fully understand the study, you will be asked to complete this consent form indicating that you understand the study and have agreed to take part in this study. Participating in this study is voluntary, and you may wish to exit the training at any time. It is up to you whether you would like to take part in this 6-week training. Your decision will not be held against you, and you can ask all the questions you want before you make your decision.

IRB NUMBER: IRB2022-0394D IRB APPROVAL DATE: 09/23/2022

#### Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the researcher, Sehrish Shikarpurya. You can email her at <a href="mailto:saathitx@gmail.com">saathitx@gmail.com</a> or call her at 678-862-8631.

This research has been reviewed and approved by the Texas A&M Institutional Review Board (IRB). You may talk to them at 1-979-458-4067, toll free at 1-855-795-8636, or by email at irb@tamu.edu. if you

- Cannot reach the research team.
- · Your questions, concerns, or complaints are not being answered by the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

#### Why is this research being done?

SAATHI training is being conducted to provide resources to families living in Texas about future planning opportunities for their son or daughter with disabilities. We are conducting this training to share resources with you, develop and increase your advocacy skills to fight for the needs of your child, and offer you the support of your peers in a group-based training setting.

While we cannot guarantee any direct to you as a result of participating in this research, potential benefits of the training include:

- Increase post high school opportunities for your child in the areas of employment, college
  education, living arrangements/environments, and financial planning.
- Develop advocacy skills to partner with the transition team to get your voice heard and make collective decisions about your child's future.
- A cohort of other parents to collaborate with, seek and offer support, and form a community.

#### How long will the research last?

We expect that you will be in this research study for 2 months. We will offer the training for 6 weeks. You will also complete a short survey a week after the training ends. We will also ask you to participate in one interview 2 months after the training. The 5-week training will be held for 1.5 hours per week.

#### How many people will be studied?

Approximately 25-30 parents will be part of SAATHI in Texas.

What happens if I say Yes, I want to be in this research?

Before the training starts:



On the first day of the training, the researchers will explain the research study details, and ask you to complete the consent form if you are interested in participating in this study. Once you agree and complete the consent form, the researchers will ask you to complete a quick assessment of your current knowledge. This survey will be available for you to take online and will take approximately 10-15 minutes to complete in total. This will take place on the first day of the session.

Once you have completed the survey, you will be enrolled in the study.

Next, you will be placed in a WhatsApp group with other parents who are attending the training with you. This will be the main form of communication we will use to ask questions, share relevant information, and communicate with you about class timings and changes.

During the training:

The training will be online on Zoom. We will have the 6 total sessions, once per week, for 1.5 hours

Each week, you will be asked to complete a session feedback form that is only 5 questions and takes 1 minute or less to complete. This is to see your perspectives of the training each week and modify accordingly. This form will take less than 1 minute to complete and will be completed online at the end of the session each week. All sessions will be recorded.

Your photos may also be captured during the training sessions by the researchers. The photos will not include your face. The photos may be used for recruitment purposes, social media, or for future SAATHI training.

After the training ends, on the last day of the training, you will be expected to complete the assessments again to see your progress. The assessments will take approximately 10-15 minutes to complete and will be completed online on the last day.

You will also be asked to complete a short online survey a week after the training is complete to help the researchers understand what you found beneficial, logistics of the training, overall experiences, and your recommendations for future training opportunities. This survey will take 10-15 minutes of your time.

After the training ends- Follow up:

Researchers will contact the participants to participate in a  $35\tilde{A}f\hat{A}\notin\tilde{A}\notin\tilde{A}\in\tilde{A}-\tilde{A}\notin\tilde{A}-\tilde{A}'$ 45-minute interview to understand how the parents used the resources presented to them in the training, the information they found beneficial over time, and their next steps of future planning for their child.

You will receive \$25 for completing the training and the surveys. You will also receive \$25 for completing the 2 -month interviews. You can earn up to \$50 for participating in SAATHI.

What happens if I do not want to be in this research?

You can leave the research at any time, and it will not be held against you. Participating in this

IRB NUMBER: IRB2022-0394D IRB APPROVAL DATE: 09/23/2022 study is voluntary and you are free to withdraw at any time as you wish.

#### What happens if I say Yes, but I change my mind later?

You can leave the research at any time, and it will not be held against you.

If you decide to leave the research, there will be no consequences. If you decide to leave the research, contact the investigator so that the investigator can answer any questions you may have and could share resources as you prefer. Please email sehrish shikarpurya at <a href="mailto:saathitx@gmail.com">saathitx@gmail.com</a> if you decide to withdraw from the study.

You will be asked the reason you are exiting this study for the researchers to be aware of and keep in mind. If you attended 3 out of 6 sessions (50% of the sessions) your data will stay with the researchers in a secured computer and could be used to share the research results. Participants will also be asked if they would like to participate in an exit interview, and if they would like to receive the training resources to explore independently.

Is there any way being in this study could be bad for me?

There are no risks or harm to you from this study. However., if at any time you feel harmed by the study or feel at risk, you may withdraw from the study.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, possible direct benefits are:

- Increased knowledge about post school opportunities, such as college programs, employment, financial planning, to support your child after high school.
- Community of other parents who are in similar positions that you can share resources with and collaborate with.
- Culturally- based training that has been developed specifically for families by a South Asian trainer

Indirect Benefits may include:

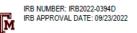
Reduced stress related to future planning for your child.

Increased advocacy skills to voice your concerns with transition team members to make informed decisions about your child's future.

Ongoing communication with cohort members and building a larger community of parents of children with disabilities.

#### What happens to the information collected for the research?

Efforts will be made to limit the use and disclosure of your personal information, including research study and other records, to people who have a need to review this information. We cannot promise complete privacy. Organizations that may inspect and copy your information include the TAMU HRPP/IRB and other representatives of this institution.

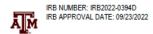


All information collected during this research will remain confidential. Research reports or publications will report data in aggregate form only and individual responses will not be identifiable. Informed consent with the participants name will not be linked to other information and no name will appear on other research protocols. The Qualtrics website is encrypted to ensure security and privacy of the information provided by participants. You may view the survey hosts confidentiality policy at: <a href="https://www.qualtrics.com/security-statement/">https://www.qualtrics.com/security-statement/</a>. Your email address and phone number will be stored separately from your survey data and is only being collected to communicate with you regarding the training and for gift card distribution purposes or if you choose to receive ongoing information about the study and the programs development. All information will be kept on a password-protected computer and is only accessible by the research team. The results of the research study may be published but no one will be able to identify you. You may view the survey hosts confidentiality policy. Paper surveys and assessments will be stored in a locked cabinet inside a locked room. Only the research team will have access to that room and the cabinet.

#### What else do I need to know?

We will also video record all sessions. We will also audio record the interviews completed at 2-month follow up. Eligible participants must agree to the video recordings and observations, audio recording of the interviews, and pictures taken during the training to participate in the study.

I agree	I disagree	
		The researcher may video record all the training sessions to aid with fidelity. The researcher will not share these recordings with anyone outside of the immediate study team or TAMU compliance.
		The researcher may audio record my interview to aid with data analysis. The researcher will not share these recordings with anyone outside of the immediate study team or TAMU Compliance.
		The researcher may audio record me for use in scholarly presentations or publications. My identity may be shared as part of this activity, although the researcher will attempt to limit such identification. I understand the risks associated with such identification.
		The researcher may take pictures during the training for the research study. The pictures may be used in future SAATHI training, social media, and to recruit future participants.



Signature of Participant	Date
Printed Name of Participant (First and Last Name)	
Signature of Person Obtaining Consent	Date



#### APPENDIX G

# SAATHI PRE-TEST

#### Consent



Thank you for your interest in SAATHI! We are very excited for you to complete this training.

Please read the attached consent document in its entirety. Once you have read the document, please answer if you agree to being a part of this study. Please email us at saathitx@gmail.com if you have any questions or concerns about the information in the consent document.

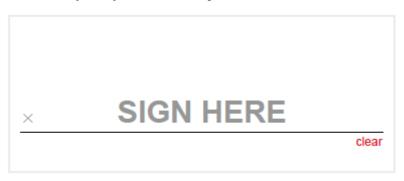
CLICK HERE TO READ THE CONSENT DOCUMENT: SAATHI CONSENT

If you want a copy of this consent for your records, you can print it from the screen. If you wish to participate, please click the "I Agree" button and you will be taken to the survey. If you do not wish to participate in this study, please select "I Disagree."

I AGREE to participating in SAATHI.

I DISAGREE to participating in SAATHI.

Please provide your signature indicating that you have read the document and that you AGREE to participate in the study.



Thank you for your interest. Please exit the survey by clicking the X at the top right hand corner of your screen.

Please email saathitx@gmail.com if you have any questions.



# **Welcome to SAATHI Transition Training!**

We are very excited for you to join this training. This training is designed to give you the knowledge to better support future planning opportunities for your child.

Please respond to the following questions to the best of your ability. We want to understand a little bit about you, your child, your experiences as a parent, and your knowledge of future planning opportunities for your child.

Your answers will help us get to know you and your needs better, understand how beneficial this training has been for you, and provide opportunities for improvements.

What is your email addre	ss? We will send important information to this email.
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	(Write your birth year)
What is your relationsh	ip to the child with special needs/disabilities?
Mother	
Father	
Legal Guardian	
Stepmother	
Stepfather	
	Other. Please explain below
What is your race?	
-	
South Asian/Desi (ex. Indi Maldives)	a, Pakistan, Sri Lanka, Nepal, Afghanistan, Bhutan, Bangladesh, and
African American or Black	
	th African (ex. Algeria, Bahrain, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Oman, Qatar, Saudi Arabia, Syria, Tunisia, United Arab Emirates and
ps://tamucehd.ca1.quaitrics.com/Q/EditS	ection/Blocks/Ajax/GetSurveyPrintPreview?ContextSurveyID~SV_eJ9snwV129HYUYe&ContextLibraryID 4/17
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18/22, 11:12 AM Asian	Qualtrics Survey Software
	Qualifics Survey Software  Biracial (ex. 2 different races). Please write them below.
	•
	Biracial (ex. 2 different races). Please write them below.
	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.
	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Asian	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Asian	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Asian	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Asian	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Asian	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Where were you born?	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.  (country)
Where were you born?  How many years have	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.
Where were you born?  How many years have Less than one year	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.  (country)
Where were you born?  How many years have	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.  (country)
How many years have Less than one year 1-5 years 6-10 years	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.  (country)
How many years have Less than one year 1-5 years 6-10 years 11-15 years	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.  (country)
How many years have Less than one year 1-5 years 6-10 years	Biracial (ex. 2 different races). Please write them below.  Multiracial (ex. 3 or more different races). Please write them below.  Other. Please describe below.  (country)  you lived in the United States?

What language do you speak the mo	ost often at home?
	li li
What is your current marital status?	
Married	
Maried	
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Divorced	
Single	
Separated	
In a relationship	
What is the highest level of educatio	n you have completed?
Less than high school	
High school graduate	
Some college	
College degree	
Professional Degree ( Master's, Doctorat	e)
What is your average household inco	ome?
Less than \$15,000	
\$15,000-\$29,000	
\$30,000-\$49,000	
\$50,000-\$69,000	
\$70,000-\$99,000	
\$100,000 or above	
What is your zipcode?	
What is your zipcode?	
	//special needs? (If you have more than one, please
only list the age for the oldest one)	
The state of the s	

https://tamuoehd.cat.qualitos.com/QictitSedon/Biodas/ApavGetSurveyPrintPreview?ContextSurveyto-6V_evSeneV12941YUVe&ContextLbrary10 617  7/1822, 11:13 AM Quatrics Survey Software  Non-binary / third gender  Prefer not to say  What kind of school does your child attend?  Public School  Private School  School for individuals with special needs/disabilities  Homeschool  My child is not currently enrolled in school  Other. Please describe below.  What is your child's diagnosed disability? (Check all that apply)  Autism Spectrum Disorder  Deaf-Blindness  Deafness  Emotional Disturbance  Hearing impairment  Intellectual Disability. Please write the specific type of intellectual disability.  Multiple Disabilities  Mental Health Diagnosis  Orthopedic Impairment  Specific Learning Disability  Speech or Language Impairment  Traumatic Brain Injury  Visual Impairment/Blindness  Other. Please describe below.	Female		
Non-binary / third gender Prefer not to say  What kind of school does your child attend?  Public School Private School School for individuals with special needs/disabilities Homeschool My child is not currently enrolled in school  Other. Please describe below.  What is your child's diagnosed disability? (Check all that apply) Autism Spectrum Disorder Deaf-Blindness Deafness Emotional Disturbance Hearing impairment Intellectual Disability. Please write the specific type of intellectual disability.  Multiple Disabilities Mental Health Diagnosis Orthopedic Impairment Other Health Impairment Specific Learning Disability Speech or Language Impairment Traumatic Brain Injury Visual Impairment/Blindness	https://tamucehd.ca1.qualtrics.com/Q/EditSection/B	Blocks/Ajax/GetSurveyPrintPreview?ContextSurveyID-SV_eJ9snwV129HYUYe&ContextLibraryID	6/17
Non-binary / third gender Prefer not to say  What kind of school does your child attend?  Public School Private School School for individuals with special needs/disabilities Homeschool My child is not currently enrolled in school  Other. Please describe below.  What is your child's diagnosed disability? (Check all that apply) Autism Spectrum Disorder Deaf-Blindness Deafness Emotional Disturbance Hearing impairment Intellectual Disability. Please write the specific type of intellectual disability.  Multiple Disabilities Mental Health Diagnosis Orthopedic Impairment Other Health Impairment Specific Learning Disability Speech or Language Impairment Traumatic Brain Injury Visual Impairment/Blindness			
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Private School School for individuals with special needs/disabilities Homeschool My child is not currently enrolled in school Other. Please describe below.  What is your child's diagnosed disability? (Check all that apply) Autism Spectrum Disorder Deaf-Blindness Deafness Emotional Disturbance Hearing impairment Intellectual Disability. Please write the specific type of intellectual disability.  Multiple Disabilities Mental Health Diagnosis Orthopedic Impairment Other Health Impairment Specific Learning Disability Speech or Language Impairment Traumatic Brain Injury Visual Impairment/Blindness	What kind of school does yo	our child attend?	
School for individuals with special needs/disabilities  Homeschool  My child is not currently enrolled in school  Other. Please describe below.  What is your child's diagnosed disability? (Check all that apply)  Autism Spectrum Disorder  Deaf-Blindness  Deafness  Emotional Disturbance  Hearing impairment  Intellectual Disability. Please write the specific type of intellectual disability.  Multiple Disabilities  Mental Health Diagnosis  Orthopedic Impairment  Other Health Impairment  Specific Learning Disability  Speech or Language Impairment  Traumatic Brain Injury  Visual Impairment/Blindness	Public School		
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Orthopedic Impairment Other Health Impairment Specific Learning Disability Speech or Language Impairment Traumatic Brain Injury Visual Impairment/Blindness	•		
Other Health Impairment Specific Learning Disability Speech or Language Impairment Traumatic Brain Injury Visual Impairment/Blindness			
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Speech or Language Impairment  Traumatic Brain Injury  Visual Impairment/Blindness	•		
Traumatic Brain Injury Visual Impairment/Blindness		nt	
Visual Impairment/Blindness		II.	
•			
	•	hor Diogga describe helow	

What is your child's gender?

Male

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7/18/22, 11:13 AM Qualtrics Survey Software No Yes What kind of future-planning services does your child currently receive? (Check all that apply) Support with employment Support with financial/legal planning Support with higher education Support with daily living goals Support with government services ( SSI, SDI, Medicaid waivers, etc.) Other. Please describe below. None of the above Have you ever received any prior training to plan for your child's future? No Yes. Please explain when (year) and organization How important is it for you to learn about future planning opportunities for your child? Not at all important Slightly important Moderately important Very important Extremely important

#### **Parent Experiences**

Please answer the following questions about your feelings and experiences

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regarding parenting a child with a special needs/disability. Please only respond for one child. Please respond as honestly as you can.

#### In the past month...

	Never	Almost Never	Sometimes	Fairly Often	Very Often
How often have you been upset because of something that happened unexpectedly?	0	0	0	0	0
How often have you felt that you were unable to control the important things in your life?	0	0	0	0	0
How often have you felt nervous and stressed?	0	0	0	0	0
How often have you felt confident about your ability to handle your personal problems?	0	0	0	0	0
How often have you felt that things were going your way?	0	0	0	0	0
	Never	Almost Never	Sometimes	Fairly Often	Very Often
How often have you found that you could not cope with all the things that you had to do?	0	0	0	0	0
How often have you been able to control irritations in your life?	0	0	0	0	0
How often have you felt that you were on top of things?	0	0	0	0	0

	Never	Never	Sometimes	Fairly Often	Very Often
How often have you been angered because of things that were outside of your control?	0	0	0	0	0
How often have you felt difficulties were pilling up so high that you could not overcome them?	0	0	0	0	0

#### **Multicultural Mastery Scale**

# **Parent Experiences**

Please respond to the following statements about your family and social support systems.

Community refers to your friends, social community, faith community, parent community, or the larger disability community.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Working together with my community I can solve many of my problems.	0	0	0	0	0
I can change many of the important things in my life with the help of my community.	0	0	0	0	0
I can do what I set my mind to do because I have the support of my community.	0	0	0	0	0
What happens to me in the future mostly depends on my being supported by my community.	0	0	0	0	0

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
Working together with family I can solve many of my problems.	0	0	0	0	0
I can change many of the important things in my life with the help of my family.	0	0	0	0	0
I can do what I set my mind to do because I have the support of my family.	0	0	0	0	0
What happens to me in the future mostly depends on my being supported by my family.	0	0	0	0	0
I can solve many of the problems I have on my own	0	0	0	0	0
I can change many of the important things in my life	0	0	0	0	0
I do well even when things are tough.	0	0	0	0	0
What happens to me mostly depends on me.	0	0	0	0	0
I can do just about anything I really set my mind to do.	0	0	0	0	0

#### **Transition Planning Knowledge**

# Transition Planning/Future Planning

Please answer the following questions about your knowledge of transition planning.

Qualtrics Survey Software

#### What is transition planning?

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Planning for your child's school goals
Choosing the right classes for school
Planning for your child's future which includes academic, independent living, social skills, and employment.
None of the above.
In Texas, at what age can you legally start transition planning?
13
14
15
16
Anytime you want.
Who else besides the parents can attend the transition planning meetings?
The child
Close family members
Extended family members
Friends
Faith leaders
Lawyers/advocates
All of the above
None of the above
Pooja is graduating high school soon, and she and her parents do not know what she will do after graduation. What could her parents do?
Wait for the teacher to tell them about future planning.
Start looking for colleges for Pooia

Discuss her transition goals in ARD/IEP meetings.

Anita likes to bake and would love to find a job one day in a bakery. Which of the following services could help her find a job? Check all that apply.

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Her school teachers

**Texas Workforce Commission** 

Texas Education Agency

All of the above

Ankit and his parents have been working with his ARD/IEP team to make sure he is improving his ARD/IEP goals. However, they feel that he is not making progress, and his ARD/IEP team is not helping him. They want to advocate for him but are unsure where to start. What can his parents can do to advocate for his needs?

Write a letter to his teachers and the school district.

File a grievance with the school district.

Call their friends and tell them about it.

Nothing. Parents do not have many rights.

What is an inclusive postsecondary education program?

A high school program for only individuals with disabilities

A college program for individuals with disabilities

A college made for only individuals with disabilities

None of the above

What is the purpose of a Texas Medicaid waiver?

To help the child with medical services

To help the child with financial services

To help the child with living services

All of the above.

At what age can a child begin to receive Supplemental Security Income (SSI) benefits?

15

16

17

18

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According to the federal law, what is due process?

Process for suing the school.

Process for protecting the rights of parents.

Process for resolving disagreements between parents and schools.

Removing a child from school

#### Advocacy

#### **Experiences with Voicing your Concerns**

The following questions address how knowledgeable and comfortable you feel advocating or voicing your concerns on your son's/daughter's behalf. Please choose the response you feel best answers the question.

	1= Not at all	2= Below average	3= Average	4= Good	5= Excellent
How knowledgeable do you think you are about your own rights as a parent of a child with a disability?	0	0	0	0	0
How comfortable do you feel with calling local, state, or national agencies to ask about services for your child?	0	0	0	0	0
How comfortable do you feel with sharing information about future planning services with other parents or community members of children with disabilities/special needs?	0	0	0	0	0

How comfortable do	1= Not at all	z- below average	3= Average	4= Good	5= Excellent
you feel with disagreeing with teachers or other professionals' recommendations regarding future planning services for your child?	0	0	0	0	0
	1= Not at all	2= Below average	3= Average	4= Good	5= Excellent
How comfortable do you feel with seeking resources regarding future planning from organizations outside of the school? (Example: researching on the internet)	0	0	0	0	0
How comfortable do you feel with arranging meetings with professionals (teachers, organizations, other stakeholders) to discuss the needs of your child?	0	0	0	0	0
How comfortable are you with choosing appropriate academic placement in annual special education planning meetings (ARD) at your child's school?	0	0	0	0	0
How comfortable do you feel with working with your city, state, and federal agencies to apply for disability benefits for your child?	0	0	0	0	0

	Not at all, 0 times	A little, 1-2 times	Sometimes, 3-4 times	Often, 4-5 times	Very often, 6 or more times
Searched on the internet about services and resources for your child	0	0	0	0	0
Called agencies or organizations to ask about services for your child	0	0	0	0	0
Asked for support from your faith/religious organizations about services for your child.	0	0	0	0	0
Asked for support from other parents about your child's needs	0	0	0	0	0
Attended trainings (in person or online) about services and your rights	0	0	0	0	0
	Not at all, 0 times	A little, 1-2 times	Sometimes, 3-4 times	Often, 4-5 times	Very often, 6 or more times
Asked for translators during meetings in school or with organizations	0	0	0	0	0
Are part of or have searched for support from online parent groups about your child's needs (Example: Facebook groups or WhatsApp groups)	0	0	0	0	0
Disagreed with recommendations from professionals, schools, or agencies about services for your child	0	0	0	0	0
Helped another family with communication with schools, agencies, or professionals	0	0	0	0	0

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	Not at all, 0 times	A little, 1-2 times	Sometimes, 3-4 times	Often, 4-5 times	Very often, 6 or more times
Asked questions to professionals about future planning services	0	0	0	0	0

#### APPENDIX H

# WEEKLY PARENT FEEDBACK SURVEY

Hello Parents! Thank you for completing today's training session. Please complete the feedback form below. Please answer the following questions as honestly as you can. This form helps me prepare for the next sessions and informs me about your experiences so far.

Please respond to the following questions on a scale of 1-5

1= Strongly Disagree

2= Disagree 3= Neither Agree nor	Disagree				
4= Agree 5= Strongly Agree					
	1= Strongly Disagree	2= Disagree	3= Neither agree nor disagree	4= Agree	5= Strongly Agree
The information presented today was clear and easy to understand.	0	0	0	0	0
I learned something new from the training session.	0	0	0	0	0
I can apply what I learned today to help plan for my child's future.	0	0	0	0	0
I feel satisfied with today's training session.	0	0	0	0	0
I feel more confident with advocating for my child's future planning needs.	0	0	0		IRB NUMBER (IRB 2022-0394D IRB APPROVAL DATE: 08/02/20:
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#### APPENDIX I

#### WEEK 7 OVERALL SATISFACTION SURVEY

#### Introduction

Hello parents! Thank you for completing SAATHI 6-week parent training!

We congratulate you for preparing for your child's transition to adulthood and look forward to continuing this journey with you.

Now that you have completed the training, we would like to learn a little more about your experiences with the training, your preferences, and your recommendations to improve the training for future participants.

Please respond as honestly as you can to the questions below.

Thank you for your participation.



What is	What is your first and last name?								

#### About the Intervention

We want to learn about your experiences with SAATHI. Please share the extent to which you agree with the following statements about the training.

	Strongly Disagree	Disagree	Neither Agree Nor Dissagree	Agree	Strongly Agree
The information presented during SAATHI training was clear and easy to understand.	0	0	0	0	0
I found the training materials to be helpful in learning more about opportunities after high school for my child.	0	0	0	0	0
The advocacy portion of the training helped me become more confident about transition to adulthood planning.	0	0	0	0	0
I feel more prepared for navigating transition to adulthood for my child after this training.	0	0	0	0	0
SAATHI provided me with a safe space to share my concerns and open up about my challenges.	0	0	0	0	0

We also want to understand how you engaged with other parents during this training and your overall experiences of being part of the SAATHI community.

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Please share the extent	to which you	agree with t	he following s	tatements a	bout
community engagemen	nt during SAA	THI.			
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I enjoyed interacting with other parents during this training.	0	0	0	0	0
I feel like my interaction with the other participants increased from the beginning of the training to the end of the training.	0	0	0	0	0
I found the Whatsapp group to be helpful in communicating with other parents during SAATHI.	0	0	0	0	0
I plan to keep in touch with some of the other parents from SAATHI.	0	0	0	0	0
I felt a sense of belonging during the SAATHI training.	0	0	0	0	0
			<b></b>		

We want to understand your well-being after SAATHI training. Please share the extent to which you agree with the following statements about your advocacy and well-being.

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I feel prepared to advocate for my child's transition outcomes after participating in SAATHI.	0	0	0	0	0
I feel comfortable speaking to transition teachers and other stakeholders about planning for my child's future.	0	0	0	0	0

	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I feel confident in my skills to start planning for my child's future.	0	0	0	0	0
I feel less stressed out about future planning after participating in SAATHI.	0	0	0	0	0
I feel more hopeful about my child's future after participating in SAATHI.	0	0	0	0	0

#### Recommendations

We would love to get your feedback about how to make SAATHI more successful in the future.

Please share the extent to which you agree with the following statements about recommendations for the future.

	Strongly disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
I would recommend SAATHI to other South Asian parents of children with disabilities.	0	0	0	0	0
I would be interested in attending additional SAATHI training in the future about future planning opportunities.	0	0	0	0	0
SAATHI improved my knowledge of future planning opportunities for my child.	0	0	0	0	0

What recommendations do you have to improve SAATHI for future parents?				
What other topics would you like to learn more about that were not offered in SAATHI?				
Please provide any other feedback or suggestions you may have about SAATHI.				

#### APPENDIX J

# WHATSAPP CHECKLIST

#### WhatsApp Measures Checklist

Timing: Measured once a week on Sunday for each cohort from week 0-4. Then measured monthly.

Start: Week 0- when cohorts will get the details of their location and details via Whatsapp End- After the 3-month interviews are conducted

Activity	Present (1 point)	Not Present (0 points)	Comments/Notes
Participants initiated a text regarding resources related to future planning			
Participants initiated a text regarding any resources. Note down the type of resources or themes.			
Participants asked questions regarding transition planning related topics			
Participants asked questions regarding training related details ( time, location, etc.)			
Participants responded to trainer's messages/comments			
Number of participants participated in message exchanges in the group. How many? Same or different individuals?			
Indicate the number of messages exchanged this week or month.			
What themes were discussed in the chat this week? ( Only note observations- not numbered)			



# APPENDIX K

# TRAINING FIDELITY CHECKLIST

Directions: Please indicate if the procedure listed below was followed or not. Please provide notes/comments if you are unclear in the boxes below each statement.

SAATHI Procedures	Observed (1 point)	Did not observe (0 points)	Does not apply to this session
Researcher has introduced SAATHI (only for the first session).			
Researcher has introduced themselves (only for the first session).			
Researcher has invited participants to share any success stories from the last session (Does not apply to the first session)			
Researcher has invited participants to share any challenges they may have with future planning (Does not apply to first session)			
Researcher has introduced the topic for the session.			
Researcher has offered space to ask questions during the session.			
Researcher has modeled an advocacy case study before putting people into groups.			
Researcher has provided clear beginning and end time for the group activity.			
Researcher has offered time at the end for Q&A.			
Researcher has asked parents to complete the session survey form.			