ABSTRACT

Title of Dissertation: BRIDGING THE CULTURAL GAP: AN EXPLORATION OF COACHING, COMMUNICATION, AND CHALLENGING BEHAVIOR IN DIVERSE FAMILIES RAISING NONVOCAL INDIVIDUALS WITH AUTISM SPECTRUM DISORDER AND INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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There has been a rise in the global prevalence of autism spectrum disorder (ASD) and intellectual and developmental disabilities (IDD), particularly among those who are nonvocal or minimally vocal and display challenging behavior, such as aggression and self-injury. Additionally, parental involvement plays a crucial role in reducing these behaviors and promoting effective communication. However, research involving parents and caregivers from culturally, ethnically, and linguistically diverse (CLD) backgrounds, especially regarding the customization of practices to meet their needs and priorities, remains limited. Therefore, examining the effects of evidence-based interventions such as functional communication training (FCT), applied behavior analysis (ABA), and behavioral skills training (BST) among minority populations is essential. This dissertation aims to fill this gap by examining the

current state of parent-implemented interventions and the coaching procedures that support them. Chapter 2 provides a systematic review of the literature on parent-implemented FCT to reduce challenging behaviors in nonvocal and minimally vocal children with ASD and IDD from CLD backgrounds. The review analyzed ten studies and found that parent-implemented FCT was directly associated with decreases in challenging behaviors and increases in independent communication. However, only half of the studies reported culturally adapted practices, and data on the generalization and maintenance of learned skills were limited. Chapter 3 presents a qualitative study exploring the experiences of Arab caregivers living in the United States (U.S.) regarding coaching and the implementation of evidence-based interventions. The importance of culturally tailored interventions and coaching for these caregivers was particularly emphasized. The findings identified four major themes, discussed alongside their subthemes, limitations, and implications for practice and research. Chapter 4 applies insights from the qualitative study to offer practical recommendations for practitioners and service providers working specifically with Arab caregivers. Overall, this dissertation suggests that future research and practice should involve families and caregivers of individuals with ASD and IDD as active partners rather than passive recipients. This engagement can deepen understanding of cultural differences within each minority group, strengthen school-home relationships, and improve the quality of life for both caregivers and their loved ones.

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Dedication

For all individuals with disabilities and their families. May we continue to learn from your experiences as we strive toward a more compassionate and accessible future for everyone.

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List of Abbreviations and Key Terms

applied behavior analysis (ABA): "the science in which tactics derived from the principles of behavior are applied to improve socially significant behavior and experimentation is used to identify the variables responsible for the improvement of behavior" (Cooper et al., 2020, p. 786).

autism spectrum disorder (ASD): "any one of a group of disorders with an onset typically occurring during the preschool years and characterized by varying but often marked and persistent deficits in social communication and social interaction, including difficulties with social-emotional reciprocity, nonverbal communication behaviors, and social relationships, along with restricted and repetitive patterns of interests, behaviors, and/or activities" (American Psychiatric Association, 2022).

behavioral skills training (BST): An empirically backed training/coaching model used to train/coach individuals to implement interventions using instruction (usually written and oral), modeling, role-playing, and performance feedback. (Parsons et al., 2012).

challenging behavior: "any repeated pattern of behavior that interferes with or is at risk of interfering with the child's optimal learning or engagement in pro-social interactions with peers and adults" (Smith & Fox, 2003, p. 6)

culturally, ethnically, and linguistically diverse (CLD): those who are not part of the mainstream culture and/or ethnic group. This includes families who have different cultural values than those of the mainstream culture, may or may not speak a language other than English at home, and may or may not come from historically underrepresented groups (Tyler et al., 2004).

functional communication training (FCT): "an antecedent intervention in which an appropriate communicative behavior is taught as a replacement for problem behavior usually evoked by an establishing operation (EO); involves differential reinforcement of alternate behavior (DRA)" (Cooper et al., 2020, p. 792).

intellectual and developmental disabilities (IDD): an umbrella term used to refer to individuals with an intellectual and/or developmental disability, as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2022).

minimally vocal or nonvocal: terms used to refer to individuals who produce little to no functional sounds but might be communicating through different verbal behaviors (i.e., alternate or augmentative communication), such as sign language, gestures, or a speech-generating device.

Chapter 1: Introduction

There is no doubt that the global prevalence of both autism spectrum disorder (ASD) and intellectual and developmental disabilities (IDD) has increased in recent years (Olusanya et al., 2023), along with the diversity of racial and ethnic backgrounds of these populations (National Center on Birth Defects and Developmental Disabilities, 2023). Moreover, around 35% of individuals diagnosed with ASD are categorized as minimally vocal (Rose et al., 2016). Additionally, about one-quarter of children diagnosed with ASD also receive a concurrent diagnosis of IDD, a condition often linked to increased levels of challenging behavior (Lundqvist, 2013). Previous research shows that up to 90% of individuals diagnosed with ASD (Jang et al., 2011) and 60% of those with IDD (Simó-Pinatella et al., 2017) manifest challenging behavior, with aggression and self-injury being among the most common. With the ever-growing diversity of racial and ethnic backgrounds comes a need to actively include and report instances of culturally, ethnically, and linguistically diverse (CLD) populations in ASD- and IDD-related intervention research.

Until recently, there has been poor inclusion and reporting of participants from CLD backgrounds in such intervention research, which may contribute to disparities in access to appropriate and timely services (Steinbrenner et al., 2022). The underrepresentation of families from CLD backgrounds, let alone Arabs, in intervention research only widens the gap between research and effective, culturally adapted practices for families, caregivers, and practitioners working with the diverse population of children with ASD and IDD. This is especially important when examining the effects of interventions on socially significant behaviors, such as reducing/eliminating challenging behavior (e.g., aggression, self-injury) and increasing appropriate communication (Steinbrenner et al., 2022).

When it comes to families from Arab backgrounds, specifically those living in the U.S. (i.e., Arab Americans), they are considered one of the fastest-growing minority populations. Between 2010 and 2024, the population increased by approximately 43%, with immigrants coming from countries across the Middle East and North Africa, with the most from Iraq, Egypt, Somalia, Yemen, and Syria (*Arab American Demographics*, 2024). As of 2024, the total number of Arab Americans is estimated to be around 3.7 million, with the majority being native-born and 86% U.S. citizens (*Arab American Demographics*, 2024). The ethnic origins of Arab Americans trace back to each Arab country, but most originate from Lebanon, Egypt, Syria, Palestine, and Iraq (*Arab American Demographics*, 2024). Although most Arabs outside the U.S. are considered Muslim, there are more Arab American Christians than there are Muslims (Rahal et al., 2022). The prevalence of Arab Americans with disabilities (both children and adults) is based on outdated estimates, with the most recent research suggesting that approximately 20% of the total Arab American population has a disability (Al Khateeb et al., 2014). However, Al Khateeb et al. (2014) suggested this estimate may be higher, given the lack of *Arab* or *Arab American* classification in the U.S. Census, which conflicts with the data on the distribution of Arab Americans by other organizations, such as the Arab American Institute.

This dissertation aims to address these issues by evaluating the research that includes and reports on families from CLD backgrounds, presenting an in-depth narrative of Arab caregivers' experiences with minimally vocal and nonvocal children with ASD and IDD, and offering recommendations for practitioners working with such families. First, the systematic review focused on research involving parent-implemented interventions, specifically functional communication training (FCT; Chapter 2). The results highlighted the need for (a) greater transparency in reporting participants' backgrounds and characteristics, including ethnicity; (b)

inclusion of families from diverse backgrounds in intervention studies; and (c) the use of culturally adapted, appropriate practices when coaching parents to implement interventions. To address this gap, the qualitative study (Chapter 3) used a case study approach to gain deeper insight into the perspectives and experiences of Arab caregivers of minimally vocal or nonvocal children with ASD and IDD who exhibit challenging behaviors. Semi-structured interviews and journals provided a better understanding of the challenges this group faced and the barriers they encountered in accessing appropriate services for their children. After completing this study, a practitioner paper (Chapter 4) was developed to share the findings from the qualitative research and offer practitioners practical recommendations for better supporting Arab caregivers of nonvocal children with ASD and IDD who display challenging behaviors.

All in all, this dissertation aims to advance the literature and shed light on an understudied topic within the field, thereby increasing awareness and understanding among caregivers and practitioners and ultimately improving communication for nonvocal and minimally vocal individuals with ASD and IDD.

Dissertation Outline

There are five main chapters in this dissertation: (1) Introduction, (2) Systematic Review, (3) Qualitative Study, (4) Practitioner Paper, and (5) Conclusion. The first chapter introduces the current research landscape related to the dissertation's focus and states its overall purpose. The second chapter presents a systematic literature review on parent-implemented interventions aimed at reducing challenging behavior in children with ASD/IDD from diverse backgrounds. The research questions for the systematic review were:

1. What are the effects of parent-implemented FCT in the reduction of challenging behavior in nonvocal children with ASD and IDD from CLD backgrounds?

    a. What are the characteristics of child and parent participants represented across these studies?

2. What methods have been used when coaching parents from CLD backgrounds on how to use FCT, and which validity and fidelity measures and outcomes were evaluated?
    a. What cultural adaptations or culturally responsive practices were implemented with parents from CLD backgrounds?

The third chapter is a qualitative study focused on exploring the experiences and perspectives of Arab caregivers living in the U.S. of children with ASD and IDD who are minimally vocal or nonvocal and exhibit challenging behavior. Specifically, it examines access to appropriate services, coaching or training, and the implementation of interventions such as ABA. Of particular importance is the need for culturally adapted interventions for these families. The research questions for this study were:

1. What challenges do Arab caregivers (living in the U.S.) of nonvocal children with ASD and IDD who engage in challenging behaviors face, specifically with finding appropriate services and being coached to implement interventions, such as ABA?
2. How do these caregivers experience coaching procedures intended to address their children's challenging behavior?
    a. How, if at all, are the coaching procedures culturally adapted?
3. How can Arab caregivers be better supported when being coached to implement interventions, such as ABA, with their nonvocal children with ASD/IDD who engage in challenging behavior?

The fourth chapter draws on the findings of the qualitative study conducted in the third chapter to provide implications for practitioners and service providers working specifically with

Arab caregivers of children with ASD and IDD in the U.S. It includes a summary of results from the qualitative study in chapter three, including caregiver challenges and experiences, along with recommendations for supporting Arab caregivers through culturally adapted practices. Finally, the concluding chapter summarizes the dissertation as a whole, presents the key findings, acknowledges limitations, and proposes recommendations for future research.

Chapter 2: Parent-Implemented Functional Communication Training to Reduce Challenging Behavior in Nonvocal Children with ASD and IDD from Diverse Backgrounds: A Systematic Review

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Challenging behavior can be defined as "any repeated pattern of behavior that interferes with or is at risk of interfering with the child's optimal learning or engagement in pro-social interactions with peers and adults" (Smith & Fox, 2003, p. 6). This may include topographies such as physical aggression, tantrums, property destruction, noncompliance, and self-injury and can result from biological or environmental factors. Self-injurious behavior has an estimated prevalence of approximately 42% in children with autism spectrum disorder (ASD; Steenfeldt-Kristensen et al., 2020) and 33% in children and adults with intellectual and developmental disabilities (IDD; Summers et al., 2017). Moreover, children with ASD and IDD who are minimally vocal or nonvocal tend to engage in more self-injurious behavior, compared to vocal children with ASD and IDD (Summers et al., 2017). The proportion of minimally vocal children with ASD is approximately 35% of the total ASD population (Rose et al., 2016), and about one-quarter of children diagnosed with ASD are also diagnosed with IDD, and such diagnoses were associated with greater levels of challenging behavior (Lundqvist, 2013). Over the years, multiple studies have focused on interventions to increase appropriate communication while simultaneously decreasing challenging behavior within this population of individuals (Zangrillo et al., 2016). With such behavior being common among almost half the population of individuals with ASD and IDD, specifically those who are considered nonvocal or minimally vocal, it is important to consider interventions that have been evaluated specifically to support their needs.

The terms *nonverbal* and *minimally verbal* have been used in the field of special education to describe children who do not speak or speak no more than a few sentences, relative to their age. Most recently, Koegel et al. (2020) defined nonverbal children as those who are at least 18 months and "demonstrate no consistent verbal expressive words" (p. 12) and minimally verbal children would be "considered to be using some words, but significantly fewer than expected levels relative to age" (p. 12). However, more attention has been recently paid to the language used to describe this population and there has been a need for a better distinction between *verbal* and *vocal* terms. In simple terms, while *verbal* refers to communication with another individual, whether through vocal speech, signing, typing, or through a speech-generating device, it does not necessarily mean the person is engaging in vocal behavior. On the other hand, *vocal* communication, which can be defined as "the transfer of information through the auditory channel via voice production mechanisms" (Bryant, 2021, p. 8445), does refer to the production of sounds when communicating with one another. For this review, we will be using the terms *nonvocal* and *minimally vocal* to refer to individuals who produce little to no age-related functional sounds but might be communicating through different verbal behaviors, such as manual sign language, gestures, or a speech-generating device.

Functional Communication Training

For children with ASD and IDD, including those who are considered nonvocal or minimally vocal, one of the most common evidence-based practices used to reduce challenging behavior is functional communication training (FCT), which was first introduced by Carr and Durand (1985) and continually backed by many peer-reviewed articles in the last few decades (e.g., Liao et al., 2021). Essentially, FCT involves three main components: (a) identifying the function driving the behavior, sometimes conducted with a functional analysis (FA), (b) teaching

an appropriate alternative response requiring the same or less effort than the challenging behavior, and (c) implementing differential reinforcement for the appropriate communicative response and simultaneously placing the challenging behavior on extinction (i.e., withholding reinforcement). Over the years, researchers demonstrated FCT to be effective at reducing challenging behavior in children and adolescents with ASD and IDD across various settings, such as schools (e.g., Carr & Durand, 1985) and homes whether in-person (e.g., Edelstein & Lenfestey, 2023) or via telehealth (e.g., Lindgren et al., 2016). As an evidence-based practice, researchers examined FCT when implemented by parents, and their findings have shown that parent implementation of evidence-based interventions allows for more sustainable, long-lasting results (i.e., generalization and maintenance; Oono et al., 2013). At its core, FCT can be considered one of the most empirically supported interventions for reducing challenging behavior while simultaneously increasing functional or independent communication in children with limited vocal abilities (Ghaemmaghami et al., 2020). However, there is still a need for more studies to examine FCT in natural settings with family members as implementers, specifically with children who are considered to be minimally vocal or nonvocal.

Current Review

Although there have been previous reviews of the literature on similar topics (Gerow et al., 2017; Liao et al., 2021), to the best of the authors' knowledge, to date no study exists synthesizing studies focusing specifically on nonvocal and minimally vocal children with ASD and IDD. This review also focused on families from CLD backgrounds while highlighting the culturally responsive coaching practices embedded in the interventions. In general, families from CLD backgrounds can be defined as those who are not part of the mainstream culture and/or ethnic group. This includes families who have different cultural values than those of the

mainstream culture (Penner-Williams et al., 2020), may or may not speak a language other than English at home, and may or may not come from historically underrepresented groups (Brown & Fitzpatrick, 2010). The purpose of this systematic review was to examine studies on parent-implemented FCT for reducing challenging behavior in nonvocal or minimally vocal children with ASD and IDD from CLD backgrounds. The research questions are: (a) What are the effects of parent-implemented FCT in the reduction of challenging behavior in nonvocal children with ASD and IDD from CLD backgrounds? (b) What are the characteristics of child and parent participants represented across these studies? (c) What methods have been used when coaching families from CLD backgrounds how to use FCT and which validity and fidelity measures and outcomes were evaluated? And (d) What cultural adaptations or culturally responsive practices were implemented with families from CLD backgrounds, if any?

Method

Eligibility Criteria

A study needed to meet the following criteria to be included in this review: (a) was an intervention study, (b) included at least one participant from a CLD family, as operationally defined as a family whose cultural values, practices, or primary language differ from those of the mainstream culture, (c) included at least one participant with a diagnosis or prognosis of ASD or IDD, (d) participants in grades P-12 (0-21 years of age), (e) participants were reported to have minimal or no vocalizations, (f) FCT was the main independent variable, (g) intervention targeted decreasing challenging behavior and was implemented by parents, (h) child outcomes were reported, and (i) the study was published in English. CLD was defined as "individuals who come from racial and ethnic groups other than the European American culture (e.g., African/Asian/Native American) and/or who may speak languages other than English as their

first language" (Brown & Fitzpatrick, 2010, p. 374). The authors also included studies conducted in a country outside North America or Europe, which would consider those participants from CLD families and therefore meet the inclusion criteria in that regard. Exclusion criteria included (a) study was not an intervention (b) study did not include at least one participant from a CLD family, (c) study did not include at least one participant with a diagnosis or prognosis of ASD or IDD between the ages of 0-21 years, (d) study did not focus on FCT as the main independent variable, (e) participant's vocalization abilities not reported or participants considered vocal, (f) intervention did not target decreasing challenging behavior, (g) intervention not implemented by parents, (h) child outcomes not reported, and (i) study not published in English.

Data Sources

The systematic search was conducted across multiple time points using EBSCO*host* databases [Academic Search Ultimate, APA PsycINFO, Education Source, and Educational Resources Information Center (ERIC)], with the latest search in December 2024 to capture the most recent literature from the ProQuest Dissertations and Theses Global database, given the few initially found eligible from EBSCO*host* databases. The authors also screened additional data sources at each time points of the systematic search by (a) reviewing the reference list of included articles and literature reviews about parent-implemented FCT (Gerow et al., 2017; Liao et al., 2021; Unholz-Bowden et al., 2020) and (b) completing a hand-search of peer-reviewed journals focused on ASD and IDD: *Autism, Education and Training in Autism and Developmental Disabilities, Focus, Journal of Applied Behavior Analysis, Journal of Autism and Developmental Disorders*.

Search Procedures

For each database search, the first author used the advanced search feature, entering three lines of keywords connected by "AND" and incorporating truncations.: (1) autis* OR "autism spectrum disorder" OR "autistic disorder" OR ASD OR developmental disabilit* OR "developmental delay" OR "developmental disorder" OR intellectual disabilit* OR "intellectual delay" OR "intellectual disorder" AND (2) "functional communication training" OR FCT OR "functional analysis" OR "functional equivalence training" OR "mand training" AND (3) "parent-implemented" OR "parent training" OR "parent intervention" OR "parent education" OR "parent coaching". Search terms related specifically to CLD were not used to avoid narrowing the scope of the search even further.

Selection Procedures

While the search was conducted across multiple time points (May 2023, September 2024, and December 2024), search results are presented here cumulatively for ease of reading. Electronic database search resulted in 284 records from EBSCO*host* databases and 2,078 records from ProQuest for a total of 2,249 records. After removing duplicates, 171 unique records remained from EBSCO*host* (see Figure 2.1 for Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram; Page et al., 2021) and 2,078 records from ProQuest. During the initial screening, the first author reviewed the titles and abstracts of all remaining records. If either the title or abstract suggested the record may meet inclusion criteria, the first author downloaded full-text copies of the records to determine eligibility. A total of 47 full-text records were downloaded for review from both EBSCO*host* and ProQuest. After screening these records, 38 records were excluded for reasons not having FCT as the main independent variable, not including a participant from a CLD background, or not reporting on the

vocalization abilities of the participants. As a result, ten studies were included in the final analysis, including one study found through the hand search.

Data Extraction

The authors coded data from the included studies according to (a) participants, (b) design, and (c) findings. For participants, we included information about the total number of participants, their ages, gender, grade level or school setting, race/ethnicity, disability(ies), diagnosis source, assessments, vocal ability (i.e., vocal, minimally vocal, or nonvocal), the current mode of communication (e.g., vocalization, gesture, etc.), and challenging behavior. The authors used the definitions presented previously by Koegel et al. (2020) to differentiate vocal ability among participants. In terms of the study design, information was coded regarding the setting of the intervention, whether FCT was the main independent variable (IV), if challenging behavior was the main dependent variable (DV), the implementer of the intervention and their background (e.g., education, employment status, etc.), the dosage and method of caregiver coaching, and any cultural adaptations or culturally responsive practices involved. Finally, using the information provided in the results section of each study, the authors narratively summarized findings to include only the most pertinent information about child and parent outcomes, effects of cultural adaptations or culturally responsive practices, and social validity. To avoid portraying incorrect information, the authors did not make inferences regarding any data that could not be found and instead coded the item as ‘not reported’.

Methodological and Quality Evaluation

The authors used quality indicators outlined by Reichow et al. (2011) to evaluate the methodological rigor of each study included in this review, which provides guidelines for both single-case and group experimental designs. We evaluated each study’s primary (high,

acceptable, unacceptable) and secondary (evident or not evident) quality indicators and then rated each study with a strong, adequate, or weak rating. Primary quality indicators for single-subject experimental designs examined participant characteristics, the independent and dependent variables, baseline condition, and visual analysis. Secondary quality indicators for single-subject experimental designs examined interobserver agreement, Kappa, blind raters, fidelity, generalization or maintenance, and social validity (Reichow et al., 2011). For a study to be classified as having a *strong* evidence rating, all primary quality indicators need to receive a *high* quality rating, with three or more secondary quality indicators rated as *evident*. An *adequate* evidence rating is given to a study with no *unacceptable* quality ratings for all primary quality indicators and has at least two secondary indicators rated as *evident*.

Quantitative Synthesis

To supplement the methodological and quality evaluation, the first author calculated Tau-*U* effect sizes (Parker et al., 2011) of the interventions using the web-based calculator (http://singlecaseresearch.org/calculators/tau-u; Vannest et al., 2016). The authors chose this statistical analysis tool because it accounts for baseline trends, measures nonoverlap between phases, and is suitable for single-case designs with small sample sizes. First, the authors calculated the Tau-*U* score for the target behavior (i.e., challenging behavior) of each participant in each study (baseline and intervention) before calculating the weighted score for each participant for the baseline and intervention phases. This was done using data derived from studies after the authors confirmed a functional relation. We used the following scale to interpret scores: *weak* (0 to -0.65), *medium-to-high* (-0.66 to -0.92), and *strong* (-0.93 to -1.00) effect (Parker et al., 2011). In other words, a *strong* effect illustrates that the use of parent-implemented FCT resulted in a decrease in challenging behavior.

Interrater Reliability

Researchers calculated interrater reliability (IRR) for each level of screening and coding. To assess the reliability of the screening procedures, two independent raters conducted an eligibility screening of all downloaded records (48 in total). IRR was calculated as the number of agreements divided by the number of agreements plus disagreements, multiplied by 100%. Initially, there were disagreements for 6 records (IRR = 87.2%), which were discussed until a consensus was reached with a 100% agreement between all coders. To assess the reliability of the data extraction procedures, two independent raters completed the data extraction of approximately half the records included in the review (5 records), with an initial agreement of 100% between all coders. Results of the methodological evaluation (i.e., Reichow rating) for all included studies were agreed upon by the first author and two independent raters, with an initial agreement of 97% before reaching 100% after discussion.

Results

Participant Characteristics

Across the 10 studies included in this review, a total of 47 parent-child dyads participated, including 48 parents and 47 children (see Table 2.1). The child participants were between the ages of 2 and 17 years, with a majority of them being male (n=35) and the remaining 12 being female. Most of the parent participants were mothers (n=34), five were fathers, and one study did not specify which parent implemented the intervention (n=9). In terms of ethnicity, child participants were identified as Brown (n=7), Saudi Arabian (n=7), White (n=7), Korean (n=5), Hispanic (n=4), Asian (n=3), Greek (n=3), Middle Eastern (n=3), Turkish (n=2), Biracial, not otherwise specified (n=1), White/Black (n=1), Costa Rican (n=1), Hispanic/ Black (n=1), Mexican (n=1), Russian (n=1), Ukrainian (n=1), and White/Native American (n=1).

Child Participants

Child participants were diagnosed with either ASD (n=31), ID (n=3), DD (n=8), or a combination of ASD and other co-occurring conditions (n=5). The overall vocal ability of these participants ranged from nonvocal to minimally vocal, with modes of communication including single-syllable vocalizations, one-word utterances, echoic utterances, intentional vocalizations, gestures, pointing, signs, picture exchange, and short phrases. Regarding their challenging behavior, examples included self-injury (hitting oneself, hair pulling), physical aggression (biting others), tantrums, noncompliance, property destruction, and elopement.

Parent Participants

Parent participants had varying backgrounds in terms of education, employment, and previous experience with function-based interventions. At the time of the studies, most parents' employment status was not reported. However, in studies that reported this information, parents were employed full-time (n=5), part-time (n=3), or were unemployed (n=5). Parents had diverse educational backgrounds, including those whose highest degree was a high school diploma (n=13), an associate's degree (n=2), unspecified college degree (n=2), bachelor's degree (n=17), a master's degree (n=5), and a doctoral degree (n=2). Except for two parents—one with prior training and the other a registered behavioral technician—all studies that reported on parents' prior training in behavioral or function-based interventions indicated parents had not received any prior training. One study (Tsami et al., 2019) reported none of the parents spoke or understood English. Two studies (Almulhim, 2023; Lee, 2016) reported on parents' marital status and indicated all were married.

Intervention Design

All studies used some form of single-case experimental design, including ABAB withdrawal (n=1), multiple-probe across dyads (n=2), contingency reversal (n=1), multi-element (n=2), and non-concurrent multiple-baseline across dyads (n=4). Most of the studies were conducted virtually (n=8), one was conducted entirely in-person, and one hybrid. In terms of setting, interventions took place in participants' homes in all studies except one, in which two participants received intervention in a therapy room. Parent-implemented FCT was the main independent variable (IV) and decreasing challenging behavior was the main dependent variable (DV) in all studies. The operational definitions for the DV of each participant varied based on the results of the FA conducted prior to FCT.

Parent Coaching

Method and Dosage

Regarding coaching procedures, providing written and verbal instructions along with feedback was common in all studies. One study (Drew et al., 2021) implemented the Behavioral Parent Training (BPT) method, which consisted of didactic instruction, modeling, rehearsal, and feedback. Another term for this type of coaching is Behavioral Skills Training (BST), which was implemented by Almulhim (2023) and Ashgar (2024). One study (Standish et al., 2023) had parents complete a series of online training modules aimed at teaching parents how to collect data, while researchers coached parents on safety procedures. Most studies also explicitly mentioned how parents were encouraged and given opportunities to ask questions throughout the coaching process and intervention. Gerow et al. (2017) used self-monitoring with parents who had a procedural fidelity rating below an average of 80% during the first three generalization data points. Gerow et al. (2019) also used a self-monitoring sheet, which was provided along

with the written and verbal instructions during the initial meeting. The remaining studies did not incorporate self-monitoring in their coaching procedures; however, Standish et al. (2023) had researchers evaluate parents' procedural fidelity using checklists.

The dosage and duration of coaching varied across the studies; however, three studies did not specify the exact dosage of the coaching provided. Gerow et al. (2017) mentioned parents reached 100% implementation fidelity for three consecutive trials within 8-16 two-minute trials, however, the duration of the coaching process was unclear. Two studies had weekly 1-hour sessions but did not clarify the duration of the coaching process, while other studies had varying lengths of parent coaching, such as one to two 1-hour sessions or 20-30-minute sessions (4x/ week) across 2-3 months.

Cultural Adaptations

Of the ten studies, half did not indicate or specify any cultural adaptations or culturally responsive practices in their parent coaching. Five studies accommodated families by offering and/or delivering written and verbal communication in the family's native languages (Almulhim, 2023; Ashgar, 2024; Lee, 2016; Tsami et al., 2019; Tsami et al., 2023). These adaptations included (a) learning about the country's culture to help foster culturally relevant discussions during appointments, (b) learning simple greetings and phrases in the families' native languages, and (c) organizing educational presentations for caregivers and teachers of the families' local communities. They considered cultural norms in treatment components (e.g., not appropriate to ask the caregiver to praise the participant with a hug in one culture). Lastly, interpreters coached researchers on the correct pronunciation of names and words in the families' native languages.

Child Outcomes

All studies reported on child outcomes either in terms of challenging behavior or both challenging behavior and independent communication (i.e., independent mands). The functions driving the challenging behavior of participants varied, with the most being access to tangible items (n=24), followed by escape (n=12), escape and access (n=5), attention and access (n=3), attention, access, and escape (n=1) and attention (n=1). All studies reported a decrease in each participant's challenging behavior, and nine reported an increase in independent mands as well. Across all studies, challenging behavior was significantly reduced, and none reported any negative outcomes (i.e., persistence or increase in challenging behavior during intervention phases). In Tsami et al. (2023), all but one participant exhibited zero levels of challenging behavior during the intervention and independently emitted mands during at least 90% of opportunities. Similarly, Tsami et al. (2019) reported challenging behavior decreased by at least 90% for all participants and remained low throughout the intervention, while all but one participant independently emitted mands during at least 90% of opportunities. Almulhim (2023), Lee (2016), and Standish et al. (2023) reported a 100% reduction in challenging behavior for all participants by the end of the study. A summary of each study's design, implementer characteristics, the dosage of training, and child outcomes is included in Table 2.2.

Procedural Fidelity and Social Validity

Parent implementation fidelity was high across all studies, ranging between 83-100%. Procedural fidelity was measured using various methods, such as a research-developed checklist or Likert scale, assessing the accuracy of both the coaching procedures by the researcher and the implementation of the intervention by parents (Drew et al., 2021; Gerow et al., 2019; Gerow et al., 2020; Standish et al., 2023) or just that of the parents (Almulhim, 2023; Ashgar, 2024;

Gerow et al., 2017; Lee, 2016; Tsami et al., 2019; Tsami et al., 2023). Social validity results across all studies illustrated high levels of intervention acceptability and its outcomes among parents. Apart from one study (Drew et al., 2021), all studies administered their social validity measures post-treatment. Most studies used a formal rating tool, such as the Treatment Acceptability Rating Form (TARF; Reimers & Wacker, 1988). Ashgar (2024) also used a revised form of TARF with child participants, with only two questions on a 3-point Likert scale. Another study (Almulhim, 2023) used a researcher-developed questionnaire with a 5-point Likert scale that measured the acceptability and disadvantages of the intervention, as well as the coaching procedures.

Methodological and Quality Evaluation and Quantitative Synthesis

Half of the studies (Almulhim, 2023; Ashgar, 2024; Drew et al., 2016; Gerow et al., 2017; Tsami et al., 2019) included in this review received a *strong* evidence-based rating based on Reichow et al. (2011), while the remaining studies (Gerow et al., 2019; Gerow et al., 2020; Lee, 2016; Standish et al., 2023; Tsami et al, 2023) received an *adequate* rating due to factors such as lack of generalization and maintenance phases or unstable data within or across phases. When calculating the effects of the intervention on reducing challenging behavior among participants, the weighted average Tau-*U* across all studies suggested a medium-to-high effect (-0.83), with individual study Tau-*U* scores ranging from -0.49 to -1.0 (see Table 2).

Discussion

The purpose of this systematic review was to synthesize studies focusing on parent-implemented FCT and its effectiveness in reducing challenging behavior (e.g., self-injury, physical aggression, property destruction) in nonvocal or minimally vocal children with ASD and IDD from CLD backgrounds. Across all studies, parent-implemented FCT was directly

correlated with a decrease in challenging behavior in children with ASD and IDD, as well as an increase in independent communication in some studies. These findings support the findings of previous reviews (Gerow et al., 2017; Liao et al., 2021), while also extending the effectiveness of parent-implemented FCT to CLD families, particularly among the diverse populations represented across the studies in this review. Previous review studies on FCT found the use of parent-implemented FCT was effective in reducing challenging behavior in children with ASD or IDD across varying settings (e.g., Gerow et al., 2018; Lindgren et al., 2020). Consistent with the findings of previous studies (Hampton et al., 2022; Suess et al., 2014; Wacker et al., 2013), mothers served as implementers of the intervention across all included studies in this review. This suggests a need for additional research to examine the effects of FCT implemented by caregivers other than mothers, such as fathers and grandparents.

While findings of this systematic review add to existing research, our results contribute to research in novel ways. Our findings suggest in parent-implemented FCT studies, the cultural and ethnic diversity of parent-child dyads provides preliminary evidence for the cross-cultural applicability of FCT as an evidence-based intervention. The cultural and ethnic diversity of parent-child dyads across the studies offers promising insight into FCT's applicability across diverse populations. However, a significant gap emerged—the lack of cultural adaptations in half of the studies included in this review is striking, despite extant research suggesting that culturally adapted interventions can significantly improve engagement and efficacy for families from CLD backgrounds (Albin et al., 2022; Londono et al., 2022). Despite the lack of cultural adaptations in some studies, social validity was consistently high, suggesting parents found FCT both acceptable and relevant, regardless of whether cultural adaptations were used. Similarly, procedural fidelity was high, indicating parents were able to implement the strategies

independently and accurately. These findings align with previous studies that also demonstrated parents could deliver FCT with high fidelity (e.g., Lindgren et al., 2020), while extending findings from previous reviews (e.g., Albin et al., 2022) that call for more studies to investigate the impact of parent coaching procedures on the accurate implementation of FCT procedures.

Though the number of participants was limited, this pattern reflects a broader issue in ASD intervention research, where samples have predominantly consisted of White participants (Steinbrenner et al., 2022), limiting the generalizability of such evidence-based practices. The consistent finding across studies that mothers are the primary implementers mirrors previous reviews (e.g., Liao et al., 2021) and highlights a potential gap in caregiver inclusion and involvement. The exclusion of other caregivers as primary interventionists who play vital roles in a child's behavior and communication development may narrow intervention reach and sustainability (Londono et al., 2024). This review extends findings from previous studies (Bradshaw et al., 2017; Cheng et al., 2022) demonstrating parents and caregivers are uniquely positioned to effectively implement FCT in naturalistic, everyday contexts, thus allowing for frequent practice opportunities that facilitate generalization and maintenance.

Parent Coaching Methods and Cultural Adaptations

The included studies in this review varied in their coaching procedures but shared common elements like instruction and performance feedback. Two studies explicitly used BST or a similar evidence-based approach for training personnel (e.g., staff, parents) in behavior-change procedures like FCT. BST is a well-established, evidence-based framework for teaching new skills and incorporates performance- and competency-based components (Parsons et al., 2012). Results from this review expand upon previous research, further supporting the

effectiveness of BST in coaching parents to implement interventions with children with ASD and IDD (Boutain et al., 2020; Martin et al., 2023).

Half of the studies included in this review outlined the cultural adaptations and responsive practices utilized with parents and noted their impact on coaching sessions and experimental procedures. These practices helped researchers gain a deeper understanding of the family's home environment and culture to better optimize coaching sessions and reduce cultural barriers between the families and researchers. These include conducting coaching and intervention sessions in the family's native language, which is similar to results from a recent study by Londono et al. (2024) that found coaching a caregiver in their native language did lead to more efficient skill acquisition for both the caregiver and the child. Studies including interpreters found the location of the interpreter did not impact the results, specifically when using telehealth, and participants did not need to be culturally matched to benefit from culturally responsive practices, per se. This illustrates there may be some flexibility in culturally adapted interventions, specifically when done via telehealth. However, a gap remains when it comes to examining the effects of telehealth on behavioral interventions with CLD families. Unlike previous reviews, which did not highlight any cultural adaptations implemented in their included studies (Gerow et al., 2017; Liao et al., 2021), the limited number of studies in this review that used cultural adaptations further highlights the need for studies to focus on implementing and reporting specific cultural adaptations utilized with families.

In the other studies, the authors may not have reported any adaptations or felt the need to utilize cultural adaptations, possibly because all families spoke and understood English proficiently, or families did not request adaptations. However, regardless of a family's cultural background, they must keep in mind different aspects that may impact the family dynamic and a

parent's ability to implement an intervention effectively (Londono et al., 2022). This may include, but is not limited to, family strengths and needs, family routines, social and economic barriers, language barriers, comfort level working solely with individuals from the opposite gender, or the comfort level of working with experimenters in one's home. Similarly, compassion, humility, and rapport-building are simple but effective cultural adaptations that may be helpful to implement during interactions with diverse families (Sivaraman & Fahmie, 2020). In recent years, to help address the points mentioned above, telehealth has played an important role in expanding access to evidence-based practices and interventions to families worldwide. Two of the studies included in this review involved families from different global geographical locations and cultural backgrounds (Tsami et al., 2019; Tsami et al., 2023) and obtained similar results in terms of child outcomes, parental procedural fidelity, and social validity. Results from these studies and other extant research (Ferguson et al., 2022; Larsen et al., 2022; Lindgren et al., 2016) highlight the positive effects of telehealth and service delivery of behavioral interventions, which have been shown to have high implementation fidelity, high social validity, and positive intervention outcomes. Since the majority of studies included in this review used telehealth during some or all phases of coaching and intervention, the consistently positive outcomes further support the effectiveness of telehealth-delivered, parent-implemented behavioral interventions.

Limitations and Directions for Future Research

There are a few limitations worth noting in this systematic review. First, this systematic review included grey literature, comprising about a third of the reviewed articles. While grey literature lacks peer review, thus, maybe considered a limitation, its inclusion reduces publication bias, provides more comprehensive and timely information, and offers a balanced

perspective (Páez, 2017). Notably, the included dissertations showed strong interventions, per Tau-*U*, and scored strong or adequate in methodological quality evaluations. Second, although inter-rater reliability was assessed during full-text screening, evaluation, and data extraction, it was not conducted during the initial search or title and abstract screening. While CLD populations can encompass a broad range of ethnic groups as defined in this review, readers should exercise caution when interpreting and generalizing findings to specific diverse groups. While FCT has a robust evidence base, ensuring equitable outcomes requires attention to how interventions are delivered, received, and maintained across diverse populations. Future review studies may consider examining parent-implemented FCT focused on specific cultural groups to understand the differential impacts and appropriateness of the intervention with cultural norms. Although this review focused on studies that examined parent-implemented FCT, it is worth noting that mothers were the implementers of the intervention in most of the studies. So, future researchers can extend these studies to include other caregivers (e.g., fathers, grandparents). This would not be in attempt to test whether FCT principles differ across populations. Rather, the goal is to examine how these principles can be effectively taught and sustained across varied cultural contexts while taking into account culturally bound variables, such as the caregiver's role in the family, that may influence implementation fidelity, engagement, and long-term maintenance (Magaña et al., 2015).

With the prevalence of challenging behavior up to 90% of nonvocal or minimally vocal children with ASD (Jang et al., 2011) and 60% of children with IDD (Reyes-Martín et al., 2022), this continues to be a critically underserved field in research. The small number of studies included in this review focused on and reported the vocal abilities of participants highlights the need for future research to report on participants' vocal abilities. This will allow for more

replicability of experimental designs and increased generalization of results. Future studies should continue to focus on the effectiveness of evidence-based practices, such as FCT, with families from CLD backgrounds, and be sure to report such information. This would help enhance the external validity and inform future research and practice. While half of the studies received strong and half adequate ratings in terms of strengths of evidence, future studies should ensure they are rigorously designed and conducted with consideration of the latest methodology standards. Finally, extending experimental designs to include generalization or maintenance data and reporting this information will also allow for enhanced validity and inform future studies on the effectiveness of the intervention with different target behaviors or implementers.

Implications for Practice

The findings from this review offer several important implications for practitioners working with minimally vocal or nonvocal children with ASD and IDD. First, the consistent reductions in challenging behavior across CLD families suggest parent-implemented FCT is a broadly effective intervention. Practitioners can recommend FCT for families from varied backgrounds, even in the absence of formal cultural adaptations. When doing so, practitioners can engage with the families to learn about family dynamics and preferences to ensure family voices are heard. Second, given most studies in this review used telehealth to deliver coaching or intervention support, these results highlight the practicality and effectiveness of telehealth as a service delivery model for practitioners to embody. This is especially true for practitioners working with families who may face barriers to in-person services due to distance, scheduling, or lack of transportation. Third, although mothers were often the primary implementers, practitioners should actively engage and coach other caregivers, such as fathers or grandparents, to increase family involvement and improve intervention sustainability across different caregiver

roles. The consistently high levels of procedural fidelity reported across studies underscore the importance of using structured coaching methods, such as BST, to ensure intervention implementation with fidelity and consistency. Altogether, these findings support the use of parent-implemented FCT as a flexible, effective, and family-centered approach to reducing challenging behavior in minimally vocal and nonvocal children from diverse families.

Chapter 3: Perspectives and Experiences of Arab Caregivers of Nonvocal Children with ASD and IDD Who Engage in Challenging Behavior: A Qualitative Study

Introduction

Over the past few decades, there has been an increase in the global prevalence of ASD and IDD, reaching approximately 0.4% and 3.1% of the global population, respectively (Olusanya et al., 2023). With the growth in ASD and IDD, there has also been an increase in studies aimed at better understanding common symptoms that impact the daily lives of individuals with these diagnoses, such as challenging behavior. Challenging behavior, as defined by Smith & Fox (2003), is "any repeated pattern of behavior that interferes with or is at risk of interfering with the child's optimal learning or engagement in pro-social interactions with peers and adults" (p. 6). Examples of challenging behavior include aggression, elopement, self-injury, and property destruction. Studies show that up to 90% of individuals with ASD (Jang et al. 2011) and 60% of individuals with IDD (Simó-Pinatella et al. 2017) engage in challenging behavior, with the most common types being aggression and self-injury.

Notably, children characterized as minimally vocal or nonvocal within the ASD and IDD populations exhibit a higher tendency to engage in self-injurious behavior compared to children who are considered vocal (Ando & Yoshimura, 1979). It is estimated that around 35% of all individuals diagnosed with ASD fall into the category of minimally vocal children (Rose et al., 2016). Further, approximately one-quarter of children with ASD also have a concurrent diagnosis of IDD, a comorbidity often associated with heightened levels of challenging behavior (Lundqvist, 2013). These concurrent diagnoses and challenging behaviors pose a significant barrier to these children's success, independence, and physical health (Eisenhower et al., 2013) and lead to stress among their caregivers (Wolstencroft et al., 2023).

This study examines the perspectives, experiences, and challenges faced by Arab caregivers of nonvocal children with ASD/IDD who engage in challenging behavior. One widely studied evidence-based framework for increasing desired behaviors while decreasing undesired or challenging behaviors is ABA (Baer et al., 1968).

Applied Behavior Analysis

Over the last few decades, a plethora of research has documented the success of ABA-based interventions in increasing appropriate behaviors, such as independent communication, and decreasing undesired behavior, such as challenging behavior (Eckes et al., 2023). Although most of the research includes individuals with disabilities such as, but not limited to, ASD and IDD (Gitimoghaddam et al., 2022; Ho et al., 2021), ABA focuses on socially significant behavior, which can improve an individual's life experience, and can be effectively implemented in relation to individuals' social, academic, and functional behaviors across ages and abilities (Aldabbagh et al., 2022; Kirkpatrick et al., 2020).

One evidence-based practice in ABA to reduce challenging behavior is FCT, first introduced by Carr and Durand (1985). The efficacy of FCT has been repeatedly demonstrated in research, including studies in which parents serve as implementers of the intervention (Gerow, 2018). Essentially, ABA-based intervention involves identifying why the undesired behavior occurs, teaching an appropriate alternative response, and implementing differential reinforcement (i.e., reinforcing the appropriate behavior while withholding reinforcement for the undesired behavior). FCT, along with other ABA-based interventions, is effective in various settings such as the home and school (Dixon et al., 2016), whether in-person (Walsh et al., 2021) or via telehealth (Nohelty et al., 2022), and when implemented by trained researchers, teachers, therapists, and parents (Tomlinson et al., 2018). Studies have demonstrated that such

interventions are effective when implemented by parents, even when targeting severe challenging behavior (Drew, 2022), and produce lasting, sustainable results through generalization and maintenance (Oono et al., 2013).

Parental Involvement

Parental involvement plays a pivotal role in facilitating the development of independent communication skills and reducing challenging behaviors among children with ASD/IDD (Cheng et al., 2022; Fettig et al., 2013). In this study, the author used the term *caregiver* to refer mostly to parents. In general, the term *caregiver refers to* individuals who provide direct care to others who need help with self-care (e.g., children, elders, individuals with disabilities, patients with chronic illnesses) (National Cancer Institute, n.d.). Research consistently demonstrates that behavioral interventions are most effective when they actively involve caregivers in the implementation process (Brookman-Frazee & Stahmer, 2018). By actively participating in interventions such as ABA and FCT, caregivers gain a deeper understanding of their child's needs and acquire the skills necessary to support their child's communication and behavioral goals in various contexts (Schreibman et al., 2015). Unfortunately, many caregivers experience a lack of support, extensive demands, economic burdens, and unsustainable coping skills. These conditions have been shown to exacerbate children's emotional and behavioral challenges and increase the impact of children's neurological disabilities on their caregivers (Karst & Van Hecke, 2012; Papadopoulos, 2021).

Furthermore, caregivers' perceptions and understandings of ASD/IDD also contribute to how children's disabilities affect them as caregivers (Ni'matuzahroh et al., 2021). This includes caregivers' beliefs and awareness about the etiology and diagnosis of ASD/IDD (Brewton et al., 2021), which may affect the way caregivers respond to prognoses or diagnoses, how they cope

with the effects of the disability, and the decisions they make related to treatments, therapies, and education (McLeod & DiSabatino, 2019). Research demonstrates the importance of considering cultural backgrounds and factors when analyzing caregivers' understandings, situational contexts, and the different impacts of ASD/IDD on them (Zakirova-Engstrand et al., 2020).

Culturally, Ethnically, and Linguistically Diverse Families

In general, families from CLD backgrounds are those who are not part of the mainstream culture by ethnicity, language, and/or social class (Terry & Irving, 2010). For those living in the West (i.e., United States, Canada, Australia, New Zealand, and most European countries), this includes families whose cultural values differ from those in the mainstream culture; they may speak a language other than English at home and may come from historically underrepresented groups (Tyler et al., 2004). As mentioned earlier, there has been an increase in parent-implemented interventions with children with disabilities over the last several decades (Cheng et al., 2022). However, there is still limited research highlighting interventions implemented by families from CLD backgrounds, which discuss their unique experiences and interactions with facilitators who coach them in implementing such interventions (Sivaraman & Fahmie, 2020). This is especially true for families from Arab backgrounds, an area where significant research gaps remain (Alallawi et al., 2020). It is important to not only understand the barriers Arab caregivers face but also to ensure appropriate, culturally adapted protocols are used when coaching them to implement interventions with children with disabilities to avoid disparities in their access to evidence-based interventions that are effective with their particular population.

Gap in the Field

There is a need for more research examining the effects of culturally adapted parent-implemented interventions, specifically in coaching procedures (Sivaraman & Fahmie, 2020).

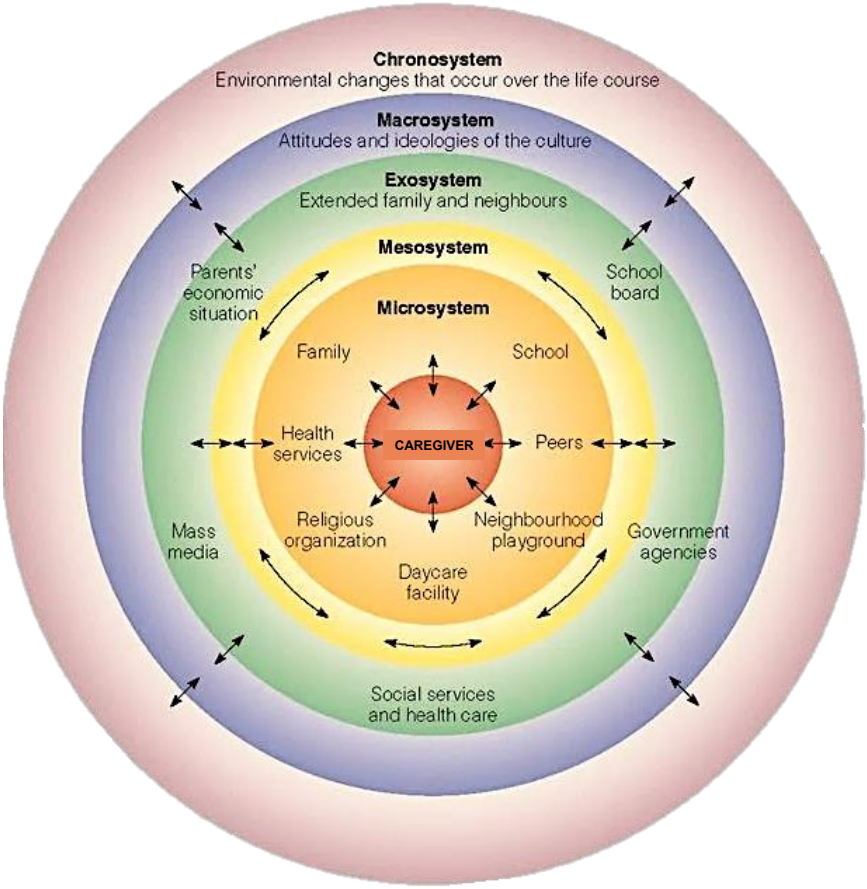
Although there has been a rise in the prevalence of both ASD and IDD among children from CLD backgrounds (Bolton et al., 2014), their families tend to encounter challenges in obtaining necessary information, assistance, and resources, as well as in navigating healthcare and educational systems (Lim et al., 2018). Moreover, with the high prevalence of challenging behavior among nonvocal and minimally vocal children with ASD/IDD (Jang et al., 2011), this is a critically under-researched topic in the field. Therefore, we need more research on the needs of CLD caregivers of minimally vocal and nonvocal children with ASD/IDD who engage in challenging behavior that captures their unique perspectives and experiences. This need is particularly urgent for caregivers from Arab backgrounds to understand the challenges they face and how best to support them, particularly through coaching and the implementation of interventions such as ABA.

Theoretical Framework

The study is guided by Bronfenbrenner's (1979) Ecological Systems Model (see Figure 3.1), highlighting the complex relationships between an individual's environment and development. This framework was used with a focus on the primary caregiver of a minimally vocal or nonvocal child with ASD/IDD who engages in challenging behavior. Examining how components of ecological theory inform parent-implemented interventions can deepen understanding of both child and caregiver experiences. More specifically, the role cultural adaptations play in these interventions can be positively impactful, as seen in previous research (Albin et al., 2022; Magaña et al., 2021; Vanegas et al., 2022) and through the integration of cultural frameworks, such as Bernal et al.'s (1995) Ecological Validity Model. This study examined how Bronfenbrenner's systems shape families' experiences with caregiver-professional interactions, service access, and coaching to implement evidence-based interventions, like ABA.

Figure 3.1

Bronfenbrenner Ecological Systems Model



Note. Adapted from Guy-Evans, O. (2025). *Bronfenbrenner's Ecological Systems Theory*. Simply Psychology. https://www.simplypsychology.org/bronfenbrenner.html

In the Ecological Systems Model, an individual's development is shaped by an intricate series of nested systems extending outward from the individual to encompass increasingly larger social and cultural contexts. In this case, the model will help explain caregivers' experiences and perceptions of their role and access to interventions to support their children, all of which are affected by various systems. The model includes five systems, beginning with the microsystem, followed by the mesosystem, exosystem, macrosystem, and finally the chronosystem. The

microsystem focuses on the immediate environment in which the child interacts with and is influenced by family, school, community, and religion. The mesosystem encompasses interactions among microsystem elements, emphasizing the importance of collaboration and communication among different stakeholders (e.g., parents, educators, service providers, community members). The exosystem includes indirect influences on the child, including extended family members, family friends, societal norms, cultural values, and support services. The macrosystem encompasses broader cultural contexts that shape the child's development and family experience, such as values, ideologies, customs, and political systems. Finally, the chronosystem incorporates all environmental changes occurring over the child's lifetime, taking into consideration historical events, environmental changes, societal and economic changes, and changes in family structure.

Given the focus of this study, this theoretical framework was used to identify factors affecting caregivers' experiences in finding appropriate services and in being coached to implement evidence-based interventions, such as ABA. Therefore, as shown in Figure 3.1, the caregiver is at the center of the model, rather than the child in the original model. More specifically, it allowed the author to articulate the key role parents play in their child's development of vital skills, such as appropriately requesting wants and needs rather than engaging in challenging behavior. This process of developing those skills involves communication and collaboration between different stakeholders identified in the child's microsystem (e.g., parents, coaches, therapists, etc.). Taking a step back, within the family's exosystem, this study also focuses on the importance of cultural values. In parent-implemented interventions, this includes engaging families as active participants throughout the process and ensuring the intervention meets their needs while taking cultural factors into consideration. In

other words, practicing cultural adaptations by modifying interventions to align with the family's cultural values, preferences, and norms is important for long-term results, provided it does not compromise the intervention's reliability and validity. As the author worked to conceptualize the experiences and perspectives of caregivers, the interactions and relationships among the systems in this framework served as the basis for their exploration, guiding their development of more in-depth understandings and implications for future research and practice.

Current Study

This study explores the perspectives and experiences of eight caregivers from Arab backgrounds, living in the U.S., of individuals with ASD and IDD who are minimally vocal/nonvocal and engage in challenging behavior in terms of coaching/training and the implementation of interventions such as ABA. Of particular significance was the importance of culturally adapted interventions and coaching for such caregivers. This study was guided by the following research questions:

1. What challenges do Arab caregivers (living in the U.S.) of nonvocal/minimally vocal children with ASD and IDD who engage in challenging behaviors face, specifically with finding appropriate services and being coached to implement interventions, such as ABA?
2. How do these caregivers experience coaching procedures intended to address their children's challenging behavior?
    a. How, if at all, are the coaching procedures culturally adapted?
3. How can Arab caregivers be better supported when being coached to implement interventions with their nonvocal/minimally vocal children with ASD and IDD who engage in challenging behavior?

Method

A case study approach was used to gain a deeper understanding of the perspectives and experiences of Arab caregivers of minimally/nonvocal children with ASD/IDD who engage in challenging behavior. As defined by Creswell & Guetterman (2019), case studies involve studying individuals or small groups in real-life contexts to further explore an issue they face. Since this study focuses on a specific ethnic background, the author used ethnographic elements to examine how culture shapes these caregivers' perspectives and experiences (Creswell & Guetterman, 2019). In this study, the author portrayed a descriptive narrative of multiple case studies (i.e., families) through a combination of individual semi-structured interviews and journal entries. Analyzing multiple data sources enabled a more in-depth understanding of each case.

Recruitment

After receiving approval from the university's IRB, the study's bilingual (English/Arabic) flyers were distributed via a combination of purposive and snowball sampling through family support groups, professional organizations, social media, newsletters, listservs, and the research team's professional contacts and networks. Recruitment continued for approximately one year after the author was unable to recruit participants for several months. The difficulty in recruitment may have been due to reasons such as the niche target population, the busy nature of the lives of the caregivers being recruited, or the lack of comfort caregivers from this minority group felt in sharing their experiences. The inclusion criteria required individuals who can speak and understand either English or Arabic and are the primary caregiver of a child who: (1) is 2-30 years old, (2) has a prognosis or diagnosis of ASD/IDD, (3) is considered minimally vocal/nonvocal (i.e., fewer than ~5 functional words), (4) engages in challenging behavior (i.e., aggression, self-injury, property destruction, etc.), (5) has at least one

caregiver from an Arab background (i.e., ethnically from an Arab country), and (6) is from a family who currently lives in the U.S. The study was restricted to participants living in the U.S. to focus on Arab caregivers living under the same federal laws on individuals with disabilities, and due to IRB regulations and restrictions with international participants. Participants who completed the study (i.e., interview) were reimbursed with a $15 gift card from an online vendor (plus $10 for journals).

Participants

A total of eight primary caregivers of 3 to 29-year-old individuals with a diagnosis of ASD/IDD who were minimally vocal/nonvocal and engaged in challenging behavior were recruited. Except for two participants, who were sisters and legal guardians of the individual they cared for, the participants were mothers. For ease of reading, the individuals with disabilities cared for by the participants interviewed will be mostly referred to as their *child*. More details about participants can be found in Table 3.1. All names are pseudonyms unless a participant requested their real name be used. Written informed consent was obtained from all participants, and confidentiality was maintained during all research procedures, as approved by the university's Institutional Review Board.

Participant Profiles

Zahra was a Palestinian-American mother of a 13-year-old boy who was diagnosed with ASD by a behavioral specialist when he was around three years old. They lived in a suburban area of the Northeast, and her son attended a self-contained school (i.e., a school district that exclusively serves students with IEPs). Her son was described as becoming increasingly easygoing and laid-back as he grew older, demonstrating a compassionate nature, such as attempting to soothe his younger brother when the younger brother was in distress. While he was

verbal and spoke clearly, he lacked conversational skills and could not engage in typical back-and-forth dialogue. He communicated literal needs but often repeats phrases he has heard, a behavior that persists from his younger years. His needs included significant sensory support, as he was previously "super sensory" and struggled to sit for more than a few minutes. In the past, his challenging behaviors included throwing himself on the floor, self-harming when frustrated, and occasionally being physically aggressive toward others, such as head-butting his mother. At the time of the interview, he might still shake or push himself when upset in public, though he has become more cautious about falling on hard surfaces.

Haifa was a Palestinian-American mother of four boys, including her 14-year-old son, who was diagnosed with ASD by a pediatric neurologist when he was one. One of her other sons also has speech apraxia. They lived in a suburban area of the Northeast, and her son attended a self-contained school. Her son was described as physically large for his age and, by his mother, as very handsome. He possessed a remarkable memory, particularly for navigation; he could recall exact driving routes, gas stations, and exits from long road trips, without a GPS. Additionally, he was skilled in math, a talented cook who understood kitchen safety, and showed a strong aptitude for mechanical tasks, like taking apart and reassembling toy vehicles. His primary needs centered on communication. Although he could vocalize needs with one or two words, he lacked conversational back-and-forth skills and struggled to express the "why" behind his emotions. Her son was also highly sensitive to sensory triggers, including high-pitched noises like babies crying, extreme heat, and physical pain, which can lead to challenging behaviors such as hitting others to make the noise stop or showing aggression when frustrated.

Iman was an Egyptian-American mother of two daughters, including her 15-year-old daughter, who was diagnosed with ASD at two years old by a psychologist. They lived in a

suburban area of the Northeast, and her daughter attended a self-contained school. Her daughter was described as verbal but not conversational. Although she could express basic needs and follow simple sentences, she could not engage in back-and-forth dialogue. Her strengths included an exceptional memory and a strong ability to follow directions and complete life skills tasks, such as filing, doing laundry, and using the dishwasher. Her daughter's primary needs involved sensory processing support, since she required repetition and eye contact to process, and improved communication regarding physical pain. In the past, her challenging behaviors included screaming, throwing objects, and hitting her head on the floor, which were often reactions to misunderstood physical pain or frustration. She would also spill water on the floor, a behavior Iman has linked to seeking attention or hormonal shifts before her menstrual cycle.

Maria was a Syrian-American single mother raising her 14-year-old daughter, who was diagnosed with obsessive-compulsive disorder (OCD) at a very early age, followed by an official autism diagnosis at age seven, and also has sub-diagnoses of ADHD and executive dysfunction. They lived in a suburban area of the Northeast, and her daughter attended a public high school. Her daughter was described as very smart, with an extremely high IQ, and has a strong affinity for music, which she uses as a tool for emotional regulation. In the past, her daughter faced significant challenges with rigidity, frequent meltdowns, and elopement, often screaming or running away when her "emotional meter" was overwhelmed by noise or changes in routine. Although she was nonverbal until age three and struggled with back-and-forth conversational skills for many years, she developed the ability to communicate her needs and now verbalizes when her anxiety is becoming unmanageable. At the time of the interview, her ongoing needs include a consistent environment, sensory management, and careful attention to how sleep and diet impact her behavior.

Aya was an Egyptian-American mother of two sons: five-year-old J and three-year-old M. They lived in a suburban part of the Southwest region where J attended a part-time special education kindergarten classroom, and M attended a part-time ABA therapy center. Both boys were born following complicated pregnancies involving gestational diabetes and insulin, with J's birth complicated by preeclampsia and M's by placenta previa. J was diagnosed with autism by a pediatric neurologist at two years, and M was diagnosed by a developmental pediatrician at three months. J was described as having "higher support requirements," while M was considered to be on the "lower end" of the spectrum for services, but still has "very high needs". Physically, both boys were described as strong "tiny bodybuilders" with excellent gross motor skills. J's strengths included a social and affectionate nature, being a "social butterfly" who loved hugs, and a love of novelty, but J struggled with language and communicated primarily through scripts or 1-2-word phrases. M was very verbal and articulate, and could be described as a "jokester" who loved making people laugh, though he struggled with pragmatic language and could be very blunt. At the time of the interview, challenging behaviors for J included biting, screaming, and elopement, while M had intense tantrums and screaming episodes.

Rania was a Libyan-American mother of four children, including her ten-year-old daughter, who stopped meeting developmental milestones at nine months and was initially diagnosed with global developmental delay. They lived in a suburban part of the Southwest region where her daughter attended an ABA clinic full-time. A genetic test at 22 months revealed two gene mutations that present as autism and intellectual disability. Her daughter is non-verbal and primarily communicates by pulling others' hands or bringing items to her family to indicate her needs. While she is described as social, affectionate, and smart when seeking things she likes, she struggles with anxiety in large gatherings, noise sensitivity, and requires total

assistance with hygiene and toileting. At the time of the interview, her challenging behaviors included intense self-hitting and face-banging (often leading to bruises), as well as hair pulling, biting, and making messes by tearing paper or spilling liquids. Rania noted these behaviors have worsened recently, possibly due to hormonal changes or unidentified physical pain.

Nadia was an Egyptian-American primary caregiver for her 27-year-old brother, a young adult diagnosed with autism and an intellectual disability at age three by a psychiatrist. He was also diagnosed with IDD and unspecified mood disorder in middle school and was described to have strong OCD tendencies. They lived in a suburban part of the Mid-Atlantic region. Her brother was described as a "big guy" who is artistic, funny, and deeply affectionate toward his family. He was verbal but had limited expressive language, primarily using speech to communicate basic needs, such as using the bathroom or asking for help. He had recently begun using an AAC device to support more complex expression. His challenging behaviors included aggression, such as charging, biting, and punching, as well as loud screaming and self-injury, specifically hitting his forehead with a closed fist. Also, his mental OCD tendencies manifested as repetitive, "nonsense" questions that he requires specific "yes" or "no" answers to. Incorrect answers to his questions, the presence of strangers in the home for work, or the denial of preferred foods like bread and carbs, which are restricted due to his diabetes, can trigger his challenging behaviors.

Bushra was a Yemeni-American legal guardian of her 29-year-old sister, who was diagnosed with Down syndrome in utero and believed by her family to also have autism. They lived in a suburban part of the Mid-Atlantic region. Her sister was nonverbal and communicated using a combination of ASL she learned from an app, intuitive gestures, and a felt communication board with images. She was described as a friendly, social, and very expressive

person who enjoyed crafts, books, and swimming. Her strengths included an exceptional memory for new words and routines. However, she faced significant challenges with OCD-like repetitive behaviors, such as flicking light switches for long periods, and she can become physically aggressive when these rituals are interrupted or when she is unable to communicate her needs. These behaviors, which included hitting, slamming doors, and breaking dishes, have intensified as she has grown older.

Materials and Setting

All parts of the project were conducted virtually via Zoom using password-protected platforms and unique links for each participant. In all cases, the interview was recorded and subsequently transcribed to ensure greater accuracy. During Zoom sessions, participants could keep their cameras on or turn them off to have only their audio recorded. To further assist with data collection, the author developed a screening survey (Appendix A) and an interview guide (Appendix B). The interview guide was created based on previous literature reviews and was pilot tested with a colleague who identified as an Arab caregiver of a child with a disability. As for the interview questions and sub-questions, they are intended to be open-ended, allowing the respondent to provide more detail in their responses. If a question was unclear or the respondent was not familiar with certain terms, the interviewer further explained the question and ensured the respondent fully understood it before attempting to respond. Along with the interviews, the author developed journal prompts (Appendix C) for participants to complete after the interview, which was optional. These were written in a Word document, along with detailed instructions, and shared with participants via the author's university email.

Data Collection

Prior to conducting interviews, interested participants completed an online screening survey (Appendix A) created through the university's Qualtrics platform. The survey questions were brief and collected information about the cultural/ethnic background of the participants, their child(ren) with disabilities, their children's communicative abilities, and challenging behavior to determine eligibility. Afterward, once eligible participants had signed the consent forms, they were sent the demographic questionnaire (Appendix B, Part 1) via the university's Qualtrics platform to complete before the interview. The questionnaire included brief questions about the demographics of both the caregiver and the individual they care for, such as the caregiver's age, highest degree earned, and employment status.

The interview questions (Appendix B, Part 2), served as a guide during the semi-structured interviews. A total of 16 questions covered four main topics: 1) child and communication, 2) challenging behavior, 3) caregiver's familiarity with interventions, and 4) goals and expectations. The first two topics provided a deeper understanding of the child's current and previous communication abilities and challenging behavior. The second topic focused on caregiver experiences accessing services and interventions, their familiarity with ABA and FCT, and experience with coaching and cultural adaptations, if any. Finally, the fourth topic provided insight into caregivers' expectations and goals for better support, as well as their goals and expectations for their child regarding their communication abilities and challenging behavior. One interview was conducted with each participant, with a mean duration of 54 minutes (range: 27–107 minutes).

Given the limited number of participants in this study, even after approximately one year of recruitment, the author also offered participants the opportunity to complete a journal entry by

responding to a few questions that allowed them to reflect further on their role as the primary caregiver (Appendix C). The questions tapped into the role their Arab background played in how they viewed themselves within their family unit and in how they raised their child (or sibling). The prompts included two sets of questions, one for primary caregivers who completed the interview and another for other caregivers (e.g., fathers) who did not participate in the interview. As recommended by Janssens et al. (2018), participants were given several options for responding, including whether to respond to all questions in English or Arabic, and whether to do so by handwriting, typing, or recording an audio message.

Data Analysis

The author began by transcribing all audio recordings of the interviews (i.e., cases). The interviews were conducted mostly in English. Since the author was fluent in Arabic, she completed the transcription and translation, which were member-checked and verified by the participant herself. Other participants occasionally used Arabic phrases or words, which the author also translated and verified with the participants through member checks. In each transcript, all identifying information was replaced with codes or pseudonyms, unless a participant requested their real name be used. Next, the author began manually coding using a hybrid of inductive and deductive approaches with open and in-vivo coding. With this, codes were developed during the coding process, and the author did not use a pre-existing codebook (Merriam & Tisdell, 2016). Sometimes, participants' exact words were used as in-vivo codes (Creswell & Guetterman, 2019). Each transcript was inductively coded using a line-by-line approach, after which the author engaged in a second round of coding to review and refine the initial codes while grouping them into broader categories (i.e., themes). The author completed this procedure for each individual interview before analyzing all interviews collectively, as

recommended in a case study approach (Crowe et al., 2011). Some codes that emerged during this stage included cultural disconnect, caregiver self-reliance, and professional dismissal. Once each interview was coded in full, the author began identifying patterns and relationships across cases, paying particular attention to similarities in perspectives and experiences as they related to the study's research questions (Braun & Clarke, 2006). With this thematic analysis approach, overarching themes were developed using evidence from the interviews to enable a deeper analysis of the results and to develop codes and themes from the collected data.

As the author inductively coded transcripts, she simultaneously used a deductive approach using the Ecological Systems Model to look for evidence of five components: (1) interactions with the immediate environment and influences from the caregiver's family, community, religion, etc., (2) collaborations and communication between the caregiver and different stakeholders such as educators, service providers, and community members, (3) indirect influences on the caregiver such as extended family members, family friends, societal norms, and cultural values, (4) broader cultural contexts that shape the caregiver and family experience, including ideologies, customs, values, and political systems, and (5) environmental changes occurring over the caregiver's lifetime, such as historical events, environmental changes, societal economic changes, and changes in the family structure. This approach, combined with the use of in vivo coding and thematic analysis, enabled the identification and development of recurring patterns and themes across cases. In addition to the interviews, some participants also chose to complete the journal. These entries were coded similarly to the interviews, with the author initially performing open coding through a line-by-line approach before identifying cross-case themes and patterns. The themes in the journal entries matched those in the interviews and were therefore combined during data analysis.

Trustworthiness

Once all the codes, categories, and themes were created, the author completed member checks by contacting participants via email and providing them with a copy of the coded transcript and journal (if applicable), along with their case summary and chosen pseudonym. Participants were given the opportunity to review the files, offer feedback, and ask questions. The author received no replies from participants requesting changes to their response interpretations, nor did any request a follow-up meeting. Since member checking helped increase the validity and reliability of the results, the author did not perform intercoder reliability checks with independent coders. To ensure the privacy and confidentiality of participants, the author assigned a pseudonym to each participant, unless a participant requested their real name be used instead. The collected data were stored on the university's password-protected platform, Box, with access restricted to the research team.

Researcher Positionality

The author's interest in this research topic comes from her personal background, which provides her with a unique perspective. She was born and raised in both the Middle East and North America, is Muslim, is bilingual in English and Arabic, and spent her elementary and higher education years in North America. Over the years, this experience has allowed her to immerse herself in both Arab cultures, in the Middle East and North America, fostering a deeper understanding of different societal norms and expectations. At the time of the study, she was pursuing a doctoral degree in special education, focusing her research specifically on ASD and IDD, minimally vocal and nonvocal children, communication, challenging behaviors, and parent-implemented, culturally adapted interventions. Before her doctoral studies, she completed her bachelor's and master's degrees in special education, as well as a post-master's certificate in

applied behavior analysis. She also worked with families and children with ASD from CLD backgrounds as a Registered Behavior Technician (RBT), applying behavioral interventions and gaining insight into some challenges these families face when working with their nonvocal children. She has also witnessed firsthand the difficulties faced by parents of a family member diagnosed with IDD who exhibits challenging behavior.

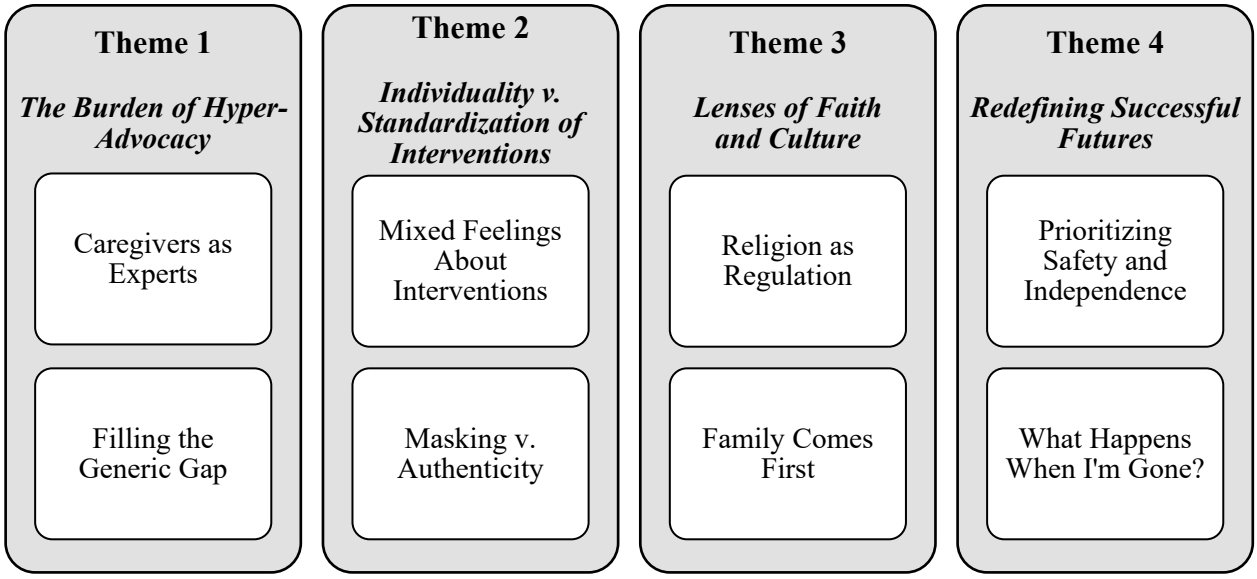
Her role as an Arab researcher, combined with her previous experience working with Arab and other CLD families, fostered stronger connections with her participants, enabling them to feel more at ease sharing their experiences with a fellow Arab. This, in turn, facilitated a deeper understanding of their perspectives, experiences, and challenges, contributing to the development of a comprehensive, detailed narrative. Overall, this helps bridge the research-to-practice gap by providing practical guidelines for practitioners working with Arab families, aiming to create more meaningful experiences and lasting, sustainable impacts.

Results

Overall, four main themes (Figure 3.2) emerged from the data when analyzing Arab caregivers' experiences raising nonvocal and minimally vocal individuals with ASD and IDD in the U.S.: (1) the burden of hyper-advocacy, (2) individuality v. standardization of interventions, (3) lenses of faith and culture, and (4) redefining successful futures.

Figure 3.2

Themes and Sub-Themes



Theme 1: The Burden of Hyper-Advocacy

The first theme was evident across all interviews and highlighted caregivers' increased sense of responsibility for roles beyond traditional caregiving, such as advocating for the individuals they supported. This added responsibility arose from perceived gaps, including dismissive medical professionals, inexperienced school staff, and intervention trainers.

Caregivers as Experts

Some caregivers believed that the success of their child's interventions mainly depended on parents' ability to understand the interventions and lead service providers. Although participants agreed that service providers are often transient and change frequently, especially in high-turnover settings, they viewed parents as the permanent experts. Many described themselves as "investigators" or "educators" who had to fill important gaps in both professional and clinical knowledge. Aya mentioned she took on an "educator role," overseeing specialists to ensure their support aligned with her children's behavioral goals. Aya stated, "So, I almost have to assume the educator role in all these scenarios with all these experts. So, I teach my pediatrician what autism is. I have to, you know, nudge these specialists to go do their thing."

Aya also mentioned the exhausting effort she made merely trying to convince the pediatrician that her eldest child was, in fact, showing signs of ASD well before his official diagnosis.

> And I was like, oh lo and behold, like it, it was on in the back of my mind the whole time. But I'll never forget that. Like she [the pediatrician] literally was in tears and apologizing and you know very, very regretful that she kept dismissing me for, like, the last year that my concerns were of no importance.

For many caregivers, their interactions with professionals extended beyond teachers and behavioral therapists to include medical professionals. Based on how the participants described their experiences with medical professionals, it was evident that these professionals' knowledge and training to work with individuals with disabilities were lacking. Iman reflected on how her daughter's outbursts were often dismissed as "autistic behavior" by professionals until she identified the cause as lactose intolerance. When asked what she wished medical providers would do differently when interacting with her daughter, she said:

> It's all about understanding. It's times, you know, it's like understanding who [is] in front of you, what they need. Do it with them. You're gonna be fine. Ignoring everything and just blaming [it] on autism, you're not gonna... we're not gonna get anything. Yeah, she's different. And I know she's different. Her understanding is not perfect. I know that. But I can deal with this. If I have the knowledge.

On a similar note, Bushra shared the challenges she faced when talking to healthcare providers about her sister's difficulties with routine or aggressive behavior, and she was met with general advice she said she would give herself, like getting sleep and exercising. She also mentioned how, as someone working in the field of public health, she already sees the gap in

training for healthcare providers who work with adults with intellectual disabilities, which makes it difficult for the families as well.

> A lot of providers that I end up taking her to, because it's not like there's a specialist that works with adults with disabilities, they're just your regular primary care family physician, and they don't know as much. And so they don't have many suggestions. They just "make sure she goes outside, make sure she's getting good sleep, [inaudible] routine, kind of like the basics". So otherwise it's just me Googling and trial and error and us trying to figure out what to do. (Bushra)

Ultimately, caregivers often found themselves taking on professional roles to bridge gaps they saw in professional training. This forced them to move beyond advocates to become the primary navigators of their child's education and medical care, highlighting the heavy burden they carry to ensure successful interventions for their children.

Filling the Generic Gap

Some participants also expressed dissatisfaction with the lack of experienced professionals and standardized parent training, which they found unhelpful for their child's specific needs. As part of the behavioral interventions their child received, some caregivers attended workshops or received coaching to implement certain strategies at home. Zahra, Haifa, and Maria attended parental workshops either through the school or non-profit organizations, while Iman and Aya received in-home coaching from different service providers, including behavioral and occupational therapists. Rania had previously received in-home coaching, and at the time of the interview, she attended monthly parent coaching at her daughter's ABA clinic. Bushra did not receive any formal coaching, and Nadia received coaching at a behavioral institute, which she mentioned did not benefit her family. On a similar note, a few caregivers

characterized the information from these workshops as “general advice.” Haifa described school-led workshops as a “joke” and a waste of time, and she said she found parent groups on social media much more helpful.

> Connecting like connecting a parent to parent that can relate to similar situation that they're going through that we can connect and they're like, you know, anonymous one, how did you redirect to your child by doing this? This is what worked for me[...] So I personally feel like the parent groups online on Facebook and online was better than what the school is providing us, honestly.

At the same time, she wished more parents were involved with their child’s school, saying, “I think parents need to be more involved and I wish parents can get paid by teaching your kid. Like, honestly, if I could stay home and teach [my son], I would. Honestly.” On a similar note, Zahra emphasized the value of being straightforward with service providers about what she did or did not want for her son. She recognized that not all parents feel comfortable doing this or simply do not know where to start, which can make it harder for them to get the services or accommodations they need. She reflected on how it was not always easy for her to ask for what she wanted.

> In the beginning, I was like, oh, I don't know, they're gonna think. I'm like... I'm such a bad person. They're gonna be like this person is so annoying. But then with time, I was just like, but this is what he needs. Like, if I don't say it, he's not going to say it, and I have to say it. You know what I mean? Like, I have to say it like I don't have a choice. Like, if I don't say it, who will you know?

Finally, a few caregivers also described a major systemic barrier they faced: the “insurance cliff” at age 21, when many subsidized services immediately end. They found this

sudden loss of services and the lack of experienced professionals available to work with adults with disabilities to be challenging and stressful. This increased their burden of filling service provider roles, such as case managers, who must find appropriate services and qualified providers to continue supporting their children as they grow older. Often, when children age out of services they previously received in school, the service and financial options suddenly become much more limited.

Theme 2: Individuality v. Standardization of Interventions

Pertaining to the second theme, participants voiced their hesitation and skepticism about certain interventions, including ABA, and expressed a desire for their children to be recognized as individuals rather than being "conditioned" to meet neurotypical standards. This also connects to aspects of the first theme, specifically bridging the gap in generic interventions and parent trainings, further highlighting the importance of individuality over standardization.

Mixed Feelings About Interventions

When asked about their experience with ABA, Zahra and Haifa both described the outcomes using the term "robot"; Zahra said she felt it was training a "little robot" through rote memorization. Haifa also expressed concern that the repetitive nature of behavior-based interventions sometimes led to unwanted behaviors, such as scripting, rather than fostering meaningful social engagement. This kind of tension caused some caregivers to selectively follow certain interventions, such as safety-related ones, while rejecting or adjusting others they viewed as interfering with or opposing their child's individuality. For example, when reflecting on her son's experience with ABA, Haifa mentioned:

The ABA came. They tried to interconvert, they tried to help, but me personally I

> think I personally don't like ABA. Honestly, I don't think these kids need repetitive behaviors and teaching them how to like repeat, repeat, repeat, repeat, repeat, repeat. Because if somebody when you repeat something, you go. I go crazy. If you hear something over and over and over and over and over again, you're gonna go crazy. And I feel like that made my child crazy until now, he's still repeat[...] Or like scripts or videos, he's repeating it.

Nadia also shared her family's positive experience with ABA, but credited the structured routine they provided, which helped reduce her child's aggression at school. However, this did not seem to carry over to the home environment, even with in-home ABA services. Conversely, caregivers like Iman, Rania, and Aya found ABA useful for their children. Similar to Nadia's experience, Rania also observed that her daughter performed better at school than at home with the structured routines. She admitted it is harder to maintain her routines at home, especially when she has other children to care for, and she does not "always have the patience or the time to just focus on her [daughter]".

When asked specifically about FCT, all caregivers, except for Rania, were initially unfamiliar with what it was. However, after explaining what it was, some realized it was indeed something they had heard about before, and could see it as a potential intervention for their child to help increase independent communication, specifically those with school-aged children.

Masking v. Authenticity

Maria avoided these behavioral interventions altogether because she "didn't want her [daughter] to be conditioned" and instead wanted her to "embrace her disability." She also expressed that she did not want her daughter to "mask her autism because that's who she is,"

instead hoping she would "be proud of who she is." When asked specifically about ABA and whether her daughter ever received those services, she responded:

> No. So I've heard both good and bad things about ABA services, and I kind of felt like, from what I've heard, I don't know a lot about it. It forces a child to do certain things that are against their nature, and I wanted her to learn how to enhance or embrace her disability rather than force her to change it. So I've heard very mixed stories about ABA, and so we never tried it. I just didn't want to take a chance with her OCD.

This desire for their child to be themselves was shared by all caregivers. Nadia discussed how her child's habit of asking silly questions and expecting specific answers was seen by behavioral specialists as "triggering" for his difficult behavior. However, the speech-language pathologist offered a different view, suggesting it might be a "bid for connection." Nadia valued this perspective, which allowed the service providers to respect his way of communicating and help her child feel understood by valuing his words and letting him express himself in his own way.

Theme 3: Lenses of Faith and Culture

The third theme highlights the lack of formal cultural adaptations by service providers and how caregivers integrate faith and culture as a response. Many of the caregivers described their faith as the lens through which they view their entire world, including their perception and understanding of their child's disability.

Religion as Regulation

Most of the caregivers interviewed identified as Muslim, and many credited their faith for helping them see their child's disability as a "gift from God" rather than a burden. Haifa explained to her family that her son having ASD is "not a shameful thing. This is a gift from

Allah [God].” When reflecting on how her mindset changed concerning her son’s diagnosis and future from a religious perspective, Haifa said:

> But you just gotta trust Allah [God] and as long as you have *tawakkul* [trust in God] and as long as you trust Allah [God]. That's the only way you're going to be at ease. So that's what keeps me sane, honestly. That's honestly that's what keeps me sane, and that's what keeps me from holding back my changing my tears into other ways. Just trust the process.

On a similar note, Zahra mentioned how she believed God gave her son the way he is, which she has fully accepted and embraced.

> This is just who he is. Like, there's nothing I can do about it, you know? You know, but Allah [God] gave him to me like this. This is the way he's gonna be was fine with me. Like, once you have that, you're just like, OK, why stress him out? Why put him in so much, so much therapy? Why drive him crazy? When it's gonna happen, when it happens.

She also talked about how she turned to her religion frequently when trying to help her son through his challenging behavior, especially when she felt the risks of medication outweighed the benefits. She decided to turn to black seed, which she gave him every day, as a change in his routine, and she found it helpful in keeping him calm.

In several other interviews, caregivers also used religious phrases such as *alhamdulillah* [praise God]*, ma sha Allah* [as God willed]*, and in sha Allah* [God willing] when discussing their children. Even when reflecting on her daughter’s disability, Rania began by saying, “She *alhamdulillah* [praise God] doesn't have all the issues that come with that gene mutation, but she still has a level of intellectual disability.” Similarly, Iman reflected on when she first noticed her daughter might have a disability and said, “For me, when I started noticing things with my

daughter, she was around 18 months old. *Alhamdulillah* [praise God], still." Aya also praised God several times when talking about her sons' accomplishments: "*Alhamdulillah* [praise God], like he was in speech and doing feeding therapy, the OT and stuff. And here he was getting socialization from the school."

Family Comes First

Family and the support that comes with it, or the lack thereof, was another theme in multiple interviews. Many caregivers emphasized the importance of having a strong support system, especially within the smaller family circle, as well as communal support from other community members, like neighbors. This point in particular resonated deeply with Maria, a single mother who raised her daughter almost entirely on her own. She mentioned feeling "disconnected" when reflecting on how many families around her come from cultures that naturally live close to one another, providing support from their mothers, fathers, siblings, cousins, and others. Moreover, when considering the different roles family members play in an Arab household, Rania believed "Arab dads are not involved." Although she acknowledged that "they try, but they're not [involved]" and are "always in the denial phase," Aya also reflected on how even "The most well-intentioned family members are still very lacking in their self-awareness." She went on to say,

> They may think they're doing us such a huge favor. But in reality, they're overlooking what I am clearly communicating our needs might be, and assuming other things. Or they take lightly certain conversations that ordinarily wouldn't offend any other parent.

On the other hand, the idea of family support and the importance of families staying together and being there for one another came up in several interviews. Two caregivers of older individuals who recently left the school system mentioned numerous conversations with service

providers about their family's preference and willingness to support their child, without placing them in a group home, for example. "We're family, and we're going to do it. Help, like help us be able to help her. Our solution is not… we don't wanna waste focus on a group home," Bushra said when reflecting on what she wished service providers knew to make their interactions more meaningful.

> I think providers need, not necessarily cultural training. I think they have it. What I think is the system needs, the system needs to understand or like acknowledge the fact that family willing to do this is not... OK, I actually, I wanna say, is not a burden. Burden is not the word to describe it. They do see it as a burden. We see it as a challenge… Can they frame it that way because needing to justify the fact that I am willing, because of my culture, because of my religion to drop my career that I've worked so hard for and have so much passion and to take care of a family member just like somebody would if your parent had a stroke, you know? (Nadia)

Bushra explained that her family was faced with two options when her sister was graduating high school: placement in a group home or enrollment in a day program. After visiting several day programs, she described each as feeling like "light versions of an institution," where adults with disabilities mostly sit around, color, watch movies, and do similar activities.

> It was just you're suggested to do a group home and then when you talk about trying to stay within the family, trying to talk about again back to those family values, they're… there just isn't many options. It's like, "well, unless you're in a group home, this is all we can do for you", which isn't much. (Bushra)

While some caregivers faced isolation or lack of partner involvement, others viewed home-based care as fundamental, despite a rigid system that prioritized group homes over family-centered support. This lack of meaningful, community-based alternatives forced caregivers to choose between inadequate day programs and significant personal sacrifices to uphold their values.

Theme 4: Redefining Successful Futures

The fourth theme focuses on what caregivers considered some of the most important goals and hopes for their children, specifically communication and daily living skills, which they emphasized as essential for their children's own safety and dignity.

Prioritizing Safety and Independence

Almost all caregivers responded to the author's question about their child's goal by saying they wanted to improve communication. Rania emphasized, "communication, communication, communication, communication." Many caregivers, including Rania, Iman, and Zahra, simply hoped their child can express how they feel or just have basic conversations. More importantly, they wanted their child to communicate vital information, such as when they are in pain or hurt. Haifa shared, "If he can communicate and tell me what's bothering him or how his day was, I'll be the happiest person alive because that would make his life so much easier." Bushra saw communication as a first step toward giving her child a more productive, meaningful routine, and also as a self-defense mechanism, especially when going out in public.

> I'm always hesitant because she can't communicate. And so if somebody were to do something to her. And she's a very, like, loving and trusting person. So she would just go along with whatever. And it always makes me very nervous for her if she wouldn't be able to communicate if something were to happen, if I were to just leave her somewhere.

Caregivers not only valued communication but also emphasize the importance of their children mastering daily living skills such as toileting and personal hygiene. Some caregivers found the lack of these skills stressful, but they also believed that increased independence in these areas would reduce their child's vulnerability. Aya shared, “I don't want them to be like fully dependent on anyone. Independence. I want them to have some in terms of like their own personal care, their hygiene, their feeding.”

What Happens When I’m Gone?

Caregivers expressed their concern about what would happen to their children when they were gone. Many shared their hope that their children would simply be “happy” and “healthy” without having to worry about the possibility of being “left to the state,” as Aya mentioned. She said, “I want them to be as comfortable as they can, to have the most independence that they can, to feel loved and cared for as much as I can.” However, she also noted how this comes at the expense of her own needs, both mental and physical. The idea of prioritizing their children's needs over their own also appeared in other interviews, where caregivers discussed the sacrifices they made to create an environment and a future in which their children could thrive. Maria mentioned, “So growing up, you know, raising her, I had to sacrifice a lot of things. We weren't able to go out, you know, and travel to the city. Things had to be on a certain schedule.” Aya spoke about the career sacrifices she made, saying, “I can't go back to work. I can't assume a career anymore. My full-time job is to call and make appointments, and fight with insurance, and figure out grants and enroll them in more this or that.” Similarly, Nadia mentioned that she and her sister both gave up their careers to become full-time caregivers.

> Like, even at the detriment to myself. I'm constantly doing this is that I will prioritize their appointments, their needs and neglect mine. Like, I may have a gym membership

and want to go for yoga, and I don't go for months because when it comes time to doing my things, I'm like, it's not important, like their stuff is. I have to make time, and regardless of the state of mind I'm in, I have to do those things for them. So Mary Poppins is around for them, and then I'm like sad girl summer for myself. (Aya)

The sacrifices these caregivers made all had a common goal: to ensure their child had access to the best possible services, in hopes of securing a better future for them, especially when they are no longer physically present.

I'm concerned that she, like, when I'm getting older, when I'm, my husband and I are getting older and not able to take care of her, we are concerned where she's, what she's going to do. Who's going to take care of her? Even though her siblings are very willing to take care of her, they always talk about how she's going to be living with one of them. But still. And then yeah, communication is the biggest part of my concern. (Rania)

Driven by the fear of their children being "left to the state," caregivers often sacrifice their careers and health to secure their children's future independence. They viewed personal neglect as a necessary trade-off for navigating complex systems to ensure long-term stability for their children, specifically when they are no longer present to care for them.

Discussion

This study examined the perspectives and experiences of Arab primary caregivers of nonvocal or minimally vocal individuals with ASD and IDD who exhibited challenging behaviors. Through this examination, the author identified four main themes: 1) the burden of hyper-advocacy, 2) individuality v. standardization of interventions, 3) lenses of faith and culture, and 4) redefining successful futures.

The participants in this study came from diverse ethnic backgrounds, had lived an average of 35.5 years in the U.S., and were highly educated, with half holding a Master's degree, two a Bachelor's degree, and one some other college degree. This supports the current understanding that the Arab community, especially those living in the U.S., is a highly educated group (Al Khateeb et al., 2014). Although prior research has connected differences in the cultural adaptation of Arab families in the U.S. to religion (Sadek & Awad, 2024), immigration timing (Rahal et al., 2022), and country of birth (Abouhala et al., 2024), there are more similarities than differences among Arab subgroups (Al Khateeb et al., 2014). This study also aimed to fill a gap in the literature regarding the underrepresentation of minority groups in research on the lived experiences of Arab caregivers of individuals with ASD and IDD (Alallawi et al., 2020). However, it is important to note that the sample size was small, and the Arab community is not a single uniform group. While the goal isn't to generalize the findings to the entire population, a larger sample could have offered a more comprehensive view of a broader range of experiences and perspectives. Despite the limited number of participants, the results suggest a disconnect between the Western clinical model and the cultural, religious, and practical realities of Arab families in the U.S., as highlighted in previous research (Al Khateeb et al., 2014; Forbes et al., 2025). In this study, Arab caregivers and their children face significant challenges, including expulsion from schools, dismissive medical professionals, and a lack of understanding or respect for family-centered decisions that oppose Western norms (Al Khateeb et al., 2014), such as rejecting institutionalization and group homes. There were varied experiences with coaching: some caregivers appreciated and benefited from family training programs provided by the school, while others regarded them as a "joke" and too generic to address their child's specific needs. These findings align with previous research pushing for more neurodivergent focused

behavioral interventions (Dwyer et al., 2026). Additionally, some caregivers rejected evidence-based practices like ABA, perceiving them as rigid and "robotic" and believing they prioritized behavioral compliance over the child's individuality. To interpret these findings, the author analyzed them through the lens of Bronfenbrenner's (1979) Ecological Systems Theory.

Drawing on Bronfenbrenner's Ecological Systems Theory, this study centers the caregiver to examine how different systems shape each family's perspectives and experiences, particularly the primary caregiver's interactions with professionals, access to services for their child, and experiences with being coached to implement evidence-based interventions. This discussion focuses on the systems pertinent to the study's findings. The innermost microsystem emphasizes the immediate environment and how the caregiver is influenced by factors such as family, school, community, and religion. Many of the caregivers in this study saw family as the primary support system and the main source of long-term care, leading some to make important lifelong decisions, such as rejecting institutional models (i.e., group homes) for their older children. This aligns with research showing that caregivers from Arab backgrounds tend to have a collectivist culture in which family values are central to their upbringing (Al Khateeb et al., 2014). This can be seen as one source of cultural disconnect between Arab collectivist culture and Western individualistic culture, which views each individual as a separate entity and tends to value personal goals (Yates & De Oliveira, 2016).

Most caregivers in this study identified as Muslim, and many discussed how their faith shaped their view of their child's disability as a gift and a blessing rather than as a punishment or burden. One caregiver shared how she incorporated religious practices to support her son's needs and another helped her son memorize a short chapter from the Qur'an (Islam's Holy Book) and provided him with black seed daily, which holds religious significance and medicinal healing

properties (Ferizi et al., 2023). Participants' use of faith as a way to reframe their view of the child's disability and as a coping strategy aligns with earlier research showing that Muslim parents often turn to their faith for support (Bernier & McCrimmon, 2021; Forbes et al., 2025). The integration of religious education, such as teaching the Qur'an, illustrate how spiritual identity and caregiving are intrinsically linked, as seen by one participant's method of teaching her son a chapter from the Qur'an. This demonstrated how closely her Muslim identity is connected to her caregiving, amplifying findings from other studies where Muslim parents of children with language impairments also taught their children to recite the Qur'an as it was seen as one of the highest goals for their child (Jegatheesan, 2011).

The mesosystem encompasses interactions among microsystem elements, highlighting the need for collaboration and communication among the caregivers, service providers, educators, and medical professionals. Results indicate that caregivers often experience a fragmented mesosystem because they frequently assumed multiple roles they believed were typically performed by others. This can lead to friction with service providers, often due to issues like a lack of transparency about intervention plans, unhelpful advice and workshops, and a failure to respect family choices and values that may differ from Western norms.

All participants cared for individuals with higher needs due to limited communication skills and challenging behaviors, which Garbacz et al. (2016) suggest can negatively impact parent-teacher relationships. Likewise, Dickson et al. (2017) found that the severity of a child's ASD and cognitive abilities significantly influence parent-teacher agreement, especially concerning interventions for repetitive and restrictive behaviors. Some caregivers in this study discontinued or avoided ABA services, fearing or disliking what they viewed as "robotic" behavioral compliance, lacking human connection and individuality. As prior research (Wilson &

Lesack, 2024) shows, caregivers' negative perceptions of ABA often stem from their view of it as rigid and overly focused on compliance and conformity. Leaf et al. (2021) highlight major concerns with behavioral interventions and provide recommendations for developing more effective, person-centered interventions for individuals with ASD. Furthermore, Dwyer et al. (2026) discuss social validity and behavioral interventions, specifically through the lens of neurodiversity, and the need to reevaluate how evidence-based interventions like ABA are perceived. For example, Dwyer et al. (2026) argue that despite a push to support neurodiversity, some interventionists still work to reduce or eliminate stimulatory or stereotypic behaviors, as seen in Nadia's case with her child's constant need to ask silly or nonsensical questions.

The exosystem includes indirect influences on the caregiver, such as extended family members, friends, societal norms, cultural values, and support services. Caregivers in this study briefly mentioned the invisible burden they bear and occasionally the lack of support or understanding from family and friends, which aligns with findings from previous studies (Chakraborti et al., 2021; Habayeb et al., 2019). The macrosystem involves wider cultural contexts that influence the family experience, including values, ideologies, customs, and political systems. A key finding in the present study is that many caregivers strongly oppose the institutionalization of their children, especially when they leave school, preferring to keep care within the family. This was a common cultural norm among all interviewees, which often caused conflicts with service providers who disagreed. As previously mentioned, this may be due to the collectivist nature of Arabs and their strong familial bond, which previous research has shown to be an important factor impacting caregiver decisions (Al Khateeb et al., 2014). Lastly, the chronosystem covers environmental changes over the caregiver's lifetime, such as historical events, societal and economic shifts, and alterations in family structure.

In summary, the themes identified from the interviews aligned with previous literature focused on caregiver experiences among minority populations, including becoming their child's primary advocate (Forbes et al., 2025), lack of trained service providers with cultural sensitivity (Khalil et al., 2025), appreciation for access to services, and varying levels of support and understanding from family (Habayeb et al., 2019). However, one major finding provided new insights into previous research, particularly regarding the Arab community within the U.S. minority population. To the author's knowledge, no study currently addresses Arab caregivers' preferences for their children's living arrangements when they reach adulthood. While some studies discuss barriers to independent living for individuals with disabilities (Reed et al., 2014), including caregiver burden (Marsack-Topolewski et al., 2023), none specifically explore the perspectives of minority groups—especially Arabs—on this issue. In many countries from the Global North (*Global North*, 2026), including the U.S., it is common for families to place their older children (i.e., adults) in group homes designed to promote independence, develop life skills, and support community integration (Bigby & Beadle-Brown, 2016; Lindsay et al., 2024). However, this view is not shared by all community members, particularly Arab caregivers. The collectivist nature of Arab culture makes placing adult children in a group home unthinkable (Al Khateeb et al., 2014). Caregivers in this study expressed frustration when service providers repeatedly raised this option; these caregivers viewed caring for their child as a lifelong responsibility and were more than willing to accept this challenge. They hoped that service providers would support them in better caring for their children without having to remove them from their homes.

The themes discussed span various levels of the Ecological Systems model, such as the microsystem, mesosystem, and exosystem. This highlights how these systems are interconnected

and emphasizes the significance of communication, collaboration, and understanding among different stakeholders. It also underscores the influence of the broader cultural context and societal norms on caregivers' lives.

Limitations

One major limitation of this study is its small sample size. As mentioned previously, although the goal is not to generalize the experiences of the caregivers interviewed, larger sample sizes allow more voices to be heard, yielding an even deeper understanding of the community's collective experience. Despite the small sample size, the demographics of the participants themselves varied, with caregivers having varying relationships to the individual with ASD and IDD, different marital statuses, educational backgrounds, years lived in the U.S., and from different states across the U.S. Except for one case where the father completed a journal entry, the findings were based on the voices of the primary caregivers interviewed (i.e., mothers and sisters). The voices of other family members, particularly male figures such as fathers, could have provided a deeper context and understanding of their unique perspectives and experiences, adding more value to any implications for practitioners working with such families. Also, this entire study was conducted virtually. Therefore, the author was unable to conduct direct forms of data collection, such as observations, and was limited to data collected via Zoom (i.e., interviews) or email (i.e., journals). Another limitation to note is that the author was the sole researcher who coded and analyzed the data, although any room for bias in interpretation was minimized through member checks completed by the participants.

Implications for Research and Practice

To address the underrepresentation of Arab populations in intervention research, researchers should focus on recruiting families from Arab backgrounds, recognizing that Arabs

are culturally diverse. Culturally responsive research should go beyond translated materials to include subtle values such as faith and family-centered care. Additionally, evidence-based methods, such as BST, which involve instruction, modeling, rehearsal, and feedback, should be used to train practitioners and researchers to interact respectfully and appropriately with Arab families. These trainings should go beyond basic cultural competence and emphasize cultural humility, considering other factors within a caregiver's macrosystem, like faith and communication styles. Furthermore, the findings of this study highlight the importance of family-centered care and engaging caregivers as active partners rather than passive subjects, for example, through participatory action research (Bowness et al., 2023). This is particularly important because many caregivers believe that the parent is the program, making their involvement in planning, implementing, and evaluating interventions essential.

In terms of implications for practitioners in educational and clinical settings, they should intentionally collaborate with families to ensure neurodivergent Arab children feel a genuine sense of belonging in schools and classrooms. Moreover, practitioners and service providers need to involve Arab caregivers in decision-making and goal-setting related to their own coaching and their child's interventions. This begins with validating the child's personhood rather than focusing solely on behavioral suppression. As shown in Maria's story of multiple school expulsions for her daughter, a lack of cultural and behavioral understanding can lead to systemic exclusion. Practical steps, such as incorporating books and curriculum materials that highlight the diverse sub-ethnicities and traditions within Arab culture, can normalize the child's identity and foster a more inclusive environment.

Furthermore, practitioners should adopt a proactive support approach, initiating conversations with parents and caregivers to explore how they can make their interactions more

meaningful. As some participants noted, they often find it more difficult to seek support from friends, family, community members, and professionals. Additionally, a few participants mentioned that simply explaining their child's diagnosis to family and the broader Arab community felt exhausting and isolating. Therefore, it is the professional's responsibility to create and maintain a safe communication channel. Practitioners are encouraged to ask families what they need—whether it's a translator, accommodations for religious observances, or clarification of familial expectations. Moreover, service providers should aim to align clinical goals with those of the family to ensure cross-cultural validation, shifting from the role of "standardized experts" to more meaningful partners with parents and caregivers working toward shared objectives.

Chapter 4: Lessons from the Lived Experiences of Arab Caregivers of Individuals with ASD and IDD: A Practitioner Paper

It is not surprising that parents and caregivers of children with ASD and IDD experience higher levels of stress and, in some cases, more depression than those caring for children without ASD and IDD (Al Khateeb et al., 2019). This stress and depression are linked to factors such as the severity of the disability (Lyons et al., 2010), the caregiver's coping style (Ekas et al., 2009), and the level of social support (Tobing & Glenwick, 2007). Additionally, many of these families face challenges in areas like finances, social stigma, and overall quality of life (Kuhlthau et al., 2014). In recent years, research has increasingly focused on understanding the experiences of caregivers from minority and underrepresented backgrounds when raising children with ASD and IDD (Blanchet et al., 2024; Conroy et al., 2021). These studies also highlight that factors contributing to caregiver stress may include disruptions to family functioning, cultural influences, misconceptions about ASD, and difficulties in navigating available services (Iadarola et al., 2017).

Previous research has shown that evidence-based practices such as ABA and FCT are effective interventions for increasing appropriate behavior and decreasing challenging behavior (Eckes et al., 2023; Greer et al., 2015). Recent research on behavioral interventions emphasizes their social validity, particularly from a neurodiversity perspective, and calls for a reassessment of how evidence-based methods such as ABA are viewed (Dwyer et al., 2026). While there's a growing emphasis on neurodiversity in behavioral research and practice, actual implementation often varies, with some interventionists still focusing on reducing or eliminating stimulatory or stereotypic behaviors. Furthermore, the effectiveness of these interventions may be reduced when delivered without consideration of the family's cultural and linguistic context (Dababnah &

Parish, 2015). For Arab caregivers, having a minimally vocal or nonvocal child who also exhibits challenging behavior creates a unique set of stressors. When a child cannot communicate their basic needs, the caregiver's role shifts from being a supportive parent to a high-stakes protector. Although recent studies have begun to emphasize the importance of culturally adapted interventions (Sivaraman & Fahmie, 2020), a significant gap remains in understanding the unique religious, cultural, and linguistic factors that shape the needs of Arab caregivers (Khalil et al., 2025). As one of the fastest-growing minority populations in the U.S., Arab Americans increased by approximately 43% between 2010 and 2024, coming from various countries in the Middle East and North African regions (*Arab American Demographics*, 2024).

This practitioner paper aims to offer valuable insights and practical recommendations based on the previous qualitative study with Arab caregivers. By addressing the unique challenges this group faces and emphasizing the importance of culturally adapted interventions, it seeks to empower caregivers and practitioners in the education field to better support nonvocal children with ASD and IDD, as well as their families within Arab communities, particularly in the U.S. The goal is to translate the lived experiences of Arab caregivers from the earlier study into actionable strategies for practitioners, service providers, and medical professionals.

Understanding Challenges Faced by Arab Caregivers

In the previous qualitative study, Arab caregivers reported a few challenges they faced when working with service providers, including educators and medical professionals. Many felt they had to over-advocate for their child and assume roles beyond that of caregiving and parenting to get the services needed for their child. This burden of hyper-advocacy was sometimes further complicated by systems that lacked specialized resources to support children with higher needs, including more intense, challenging behaviors.

This need for advocacy can stem from caregivers feeling that their child's diagnostic symptoms are dismissed, often leading them to push back against professionals who fail to acknowledge what the caregivers are trying to tell them about their child. With at least one caregiver we interviewed, this push back ultimately led to the long overdue official diagnosis of her son with ASD, as she suspected previously.

Moreover, many Arab caregivers shared their experience with interventions, including ABA, that they found to be too "robotic", focusing on skills they did not deem practical or valuable for their child. On the other end of that spectrum, the coaching they received as parents and caregivers was often too "generic" and failed to address their child's specific needs. One caregiver described school-led workshops as a "joke", stating, "

Finally, some Arab families encounter an abrupt end to services when their child reaches adulthood, specifically at 21 years. These caregivers are then burdened with navigating a system that lacks experienced providers when trying to help their child transition to adulthood. Caregivers often face the challenge of finding appropriate services, the financial support to pay for such services, or even medical professionals who know how to interact with individuals, specifically adults, with disabilities appropriately.

Experiences with Service Providers and Coaching

The findings from the previous qualitative study suggest that Arab caregivers often experience standard behavioral coaching as somewhat of a threat to their child's authenticity. Although many parents complimented ABA and found it helpful for their child, a couple of caregivers described the interventions as "robotic" and "repetitive," with a rigid, compliance-based procedure that focused too much on repetition. Along with the ABA therapy their child received, some parents were also involved in some form of parent coaching or training, usually

from the school or a non-profit organization. However, almost all noted a lack of formal cultural adaptations in these trainings, and some found them too "generic" and unhelpful in addressing their child's specific needs.

On the other hand, some caregivers had positive experiences with service providers who accommodated their specific familial and cultural norms, without having to advocate too hard. For example, one caregiver appreciated that their request to have only female providers work with her daughter was honored. On a similar note, one caregiver shared how her family also did not want just a male therapist to provide in-home services to their older son when only the mother was home with him. In this case, with the help of state regulations, they were able to have one male and one female therapist provide in-home services. This same family also appreciated that, when their son would say certain words only in Arabic, therapists "differentiated and honored it" without trying to correct him in an invasive way.

Recommendations for Supporting Arab Caregivers

Based on the findings presented above, some practical ways for service providers in educational and medical settings to better support Arab caregivers include: 1) implementing BST with cultural nuances, 2) actively involving families in coaching and intervention processes, and 3) proactively seeking to adopt culturally adapted interventions and coaching.

Recommendation 1: Implementing BST with Cultural Nuance

BST is an evidence-based framework primarily used to train individuals on how to implement behavioral interventions or assessments. Typically, the trainers are professionals such as researchers, behavioral therapists, and other service providers. Trainees may include other service providers, students, teachers, parents, and caregivers (Shayne & Miltenberger, 2012). Although BST has already proven to be an evidence-based model for training individuals in

implementing specific interventions, there is still room to enhance the cultural elements integrated across its four main phases: instruction, modeling, rehearsal, and feedback.

Instruction. The initial step in BST, *instruction*, involves trainers clearly explaining the purpose of the training and the target skill or procedure the trainee needs to learn (Reed et al., 2018). This explanation should be provided by a knowledgeable and credible person in the field, using written instruction, oral instruction, or both. An improved version of written instruction, developed by Graff and Karsten (2012), minimizes technical jargon, includes visuals and diagrams when possible, and provides step-by-step examples. This approach increased trainees' procedural accuracy following BST. When considering culturally adapted BST, especially during the instruction phase, trainers working with families can aim to incorporate the family's values, whether cultural or religious, while actively involving families in planning. This phase should focus on how to functionally integrate family values into protocols. Additionally, this is when trainers can explicitly ask families what they value most, the outcomes they seek from the training, and any family or cultural norms they wish to include. If needed, trainers may also provide translations of any written instructions used during the training.

Modeling. The second step, *modeling*, involves the trainer demonstrating exactly how to perform the target skill so that trainees can replicate the behavior (Reed et al., 2018). Whenever possible, trainers should demonstrate the behavior in a real-life setting where the skill is expected to be performed (Shapiro & Kazemi, 2017). There are two main types of modeling commonly associated with BST: in vivo and video modeling. In vivo modeling requires an individual to demonstrate the behavior precisely as intended each time. Meanwhile, studies have shown that video modeling has become a much more popular option recently due to its many advantages over in vivo modeling (Shapiro & Kazemi, 2017). Most importantly, video modeling offers a

more accurate and consistent training experience across all trainees and over time, since they can view the same video multiple times to observe the target skill.

Rehearsal. The third step, *rehearsal*, is often one of the most important parts of BST because it allows trainees to practice the target skill while being observed by the trainer (Reed et al., 2018). Rehearsals can be conducted with other trainees in role-play situations or, if appropriate, in the actual environment with individuals who would benefit from the training (e.g., students in a classroom). Usually, rehearsals continue until the trainee reaches a set mastery level. During this phase, trainers can also provide immediate feedback, as well as feedback given after rehearsal. When adapting to different cultures, especially given that Arabs are often collectivist, it may be helpful to involve other family members (e.g., fathers, siblings, grandparents) in the rehearsal, especially if it takes place in a natural setting, such as the trainee's home. Additionally, since modesty is highly valued in many Arab families, using gender-matched models during this phase may be especially appreciated (i.e., female trainers with female trainees and male trainers with male trainees).

Feedback. After trainers complete instruction, modeling, and rehearsal, they proceed to the final step of BST: *feedback* (Reed et al., 2018). This step can also occur alongside rehearsal and is intended to help trainees understand exactly what they did correctly and what needs improvement. Feedback on areas for improvement should also include specific steps for successfully performing the target skill; it should be tailored to each trainee and can be provided verbally or in writing (Parsons et al., 2012). To maintain the partnership between trainers and trainees (i.e., professionals and caregivers), when providing feedback, trainers can use a more collaborative approach rather than offering solely corrective, direct feedback. Similar to the

instruction phase, feedback may also be provided in written and translated formats to meet trainees' needs.

After completing the formal BST, trainers are strongly encouraged to continue supporting trainees through ongoing progress monitoring, feedback, coaching, directed rehearsal, and reinforcement (Reed et al., 2018). This helps ensure greater procedural fidelity as trainees apply the skills or interventions they learned in real-world settings. Progress monitoring involves trainers collecting data (for example, using a checklist) on trainee performance to identify skills that may need additional support. Feedback and coaching following the initial BST will be similar, with trainers providing specific feedback and coaching if needed to help trainees improve. For trainees who require extra practice with certain skills or intervention steps, trainers may opt for directed rehearsal, allowing trainees to practice those skills again. Finally, reinforcement should be used to motivate trainees to maintain desirable behaviors over time. Examples of reinforcement include, but are not limited to, money, paid time off, gift cards, and others.

Figure 4.1

BST Components and Support Techniques

	Technique	Description
BST Component	Instruction	Provide verbal and/or written description of the target skill or intervention; Actively involve trainee when deciding on a target skill to take into account family values*; Provide translations of written description, if needed*
	Modeling	Demonstrate correct performance of the target skill (in vivo or video)
	Rehearsal	Provide opportunity for trainee to practice the target skill (with trainer, other trainee, or child, if appropriate); Use gender-concordant models when rehearsing with trainees *; Involve other trainees (i.e., other family members) in the process
	Feedback	Deliver specific and timely feedback during and after rehearsal (positive and corrective); Provide translations of written feedback, if needed*

Support Techniques	Progress Monitoring	Collect data on treatment integrity and procedural fidelity
	Feedback & Coaching	Deliver information about performance (positive and corrective) and provide guidance, if needed; Provide translations of written feedback, if needed*
	Directed Rehearsal	Allow trainee to practice any intervention steps or skills that need correcting; Use gender-concordant models when rehearsing with trainees (e.g., female trainer with female trainee)*;
	Reinforcement	Provide reinforcement (any item or event of value to trainee) to increase likelihood of treatment integrity

** suggested cultural adaptations that may be beneficial for Arab caregivers*

Note. Adapted from Reed, F. D. D., Blackman, A. L., Erath, T. G., Brand, D., & Novak, M. D. (2018). Guidelines for using behavioral skills training to provide teacher support. *Teaching Exceptional Children*, *50*(6), 373–380. https://doi.org/10.1177/0040059918777241

Recommendation 2: Actively Involve Caregivers in Coaching and Intervention Processes

Although we cannot expect trainings like BST to cover every cultural nuance in detail, service providers can ensure they are well-informed about the cultures of the families they serve. Specifically, they can ask families about their cultural or religious practices and family norms to better understand and make interactions more meaningful. For example, as shown in the previous qualitative study, one caregiver reported finding it challenging to explain her child's specific needs using generic intake forms and procedures that do not allow for detailed explanations. Simply allowing caregivers space to detail specific concerns or cultural nuances may be helpful. Other caregivers expressed their desire for service providers to respect their families' decisions to deny group homes for older children, to request therapists of a specific gender for in-home services, and to incorporate meaningful educational programming about their family's religious holidays in schools. Actively involving these caregivers as collaborators helps ease the burden

they feel of trying to fill the shoes of practitioners and professionals who may not be meeting their child's needs. Service providers should adopt a holistic approach when working with these families, keeping in mind that their minority background may make it more difficult to navigate systems successfully and engage with professionals while staying true to their culture and faith. As a caregiver from the previous study noted, "the parent is the program," yet many families feel dismissed by professionals who fail to take their concerns seriously. Focusing on the caregiver in the intervention, practitioners recognize their role as the primary shaper of the child's environment, transforming the clinical relationship from simple compliance to a true partnership.

Recommendation 3: Service Providers Proactively Implement Culturally Adapted Practices

Ultimately, caregivers should not bear the sole responsibility for requesting services and accommodations. Service providers need to establish and simplify a safe, nonjudgmental communication channel where their proactive questions can lead to meaningful service experiences. These culturally adapted practices may include modifying behavioral interventions, respecting dietary restrictions, and integrating religious and cultural values. For example, when discussing coping strategies, providers can ask families whether they use any culturally significant methods at home, such as reciting verses from the Qur'an, and can incorporate them. Practitioners can work to honor cross-linguistic validation by welcoming a child's use of Arabic vocabulary, especially when their communication is limited. Additionally, as previously mentioned, when engaging with Arab caregivers, providers can foster a more comfortable environment by offering gender-concordant care whenever possible, including coaching sessions with the caregiver.

Results from earlier studies show that this specific accommodation was highly appreciated and made families feel more comfortable working with their child's service

providers, particularly during in-home sessions. Finally, it is important to include lessons and materials about cultural and religious holidays significant among Arabs, such as Ramadan and the two Eids (Eid al-Fitr and Eid al-Adha), which are often not covered in schools. Although most participants in the previous study identified as Muslim—possibly influencing the focus on faith-based practices—it is important to keep in mind that Arabs come from many different religious and ethnic backgrounds, all of which deserve culturally adapted approaches.

As caregivers reported in the previous study, some find it difficult or intimidating to ask for certain accommodations, while others are unsure about what to request to improve their interactions with service providers. These caregivers often feel lonely and isolated, carrying so much that they become overwhelmed and unsure how to approach service providers and ask for what they need. Therefore, proactive service providers—such as educators, therapists, and medical professionals—can help reduce this burden by offering accommodations up front that respect the family's cultural values. Furthermore, they can help organize support groups for such Arab and/or Muslim caregivers to help alleviate the loneliness and isolation many feel.

Conclusion

In summary, supporting Arab caregivers has become more important in recent years with the significant growth of the Arab community, especially in the U.S. This requires intentional changes from professionals and practitioners who aim to provide meaningful services to these families. For these families, raising a minimally vocal or nonvocal child with ASD or IDD who also exhibits challenging behaviors creates a level of stress and strain that exceeds typical caregiving experiences. Often, these caregivers find themselves taking on roles beyond their expertise to find and secure the services their child needs to thrive. The emotional and physical toll of this role is sometimes heightened by the difficulty of navigating unfamiliar educational

and medical systems, anxiety about who will advocate for their child if they cannot, and longing for communal support from family and friends.

Current professional interactions often fail to address the specific needs of Arab caregivers, frequently offering standardized strategies and workshops that overlook deep cultural and religious values. When parental coaching or training is delivered generically, families often feel that their child's unique character and needs are being ignored in favor of behavioral compliance. This disconnect often forces caregivers to take on roles of educators and medical professionals as they adapt protocols to suit their family's needs and values. This ongoing effort to bridge the gap between current clinical and educational interventions and cultural realities remains exhausting and is largely unrecognized as a burden for these primary caregivers.

To foster a more meaningful and inclusive environment, practitioners need to recognize the extra burden placed on caregivers when they are forced to assume the roles of other professionals to meet their children's needs. They should intentionally reshape their training and collaboration approaches, actively involving caregivers in the process. Culturally adapted interventions that incorporate the family's culture, faith, and language are essential for improving engagement and outcomes for Arab caregivers. This might start with moving beyond simple instructional methods and training and instead co-designing family-centered interventions that reflect the family's existing values and priorities. Professionals should proactively seek to understand the cultural nuances of the families they serve, remaining compassionate, empathetic, and nonjudgmental toward family decisions that may differ from Western norms. By positioning the caregiver as an active partner in designing their child's program and aligning goals with the family's priorities, providers can help create a system of care that respects individual dignity and the family's cultural and religious values.

Chapter 5: Conclusion

With the rising global prevalence of both ASD and IDD in recent years (Olusanya et al., 2023) and the diverse ethnic backgrounds of these populations (National Center on Birth Defects and Developmental Disabilities, 2023), there is a growing need for research to identify interventions and cultural adaptations that address the needs of these groups. Specifically, the underrepresentation of families from CLD backgrounds and Arab backgrounds in particular continues to widen the gap between research and practice for these families. This is especially crucial when examining the effects of interventions on socially significant behaviors that affect their children's daily lives, such as reducing challenging behaviors and increasing appropriate communication (Steinbrenner et al., 2022). Therefore, this dissertation aimed to address these issues first by systematically reviewing the literature.

The systematic review in Chapter 2 aimed to examine studies focused on parent-implemented FCT that sought to reduce challenging behaviors in nonvocal or minimally vocal children with ASD and IDD from CLD backgrounds. The review highlighted several key needs: (a) greater transparency about participants' backgrounds and characteristics, such as ethnicity; (b) broader inclusion of families from diverse backgrounds in intervention research; and (c) the use of culturally adapted and appropriate practices when guiding parents in implementing interventions. Additionally, a notable research gap was identified: participation by Arab caregivers was limited. This made it challenging to understand their experiences and perspectives in raising nonvocal or minimally vocal children with challenging behaviors. To address this, the qualitative study in Chapter 3 employed a case study approach to explore the perspectives and experiences of Arab caregivers of minimally vocal or nonvocal children with ASD and IDD who exhibit challenging behaviors. A primary focus of the study was the caregivers' experiences with

coaching and training, and whether these interventions and trainings were culturally adapted. Findings from this study were then translated into practice in Chapter 4, which offers practical recommendations for service providers and practitioners working with these families. This final chapter summarizes the findings from previous chapters, along with implications for future practice and research, future directions, and conclusions.

Systematic Review

The systematic review (Chapter 2) sought to examine studies on parent-implemented FCT for reducing challenging behavior in nonvocal or minimally vocal children with ASD and IDD from CLD backgrounds. Although earlier reviews have addressed similar topics (Gerow et al., 2017; Liao et al., 2021), the authors are unaware of any existing study that specifically synthesizes research on nonvocal and minimally vocal children with ASD and IDD. This review additionally emphasizes families from CLD backgrounds and highlights culturally responsive coaching practices within the interventions. The review identified 10 studies that met the inclusion criteria and evaluated their descriptive characteristics of the participants, study design, and findings, as well as methodological rigor using Reichow et al. (2011) standards and Tau-*U* effect sizes.

The results confirmed prior reviews and demonstrated that parent-implemented FCT is effective for CLD families, particularly within the diverse populations represented in the included studies. Furthermore, half of the studies in the review earned a strong evidence-based rating according to Reichow et al. (2011). The other studies received an adequate rating due to issues like missing generalization and maintenance phases or inconsistent data within or across phases. Additionally, the weighted average Tau-*U* across all studies indicated a medium-to-high effect (-0.83), with individual Tau-*U* scores ranging from -0.49 to -1.0. However, some

limitations of the review included the small number of studies that focused on and reported participants' vocal abilities, and inconsistency across studies in reporting cultural adaptations, if any, and in extending experimental designs to include generalization and maintenance data, which would enhance validity and inform future research.

Qualitative Study

The qualitative study (Chapter 3) aimed to address a gap identified in the systematic review (Chapter 2): the need to include families from diverse backgrounds, including Arab communities. This study used a case study approach to better understand the perspectives and experiences of Arab caregivers of minimally vocal or nonvocal children with ASD and IDD who display challenging behavior. Eight primary caregivers of individuals aged 3 to 29 with ASD/IDD—who were minimally vocal or nonvocal and exhibited challenging behaviors—were recruited. Four main themes emerged from the data regarding Arab caregivers' experiences raising nonvocal or minimally vocal children with ASD and IDD in the U.S.: 1) the burden of hyper-advocacy, 2) the tension between individuality and standardization in interventions, 3) the influence of faith and cultural perspectives, and 4) redefining what constitutes successful futures.

Data analysis, based on Bronfenbrenner's Ecological Systems Theory, showed that Arab caregivers and their children face significant challenges, including expulsion from schools, dismissive medical professionals, and a lack of understanding or respect for family-centered decisions that oppose Western norms. Caregivers held mixed views on coaching: some valued school-based family training, while others found it too generic. Some rejected evidence-based practices like ABA, perceiving it as rigid and overly focused on compliance at the expense of the child's individuality. To better include Arab populations in intervention research, researchers should focus on recruiting families from diverse Arab backgrounds, recognizing the cultural

diversity within Arab communities. The study also emphasized the importance of involving caregivers as active collaborators rather than passive subjects, such as through participatory action research. For practitioners in educational and clinical settings, it is essential to intentionally work with families and caregivers as active collaborators to help neurodivergent Arab children feel truly included and valued in schools and classrooms.

Practitioner Paper

Findings from the previous qualitative study helped shape the practitioner paper (Chapter 4), which aimed to provide valuable insights and practical recommendations for practitioners and service providers working with Arab caregivers and families. Some major challenges Arab caregivers identified when working with service providers, including educators and medical professionals, include feeling over-advocated for and having to take on roles beyond caregiving and parenting to obtain the services their children need. The findings also revealed that Arab caregivers experienced mixed feelings and experiences with coaching, particularly regarding service providers accommodating their specific family or cultural norms. Similarly, there were varied experiences with behavioral interventions, such as ABA, with some not finding it beneficial and others praising it for its positive impact on their child.

Based on the findings, practical strategies for service providers in educational and medical contexts to enhance support for Arab caregivers include: 1) applying BST with attention to cultural details, 2) engaging families actively in coaching and intervention efforts, and 3) actively pursuing culturally adapted interventions and coaching methods. Ultimately, interventions that incorporate the family's culture, faith, and language are crucial for enhancing engagement and outcomes among Arab caregivers.

Future Directions and Conclusions

It is important to note that both the systematic review and the qualitative study involved small sample sizes. Future research should continue to focus on the effectiveness of evidence-based practices, such as FCT, BST, and ABA, particularly with families from CLD and Arab backgrounds. However, when designing behavioral interventions, researchers should consider the social validity of these approaches and apply a true neurodiversity perspective to avoid implementing strategies that conflict with the nature of neurodiverse populations. Specifically, studies should report participants' demographic information and aim to recruit families from minority populations. When developing and evaluating culturally adapted interventions, researchers can include the beneficiaries—such as parents, caregivers, and educators—as active collaborators and partners. Engaging in family-school partnerships and involving families in decision-making and goal-setting has already been shown to promote positive outcomes (Santiago et al., 2021); however, more research is needed to explore these partnerships within minority populations.

Additionally, although the goal of the qualitative study is not to generalize the findings from the interviewed caregivers, a larger sample size could have included more voices and offered a richer understanding of the community's shared experience, considering the case-study method used. Ultimately, future research and practice should aim to actively involve families and caregivers of individuals with ASD and IDD, viewing them as partners rather than passive recipients. This involvement may deepen understanding of how to better serve each minority population's cultural nuances, ultimately strengthening school-home relationships and improving the quality of life for both caregivers and their children.

Appendix A

Screening Questions

Note: Informed consent and an explanation of the study will be provided before the screening.

1. **What is your relationship to the child?**
    a. Parent
    b. Primary caregiver: please specify.
2. **Does the child have a prognosis or diagnosis of autism spectrum disorder (ASD) or intellectual and developmental disability (IDD)?**
    a. Yes/No (if not, please specify.)
3. **How old is the child?**
    a. 2-17 years
    b. Older than 17 years
4. **Does your child use a communication device?**
    a. Yes/No (if yes, please specify.)
5. **Are they considered vocal, minimally vocal, or non-vocal?**
    a. Vocal (neurotypical functional language)
    b. Minimally vocal (significantly fewer than expected levels relative to age)
    c. Nonvocal (no functional language; child over 18 months)
6. **Does your child engage in challenging behavior [e.g., aggression, self-injury, elopement (running away), biting, property destruction (e.g., throwing furniture)]?**
    a. Yes/No (if yes, please specify.)
7. **What is/are your cultural/ethnic background(s)?**
    a. White (German, Irish, English, Italian, Polish, French, etc.)
    b. Hispanic or Latino (Mexican, Puerto Rican, Cuban, Salvadorian, Colombian, etc.)
    c. Black or African American (African American, Jamaican, Haitian, Nigerian, etc.)
    d. Asian (Chinese, Filipino, Korean, Pakistani, Indian, etc.)
    e. American Indian or Alaska Native (Navajo Nation, Mayan, Aztec, etc.)
    f. Middle Eastern or North African (Lebanese, Syrian, Moroccan, Egyptian, etc.)
    g. Native Hawaiian or Pacific Islander (Samoan, Fijian, Marshallese, Tongan, etc.)
    h. Other (specify):
8. **What is your primary native language?**
9. **Is English considered your second language?**
10. **Do you live in the United States?**
    a. Yes/No
11. **Please provide your contact information**:
    a. Name, email, phone (optional)

Appendix B

Interview Guide

Part 1: Demographic Questions

To be completed by caregivers after receiving signed consent forms and prior to the interview. ***All questions are optional****, however, will add great value to the overall data analyses and results. Answers will be kept confidential and cannot be traced back to a certain participant.*

Caregiver Information

1. Your name:
2. What age group do you fall in?
    a. 20-30 years
    b. 31-40 years
    c. 41-50 years
    d. 51-60 years
    e. 61 and older
3. What is your gender?
    a. Female
    b. Male
4. What is your specific Arab ethnicity (i.e., country of origin)
5. What is your religious affiliation?
6. What state do you live in?
7. What type of city/town do you live in? (rural, suburban, urban)
8. What is the highest level of education you completed?
    a. Some high school
    b. High school diploma or GED
    c. Trade school
    d. Associate's degree (e.g., AA, AS)
    e. Bachelor's degree (e.g., BA, BS)
    f. Master's degree (e.g., MA, MS, MBA)
    g. Professional or doctoral degree (e.g., MD, PhD, DDS, JD)
    h. Other, please specify:
9. What is your current occupation?
10. Do you have other children diagnosed with a disability?
    a. Yes (if yes, how many and what is their diagnosis?)
    b. No

Child Information

1. How old is your child?
2. What is your child's gender?
3. What is your child's ethnicity (if different from caregiver's)?
4. What is your child's educational placement?
5. How old was your child when they were diagnosed?
    a. What type of professional diagnosed them (e.g., pediatrician, psychologist, etc.)?

Part 2: Interview Questions

Thank you for taking the time to speak with me today, I sincerely appreciate your time. I am excited to learn more about your child and your perspectives and experiences as their caregiver. This interview will take approximately 1 hour, but please know you can stop the interview any time you do not feel comfortable continuing. I want you to think of this as an informal conversation, so please feel free to ask for me to repeat or clarify any questions. Do you have any questions before we begin? Now, I will go ahead and start the recording. If you would like to turn your camera off, please feel free to do so. I want to reiterate your confidentiality and that these recordings will be safely stored in a password-protected platform before being deleted upon completion of the study. The purpose is to help transcribe the interviews, which will also be shared with you, for increased accuracy.

Child & Communication

1. **Tell me more about your child. What are their strengths, needs, likes, and dislikes?**
2. **What form(s) of communication does your child use? How often?** *(Choose all options that apply and for each one indicate how often: Never; Rarely; Occasionally; Frequently)*
    a. Vocalization (using functional or non-functional language, meaning language you understand and has actual meaning compared to language that does not have meaning), Eye gaze, Gestures/pointing, Sign language, Picture exchange, Speech-generating device (e.g., iPad, Dynavox, etc.)
3. **Does your child use a communication device?**
    a. If yes, what type of device do they use?

Challenging Behavior

4. **What types of challenging behavior does your child engage in?**
    a. How often do they engage in each behavior?
    b. How are others impacted by the behavior?
    c. What are some possible triggers or reasons your child engages in these behaviors?
5. **Walk me through what happens when your child engages in challenging behavior.**
    a. What goes on in your mind?
    b. What steps do you take to help solve the problem?
    c. How do you attempt to communicate with your child?
6. **Thinking about the strategies you use with your child to de-escalate their behavior (help calm them down), what locations do you usually find yourself doing so?**
    a. What specific locations are inside the home (e.g., living room, kitchen, etc.)?
    b. What specific locations are outside the home, aside from school (e.g., grocery store, park, etc.)?

7. **What interventions or strategies do you currently use or have previously used to deal with the challenging behavior?**
    a. Where did you hear about the strategies/interventions being used?

Caregiver's Familiarity with Interventions

8. **What interventions or services does your child receive or are you familiar with?**
    a. Where did you hear about these services?
    b. Are there any parent coaching or training sessions involved?
9. **What do you know about applied behavior analysis (ABA)?**
    a. Has your child ever received ABA services?
        i. If yes, what type of location did they receive services in? (e.g., home, school, one-on-one, etc.)
10. **What is your familiarity level with functional communication training (FCT), an intervention used to teach communication skills?** *[Never heard of it; heard of it, but don't know much; know a decent amount of information about it; know it quite well; know it quite well and tried it with our child (via a professional)]*
11. **Are you familiar with other research-based or evidence-based practices?**
    a. If yes, did you try implementing it with your child?
12. **For any strategies or interventions, you implement(ed), did you receive any formal coaching or training?**
    a. If yes, was it face-to-face, virtual, or hybrid?
    b. Who conducted the coaching? (e.g., researcher, graduate student, psychologist)
    c. What was the dosage of the coaching? (e.g., 1-hour session weekly)
13. **Do you feel the interventions or coaching procedures are adapted to meet your needs (cultural, linguistic, etc.)?**

Goals and Expectations

14. **Thinking about your ethnic and cultural background, what do you wish service providers knew to help make your interactions more meaningful?**
    a. Think about communication styles, family norms, cultural norms, etc.
    b. Are there specific cultural norms you hope others respect at all times?
15. **What expectations and priorities (i.e., goals) do you have in mind for your child related to their communication and challenging behavior?**
16. **Is there anything else you'd like to discuss relating to your child's communication and challenging behavior?**

Appendix C

Journal Instructions and Prompts

Dear Caregiver,

Thank you again for being part of this virtual Arab Caregiver Study. These journal prompts are a follow-up to help me better understand your experiences as an Arab family raising a child with autism in the U.S. Please review the instructions below before responding and reach out with any questions. **As always, all personal information will be kept confidential** (I will not use your real names or personally identifying details).

Instructions:

- All questions are optional.
- You can respond in Arabic or English.
    - Please email me if you would like an Arabic translation of the questions**.**
- There is **no right or wrong way** to answer. Write as much or as little as you'd like – a few sentences, a short story, or just your thoughts in bullet points.
- You can write by hand, type, or even record an audio message if preferred.
- One set of questions is for you (the mother/caregiver), and the other set of questions is for another primary caregiver (e.g., the father), if they choose to participate.
    - **Note: the other primary caregiver does not need to be Arab to participate.**

Send your response in the way that's easiest for you:

- Take a photo of handwritten responses and email them to me.
- Type your responses in this document or an email**.**
- Send a voice note.

Please complete these prompts at your own pace and email your responses back to me by **DATE (if possible).** Once I receive your responses (and the signed consent form), I will email you with your compensation details.

Thank you again for your time, trust, and openness. I *sincerely* appreciate it.

Note. Journal prompts begin on the next page.

Journal Prompts

Feel free to type your responses directly in this document and email them back to me. If another primary caregiver is also participating, they may use the same document as yours or email me their own completed copy.

For mothers or primary caregivers who completed the initial interview

- "Describe a moment when your Arab identity provided you strength, patience, or wisdom in supporting your child."
- "In Arab culture, mothers (or female caregivers) are considered the emotional foundation of the family. How do you maintain your well-being while caring for others?"
- "What specific values from your Arab heritage would you like to pass on to your child (or sibling), particularly regarding communication?"
- "How do you and your family members support one another in caring for your child (or sibling)? What advice would you share with other mothers (or female caregivers) in similar situations?"

For a primary caregiver (e.g., fathers) who was not part of the interview
Relationship to the Child (e.g., father, uncle, etc.):

Ethnicity/Country of Origin:

- "As a father (or primary caregiver), what does raising a child with autism mean to you, and how has this journey changed your understanding of fatherhood (or caregiving)?"
- "Which aspects of your heritage (Arab or other) and values shape how you support your child's development today?"
- "Fathers (or primary caregivers) engage with their children in different ways—some take visible leadership roles while others provide quiet support. How would you describe your role in your family, and what type of involvement feels most natural to you?"
- "How do you and your family members support one another in caring for your child? What advice would you share with other fathers (or primary caregivers) in similar situations?"

Table 2.1

Participant Characteristics (Children)

Study	Total N	Age	Gender	Ethnicity/Cultural Background	Disability	Challenging Behavior	Vocal Skills	Current Mode of Communication
Almulhim, 2023	4 dyads	3-9 yrs.	M (n=3) F (n=1)	Middle Eastern (n=3) Brown (n=1)	ASD	physical aggression, tantrums; self-injury; noncompliance; property destruction; elopement	minimally vocal; nonvocal	limited vocalizations; gestures; 2–3-word sentences
Ashgar, 2024	3 dyads	4-6 yrs.	M (n=2) F (n=1)	Saudi Arabian (n=3)	DD	physical aggression; tantrums; self-injury	minimally vocal	limited vocalizations; 1–2-word sentences
Drew et al., 2021	3 dyads	8-17 yrs.	M (n=3)	White (n=2) White/Black (n=1)	ASD; ID	self-injury; aggression; noncompliance; screaming/yelling	minimally vocal; nonvocal	one-word utterances; gestures; non-word utterances
Gerow et al., 2017	3 dyads	2-3 yrs.	M (n=3)	White (n=1) Hispanic (n=1) Hispanic/Black (n=1)	ASD; DD	tantrums; physical aggression	minimally vocal	intentional vocalizations; single-syllable communication; one-word intentional requests
Gerow et al., 2019	3 dyads	3-7 yrs.	M (n=3)	White (n=1) White/Native American (n=1) Hispanic (n=1)	ASD	screaming; aggression; hair pulling; noncompliance; flopping on the floor	minimally vocal; nonvocal	gestures; one-two-word utterances; echoic utterances
Gerow et al., 2020	3 dyads	2-3 yrs.	M (n=3)	White (n=2) Hispanic (n=1)	DD	aggression; disruption; biting; hitting; crying; falling to the floor	minimally vocal; nonvocal	limited vocalizations; picture exchange (not consistent)
Lee, 2016	5 dyads	2-6 yrs.	M (n=3) F (n=2)	Korean (n=5)	ASD	aggression; property destruction; self-injury	minimally vocal; nonvocal	pointing; gestures; signs; limited vocalizations
Standish et al., 2023	2 dyads	9-17 yrs.	M (n=2)	White (n=1) Biracial (n=1)	ASD; ASD & ADHD	aggression; property destruction; self-injury	vocal and nonvocal	limited manual signs; leading caregiver
Tsami et al., 2019	12 dyads	3-13 yrs.	M (n=8) F (n=4)	Greek (n=3), Turkish (n=2), Saudi (n=2), Costa Rican (n=1), Mexican (n=1), Ukrainian (n=1), Russian (n=1), Hispanic (n=1)	ASD	screaming, aggression, self-injury, property destruction	minimally vocal; nonvocal	limited vocalizations
Tsami et al., 2023	6 dyads	4-10 yrs.	M (n=5) F (n=4)	Brown (n=6) Asian (n=3)	ASD; ID; DD	screaming; aggression; property destruction; self-injury; flopping	minimally vocal; nonvocal	gestures; short phrases; non-verbal; word approximations

Note. All dyads are parent-child dyads; ASD = autism spectrum disorder; ID = intellectual disability; DD = developmental disability

Table 2.2

Study Design, Implementer Characteristics, and Coaching

Study	Design	Setting	Implementer	Background	Dosage of Coaching	Cultural Adaptation	Child CB Reduced?	Weighted Tau-*U*
Almulhim, 2023	non-concurrent multiple baseline across dyads	virtual; participants' homes (all participants)	Mother (n=4)	all had no prior training; all married with 2-4 children; college education + full-time teacher (n=2); unemployed + high school diploma (n=2)	2-3 weeks	written and verbal communication were delivered in Arabic at a language level no higher than 8th grade	Yes	-0.98 [-0.93 to -1.0]
Ashgar, 2024	multiple baseline across participants	virtual; participants' homes (all participants)	Mother (n=1) Father (n=2)	all had no prior training; master's (n=1); bachelor's (n=2)	1 session (1.5 hrs. until mastery)	none specified; but author included translations of documents in appendix	Yes	-1.0 [-1.0 to -1.0]
Drew et al., 2021	ABAB withdrawal design	virtual; university (consultant); participants' homes (all participants)	Mother (n=3) Father (n=1)	employed full-time and vocational training (n=1); employed part-time with college degree (n=1) unemployed and finished high school (n=1); prior training NR	On average 56 m 11 s; each parent reached mastery in 1 session	none specified	Yes	-0.87 [-0.79 to -1.0]
Gerow et al., 2017	multiple probe across dyads	in-person (participants' homes for all sessions, except 1 generalization playground)	Mother (n=2) Father (n=1)	completed some college coursework and unemployed (n=1); completed high school and worked full time (n=1); completed some college coursework and worked part-time (n=1); prior training NR	not specified	none specified	Yes	-0.69 [-0.6 to -0.8]
Gerow et al., 2019	concurrent multiple probe across dyads	in-person (training); virtual (remaining sessions: participants' homes)	Mother (n=3)	all had no prior training; some college coursework, unemployed (n=1); bachelor's, self-employed full-time (n=1); part-time from home, some college coursework (n=1)	not specified	none specified	Yes	-0.94 [-0.88 to -0.89]

Gerow et al., 2020	contin-gency reversal phase	in-person (n=2); virtual (n=1); all participants were in their homes	Mother (n=3)	all had no prior training in functional analysis or function-based interventions; education and employment NR	not specified	none specified	Yes	-0.78 [-0.65 to -0.91]
Lee, 2016	multi-element design	virtual; university (consultant); participants' homes (all)	Mother (n=5)	all had no prior training; all married; bachelor's (n=3); associate's (n=1); high school diploma (n=1)	1 hour weekly	written and verbal communication was delivered in Korean	Yes	-0.79 [-0.58 to -1.0]
Standish et al., 2023	multi-element design	virtual (participants in home or hotel)	Mother (n=2)	all had no prior training; all had a college degree	5 days	none specified	Yes	-0.82 [-0.64 to -1.0]
Tsami et al., 2019	multi-element design	virtual; university (therapists); participants' homes (n=10); therapy room (n=2)	Mother (n=11) Father (n=1)	all did not speak or understand English; prior training in behavior analysis (n=1); bachelor's degree (n=6); associate's (n=2); master's (n=1); high school diploma (n=2), unspecified (n=1)	Two 1-hour appointments prior to FA coaching (between 6-22 appointments including coaching and intervention)	coaching sessions conducted with interpreters or native language directly by therapist (Greek & Turkish); translation of forms to native languages (Spanish, Arabic, Russian)	Yes	-0.82 [-0.64 to -1.0]
Tsami et al., 2023	non-concurrent multiple baseline across dyads	virtual; university (experimenters); third location (interpreters); homes (all)	parents (n=9, not specified)	no prior training (n=8); registered behavior technician (n=1); PhD (n=2); master's (n=3); bachelor's (n=2); high school diploma (n=2) culturally matched (n=5); not culturally matched (n=4)	1 hour weekly	communication in English, Urdu, & Vietnamese, with interpreters & translated material. Experimenters learned key phrases beforehand & held presentations for caregivers & teachers in local communities in Vietnam & Pakistan.	Yes	-0.67 [-0.49 to -0.97]

Note. CB = challenging behavior; NR = not reported; Tau-*U* effect scale: *weak* (0 to -0.65), *medium-to-high* (-0.66 to -0.92), and *strong* (-0.93 to -1.00)

Table 3.1

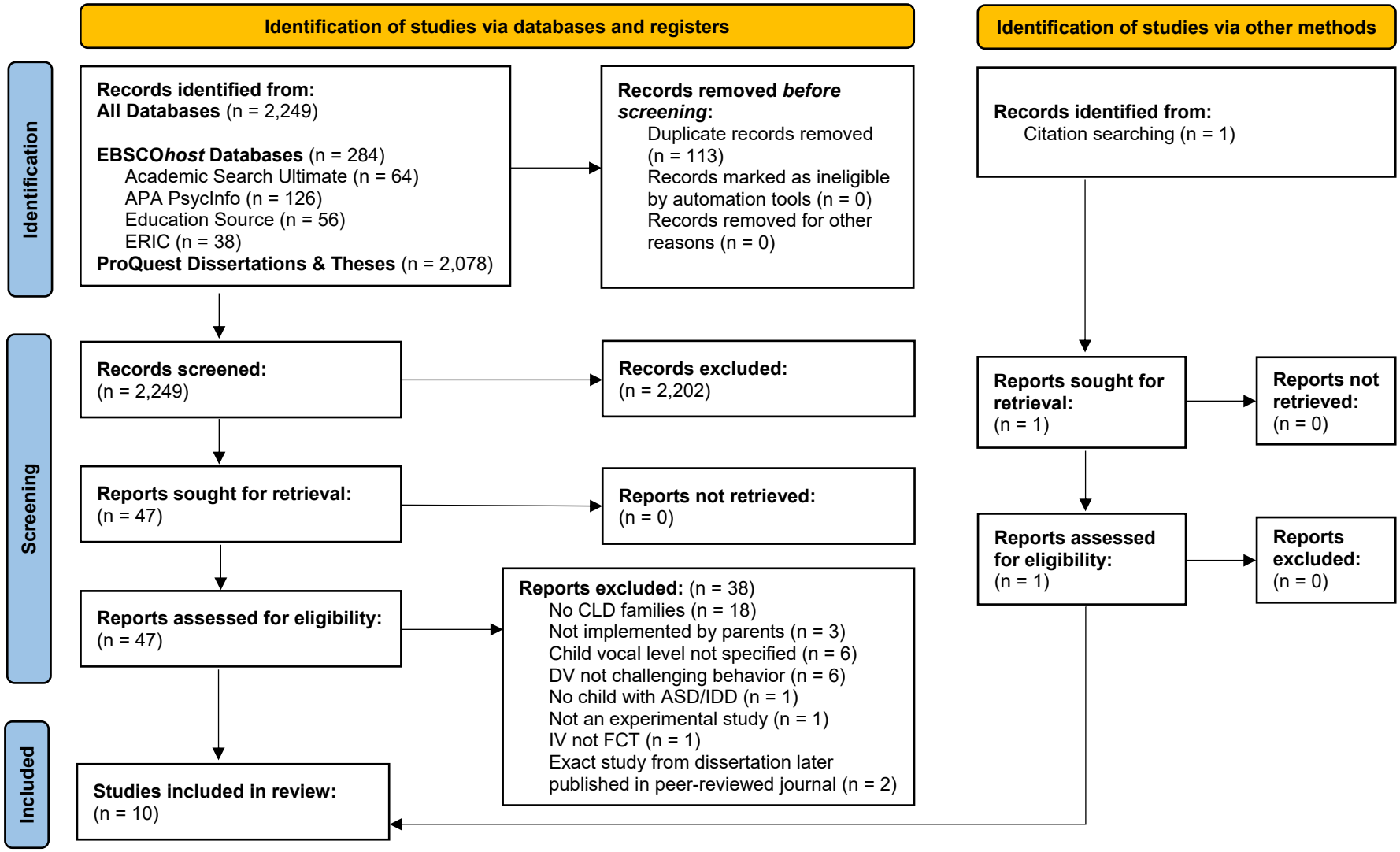
Participant Demographics (Primary Caregivers)

Name	Relation to IWD	Age Group	Arab Ethnicity	Religious Affiliation	Highest Education	Field of Degree	Profession	Years in U.S.
Zahra	Mother	31-40 yrs.	Palestine	Muslim	Bachelor's degree	Information Studies	Regional Coordinator for Nonprofit	30 yrs.
Haifa	Mother	31-40 yrs.	Palestine	Muslim	High school diploma	N/A	Hair Stylist	38 yrs.
Iman	Mother	51-60 yrs.	Egypt	Muslim	Bachelor's degree	Fine Arts	Assistant Manager for Family Business	18 yrs.
Maria	Mother	41-50 yrs.	Syria	Jewish/ Marinate Catholic	Master's degree	Industrial/ Organizational Psychology	Stay at Home Mom & Life Coach	46 yrs.
Aya	Mother	31-40 yrs.	Egypt	Muslim	Master's degree	Psychology/ Higher Ed. Admin	Stay at Home Mom	37 yrs.
Rania	Mother	41-50 yrs.	Libya	Muslim	Other college degree	-	Stay at Home Mom	21 yrs.
Nadia	Sister	21-30 yrs.	Egypt	Muslim	Master's degree	Speech & Language Pathology	Caregiver	30 yrs.
Bushra	Sister	31-40 yrs.	Yemen	Muslim	Master's degree	Public Health	Doctoral Candidate	32 yrs.

Note. All names are pseudonyms, unless otherwise requested by the participant. ASD = autism spectrum disorder; IDD = intellectual and developmental disabilities; IWD = individual with disability

Figure 2.1

PRISMA Flow Diagram of Search and Selection Procedures



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