ARAB AMERICAN PARENTS’ EXPERIENCES
OF SPECIAL EDUCATION AND DISABILITY:
A PHENOMENOLOGICAL EXPLORATION

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Within the field of school psychology there exists literature for school psychologists working with specific ethnic and linguistic groups (Frisby & Reynolds, 2005; Tomes, 2011). The Arab American population is estimated to be 3.6 million (Arab American Institute, 2012). However, there is a paucity of school psychology research on Arab American students and families (Goforth, 2011; Haboush, 2007). As active members of the special education process, school psychologists will benefit from information regarding Arab American cultural and religious beliefs about special education and disabilities. Such information will assist them in providing culturally sensitive and appropriate services to students and families.

This study utilized a phenomenological qualitative approach to illuminate Arab Americans parents’ experiences with their children’s encounters with the special education process and perceptions of their children’s disabilities. Phenomenological data analysis revealed four core themes. First, parents attached significance to specific steps within the special education process and to cultural stigmas around special education and disabilities. Next, parents reflected on special education services and key relationships. Additionally, parents discussed their children’s abilities, their understandings of special education, and their advocacy work. Finally, parents reported that their goals for their children had not changed as a result of the special education process, although the goals
were tailored to their children’s identified disabilities. These findings have significant implications for professionals working with Arab American students and their parents. Recommendations are made for culturally sensitive school psychology practice with Arab Americans. Suggestions are provided for further research on this important yet under-researched topic.
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CHAPTER I

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

School psychologists have several general professional roles and responsibilities. They help students succeed academically, behaviorally, emotionally, and socially, and do so by working with students, parents, teachers, administrators, and community providers (National Association of School Psychologists [NASP], 2010a). Overall, this requires school psychologists to assess individual children; plan and implement behavioral, emotional, and educational interventions; and consult with educators and parents (Fagan & Wise, 2000). It has been suggested that school psychologists also have a role as social justice advocates, wherein they address difficult topics such as power imbalances and they face resistance to effect social change (Rogers & O’Bryon, 2008). Within these various roles and throughout these responsibilities, school psychologists are bound and guided by professional and ethical standards, which are discussed in the following section. In order to provide culturally appropriate services, school psychologists must consider all cultural aspects of the student (e.g., linguistic background, beliefs, family structure, worldview) and display competence with the variety of cultural groups with whom they will work (Jacob, Decker, & Hartshorne, 2011).

The current Arab American population is estimated to be close to 3.6 million (Arab American Institute [AAI], 2012). This indicates that school psychologists are increasingly likely to work with an Arab American student (Haboush, 2007). Specific cultural and social characteristics and needs differentiate this group from other ethnic minority groups in the United States (Goforth, 2011). School psychologists who seek
guidance regarding culturally competent practices will unfortunately find a dearth of published literature on the needs of Arab American students and families (Goforth, 2011; Haboush, 2007). Currently, school psychologists appear to have limited preparation and resources to recognize the nuances of Arab Americans’ approaches to education, disabilities, family, special education, and mental health (Goforth, 2011; Haboush, 2007). This study contributes to the existing multicultural research in school psychology by examining these nuances.

Using a phenomenological approach, this qualitative study reveals and reflects on the experiences of Arab American parents with their children’s special education process. These experiences are considered in relation to culturally specific Arab American views on disabilities and child development. This study references the few qualitative studies that explore the experiences of Arab American students and acknowledges the gap in the published literature on this topic. Additionally, this study contributes to the literature and informs school psychologists on Arab Americans, a heterogeneous group that comprises a small but rapidly increasing portion of the United States (U.S.) population. This important research contributes to school psychologists’ professional and ethical responsibilities for cultural competence. The research and recommendations encourage improved special education outcomes for Arab American students and their families. School psychologists’ professional and ethical responsibilities are described next.

**Professional and Ethical Standards for School Psychologists**

The two guiding professional associations for school psychologists are the National Association of School Psychologists (NASP) and the American Psychological
Association (APA). NASP represents approximately 23,000 school psychologists, which is a sizable portion of the estimated 32,000 practicing school psychologists in the U.S. (Charvat, 2005; Gorin & Nealis, 2002). In contrast, APA is a 117-year-old association of over 152,000 members who belong to various psychological fields (APA, 2010). The Division of School Psychology (Division 16) is one of 54 APA divisions and has a membership of approximately 2,500 (Fagan & Wise, 2000). Both associations issue professional and ethical standards that are guidelines for school psychologists.

Broadly speaking, school psychologists are bound by four professional and ethical standards. These include: respect for the dignity of others, responsible caring, integrity in professional relationships, and responsibility to society and the community (Jacob et al., 2011). These guidelines dictate the manner in which school psychologists deliver services.

More specifically, NASP’s *Principles for Professional Ethics* focus on four broad ethical themes: respect for dignity and rights of all individuals; professional competence and responsibility; honesty and integrity in relationships; and responsibility to schools, families, communities, the profession, and society (NASP, 2010b). The *Ethical Principles of Psychologists and Code of Conduct* (APA, 2010) is the corresponding APA document that addresses ethical standards within five general principles:

- Beneficence and nonmaleficence (benefit clients and do them no harm)
- Fidelity and responsibility (establish trusting relationships and respect the professional and scientific responsibilities to the community)
- Integrity (encourage honesty, accuracy, and truth in science)
• Justice (promote just practices and respect for all individuals)
• Respect for people’s rights and dignity (including respect for confidentiality, privacy, and self-determination).

School psychologists are bound and guided by professional and ethical standards that also include the promotion of culturally competent practice. This competence is required in the following six school psychological domains: legal and ethical issues; school culture, educational policy, and institutional advocacy; psychoeducational evaluation; academic, therapeutic, and consultative interventions; work with interpreters; and research (Rogers et al., 1999). School psychologists demonstrate such competence throughout all levels of service delivery to children from all cultures and backgrounds (NASP, 2009).

NASP and APA have several documents that relate to this topic. These documents are guidelines that relate to different aspects and definitions of diversity, as well as to cultural competence in the field. Three significant NASP documents outline the requirement for cultural competence in the profession. These include NASP’s (2010b) Principles for Professional Ethics, in which cultural competence is one of the professional competencies required of school psychologists. Such competence is demonstrated by the pursuit of “knowledge and understanding of the diverse cultural, linguistic, and experiential backgrounds of students, families, and other clients” (NASP, 2010b, p. 6). School psychologists require an understanding and knowledge of characteristics of diversity to competently provide assessments, interventions, or consultation (NASP, 2010b). Therefore, they must “have or obtain the training or
supervision necessary to provide effective services, or they make appropriate referrals” (NASP, 2010b, p. 6).

Additionally, NASP’s (2010c) Model for Comprehensive and Integrated School Psychological Services includes service delivery guidelines for school psychologists. These guidelines urge school psychologists to: (a) possess knowledge of individual abilities and differences, (b) develop culturally appropriate interventions, (c) recognize subtle biases in their work (i.e., in themselves, others, and in their evaluation and intervention techniques and instruments), and (d) work to eliminate these biases (NASP, 2010c). Finally, NASP’s (2010a) Standards for Graduate Preparation of School Psychologists include a section on Diversity in Development and Learning, which recognizes the variety of backgrounds of today’s students and their families. It encourages school psychologists to possess knowledge of:

- Psychological and educational principles and research related to diversity factors for children, families, and schools, including factors related to culture, context, and individual and role differences (e.g., age, gender or gender identity, cognitive capabilities, social-emotional skills, developmental level, race, ethnicity, national origin, religion, sexual and gender orientation, disability, chronic illness, language, socioeconomic status). (NASP, 2010a, p. 15)

APA has two similar documents that outline standards relating to culturally competent practice. First, the Guidelines on Multicultural Education, Training, Research, Practice, and Organizational Change for Psychologists (APA, 2002) include a series of principles regarding attitudes, sensitivity, research, education, and clinical
practice relating to cultural and ethnic diversity. Additionally, the Guidelines for Providers of Psychological Services to Ethnic, Linguistic, and Culturally Diverse Populations (APA, 1990) offer a very detailed set of recommendations for psychological service providers for work with ethnically, linguistically, and culturally diverse populations. These guidelines require providers to possess a framework from which to reflect on sociocultural diversity in communication, expectations, and values. Further, providers must: (a) understand the importance of culture, race, and ethnicity in sociopsychological and economic development; (b) grasp the impact that socioeconomic and political factors have on psychosocial, political, and economic development; and (c) assist clients in understanding their own sociocultural identification (APA, 1990). Taken together, these NASP and APA documents unequivocally expound the responsibility of school psychologists to provide culturally competent practice to all students and families. Given the increasing likelihood that school psychologists will work with Arab American students and families, cultural competency with Arab Americans is necessary (Haboush, 2007). In the next section, this population is described in more detail.

**Arab Americans**

Before discussing Arab Americans further it is necessary to explain who this population is, the current trends in identifying oneself as Arab American, and the group’s history in the U.S. Data from the 2010 U.S. Census revealed that approximately 1.8 million individuals with Arab ancestry are living in the U.S. (U.S. Census Bureau, 2011). This represents a 72% increase from the 2000 U.S. Census (AAI, 2012). Since the first U.S. Census to measure ethnic origins in 1980, the number of Americans who claim Arab
Ancestry has more than doubled (AAI, 2012). This makes Arab Americans one of the fastest growing Arab diaspora populations in the world (AAI, 2012). AAI surmised that the actual numbers are drastically higher and they estimated that up to 3.6 million Arab Americans live in the U.S. (AAI, 2012). AAI (2012) referred to significant under-reporting of Arab ancestry by the U.S. Census Bureau due to the following limitations: the exclusion of individuals from several Arab League member countries, out-marriage among third and fourth generations, and distrust or misunderstanding among recent immigrants of government surveys. The largest concentrations of Arab Americans live in Los Angeles, CA; Detroit, MI; New York, NY; Chicago, IL; and Washington, DC (AAI, 2012).

This sizeable population in the U.S. deserves to be treated with cultural competence by school psychologists (Haboush, 2007). There is a glaring lack of published literature on this minority group (Goforth, 2011; Haboush, 2007). School psychologists require more research with Arab Americans to increase their cultural knowledge and competency. In the next section, Arab Americans are defined as a group.

**Definition**

The term *Arab American* must first be clarified before discussing the group and before explaining the need for more research. The term does not refer to one homogenous group of individuals in the U.S. Instead it refers to a heterogeneous group that is united by the Arabic language. Thus, Arab Americans—a cultural and linguistic term—are Arabic speakers or descendants of an Arabic speaker.
These Arabic speakers originally come from one of 22 countries in Northern Africa and Western Asia that are members of the League of Arab States, or the Arab League (Arab League Online, 2012). This group of member countries is also commonly referred to as the Arab world. The countries in the Arab world include Algeria, Bahrain, the Comoros Islands, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Mauritania, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the United Arab Emirates, and Yemen (AAI, 2012). In September 2012, the Arab League suspended Syria’s membership due to its brutality toward political opponents; the group’s membership then became 21 countries (Arab League Online, 2012). The term Arab world is used in this study to refer to this geographical and linguistic region.

Other geographical and geopolitical terms are also used to describe parts of the Arab world. For example, the Middle East refers to the region of the world that includes several of these Arabic-speaking countries, as well as other countries that are non-Arabic-speaking, such as Turkey, Iran, and Afghanistan. Therefore, not all Middle Easterners are Arabs. Additionally, the MENA (Middle East-North Africa) region refers to 18 of the Arab world countries, in addition to Iran, Israel, and Malta (World Bank, 2011).

Religiously, the majority of Arabs in the Arab world are Muslim; only a small number of individuals in the region affiliate with other religions such as Christianity, Judaism, Baha’i, and Hinduism (Izady, 2013). In contrast, individuals of Arab ancestry within the U.S. tend to be Christian, with the most recent figures identifying only 24% of Arab Americans as Muslim (AAI, 2002a). In 2001, Samhan noted that since the 1950s
Arab Muslims had become the fastest growing—although still minority—segment of the Arab American population. The majority of Muslims in the U.S. are not Arab American but are actually either African American or an immigrant of South Asian or Western European descent (AAI, 2012).

Altogether, Arab Americans are heterogeneous with regard to religion, acculturation level, Arabic dialect, social class, education level, national origin, generation in the U.S., and immigration history (Moradi & Hasan, 2004). Even within the same family, parents can come from different countries of origin and have different immigration, discrimination, and trauma experiences (Kira, Lewandowski, Somers, Yoon, & Chiodo, 2012). This variability in background among Arab Americans reflects their long and rich immigration history into the U.S. This immigration history has directly influenced their racial classification, which is described next.

**Classification and Identification as Arab American**

Arabs began immigrating to the U.S. as early as the 1600s and their history has included three major waves of immigration. The first wave began in the 1880s and lasted until 1914, as there was a large wave of Christian Arab emigrants moving for economic, political, and religious reasons from the areas that are currently Lebanon and Syria (Dwairy, 2006). The second wave began after the formation of Israel in 1948 and continued until the 1960s (Dwairy, 2006). The third wave began after the 1967 war between Israel and the Arab world and has consisted of immigrants seeking political and economic stability (Dwairy, 2006). Between 1980 and 1990, the Arab American population increased by 41% to almost 860,000 (De la Cruz & Brittingham, 2003).
Thereafter between 1990 and 2000, there was another significant population increase of 38% to almost 1.2 million (De la Cruz & Brittingham, 2003). Most recently, between 2000 and 2010 the population increased 72% to almost 1,970,000 (U.S. Census Bureau, 2011). AAI would likely consider these numbers an undercount, however. Their latest estimates double the recent Census figure and place the current population above 3.6 million (AAI, 2012).

Historically, the first Arabs immigrating to the U.S. in the late 19th century were light-skinned (Cainkar, 2006). Given their appearance, they were classified as White (Cainkar, 2006). Per current federal standards, Arab Americans continue to be classified as White (Hixson, Hepler, & Kim, 2011).

One consequence of this categorization system is that Arab Americans are not considered a minority group and therefore, are not granted minority group status by a federal agency or department (Zogby, 1993). This means that Arab Americans do not receive protection under anti-discrimination laws (Zogby, 1993). Such protections would be helpful given Arab Americans’ vulnerability to negative distortions and systematic discrimination before and after 9/11 (Said, 1978; Samhan, 1987; Shaheen, 1984, 1997, 2001; M. F. Suleiman, 1996; M. W. Suleiman, 1988, 1999; Wingfield, 2006; Zogby, 2000). These distortions are evident in popular culture and the media, which have a pattern of misrepresenting and vilifying Arab Americans (Shaheen, 1984, 1997, 2001; M. W. Suleiman, 1988, 1999; Wingfield, 2006; Zogby, 2000). Since 9/11 and the beginning of the “War on Terror,” discrimination against Arab Americans has only increased (AAI, 2002b; Baker et al., 2004; Samhan, 2001). This discrimination includes anti-terrorism
government policies that selectively and disproportionately affect Arab Americans and Muslims (Ghaffar-Kucher, 2009; Samhan, 2001).

During the last few decades, efforts have begun to change Arab Americans’ federal racial classification. In 1990, after significant research and advocacy work by the AAI, the U.S. Census included its first classification of Arab Americans as an ethnic community (Zogby, 1993). In 1993, the AAI lobbied Congress to change the group’s classification to Middle Eastern (Zogby, 1993). Immediately before the 2000 and 2010 Censuses, Arab Americans were actively encouraged to participate so they could be counted and recognized as a distinct ethnic group (Samhan, 2010).

Given Arab Americans’ complicated location in U.S. society and their diverse national and religious origins, it is understandable that the term Arab Americans is not embraced by the entire population (Baker et al., 2004). Additionally, there is conflict over whether to embrace the term White (Samhan, 2010). To illustrate, experiences before and after 9/11 have made some Arab Americans “not feel treated like the White majority population, and therefore . . . not relate to that racial classification” (Samhan, 2010, p. 6). Sometimes the self-identification decision involves cultural identity and discrimination: if they select Arab American they are exposed to stereotypes and harassment; if they select White they are rejecting their culture (Beitin & Allen, 2005). Some research demonstrates that American citizenship and legal status are crucial conditions in whether an individual chooses to identify as Arab American (Witteborn, 2007). Religion also factors into the decision: Christian Arab Americans are less likely
to embrace *Arab American* and are more likely to prefer *White* (Ajrouch & Jamal, 2007; Baker et al., 2004).

Despite these mixed opinions on the most appropriate terminology, *Arab American* is used throughout this document. Currently, this cultural and linguistic term is widely used by leading Arab American organizations such as the AAI and American Arab Anti-Discrimination Committee and it has been cited in some research as the preferred term by a majority of Arab American participants (Baker et al., 2004). The next section includes a brief discussion of some overarching cultural characteristics and commonalities among Arab Americans.

**Commonalities**

In the social sciences, individuals can be clustered by a variety of characteristics (e.g., age, gender, socio-economic status, geographical location) to discuss general commonalities among individuals in a group. Gregg (2005) cited Arabic language texts and surveys that supported the existence of common psychological characteristics in the Arab world (e.g., Abrahim, Yassin, & Qaziha, 1981; Khalifa & Radwan, 1998). Similarly, Wilson (1996) noted that some attitudes and beliefs are “shared by many Arabs and seem to cross national and social class boundaries” (p. 68). In this section, Arab American individuals are clustered to discuss some commonalities in their social and psychological development, family structure, and cultural beliefs.

Arab Americans are a heterogeneous group, however, that cannot be indisputably summarized by one exclusive and unifying set of beliefs and behaviors (Moradi & Hasan, 2004). Further, it would be cavalier and an oversimplification to assume that individuals
from such a diverse set of backgrounds (e.g., differences in recency of immigration, religion, etc.) could be combined and discussed as one unified group. Despite this, it is helpful to consider general tendencies and commonalities in behaviors, values, and attitudes, especially as they relate to more recent emigrants from the Arab world and individuals whose families have maintained strong cultural ties to the region. Therefore, the primary intent of this section is to discuss some similarities across behavioral, familial, and belief systems of Arab Americans. In the following section, social behavior is discussed.

**Social behavior.** Arab culture highly regards hospitality and generosity and guests are often treated as members of one’s family (Al-Krenawi & Graham, 2000). Friendships are connected more with mutual assistance, support, and permanence for Arabs than are American friendships, which can tend to be oriented to entertainment and emotional purposes (Abu-Hilal, 1982). For Arabs, requests from friends should not be refused even if the individual does not intend to fulfill the request (Dwairy, 2006). This behavior is perceived as a courtesy rather than dishonesty because it would be considered disrespectful to refuse outright a friend’s request (Dwairy, 2006).

Among recent Arab immigrants in the U.S., some commonalities can exist regarding cultural beliefs and their expression through communication. Due to the large Muslim population and the prevalence of Islam in the Arab world, Christian Arabs maintain many of the same cultural practices and traditions as do Muslim Arabs (Goforth, 2011). Therefore, the predominant belief in predestination, for example, is evident in the communication patterns of Muslim and Christian Arabs (e.g., the use of the term
insha’allah, or God willing, when making plans for the future). It is customary when commenting on someone’s good fortune or possessions to say masha’allah, or God protect you, because it indicates a lack of envy and is believed to ward off the evil eye (Nydell, 2012). Personal contact for communication is preferred and there is an emphasis on greetings and pleasantries, taking one’s time, and being relaxed (Moosa, Karabenick & Adams, 2001). Further, direct confrontation is undesirable and so Arab Americans might prefer to receive criticism indirectly or utilize an indirect way of communication to express themselves (Hakim-Larson, Kamoo, Nassar-McMillan, & Porcerelli, 2007; Wilson, 1996). Although the Arab American population is heterogeneous, school psychologists will likely experience some of these cultural commonalities when providing services to Arab American students and families, especially those who are more recent immigrants to the U.S.

**Family.** Within the typically patriarchal Arab family structure, men and women have vastly different characteristics and expectations. The men’s realm is outside of the home while the women’s is within (Nydell, 2012). Child rearing typically remains a domain for women, including issues related to the children’s education and cultural and spiritual development (Bouhdiba, 1997). Age confers wisdom, and parents (especially the father) and older siblings (especially brothers) should be respected first (Nydell, 2012). There is an emphasis on family relationships, loyalty, and obligations (Nydell, 2012).

Children should be brought up well, which is exemplified by respectful behavior in front of adults, and such well-mannered children enhance the reputation of the family
(Nydell, 2012). Frequently, different expectations exist for children based on their
gender, such that female teenagers can have a separate set of rules and expectations than
their brothers (Dwairy, 2006). When children grow up to become adults, there is an
expectation for adults to marry and produce children (Gregg, 2005). In fact, being an
unmarried adult is stigmatized (Inhorn, 2012). Crabtree (2007a) explained, “Procreation
is not only expected in marriage but is much desired as conferring a level of authority that
marks the transition from subordinate youth to adult authority” (p. 578).

Arab Americans tend to position themselves within their American community by
their ancestral country, village/city of origin, religion, and extended family affiliation
(El-Aswad, 2006). Individual Arab American family members are expected to sacrifice
for the sake of the reputation and success of their group (e.g., the family and extended
family; El-Aswad, 2006). Shame is frequently used as a control mechanism
(Hakim-Larson et al., 2007). This can be seen in the invocation of guilt if the individual
has acted outside of the confines of socially acceptable behavior, at which point the
individual can be threatened with being labeled as a disappointment to the family
(Dwairy, 2006).

Arab culture is generally more collectivist than Western culture and is focused
more on interdependence than on individualism and privacy (Al-Krenawi & Graham,
2000). Dwairy (2006) wrote, “In collective/authoritarian societies independence has a
different and sometimes opposite meaning. Emotional interconnectedness, conformity
and submissiveness to norms and values, and loyalty to the familial and social authority
are among the indicators of maturity” (p. 73). This is discussed further in the next section
on parental expectations around children’s development and beliefs related to intelligence and disabilities.

**Beliefs and expectations.** Research in the area of social and moral development of children in the Arab world sheds light on cross-cultural differences that school psychologists are likely to encounter when working with recently-immigrated Arab American students and families. This research includes differing cross-cultural expectations for the stages of development through the lifespan. Moreover, it details cross-cultural definitions and beliefs specific to Arabs and Arab Americans regarding intelligence and evaluation, disability, and counseling. The first topic to be discussed is expectations around child development, which differ in some important ways from those in the U.S.

**Child development.** Expectations for the child developmental stages can differ greatly in the Arab world. Gregg (2005) explained that infant care in the region emphasizes kinesthetic and tactile communication over face-to-face interaction, and minimizes separation between mother and child. This emphasizes then a strong interdependent bond between mother and child that lasts throughout life (Gregg, 2005). Children in the region are dependent on their parents for longer than most American children are and there is less parental concern about independence skills (Gregg, 2005). Therefore, self-help skills are not always taught as early for children in the region as they are in American families (Wilson, 1996). Similarly, Abu-Hilal and Bahri (2000) noted that children are socialized in a way that does not encourage independence and responsibility, and that parenting styles tend to be more autocratic and protective.
Intelligence, discussed next, can also be a construct that has different cross-cultural meanings.

**Intelligence.** The term *intelligence* will likely hold different meaning for some Arab American families because it is conceived of differently between Eastern and Western cultures (Nisbett, 2003). In the West, intelligence is measured by skill in rational debate or category formation (Nisbett, 2003). In contrast, in the East it means how an individual behaves socially and identifies contradictions or complex thoughts (Nisbett, 2003).

In Arabic, the word for self or soul is *nafs* (Yaqoob, 2000). This broad term also relates to individual personality and includes “the *qalb* (heart), the *ruh* (spirit), the *aql* (intellect) and *irada* (will)” (Mohamed, 2012). *Aql*, which relates to social maturity, reason, self-control, and the self-prevention of misbehavior, is the closest approximation to the Western construct of *intelligence* (Al-Jabiri, 2002, as cited in Dwairy, 2006; Gregg, 2005). Another translation of *aql* is emotional and mental maturity (Dorsky, 1986). *Aql* develops in late childhood around the typical development of social etiquette (Gregg, 2005). Therefore, the assessment of intelligence can be complicated when working with Arab American students and their parents, as is discussed in the next section.

**Assessment.** The assessment of intelligence, personality, and psychiatric disorders in Arab American clients can be made more difficult by the lack of local norms on some clinical and psychoeducational measures. As explained above, constructs for intelligence are not synonymous in Arabic and English. Therefore, when school psychologists explain to Arab American parents that they will be conducting intelligence testing or
when they describe the results of a special education evaluation, some parents could make different assumptions about the tests and results.

Personality and clinical psychology assessments might also be difficult to translate across languages and cultures. To illustrate, there are three different types of selves (*nafs*): *nafs ammara*, which is equivalent to the concept of id and demonstrates an individual’s negative drives (Yaqoob, 2000). *Nafs lawwama* relates to the superego in that it expresses regret and is aware of right and wrong (Yaqoob, 2000). *Nafs mutmainnah* exists when an individual is self-content, which is the ideal state of existence (Yaqoob, 2000). To possess *nafs mutmainnah*, an individual must be capable of genuine remorse and self-discipline to control the urges of the *nafs ammara* (Yaqoob, 2000). Because in English one does not distinguish these differences in the word *self*, English-language measures and explanations that include the word will likely not translate correctly.

Personality measures can include projective techniques and free association tasks. Some projective tools utilize culturally specific images that do not have similar meanings for Arab Americans (Dwairy, 2006). The features of projective drawings by Arab Americans also tend to be interpreted as indicative of intrapsychic difficulties rather than cultural values (Haboush, 2007). Further, measures of self-esteem and self-concept actually measure different constructs cross-culturally (Sayed, 2003). This is because, as mentioned above, terms like *self* have different meanings between Arabic and English (Yaqoob, 2000). Altogether, the evaluation process with a school psychologist can be an unusual and discomfiting experience for Arab Americans (Haboush, 2007). In the next
section, the broad construct of disability and its translation—linguistically and culturally—are discussed.

**Disability.** This study’s exploration of the experiences of Arab American parents with the special education process must include a brief discussion of the following topics related to the Arab world: terminology for disabilities, beliefs in their etiology, social consequences and stigma, and treatment options for mental illness.

**Terminology.** English speakers without knowledge of Arabic will miss the nuances of the linguistic and cultural translations of etymologically related Arabic terminology for disabilities. Disabilities are often described using stigmatizing language in Arabic (Gharaibeh, 2009). For example, a disability in children is *i’aqa* (handicap or hindrance; Gharaibeh, 2009). A disabled male individual is *mu’aq* and a female is *mu’aqah* (Gharaibeh, 2009). These words mean *retarded, delayed, or backward* (Gharaibeh, 2009). The term *mu’aq* is connotative with *vegetative*. These related terms are often used to refer to a group of disabilities that are separated into distinct categories in English.

In the Arab world, Gharaibeh (2009) explained, “there are degrees of stigma, a hierarchy of some sort” (p. 70) for disabilities. For example, intellectual and developmental disabilities and mental illnesses are considered worse than physical and sensory disabilities, which are considered worse than severe visual impairments and blindness (Gharaibeh, 2009). Arab females with any disability are stigmatized more than males and are also more likely to be institutionalized (Gharaibeh, 2009). Even parents, as Crabtree (2007b) found, sometimes adopt the stigmatizing terminology when describing
their own children. One participant in Crabtree’s (2007b) research described individuals with physical disabilities, in contrast to individuals with non-apparent disabilities, as having “clean brains” (p. 59). To summarize the complex negative effects of this stigmatization, Gharibeh (2009) said, “The vicious cycle of disability and poverty leads to secondary adverse effects on mental health if not secondary mental health disability” (p. 71).

The Arabic phrase for special education is talim al mu’aqeen. Talim relates to education or learning. Mu’aqeen is the plural of the pejorative word mu’aq. Therefore, when special education is discussed in Arabic and interpreted by Arab Americans in the U.S. it has derogatory associations. As discussed in Chapter 3, this terminology was relevant for some participants in this study in terms of their negative mental associations with special education. The next section explores different conceptualizations and beliefs in the Arab world about the causes of disabilities.

Etiology. In the Arab world, disabilities can be understood not only in a pure medical model but also as a plan from God (Crabtree, 2007c). They can also be perceived to be caused by jinn, or supernatural beings (Atshan, 1997). Similarly, several ethnographies conducted in the Arab world (e.g., Dorsky, 1986) include reports from informants who cite the evil eye as a cause of mental and physical illness. Naggar Gaad (2004) identified a tendency in the Arab world to perceive disabilities, especially what he called mental disabilities, as contagious to others including a pregnant woman’s fetus.

These beliefs also relate specifically to mental illness. In the Arab world, individuals tend to have different views of emotional and mental disorders than in the
Ahmead, Rahhal, and Baker (2010) found mental health professionals in the region were divided between medical and psychological understandings of the causes of mental illness. Some explanations for mental illness include it being a test from God (Al-Krenawi & Graham, 2011). Some supernatural explanations are also provided, such as the evil eye, witchcraft, and possession by jinn (Abdel-Latif, 1989; Al-Adawi et al., 2002; Al-Krenawi & Graham, 2011; Dwairy, 2006; Morsy, 1993; Sanua, 1979). Those who are most vulnerable to curses from the evil eye are children; pregnant women; and individuals with extreme beauty, fortune, or happiness (Kulwicki, 1987). Jinn could come to possess an individual and cause mental illness if the individual or his or her family member committed a sin or lost faith in God (Dwairy, 2006; Kulwicki, 1996).

Mu’aq seems to be the more formal term when describing disabilities including mental illness. Its colloquial equivalent is jinnoon. Jinnoon is also used at times to describe chronic disorders like intellectual disabilities, neurotic disorders, and psychotic disorders (Dwairy, 2006). The term is related etymologically with the word jinn. An individual with a mental illness or intellectual disabilities is called majinnoon, meaning someone who is possessed by jinn. This terminology and its association with evil spirits further illustrate how the language reflects cultural beliefs. It also demonstrates the opposite: that the language continues to reinforce this cultural belief system. Given the available terminology in Arabic to describe different disabilities, it can be understood how the words carry such stigmatization in the region. In the next section, this stigmatization and other negative consequences of disabilities are discussed.
Consequences and stigma. There is a general lack of published literature on disabilities and families in the Arab world (Crabtree, 2007c). The stigma of disabilities in the region has been well documented, however (Al-Kandari & Al-Qashan, 2010; Al Thani, 2006; Boukhari, 1997; Wehbi & Lakkis, 2010). Prospects for individuals with disabilities and their families are diminished by the disabilities (Crabtree, 2007a). In the Arab world—including the United Arab Emirates (U.A.E.), where Crabtree (2007a) conducted her research—men are allowed in Islam to marry multiple times. Therefore, some mothers in Crabtree’s (2007a) research hid their children’s disabilities for fear that they would be repudiated and divorced. They also worried that their husbands would be allowed to take second wives due to childbearing issues, which tend to be blamed on mothers (Crabtree, 2007a).

These negative social implications of disabilities extend to siblings, especially sisters, who tend to face diminished marriage prospects (Turmusani, 2003; Young, 1997). As a result, family members with disabilities might simply be kept hidden from the public (Al-Kandari & Al-Qashan, 2010; Boukhari, 1997). Wehbi and Lakkis (2010) found that for this reason, some births of disabled daughters in Lebanon were never officially registered in municipal records.

Mental illness is seen as a cultural and religious taboo, as a sign of weakness, and as a source of shame. This is because it is believed that one cannot become mentally ill if he or she has been properly following religion (Hammoud, White, & Fetters, 2005). Similar to Gharaiibeh’s (2009) summary above, Peters (2009) noted that in the Arab
world, “Culturally embedded attitudes render the severity of an impairment inconsequential compared to the social consequences of disablement” (p. 9).

It is generally unusual to encounter an individual of any age with a disability in public in the Arab world (Crabtree, 2007b; Reilly, 2011). This could be associated with the stigma described above, as well as with the lack of handicapped-accessible facilities and transportation. One consequence of this invisibility is the general disregard of individuals with disabilities as important members of society (Reilly, 2011). Crabtree (2007b) interviewed parents in the U.A.E. who had negative experiences due to strangers’ intolerance and ignorance toward their children with disabilities. In one case, an *imam* (a Muslim religious leader) told parents that their child should be confined to the home and should not be seen in public (Crabtree, 2007b). Another participant reported that a mother had pulled her daughter away from the participant’s son—who had a physical disability—and chastised her daughter to stay away from him because he was “dangerous” (Crabtree, 2007b, p. 57). School psychologists working with Arab Americans require knowledge about these consequences and the cultural stigma around disabilities. Additionally important to understand are the potential conflicts relating to counseling cross-culturally with Arab Americans, which are discussed next.

*Counseling.* School psychologists are responsible for helping students succeed in several ways, including emotionally and socially (NASP, 2006). Mental health is a core component of school psychology, as school psychologists are trained to connect students’ mental health to their learning and behavior (NASP, 2006). As described in the next section on special education in the U.S., students who have a mental illness and whose
academic performance is negatively impacted by it can qualify for special education. Some students in special education with identified mental illnesses may be eligible for mental health services and interventions from school psychologists including: screenings for emotional disturbances, functional behavioral assessments, social skills instruction, student or family referrals to community mental health agencies, and small group or individual counseling (NASP, 2006).

In the U.S., the field of counseling is rooted in the White/Western majority culture (Sue & Sue, 1999; U.S. Department of Health and Human Services, 2001). This can cause problems when mental health professionals attempt to apply established normative group-based theories to clients from different cultural backgrounds and tend to overlook cultural, ethnic, and linguistic diversity (Constantine, 2001). There is a body of school psychology literature regarding cross-cultural competencies (e.g., Frisby & Reynolds, 2005; Tomes, 2011) so professionals can avoid misinterpretations and improper behavioral responses, as well as demonstrate verbal and nonverbal communication skills that are culturally sensitive.

The literature explains that there can be differing conceptualizations of counseling held in the Arab world as compared to the U.S. Although some services such as behavior therapy and family therapy are provided, psychotherapy is generally not available (Lambert, 2008). In fact, seeking mental health services is generally seen as a sign of weakness or insanity so many people in the Arab world do not seek assistance of their own volition (Al-Busaidi, 2010; Lambert, 2008). The most common mental health
interventions in the Arab world are actually from psychiatrists who dispense medicine (Ibrahim & Ibrahim, 1993).

In the Arab world, expectations of a mental health professional and the counseling relationship can differ (Sayed, 2003). A psychologist is expected to be authoritative and teacher-like and is viewed as omnipotent in relationship to the passive client (Al-Krenawi & Graham, 2000; El-Islam, 2008; Sayed, 2003). Understandably, this could complicate Western psychologists’ or counselors’ expectations of collaboration during counseling with Arab American clients. This could then render talk therapy ineffective because the clients might think that they must provide expected answers (Buda & Elsayed-elkhoully, 1998; Sayed, 2003). It could also be difficult for an Arab American client to work with a mental health professional of the opposite sex (Hall & Livingston, 2006).

There can be limitations to Western-style counseling as a treatment for mental illness with Arab Americans. Mental health services are sometimes negatively regarded because of fears of family disloyalty by exposing personal issues to non-family members (Dwairy, 2006; Nobles & Sciarra, 2000; Sayed, 2003). In other words, speaking negatively and disclosing unflattering facts about oneself and one’s family is not culturally respectable and results in a lowered reputation (Nydell, 2012). Therefore, clients may be uncomfortable and ashamed to discuss personal and familial mental illness, abuse, and sexual activities (El-Islam, 2008; Hall & Livingston, 2006). Some Arab Americans may worry that their decision to seek extra-familial mental health assistance could be stigmatized or that their secrets could be divulged to others in the community (Youssef & Deane, 2006).
Some research in the Arab world has revealed preference for mental health treatment from traditional and religious leaders (Al-Krenawi & Graham, 2011). This could be because these leaders live within the local community, have similar worldviews, make no diagnoses, and utilize brief spiritual treatments (Al-Krenawi & Graham, 2011). The above explanations of the cultural conceptualization and implications of disabilities are important for school psychologists to know when working with Arab American students. These students are discussed next.

**Students**

The student population in the U.S. includes a significant number of Arab Americans (Goforth, 2011; M. F. Suleiman, 2001). School psychologists working with Arab American students and their families must be aware of specific considerations: (a) the learning environment for Arab American students; (b) issues specific to Arab American students in special education; and (c) the experiences of recent Arab American immigrants in U.S. schools regarding language, adjustment, and the status of special education in the Arab world. A discussion of these aspects follows below.

**Learning Environment**

Since September 11, 2001, reports of prejudice and discrimination against Arab Americans have increased (Ibish, 2003). Several factors contribute to the subordination of Arab Americans. They include violence (racial hatred and patriotic fervor), marginalization (based on government policies), and culturalized imperialism (messages that Arabs are enemies of freedom; Abu El-Haj, 2006).
Within the school setting, knowledge of the Arab culture has been lacking, stereotypical or incorrect, which causes Arab American adolescents to feel alienated and misunderstood (Adeeb & Smith, 1995; M. F. Suleiman, 2001). For example, Abu El-Haj (2007) researched Palestinian American high school students and found their identities to be affected by negative messages they received post-9/11 about Arabs and Arab Americans. The students recounted tensions they experienced in school, such as teacher harassment and being portrayed as terrorists (Abu El-Haj, 2007). Similarly, Ayish (2003) found that Arab American Muslim high school students were highly visible in negative ways in the overall American culture and in the school curriculum. These high school students felt disconnected from their peers, school, and society (Ayish, 2003).

Importantly, students’ academic achievement is influenced by their perceptions of their self-worth (Hamacheck, 1995). This can result in cultural conditioning of Arab Americans’ self-image, meaning that the majority group’s negative assumptions about Arab Americans diminish their success and participation in society and in the classroom (M. F. Suleiman, 1996). In one study, Arab American adolescent students’ scholastic competence was significantly related to their experiences of discrimination, while their self-concepts were significantly related to self-perceived classmate support (Tabbah, Miranda, & Wheaton, 2012). Additionally, Arab American students’ academic achievement and social adjustment were identified to be largely based on their self-perceptions of their abilities and self-worth (Al-Khatab, 1999). For those Arab American students who are Muslim, there can be a general lack of knowledge among
teachers about Islam and negative reactions to the religion (Mastrilli & Sardo-Brown, 2002).

Within the classroom, certain discussions might bring complicated social issues to the surface. The school climate in the U.S. is currently one in which Arab American students are often uncomfortable arguing or expressing opinions against the mainstream lest they be labeled as terrorists or unpatriotic (Giroux, 2002). Further, Arab American students can experience imperative patriotism, which is the feeling that dissent related to the U.S. government and its foreign affairs is unpatriotic and therefore unfavorable (Salaita, 2005). Arab American students can feel like they are living in double exile, which occurs when an individual feels alienated living within both the diaspora and one’s homeland, never truly fitting in (Said, 1984).

Unfortunately, it is unusual for Arab American students to encounter a story in public school that validates their Arab culture (Al-Hazza & Bucher, 2008). In fact, even before September 11, 2001, many educators were unaware of the Arab American students in their classrooms (Nieto, 2003). Afterward, Arab American students frequently faced discrimination (e.g., Abu El-Haj, 2006; Ghaffar-Kucher, 2009). However, it has been found that implicit negative attitudes in the classroom toward Arab American students can be moderated when the class is exposed to positive material about Arab Americans (Park, Felix, & Lee, 2007).

The above material is included to illustrate the challenges that are unique to Arab Americans within school settings. The following section discusses special education in U.S. schools, as well as issues specific to Arab American students in special education.
Special Education in the U.S.

Special education is defined by the U.S. Department of Education (2004) as:
Specially designed instruction, at no cost to the parents, to meet the unique needs
of a child with a disability, including (a) instruction conducted in the classroom,
in the home, in hospitals and institutions, and in other settings; and (b) instruction
in physical education. (p. 118)

The Individuals with Disabilities Education Act (IDEA) addresses special education and
was last amended by Congress in 2004, when it was renamed the Individuals with
Broadly, IDEA guarantees services to children with disabilities throughout the U.S.
Additionally, it governs early intervention, special education, and related services to
individuals with disabilities who are aged birth to two or age three to 21 (U.S.
Department of Education, 2006).

The process of identifying a child with one of the disabilities that falls under
IDEA is essentially a labeling process. The value of such labels has been debated (e.g.,
McDermott, Goldman, & Varène, 2006). While the philosophical underpinnings of
such debates are complex and beyond the realm of this study, it is generally agreed upon
that ultimately these labels identify students’ abilities and needs to allow them access to
necessary special education services (Watson, 2008).

There are two routes for students to be identified as eligible for special education
services. The first route is a process that occurs entirely within the school and utilizes
special education law and state guidelines to determine whether a student has a disability
and qualifies for special education services (U.S. Department of Education, 2004). As outlined later in this section, the process to determine eligibility for special education services through this route typically includes a referral for a comprehensive evaluation, an evaluation, and, if determined eligible, an identification of a specific disability that requires special education services (U.S. Department of Education, 2004). Eligibility is indicated when both (a) the child appears to meet the criteria of a specific disability as defined by IDEA (as interpreted by the state in which the child resides), and (b) the disability appears to have an adverse impact on the student’s performance in school, thereby necessitating special education services (U.S. Department of Education, 2004).

The second route to determine special education eligibility occurs partly outside of the schools when a health or mental health professional conducts an evaluation and makes a medical or clinical diagnosis, which is then shared with the school’s evaluation team (U.S. Department of Education, 2004). However, the clinical or medical diagnosis alone does not provide automatic access to special education and related services in the school setting because no single assessment or measure can be utilized to determine if the student has a disability requiring special education (U.S. Department of Education, 2004). Instead, the school evaluation team considers the medical or clinical diagnosis along with the student’s other assessment data (U.S. Department of Education, 2004). It is at this point that the process shifts from being a medical or clinical process to a legal one. As described above, the school’s evaluation team must determine if the student’s performance in school is negatively affected by the disability (U.S. Department of Education, 2004). If the evaluation team determines that this might be occurring, the
student is evaluated for special education eligibility (U.S. Department of Education, 2004). At this point the steps from the first route are followed. Namely, the evaluation team must determine that the student has a disability that is (a) one of the 13 disabilities included under IDEA and (b) negatively affecting the student’s performance in school (U.S. Department of Education, 2004). If this is determined, the student is identified as eligible for special education services (U.S. Department of Education, 2004).

As explained by the U.S. Department of Education (2004), the 13 categories of disabilities that fall under IDEA are the following:

- Deaf-blindness: The combination of hearing and visual impairments that adversely affects a child’s educational performance (U.S. Department of Education, 2004).
- Deafness: “A hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without

- Emotional disturbance: This term includes schizophrenia and does not refer to social maladjustment (U.S. Department of Education, 2004). It requires a student to demonstrate at least one of the following conditions to a marked degree and over a long period of time that adversely affects his or her educational performance (U.S. Department of Education, 2004, pp. 12-13):
  
  (a) An inability to learn that cannot be explained by intellectual, sensory or health factors.
  
  (b) An inability to build or maintain satisfactory interpersonal relationships with peers and teachers.
  
  (c) Inappropriate types of behavior or feelings under normal circumstances.
  
  (d) A general pervasive mood of unhappiness or depression.
  
  (e) A tendency to develop physical symptoms or fears associated with personal or school problems.

- Hearing impairment: “Impairment in hearing, whether permanent or fluctuating, that adversely affects a child’s educational performance, but that is not included under the definition of deafness” (U.S. Department of Education, 2004, p. 13).

- Multiple disabilities: Impairments that occur simultaneously, “the combination of which causes such severe educational needs that they cannot
be accommodated in special education programs solely for one of the impairments. Multiple disabilities does not include deaf-blindness” (U.S. Department of Education, 2004, p. 13).

- Orthopedic impairment: A severe orthopedic impairment that adversely affects a child’s educational performance (U.S. Department of Education, 2004). It is caused by a congenital anomaly, disease, and other causes such as cerebral palsy (U.S. Department of Education, 2004).

- Other health impairment: “Having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment” (U.S. Department of Education, 2004, p. 13). This adversely affects a child’s educational performance and can be the result of Attention-Deficit/Hyperactivity Disorder Hyperactivity Disorder (ADHD), asthma, epilepsy, diabetes, and several other conditions (U.S. Department of Education, 2004).

- Specific learning disability (SLD): A disability “in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, that may manifest itself in an imperfect ability to listen, think, speak, read, write, spell or to do mathematical calculations” (U.S. Department of Education, 2004, p. 13).

- Speech or language impairment: “A communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice

- Traumatic brain injury: “An acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that affects a child’s educational performance” (U.S. Department of Education, 2004, p. 13). Such an injury impairs “one or more areas, such as cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech” (U.S. Department of Education, 2004, p. 13).


IDEA requires that students suspected of any of the above categories of disabilities be evaluated according to the following: (a) a variety of appropriate assessment tools and strategies to measure the student’s functional, developmental, and academic skills; (b) a reliance on more than just one measure as the criterion to determine a disability or educational plan; (c) a combination of assessment materials to explore factors such as the student’s cognition, behavior, physical abilities, and development (U.S. Department of Education, 2004). Further, the assessment materials as a whole must be: (a) nondiscriminatory; (b) in the student’s native language or other appropriate mode
and in a manner that best measures the student’s academic, developmental, and functional abilities; (c) valid and reliable; (d) administered by trained personnel according to the instructions provided by the assessment’s producer; (e) capable of assessing the student in all areas appropriate to the suspected disability including health, vision, hearing, social and emotional skills, general intelligence, academic performance, communication, and motor abilities; and (f) able to accurately measure the student’s skills despite any sensory, manual, or speaking impairments (U.S. Department of Education, 2004). Finally, any identified disability must not be the result of the student’s limited English proficiency or receipt of inappropriate instruction in reading or math (U.S. Department of Education, 2004).

As part of the reauthorization of IDEA in 2004, provisions for the identification of an SLD were also outlined. These provisions require the state to make one of the following determinations when identifying an SLD: (a) the student has not made progress to reach age or grade-level standards in at least one of eight skill areas (e.g., oral expression, listening comprehension, written expression, basic reading, reading fluency, reading comprehension, mathematics calculation, and mathematics problem solving) in response to scientific, research-based intervention; or (b) the student’s achievement or intellectual abilities meet a pattern that is determined by the evaluation team to indicate an SLD (U.S. Department of Education, 2004). Before identifying an SLD, the evaluation team must determine that the findings are not primarily the result of a visual, hearing, or motor disability; mental retardation; emotional disturbance; cultural factors; environmental or economic disadvantage; or limited English proficiency (U.S.
Department of Education, 2004). To ensure that the student’s underachievement is not due to inappropriate math or reading instruction, the evaluation team must establish that the student was instructed in a general education setting by qualified educators and that repeated achievement assessments were made (U.S. Department of Education, 2004). These results must have been provided to the student’s parents (U.S. Department of Education, 2004).

The reauthorization of IDEA does not require that an SLD be identified based on a discrepancy between the student’s achievement and intellectual abilities (U.S. Department of Education, 2006). Additionally, states may select to utilize a process to determine if the student responds to scientific, research based interventions (U.S. Department of Education, 2006). Such interventions are often termed *Response to Intervention (RtI)*, which is a method of early intervention for students who show difficulty learning (Johnson, Mellard, Fuchs, & McKnight, 2006). RtI is also a means to measure student data and utilize the data to form instructional determinations (Mellard, Byrd, Johnson, Tollefson, & Boesche, 2004).

Following IDEA’s reauthorization, the current process of identifying a student with an SLD has been described as being “in transition” because school psychologists tend to vary in their primary identification methods (Unruh & McKellar, 2013, p. 353). One recent study reported that a sample of school psychologists tended to use one of only two methods of SLD identification (Unruh & McKellar, 2013). A slight majority of the group reported primarily using the discrepancy model, which is an example of a pattern that can be determined by the evaluation team to identify an SLD (Unruh & McKellar,
The discrepancy model typically includes a statistically significant difference between the student’s intellectual and achievement abilities, however that difference varies by states’ SLD eligibility guidelines (McKenzie, 2009).

Fewer participants in Unruh and McKellar’s (2013) research reported primarily using RtI data, which is the result of scientific, research-based interventions described above. RtI is not a diagnostic process to identify disabilities, although it is used in such a manner in several areas (McKenzie, 2009). Instead, it is a screening measure to identify learning difficulties and to indicate the need for a comprehensive evaluation (Kavale & Spaulding, 2008). Briefly, RtI begins with school-wide screenings of all students (primary prevention; Johnson et al., 2006). Those students who score below a cut-off point receive a screening to predict which of the students are at risk for poor learning results (Johnson et al., 2006). They receive more individualized interventions such as small-group instruction (secondary prevention) in addition to the core instruction (Johnson et al., 2006). Students who do not improve from these interventions move on to more intensive and individualized supports (tertiary prevention; Johnson et al., 2006). Students who do not respond to intensive and individualized supports or do not make appropriate progress require further assessments by the evaluation team to explore the presence of different learning needs (Kavale & Spaulding, 2008). Those students who fail to respond at the tertiary level of support may be referred for a multifactored evaluation to determine eligibility for special education and related services. Finally, tertiary interventions, or special education, are designed to provide scientifically based instruction to address individual student needs (Johnson et al., 2006).
As Unruh and McKellar (2013) found, school psychologists hold different opinions when comparing methods to identifying an SLD. The debate on the issue has been described as being essentially between the utilization of RtI data and the discrepancy model (Callinan, Cunningham, & Theiler, 2013). However, McKenzie (2009) argued, “the evaluative structures within RtI and traditional SLD determination can not only coexist, but can also enhance earlier identification of underachievement” (p. 214). Despite the debate, all professionals can agree that students with an SLD should be identified as early as possible to receive the appropriate remedial instruction (Callinan et al., 2013).

Under IDEA, Congress requires each state to provide parents with a notice of procedural safeguards to explain their rights to them when their child is initially referred for a special education evaluation (U.S. Department of Education, 2006). This notice includes descriptions of the following: the law under IDEA, how a parent can collaborate with the local school district to determine if a student has a disability, the steps that are involved in the determination, and whether the disability qualifies the student for special education and related services (U.S. Department of Education, 2006). Each state can individualize its notice and add content as long as the required content is included and unchanged (U.S. Department of Education, 2006).

The Ohio Department of Education, Office for Exceptional Children (ODE/OEC) prepared Ohio’s procedural safeguards notice (ODE/OEC, 2012). The notice outlines the process of determining if students require special education. Briefly, the steps of this process are:
• Parents or the school can make a formal request for assistance if there is suspicion that a student has a disability (ODE/OEC, 2012). This step is referred to as the referral for an evaluation for special education eligibility (ODE/OEC, 2012).

• Parents are invited to participate in an Intervention Assistance Process, in which a team of school staff members (i.e., the student’s teacher(s), school administrator, school psychologist, and speech language pathologist) determines if the student has been responding to classroom interventions or if additional information is needed (ODE/OEC, 2012). This information could include a screening, observation, or interview (ODE/OEC, 2012). Parent permission is required before collecting this additional information (ODE/OEC, 2012).

• After additional information is collected, the evaluation team determines whether a formal evaluation for special education is required (ODE/OEC, 2012). Parents must approve this formal evaluation plan before it can be conducted (ODE/OEC, 2012).

• Once the evaluation is complete, parents are invited to review the results with the evaluation team and the team determines if the student has a disability that requires special education (ODE/OEC, 2012). The parents can agree or disagree with the team’s decision (ODE/OEC, 2012).

• If the student is identified with a disability that requires special education services, parent permission must be obtained before proceeding with the
development of an Individualized Educational Plan (IEP; ODE/OEC, 2012).

Once parents grant permission, the IEP is developed and the student begins receiving special education (ODE/OEC, 2012).

- Once services begin, the student’s progress is measured and reported to parents and there is a regular triennial reevaluation to determine if he or she still requires services (ODE/OEC, 2012).

It is important to note that this entire process cannot proceed without parental permission and that ultimately parents make the decision of how far along through the process they allow their child to advance. As explained above, a medical doctor or psychologist first diagnoses a student with a disability, which does not automatically mean the student is eligible for special education services (ODE/OEC, 2012). Instead, the student’s parents take the diagnosis to the school’s evaluation team who then determine if the student’s performance in school could be negatively affected by the disability (ODE/OEC, 2012). If they believe that this could be the case, a formal referral for evaluation for special education eligibility is made (the first step in the list above) and the above steps are then followed (ODE/OEC, 2012).

The IEP is a written document that outlines the educational goals and objectives for a student with a disability (ODE/OEC, 2012). ODE/OEC (2012) requires the following information to be included in each IEP:

- Information about the student’s future
- The student’s current learning and functioning abilities
- Short-term objectives to meet the student’s annual goals
Special education services and any *supplementary aids, related services, or accommodations* to help the student with the following:

- Meet their annual goals
- Participate in the general curriculum and school activities
- Learn with other students with and without disabilities

The three terms from above—supplementary aids, related services, and accommodations—should be briefly defined. *Supplementary aids* include supports and services that enable students with disabilities to participate as much as possible in the general education curriculum (ODE/OEC, 2012). *Related services* include physical and occupational therapy, speech-language pathology services, and psychological services (ODE/OEC, 2012). *Accommodations* are made in the student’s assessments, presentation of material, response style, location of instruction, and timing and scheduling of instructional activities (ODE/OEC, 2012).

IDEA mandates that each student with a disability be educated in the least restrictive environment (LRE), which is first considered to be a general education setting with the use of supplementary aids and services so students with disabilities can be educated to the greatest extent possible alongside their peers without disabilities (U.S. Department of Education, 2004). In such a setting, students with disabilities can benefit by interacting with and observing peers, gaining social support, and developing social cognition (Guralnick, Connor, Hammond, Gottman, & Kinnish, 1996; Jenkins, Odom, & Speltz, 1989; Kochhar, West, & Taymans, 2000). Separate schools and classes are utilized only when the severity or nature of the students’ disabilities interfere with the
educational process such that supplementary aids and services in the general educational setting are inadequate (U.S. Department of Education, 2004). ODE/OEC (2012) requires that IEPs reflect this mandate, seeking to maximize the students’ education in the LRE. IEPs are then updated each year in an IEP Team meeting with the school staff and the student’s parents (ODE/OEC, 2012).

IDEA also mandates that parents of students with disabilities are full members of their children’s educational team (U.S. Department of Education, 2006). Their participation is highly valued and encouraged in drafting IEPs (U.S. Department of Education, 2004). The success of special education services is often influenced by parents agreeing to support the process; if they are unsupportive it can negatively affect the success of the services (Plunge & Kratochwill, 1995).

Based on the existing literature about the Arab American culture, it can be deduced that some cultural differences might affect Arab American parents’ reactions to the special education evaluation process. Unfortunately, there are no specific figures on the prevalence of Arab American students in special education (Abadeh, 2006). However, the literature does suggest specific hurdles that could arise for Arab American parents during their children’s referrals for special education eligibility evaluation and identification with disabilities requiring special education.

For example, one hurdle might be the differing concept of intelligence that can exist between Arab Americans and Westerners (Nisbett, 2003). Differing perceptions of the nature, causation, and treatment of disabilities will affect parents’ responses to the intervention process and the services assigned to their children (Diken, 2006). Therefore,
school psychologists might experience contrasting conceptualizations of disabilities and responses to interventions when working with Arab American parents.

An additional hurdle in the evaluation process could be the different attitude among Arab American parents toward children’s independence skills. As mentioned, the Arab American culture typically has differing expectations for children’s independence (Abu-Hilal & Bahri, 2000). Therefore, Arab American parents might not yet have introduced or encouraged certain skills (e.g., dressing, critical thinking, etc.) at the time of a special education evaluation. However, school psychologists might consider any lack of such skills as an indicator of developmental delays although the cause might simply be a lack of encouragement or instruction.

A final hurdle in the evaluation process could be that Arab American parents might refuse special education evaluation referrals for their children. This could occur for several reasons. One reason could be that the parents are experiencing a set of feelings of guilt and shame due to their perceptions of the cultural, religious, and social significance and stigma of the diagnoses (Sharifzadeh, 1998). Parents’ reluctance or refusal for evaluations could ultimately be related to the cultural stigma around disabilities (Haboush, 2007).

In the following section, students who are recent emigrants from the Arab world are discussed. Also included are specific challenges they might face related to language and school adjustment in the U.S. The students’ and their parents’ potential perceptions of special education are reviewed.
Recent Immigrants

Students moving from the Arab world to the U.S. will likely encounter some issues relating to language, adjustment, and differences in the status of special education. Although these topics will not pertain to all students from the Arab world, school staff including school psychologists would be wise to consider these issues. Included in this section are the following issues: (a) acquisition of and communication in English for Arabic native speakers, (b) adjustment issues within a culture that stresses independence over interdependence, and (c) differing conceptions of special education, which is practiced much differently in the Arab world than it is in the U.S.

Language considerations. Arabic is a phonetic language comprised of eight vowels and 32 consonants and it is read from right to left (Kwilinski, 1998; Wilson, 1996). There are actually three varieties of Arabic: Classical Arabic is the written form that is original to the Quran, the Islamic sacred book, and dates back more than 1,000 years. This classical form is used in writing and formal settings like lectures and news broadcasts. Colloquial Arabic is spoken in daily life and in films. Due to the large size of the Arab world, there are many dialects and sub-dialects of Colloquial Arabic—some which are as divergent from each other as are Spanish and Italian—such that someone who speaks one dialect of Colloquial Arabic may not understand a speaker of another dialect. Formal Spoken Arabic is similar to Classical Arabic but is spoken with the local dialect’s structure and used as a common language between Arabic speakers who do not speak the same dialect of Colloquial Arabic (Nydell, 2012). Classical Arabic is quite difficult to learn due to its grammar and large vocabulary, and even after six years of
education the Arabic speaker may still be functionally illiterate (Wilson, 1996). In schools with Arab American students who are recent immigrants, professional development related to the following topics has been recommended: (a) effective instructional practices regarding students transitioning from Arabic to English, (b) the cultural aspects of Arabic, and (c) a brief analysis of its composition (Palmer, El-Ashry, Leclere, & Chang, 2007). This information would allow school staff to understand the adjustment of the students to the English language and to school in the U.S.

**Adjustment.** Arab American students who are recent immigrants might behave in ways that are more common in the Arab world. The region is described as having a collectivist and interdependent culture (Dwairy, 2006; Gregg, 2005). Similarly, schools in the Arab world emphasize cooperation and sharing in class work (Buda & Elsayed-elkhouly, 1998; Wilson, 1996). Teachers in the U.S. might therefore be surprised when Arab American students prefer to collaborate on work assignments rather than work individually.

Additionally, the culture of the Arab world is largely dependent on negotiation and personal connections (Kwilinski, 1998). It would not be unusual for a student recently emigrated from the Arab world to utilize these techniques with people in authority. For example, they may perceive a final grade as something to be negotiated and ask for assistance with improving their grade, or they may view their grade as temporary until they can negotiate a more favorable grade (Wilson, 1996). Lambert (2008) explained this culture of negotiation most succinctly: Arab American “students are unfamiliar working within a system of uniformly applicable rules, and most familiar
operating in an environment of benefaction, partiality, and *wasta* [the use of personal connections and favors to navigate through bureaucracy]” (p. 105).

Schools in the Arab world are more autocratic and its students are not socialized to be independent (Abu-Hilal & Bahri, 2000). At home, children in the Arab world are also raised in a generally authoritarian setting (Dwairy, 2006). In the U.S., students who are recent emigrants from the Arab world might have different expectations of school. For example, they might expect the same emphases that they experienced during their schooling in the Arab world: memorization, compliance to authority, and listening rather than creating (Dwairy, 2006; Wilson, 1996). The students could struggle, therefore, when expected to debate ideas and question authority in the schools (Haboush, 2007). Further, they might initially demonstrate immature or dependent behavior due to moving away from the authoritarian culture and losing their social compass (Hakim-Larson et al., 2007).

Students and their parents who are recent emigrants from the Arab world might experience confusion or strong reactions to special education in the U.S. Their reactions could relate to their knowledge of special education practices based in the Arab world. The state of special education in the Arab world is currently undeveloped, which is discussed in the next section (Amr, 2011; Bradshaw, Tennant, & Lydiatt, 2004).

**Status of special education in the Arab world.** Students who are recent emigrants from the Arab world are likely unfamiliar with special education as it exists in the U.S. Across the Arab world, there is a widespread lack of special education services. Students with disabilities are often not educated due to an absence of special education
services and due to the tendencies of both public and private schools to refuse admission (Amr, 2011; Bradshaw et al., 2004). For the minority of students with disabilities who do get an education, it is often in residential institutions or separate schools (Bradshaw et al., 2004; Wehbi & Lakkis, 2010).

Countries in the Arab world have differing special education services in place, as illustrated by the following examples from four countries in the Arab world. In the U.A.E., Crabtree (2007b) explained, special education can be “a valued, but for many unreachable, commodity, where the majority of schools have yet to adapt their curriculum and teaching methods so as to be more accessible to a special needs population” (p. 60). Inclusion of students with disabilities into mainstream U.A.E. schools is typically limited to expensive expatriate private schools (Crabtree, 2007b). However, special education has been described as an issue of concern to U.A.E. policy makers and advocates (Khamis, 2007). In Lebanon, private schools can reject students with disabilities so the majority instead enrolls in separate institutions (Arab Resource Collective, 2006). Only 20 schools in the country accept children with disabilities (Arab Resource Collective, 2006). In Egypt, it is well known that individuals with intellectual disabilities are not provided proper education (Gobrial, 2012). Until quite recently, children with intellectual disabilities and Down’s syndrome in Egypt were confined to their homes (Gaad, 2004). In fact, when these children were allowed to attend special segregated schools, their parents were found to be so pleased that their children could attend school at all that they did not contest the segregation (Gaad, 2004). Finally, in Kuwait there are no teacher education programs in learning disabilities (Bazna & Reid,
Research found that teaching assistants at a special needs school in Kuwait had previous knowledge of only physical types of disabilities (Bazna & Reid, 2009). Given these examples, it is easily understood why the process of inclusion in schools in the Arab world has been described as being in its infancy (Gaad, 2004; Khochen & Radford, 2012). In Egypt, inclusion is considered by many parents and teachers to be something that is only done internationally (Gaad, 2004). Teachers, both in Egypt and in the U.A.E., reported overwhelmingly negative opinions on the inclusion of children with intellectual disabilities (Alghazo & Naggar Gaad, 2004; Gaad, 2004). Opinions on inclusion are driven largely by cultural beliefs and values (Gaad, 2004). Gaad emphasized the importance of analyzing cultural attitudes toward individuals with disabilities “if one is to examine the extent to which including disabled students in the mainstream is currently accepted, criticized, rejected or applied” (p. 314). Such an examination in the Arab world would undoubtedly yield a preponderance of negative attitudes. This is discussed further in the next section on related research, which includes cross-cultural beliefs and perceptions of disabilities in the Arab world. The next section also addresses other research related to this study, such as supports for parents of children with disabilities and parent-school communication.

Related Research: Parents of Children With Disabilities

The small size of the published literature regarding special education with Arab Americans or even with Arabs in the Arab world becomes quickly apparent to anyone who attempts to learn more about the topic. While Haboush’s (2007) article is helpful in informing school psychologists about some commonalities among Arab Americans, the
most readily available information in the social sciences about Arab Americans relates to counseling (e.g., Abu-Ras, Gheith, & Cournos, 2008; Dwairy, 2006; El-Islam, 2008; Gregg, 2005; Hakim-Larson et al., 2007; Hall & Livingston, 2006; Lambert, 2008; Moradi & Hasan, 2004; Nassar-McMillan & Hakim-Larson, 2003; Nobles & Sciarra, 2000; Sayed, 2003). However, these sources do not inform school psychologists on the intricacies of the following Arab American parental attitudes about a student’s: (a) initial referral for an evaluation, (b) identification with a disability requiring special education, and (c) participation in special education. Additionally, there is a lack of information about the following relating to Arab American parents: (a) perceptions of their children’s disabilities and needs, (b) supports relating to special education and disabilities, (c) perspectives on advocacy, (d) parent-school communication, and (e) goals and expectations for their children. This study contributes to the field by researching Arab American parents’ experiences with and understanding of the special education process, as well as the topics listed above that have been otherwise undocumented.

This research project utilized a phenomenological qualitative approach to illuminate the experiences of Arab Americans parents who have interacted with the special education system on behalf of their child. While there have been a few phenomenological studies that explore psychological and educational experiences of Arab Americans (e.g., Arab American students’ identity formation: Ahmed, 1998; Ajrouch, 2000, 2004), there has been no prior phenomenological research with Arab American parents and there is no singular study that can directly inform this study.
Therefore, the core areas of this research study are broken down to allow for easier comparison to related studies unrelated to Arab Americans. Altogether, the themes of the published literature that inform this study relate to all parents of children with disabilities. The themes include: (a) parental beliefs and understandings of children’s disabilities, (b) the impact of children’s disabilities on parents, (c) parent supports, (d) parent advocacy, (e) parent-school communication, and (f) parents’ goals and expectations for their children. Grouped together, the literature described below provides a more substantial foundation of related research within which to situate this study.

**Parental Beliefs and Understandings of Children’s Disabilities**

The process through which parents learn about their children’s disabilities has been described as a time of crisis (Hatton, Akram, Robertson, Shah, & Emerson, 2003). During the process, which has also been called disclosure, a parent is confronted with his or her child’s disability and needs (Hatton et al., 2003). The diagnosis (or disclosure) process—and in the context of the school setting, the identification process—ultimately initiates parents into a new world with “new rules, barriers, requirements, decisions, and even a new language” (Bingham, Correa, & Huber, 2012, p. 372).

This disclosure process has not been well researched (Bingham et al., 2012). The limited research on the topic has identified several common parental reactions during the process including: denial, the feeling of being overwhelmed, fear, frustration, isolation, guilt, and other negative emotions (Graungaard & Skov, 2006; Hatton et al., 2003; Hess, Molina, & Kozleski, 2006; Ho & Keiley, 2003). Russell (2003) noted that after parents enter into this new world, “Emotionally many will need support to adjust to their new-
found situation and the continued care of their child” (p. 144). Parents will also need to learn about their children’s diagnoses and the support services available to them (Russell, 2003).

As a result of the identification process, parents must reconcile the news and sometimes even mourn the loss of the future plans they had for their children (Bowlby, 1980; Leerkes & Burney, 2007; Marvin & Pianta, 1996; Moses, 1987). King et al. (2006) found some parents also consequently reconsidered their belief systems around parenting. The literature has addressed the process of parents accepting the disability diagnoses of their children, which is also described as a resolution process (e.g., Oppenheim, Dolev, Sher-Censor, Koren-Karie, & Yirmiya, 2007; Pianta, Marvin, Britner, & Borowitz, 1996). This process is necessary for professionals to consider when working with parents who are learning of their children’s disabilities and who might hold differing cultural perspectives on identified disabilities.

Professionals working with individuals from other cultures might be unaware of different culture-specific perspectives on disabilities. However, this limits professionals’ understandings of individuals’ beliefs and responses to disabilities (Kayama & Haight, 2012). Cultural factors affect parents’ beliefs on the etiology of disabilities, coping reactions, help-seeking behaviors, and expectations for their children’s social interactions (Dennis & Giangreco, 1996; Groce, 1999; Ingstad & Whyte, 1995). These beliefs also influence which physical and mental conditions are viewed as disabilities, how the disabilities are categorized, and the value assigned to individuals with disabilities (Kayama & Haight, 2012).
In addition to cultural beliefs, cultural orientations can affect how individuals consider disabilities (Hwa-Froelich & Westby, 2003). These orientations can be *independent* or *interdependent* (Hwa-Froelich & Westby, 2003). In independently oriented cultures, such as the U.S.’s majority White population, disabilities are considered to be delays in developmental areas such as cognition, motor, behavior, communication, and sensory (Hwa-Froelich & Westby, 2003). Invisible disabilities “are recognized more in cultures that are more literate and technologically advanced because these disabilities affect a person’s ability to function independently in formal, academic settings and live independent of their families as young adults” (Hwa-Froelich & Westby, 2003, p. 313). In comparison, in interdependently oriented cultures, there is a greater range of disability that is acceptable because of the cultures’ requirements for less independence (Hwa-Froelich & Westby, 2003). The Arab culture is an example of an interdependent culture (Dwairy, 2006; Gregg, 2005). Individuals with disabilities “can survive and function well in an interdependent culture because there is always someone available and willing to help a person less able to function in any setting” (Hwa-Froelich & Westby, 2003, p. 313). The prioritization of skills for individuals with disabilities, therefore, differs between the two cultural orientations. For example, in interdependent cultures parents might emphasize interpersonal skills and obedience (Hwa-Froelich & Westby, 2003). In independent cultures parents might focus instead on individuality and self-esteem (Hwa-Froelich & Westby, 2003).

Parental perceptions of disabilities have been examined cross-culturally in a small number of qualitative studies with individuals from interdependent cultures. For example
in the U.S., research on parental perceptions of their children’s disabilities found religious interpretations were made by Latino mothers (Skinner, Bailey, Correa, & Rodriguez, 1999) and South Asian Muslim parents (Jegatheesan, Miller, & Fowler, 2010). One study researched parental perceptions in the U.A.E. and found differences in perceptions that were based on the gender of the children (Crabtree, 2007c). Two additional studies compared parent perceptions across cultural orientations. For example, comparisons were made between Southeast Asian-American parents who were recent immigrants and American Head Start staff members (Hwa-Froelich & Westby, 2003), as well as between Asian British parents who were recent immigrants to the United Kingdom and White British parents (Fatimilehin & Nadirshaw, 1994). Both studies found significant patterns in cross-cultural differences between parents’ perceptions and interpretations of their children’s disabilities. Taken together, these few studies highlight the importance of culture on parents’ belief systems about their children’s disabilities.

While the above research involves parents from interdependent cultures living in the U.S. or in the Arab world, to date there has been no research with Arab American parents regarding their children’s disabilities. Although two general articles (Goforth, 2011; Haboush, 2007) exist for school psychologists working with Arab American parents and students, there are no specific suggestions for discussing and identifying disabilities with Arab American parents. Also missing are recommendations to interpret their reactions to the identification of their children’s disabilities and to understand the social impact of disabilities in Arab American culture. The following section discusses related research on the impact of children’s disabilities on parents.
Impact of Children’s Disabilities on Parents

Some research has been conducted on the impact of a child’s disability on the functioning of his or her parents. Parents caring for their children with severe disabilities may feel guilt, self-blame, depression, and helplessness (Meyerson, 1983). Some parents also experience high levels of frustration and stress (Hill, 2001; Smith, Oliver, & Innocenti, 2001). Specifically, research with parents of children with ASDs (autism spectrum disorders) found that the parents experienced more conflict, divorce, and demands than others (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003; Hodapp & Krasner, 1995). In the next section, two issues related to parent coping are explored: parent supports and advocacy.

Parent Supports

There can be many forms of support to assist parents in accepting and caring for their children with disabilities. Several types of supports are described below. Although none of these supports have been researched specifically with Arab American parents, the following review is relevant to the broader issue of parents coping with their children’s disabilities:

- *Respite care,* or short-term childcare for children with disabilities or chronic illnesses, can provide parents with direct relief, as well as benefits such as relaxation, enjoyment, stability, family unit preservation, community involvement, time off, and personal enrichment (National Information Center for Children and Youth with Disabilities [NICHY], 1996).
• **Formal family support programs** can assist parents in accepting their children’s disabilities, which in turn increases marital satisfaction, improves family life, and decreases parental stress (Blacher, Shapiro, Lopez, Diaz, & Fusco, 1997). These supports are important because a lack of parental acceptance and understanding can cause discord between partners and result in distress (Hatton et al., 2003).

• **Teachers** can be supportive of parents when they provide caring communication, demonstrate caring behavior, and help parents understand their children’s disabilities (Hess et al., 2006).

• **Parent support groups** can help parents feel less stress and negative affect (Kerr & McIntosh, 2000; Preyde & Ardal, 2003). However, a study with South Asian Muslims who had recently immigrated to the U.S. found that the parents, especially the mothers, who attended support groups felt uncomfortable expressing themselves in front of male strangers (Jegatheesan et al., 2010). The parents were also nervous and shy about speaking in public due to language barriers (Jegatheesan et al., 2010).

• **Parent education** can increase knowledge of parenting skills, minimize stress, and allow them to address their children’s needs (Mahoney et al., 1999; McIntyre & Phaneuf, 2007; Shumow, 1998). Parent education programs are effective when they address families’ individual needs (Warren, Fey, & Yoder, 2007). There are a variety of methods and models for parent education (Koegel, Bimbel, & Schreibman, 1996; McIntyre & Phaneuf, 2007). Some
models emphasize the less hierarchical family empowerment model over the family training model (Bailey, 2001; Puig, 2012). Professionals providing parent education are advised to utilize a model of interactions that respects the cultural beliefs and values of both the parents and the professionals (Barrera & Corso, 2003). Unfortunately, there is very little research on parent education relating to children with special needs in culturally diverse families (Santarelli, Koegel, Casas, & Koegel, 2001). In the next section, cultural considerations are discussed in regard to parent advocacy.

Parent Advocacy

Parent advocacy has been researched within several different populations in the U.S. and around the world. The following studies do not relate to the advocacy of Arab American parents’ specifically, although they reflect the current body of research on parent advocacy in general:

- Parents of children with significant disabilities who helped other families advocate for educational services (Nespor & Hicks, 2010).
- Parents who considered advocacy to be a necessary moral obligation to improve their children’s educational services (Wang, Mannan, Poston, Turnbull, & Summers, 2004).
- Parents’ advocacy regarding their children with ASDs (Dawson & Osterling, 1997; Jegatheesan et al., 2010; McCabe, 2007; Ryan & Cole, 2009).
- Parents of young adults with severe developmental disabilities who considered their parental responsibilities to be a dedication to their children’s
development and education (Shapiro, Monzó, Rueda, Gomez, & Blacher, 2004).

- Parents who had emigrated from Korea to the U.S. and advocated for their children with developmental and intellectual disabilities (K. Kim, Lee & Morningstar, 2007).

- Parents who faced barriers to advocating for their children due to the following issues: unfamiliarity with diagnostic criteria, lack of knowledge of the educational system, and requirements to interact with school staff and navigate special education law (Phillips, 2008).

Parents’ advocacy for their children in special education can entail frequent communication with school staff. The next section reviews research on communication between parents and school staff. Such communication in cross-cultural settings is also discussed.

**Parent-School Communication**

IDEA encourages parent participation during the planning and decision-making processes related to their children’s special education (U.S. Department of Education, 2006). Parents’ participation is believed to assist their children’s success and opportunities (Epstein, 2005). Throughout this participation, parents and school staff must forge successful partnerships. Some characteristics of effective parent-professional relationships are “mutual respect, trust and honesty; mutually agreed-upon goals; and shared planning and decision-making” (Keen, 2007, p. 340). Other important qualities
are respect, compassion, patience, and commitment to the children (Jegatheesan, 2009; Jegatheesan et al., 2010).

Conflict during parent-school communication often relates to different conceptualizations of the needs of children (Lake & Billingsley, 2000). When such different conceptualizations exist cross-culturally, they could stem from contrasting cultural beliefs or ineffective cross-cultural communication. Cultural perspectives and beliefs often inform parents’ perspectives on disabilities (Dennis & Giangreco, 1996; Groce, 1999). In the same way, culture can impact one’s expectations for and perspectives on communication between parents and schools (Phillips, 2008).

Appropriate and sensitive cross-cultural parent-school communication is key throughout the identification process because poor communication with parents could result in their non-acceptance of their children, lack of knowledge about disabilities, and low utilization of family support services (Hatton et al., 2003).

Parental involvement in their children’s educations is highly promoted by IDEA, yet its rules and regulations related to special education were “developed primarily in the context of traditional, white, middle-class, western assumptions and ideals” (Dennis & Giangreco, 1996, p. 104). The U.S. special education system has been described as having “culture-bound policies” rooted within it (Harry & Kalyanpur, 1994, p. 149). These assumptions and policies could be expected to conflict with the beliefs and values of many of the families and students IDEA serves (Dennis & Giangreco, 1996; Harry, Rueda, & Kalyanpur, 1999). This conflict could be predicted to negatively affect parent-school communication.
Some research has explored parents’ responses to cross-cultural communication with their children’s school staff. For example, some parents had positive responses to staff’s cultural sensitivity (Dennis & Giangreco, 1996). Other parents preferred schools to recognize their cultural beliefs (Kalyanpur & Harry, 1999). Negative reactions to school communication were reported by some parents when they were overwhelmed and confused by the complex and technical terminology used in special education materials and meetings (Jegatheesan, 2009). These parents lacked information about service delivery, parental rights, IEPs, and their children’s disabilities although school staff did not realize that the content was new to them (Jegatheesan, 2009). At times, parents were apprehensive about challenging school staff or requesting more special education services (Dennis & Giangreco, 1996; Jegatheesan, 2009). Some parents experienced poor communication due to a mismatch between their beliefs and priorities about their children’s goals (e.g., independence) and those of the professionals (Jegatheesan et al., 2010). In one study, insensitive cross-cultural communication resulted in parents terminating home therapy services (Jegatheesan et al., 2010).

The importance of culturally appropriate parent-school communication is highlighted in the above studies. Such communication is important from the very beginning of parents’ experiences with special education because, as Lo (2012) stated, “Parents’ perceptions of IEP meetings begin as soon as they receive the IEP meeting invitation” (p. 16). Further, Lo found that parents were satisfied with the schools’ communication when they were welcomed at the school for meetings and prepared with information such as who would be in attendance. Respectful cross-communication was
described as including jargon-free language, open-ended questions to check for parents’ understanding, and attention to parents’ verbal and nonverbal body language (Jegatheesan et al., 2010; Lo, 2012). Parents might have differing knowledge of Western categories for clinical and educational disabilities (Tincani, Travers & Boutot, 2009). In such cases, the clinical evaluation process can be related to the parents’ “local world of experience” (Yeung & Kam, 2008, p. 540) with accessible and non-stigmatizing language, references to the parents’ social system, and culturally contextualized symptoms and diagnoses.

The above studies do not involve communication between schools and Arab American parents. Few recommendations in this area exist for school psychologists. Those that are available relate to the culture’s emphasis on confidentiality, the effect of parents’ experiences with autocratic schools in the Arab world on their communication with U.S. schools, and the importance of framing educational goals and objectives for parents in a manner that is consistent with religion and culture (Goforth, 2011; Haboush, 2007). Parents’ goals and expectations for their children with disabilities, and the cultural influences on these goals, are discussed in the next section.

**Parents’ Goals and Expectations for Their Children**

Parents begin to connect to and imagine their children before they are born (Moses, 1987). After learning of their children’s disabilities, parents can go through a period of grieving over the perceived loss of their ideal children (Marvin & Pianta, 1996). Their reactions to the disabilities are often a response to the disruption of their optimistic expectations and mental images of caregiving and attachment (Leerkes & Burney, 2007;
Marvin & Pianta, 1996; Moses, 1987). Thus, it is common for parents to experience denial around the identification of their children’s disabilities (Ho & Keiley, 2003; Moses, 1987).

Parents’ expectations and goals for their children are closely related to their culturally informed belief systems and perspectives on child development (U. Kim & Choi, 1994; Lebra, 1994). A cultural group’s values can be considered in relation to the following two orientations: (a) independent and individual or (b) interdependent and collective (Greenfield, 1994; Hwa-Froelich & Westby, 2003). These orientations are each associated with certain thought and behavior patterns and with specific cultural goals (Greenfield, 1994). Thus, parents’ goals and expectations for their children can be informed by their values stemming from their independent or interdependent orientations.

An independent orientation and an emphasis on self-determination are dominant in the U.S., which has a Western, Anglo-European majority culture (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Welterlin & LaRue, 2007). This has been noted in studies such as Zhang’s (2005), which revealed that Asian, African American, and immigrant parents promoted self-determination for their children less, in contrast to parents of Caucasian and nonimmigrant descent.

Families and school professionals can conflict due to differing cultural orientations. Such conflict can arise as they conceptualize disabilities, set goals, and select appropriate interventions for children (Hwa-Froelich & Westby, 2003; Kalyanpur & Harry, 1999). As a result of divergent orientations, children could receive services that
the parents do not want or value (Hwa-Froelich & Westby, 2003; Kalyanpur & Harry, 1999).

School psychologists would benefit from knowledge regarding these contrasting cultural orientations and their impact on parents’ decisions and values. Additionally important is an appreciation for parents’ potential reactions to the identification of disabilities in their children. The related research described throughout the above sections does not pertain specifically to Arab American parents. The current deficit in the literature and the importance of this research project are summarized in the next section.

**Statement of the Problem**

While Arab Americans are certainly a heterogeneous group, they are still culturally different from the White dominant culture in the U.S. (Wingfield, 2006). These cultural differences can be seen in social behavior, family structure, and beliefs and expectations related to children’s social and moral development, intelligence, and disabilities. Recently emigrated students from the Arab world and their parents will likely have different perspectives on special education (Haboush, 2007).

It is estimated that there are now 3.6 million Arab Americans (AAI, 2012). Historically, Arab Americans have long been invisible in the U.S. (Naber, 2000). Their inclusion in the White racial category means that they continue to be invisible in the sense that they are not accurately counted or granted minority status by a federal agency or department (Zogby, 1993).
This Arab American invisibility is reflected in the school psychology literature, where only two introductory articles (Goforth, 2011; Haboush, 2007) apprise professionals on commonalities among Arab Americans. To inform themselves, school psychologists can review what Ahmed (1998) described as the scant educational research about the adjustment of Arab American students, or they can peruse the small body of research and literature specific to Arab Americans in counseling (e.g., Abu-Ras et al., 2008; Dwairy, 2006; El-Islam, 2008; Gregg, 2005; Hakim et al., 2007; Hall & Livingston, 2006; Lambert, 2008; Moradi & Hasan, 2004; Nassar-McMillan & Hakim-Larson, 2003; Nobles & Sciarra, 2000; Sayed, 2003). However, this clinical counseling literature does not reference cultural implications or family dynamics that are specific to school settings. In other words, literature and research specific to clinical counseling will not always be transferable to the school setting.

School psychologists are required by their professional organizations, the APA and NASP, to be culturally competent in their practices (APA, 2010; NASP, 2010a). This calls for school psychologists to be competent working with the sizeable population of Arab American students and their families (Goforth, 2011; Haboush, 2007). However, without supporting literature to inform them, school psychologists are ill equipped to educate themselves about this distinct minority group.

The current school psychology literature only mentions that some Arab American parents might express reluctance to allow their children to be classified for special education eligibility (Haboush, 2007). It does not explore their potential responses to their children’s identified disabilities, their openness to special education, or their
experience with the special education process. In fact, if school psychologists were to look deeper they would find that the research specific to Arab Americans regarding perceptions of disabilities, supports available to parents of children in special education, and communication between parents and schools is nonexistent. Without knowledge of the culturally-influenced beliefs about special education and disabilities in the Arab world, as well as how these beliefs compare to those held by Arab American parents, school psychologists are at risk of inappropriately or insensitively selecting and providing services and interventions. Ultimately, this could have negative implications for students’ development, self-concept, education, and future. Additionally, parents might never understand their children’s disabilities or be equipped to facilitate their success.

The experiences of Arab Americans students in special education and their parents must be explored, therefore, so school psychologists can be capable of providing best practices. This phenomenological study did so, considering the individual experiences of some Arab American parents with the special education process and emphasizing their descriptions of their experiences. This study, the first of its kind, begins a necessary and overdue exploration of Arab American parental experiences of the special education process.

**Research Questions**

The research questions that guided this study are the following:

- *How do Arab American parents experience the process of their children being referred for special education evaluation and being identified as eligible for special education services?*
• Which aspects of Arab American parents’ experiences with the special education referral, evaluation, and identification process stand out as most significant to them?

In this question, aspects refer to people, events, or settings related to the special education process. The parents also shared feelings, words, meta-messages, self-realizations, attitudes, and so forth, that they recalled from their experiences of the process.

• How do the parents understand and contextualize their children’s identified disabilities and special education eligibility?

In this question, contextualize refers to how the parents put into context, framed, or grasped the disabilities and needs of their children.

• How have the parents’ expectations or plans for their children changed (if at all) as a result of their special education experiences?

Altogether, these research questions address Arab American parents’ experiences of the special education process and the impact of their experiences.

Summary

There are approximately 3.6 million Arab Americans living in the U.S. (AAI, 2012). School psychologists are increasingly likely to work with Arab American students and their parents (Goforth, 2011; Haboush, 2007). Professional and ethical standards require school psychologists to be culturally competent with the populations with whom they work (APA, 1990, 2002; Jacob et al., 2011; NASP, 2010a, 2010b, 2010c). However, the school psychology literature lacks information regarding this
substantial population (Goforth, 2011; Haboush, 2007). Therefore, research is required to explore Arab American parents’ experiences with the special education process. Such knowledge will assist school psychologists in understanding Arab American parents’ responses during the special education process and in following best practices with Arab American students and their families. In the next chapter, this study’s research methodology is outlined.
CHAPTER II
RESEARCH DESIGN AND METHODS

In this study, I considered six Arab American parents’ lived experiences of the special education process by exploring their descriptions of the experiences in their own words. As described in Chapter 1, this topic had not been previously researched. In the following section, I describe qualitative research and explain how these methods were most appropriate for exploration of this study’s topic.

Characteristics of Qualitative Research

As Hoepfl (1997) explained, qualitative researchers seek “illumination, understanding, and extrapolation to similar situations,” which is in contrast to quantitative researchers who seek “causal determination, prediction, and generalization of findings” (p. 48). There are many reasons to select qualitative research. For ease of explanation, these reasons are clustered below into categories specific to the following areas: the research topic, the population being studied, the desired impact of the research, and the data collection methodology.

Qualitative research methods are often selected when there is not already an established body of research on the topic (Giorgi, 1997). It can also be helpful when the topic being explored includes “the meaning individuals or groups ascribe to a social or human problem” (Creswell, 2013, p. 44). Qualitative methods are recommended when quantitative measures are insensitive to individual differences or issues of race, gender, and economic status (Creswell, 2013).
The researcher selects qualitative methods if the population being researched includes “silenced voices” (Creswell, 2013, p. 48). This can assist researchers in forming theories for specific populations when only current theories are inadequate or incomplete (Creswell, 2013). Researchers also select qualitative methods when there is a desire to empower participants “to share their stories, hear their voices, and minimize the power relationships that often exist between a researcher and the participants in a study” (Creswell, 2013, p. 48).

Qualitative research can be selected because of its typically broad impact. Denzin and Lincoln (2011, p. 3) explained that this is because the research “consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self.” Qualitative research facilitates the development of complex perspectives on and understandings of an issue as well as the contexts in which it is addressed by participants (Creswell, 2013).

Qualitative research can also be attractive due to its methodology. As qualitative researchers interact with participants, they focus on meanings assigned by the participants to the phenomena of interest (Creswell, 2013; Denzin & Lincoln, 2011). Participants are selected based on who can describe and reflect on the experience being investigated rather than on who represents an even distribution within the population (Polkinghorne, 2005). In interview-based qualitative research, the participants use their own words to describe their experiences and the researchers employ open-ended questions to explore the nuances of participants’ individual understandings and experiences (Nastasi &
Schensul, 2005; Patton, 2001; Urdan, Solek, & Schoenfelder, 2007). Ultimately, the topic being explored in qualitative research “unfolds naturally in that it has no predetermined course established by and for the researcher such as would occur in a laboratory or other controlled setting” (Patton, 2001, p. 39).

Broadly, the core components of qualitative research are:

- Research is conducted in a natural setting where researchers interact with participants (Creswell, 2013).
- There is a focus on the meanings assigned by the participants rather than by the researchers (Creswell, 2013).
- The researcher is the instrument for data collection (conducting observations, interviews, and reviewing documents) by gathering a holistic account of the topic that comprises multiple participant perspectives (Creswell, 2013).
- Multiple data sources are used and reviewed for themes across all sources (Creswell, 2013).
- An emergent research design is used, such that an initial plan is difficult to define until the researcher is in the field collecting data and learning about the issues from the participants (Creswell, 2013).
- The researcher utilizes reflexivity during the study by communicating how their background informs their interpretation of the data and their intentions from the study (Creswell, 2013).
• Themes, categories, and patterns are constructed “from the ‘bottom-up,’ by organizing the data inductively into increasingly more abstract units of information” (Creswell, 2013, p. 45).

• A holistic account of the issue is developed, with multiple perspectives reported (Creswell, 2013).

There are several types of qualitative research altogether. Hatch (2002) reflected, “It could be said that there are as many kinds of qualitative research as there are qualitative researchers” (p. 20). Creswell (2013) called the options for qualitative approaches “baffling” (p. 7). Five main approaches have been cited as being popular in behavioral, social, and health science literature: narrative, phenomenology, grounded theory, ethnography, and case studies research (Creswell, 2013). Briefly, narrative inquiry involves the collection and analysis of the stories of a single participant or a small group of participants through interactions such as interviews and focus groups (Creswell, 2013). Grounded theory intends to discover or generate a theory or explanation of a process that is grounded in data collected through interviews, observations, or documents (Creswell, 2013). Ethnography involves extended participant observations of typically larger groups of culture-sharing individuals in order to document and examine shared patterns of values, beliefs, behaviors, and languages (Creswell, 2013). Case studies involve the “intensive description and analysis of a phenomenon or social unit such as an individual, group, institution, or community” (Merriam, 2002, p. 8). Case studies’ data collection and analysis can include—but are not necessarily—qualitative methods such as interviewing (Merriam, 1998). Phenomenology explores common experiences of
individuals through interviews to identify the essences of the experience or phenomenon (Creswell, 2013). The phenomenological researcher identifies and separates from personal assumptions and experiences (McLeod, 2001; Wertz, 2005). As described later in the chapter, phenomenology was the approach selected for this research study.

Qualitative research is often conducted in areas of psychology such as counseling psychology, however, it is less common in the field of school psychology (Leech & Onwuegbuzie, 2007). To illustrate, a review of empirical studies published in the four major school psychology journals (i.e., Journal of School Psychology, Psychology in the Schools, School Psychology Quarterly, and School Psychology Review) during the 2001-2005 period found that only 1.37% of the total number of studies were based on pure qualitative research (Powell, Mihalas, Onwuegbuzie, Suldo, & Daley, 2008). Leech and Onwuegbuzie (2007) attributed this lack of qualitative research in school psychology to the following issues: researchers must possess expertise in designing and carrying out qualitative studies, the field does not emphasize the benefits of qualitative data, and many school psychologists are unaware of the great number of tools available to conduct such research.

A sampling of some recent qualitative studies relating to school psychology illustrates how nuanced and informative the results can be. One can imagine how different the breadth and scope of the research would have been in the following studies if a quantitative approach had been used instead of a qualitative approach:

- Experiences of African-American male adolescents with racial microaggressions (hostile and derogatory indignities) in a traditionally White
middle school (Henfield, 2011). Findings revealed the adolescents’ awareness of and abilities to discuss different types of microaggressions (Henfield, 2011).

• Perspectives of special education directors on Response to Intervention (RtI) in secondary schools (Sansosti, Goss, & Noltemeyer, 2011). Findings revealed the following themes: the importance of systems structures in RtI implementation; necessary changes in roles and attitudes of educational professionals, parents, and community members; evidence-based practices as essential to RtI success; and training and professional development needs (Sansosti et al., 2011).

• Experiences of African American students within gifted education programs (Henfield, Moore, & Wood, 2008). Findings revealed challenges the students faced in defining their identity for themselves and for others after being labeled not Black enough (Henfield et al., 2008).

• Perspectives of teachers in Nigeria on the mental health needs of students (Ibeziako, Bella, Omigbodun, & Belfer, 2009). Findings revealed teachers’ favorable attitudes toward mental health services offered in school and toward making referrals for such services (Ibeziako et al., 2009). Teachers from urban and rural public schools tended to associate mental illness with learning problems and with terms such as low IQ, moron, mental retardation, and “lack of proper reasoning capacity” (Ibeziako et al., 2009, p. 150).
Parental experiences of children with ASDs transitioning to mainstream secondary schools (Tobin et al., 2012). Findings revealed the following themes: functions of the children’s educations, coping skills, the process of preparing for the transition, and parental satisfaction with school communication networks (Tobin et al., 2012).

This study explores Arab American parents’ experiences with their children’s special education process as well as their narratives on an individual and collective basis. Qualitative research was the best method to capture the variety of their personal experiences and to explore the nuances and depth of their individual narratives. Several approaches to qualitative research exist (Creswell, 2013; Hatch, 2002). Phenomenology was selected as the best approach for this study due to its focus on a close analysis of experience. This approach is explained next.

**Characteristics of Phenomenology**

Phenomenology is recommended, and even considered imperative, when the qualitative researcher seeks to discover the construction of individuals’ personal and social worlds (McLeod, 2001). Although phenomenological research is common in the field of psychology, it is uncommon within the field of school psychology. Even less common are phenomenological accounts of the experiences of parents with the special education process.

While not specific to the field of school psychology, the following phenomenological studies are examples of research at the intersection of education and psychology. They begin to illustrate the range of application and the subtleties possible
with phenomenological research. Additionally, they contribute nuanced and sensitive perspectives on individuals’ experiences with an array of school psychology-related issues:

- Experiences of adolescent students attending a new school in the United Kingdom (Sancho & Cline, 2012). Findings revealed themes of increasing maturity and independence, experiencing a new school context, and belonging (Sancho & Cline, 2012).

- Experiences of seven gifted individuals who dropped out of school (Zabloski & Milacci, 2012). Findings revealed themes of significant relationships and former teachers’ influences on the participants (Zabloski & Milacci, 2012). Each of the individuals had experienced different traumas during middle school that affected their academic performances and might have also contributed to their later leaving school (Zabloski & Milacci, 2012).


- Experiences of 16- to 19-year-old males who reported feeling alienated from their school systems (Schulz & Rubel, 2011). Findings revealed themes of the need to belong, loss of trust in adults at school, and fear of failure and disappointing others (Schulz & Rubel, 2011).
Originally, phenomenological research was developed by Edmund Husserl and Alfred Schutz to explore consciousness within modern science (Husserl, 1913/1983). Phenomenology is situated within the Weberian tradition of verstehen, which means to understand in German. Phenomenology explores the experiences of a group of individuals who have a shared experience or shared phenomenon—whether it be an unusual or a general phenomenon (Creswell, 2013). The phenomenon in this study is the Arab American parent participants’ experiences with the special education process, which included their children’s referrals for evaluation and identification with disabilities, the parents’ understandings of the disabilities and special education eligibility, and their plans for their children’s futures.

In phenomenology, the researcher “learns to see naively and freshly again, to value conscious experience, to respect the evidence of one’s senses, and to move toward an intersubjective knowing of things, people, and everyday experiences” (Moustakas, 1994, p. 101). The phenomenological researcher must remain open for significance in the process of understanding a phenomenon (Giorgi, 1971). Intuition, description, and reflection are required of both the phenomenological researcher and the participants (Giorgi, 1971). The researcher must also possess a combination of wonder and empathy and must be able to withdraw from existing assumptions (McLeod, 2001; Wertz, 2005).

There are several approaches to phenomenological research. Giorgi and Giorgi (2007) explained that given the difference between the major phenomenological philosophers, “It should not be surprising that different strategies emerge when psychologists seeking to ground their work in phenomenological philosophy use different
thinkers as their primary source” (p. 165). Giorgi and Giorgi (2007, p. 165) reviewed the following five approaches, which all diverge greatly from each other but are bound by their phenomenological focus on participants’ experiences or on the interpretation of their experiences:

- Goethean pre-philosophical experimental phenomenology
- Grass-roots phenomenology
- Interpretive phenomenology
- Descriptive pre-transcendental Husserlian phenomenology
- Husserlian phenomenology based on a return from the transcendental.

While a thorough explanation of the differences between these five approaches is outside the scope of this study, the fourth approach—descriptive phenomenology—is set apart from other forms of phenomenology because the researcher utilizes epoché, which is also known as bracketing (Spiegelberg, 1965, 1975). During epoché, the researcher brackets, or sets aside, his or her biases and prejudgments so they do not interfere with the data collection and data analysis (Moustakas, 1994). To briefly contrast, the interpretive approach to phenomenology requires the opposite: the researcher’s biases are instead “embedded and essential to interpretive process” (Laverty, 2003, p. 28).

Descriptive phenomenology requires the researcher’s attentive descriptions of participants’ everyday conscious experiences (Polit & Beck, 2008). Essentially, descriptive phenomenology comprises three steps: intuiting, in which the researcher starts to know about the phenomenon from participants’ descriptions and does not evaluate; analyzing, when the researcher identifies the essence of the phenomenon and dwells on
the data to find emerging common themes; and describing, in which the researcher communicates the critical elements of the phenomenon (Spiegelberg, 1965, 1975).

The descriptive phenomenology approach was selected for a few reasons. First, it emphasizes the description of a phenomenon without the researcher’s presuppositions (Spiegelberg, 1975). This was necessary so I could bracket my personal experiences with populations related to this study, which I describe later in this chapter (Hoepfl, 1997). In doing so, I would be able to work toward answering my overarching research question, which was how the participants experienced the special education process. An additional reason descriptive phenomenology was selected was that this research project explores a topic that has not previously been researched. Descriptive phenomenological research is often recommended for such un-researched or under-researched topics (Giorgi, 1997). In the next section, participant recruitment for this study is described.

Participants

As Thomas and Pollio (2002) explained, the goal of including more than one participant in phenomenological research is to “produce variations,” which make it “somewhat easier to discern the essential structure of a phenomenon” (p. 41). Six Arab American families were recruited for this study and each family had at least one child who had been referred for a special education evaluation. The criteria for selecting the families were:

- Primary caregivers identified as Arab American.
- Families had a child who had been involved in the special education process (i.e., beginning with the initial referral for evaluation, and possibly also
including the identification of a disability requiring special education and the delivery of special education and related services).

• Families had these special education experiences within the last five years.
• At the time of the experience, the child was in a grade from early childhood (age 3) to sixth grade.
• At least one of the parents in each family could speak English fluently enough to avoid the use of an interpreter during the interviews.
• As much as possible, the group would be balanced in terms of the children’s gender and the families’ religion and generation in the U.S.

As described in Chapter 1, the social stigma of having a child diagnosed with a disability might prompt some Arab Americans to refuse a special education evaluation or special education services for their children (Haboush, 2007). From the beginning of the study, I was interested in families’ different experiences of the special education process rather than only the end result of the process. Parents who refused to participate in the process were also considered to be of importance to the research. Therefore, I welcomed the participation of parents with any experience with the special education process, including families who had not allowed their children to be evaluated or to receive special education services. However, as discussed in Chapter 4, no such parents were located to participate in the study. All six parent participants had children who had been identified with a disability requiring special education and who had received special education services.
It should be noted that throughout this document pseudonyms have replaced all proper names of participants and their children. To eliminate the possibility of biographical information assisting in the identification of participants, the following details have also been replaced with pseudonyms or simply omitted: the names of the participants’ towns and schools, their home countries in the Arab world, the ages of their children’s siblings, and the specific names for two children’s genetic disorders.

The six parents who were selected for participation are summarized below. Lengthier descriptions of the participants are included in Chapter 3 but are abbreviated here to present a brief overview. The parent participants included:

- Afaf was the mother of four children including 10-year-old Ali. Afaf and her family had been living in the U.S. for two years. After a year in the U.S. schools, Ali was referred for a special education evaluation and then identified with a disability requiring special education.

- Boshra was the mother of four children including 8-year-old Bassem. Boshra and her husband had been living in the U.S. for over two decades. Bassem was diagnosed with a severe ASD at the age of three, at which point he began receiving special education services.

- Camilla was the mother of four children, three of whom had been enrolled in special education (Culthum, Cazem, and Carem). Camilla was born in the U.S.; her husband and her parents were born in the Arab world. Two of her children were identified with SLDs and one child was identified with Asperger’s disorder.
• *Dima* was the mother of five children, including two (Dalal and Dawud) who were enrolled in special education. Dima was born in the U.S.; her husband and her father were born in the Arab world. Dalal was identified with ADHD and Dawud was identified with a speech impairment.

• *Eqbal* was the mother of three children including 9-year-old Ebtisam. Eqbal and her family were born in the Arab world and had been living in the U.S. for three years. Ebtisam had been diagnosed with a genetic disorder that affected her speech and cognitive abilities.

• *Fawaz* was the father of three children including 11-year-old Faisal. Fawaz and his wife had been living in the U.S. for two decades. Faisal had been diagnosed with a genetic disorder that affected his gross and fine motor skills.

**Recruitment Procedure**

After receiving approval from Kent State University’s Institutional Review Board (IRB) Committee (see Appendix A), I contacted two Arab American school psychologists in the area to ask for referrals to families meeting the selection criteria. The email I sent to these school psychologists is in Appendix B. They were bound by professional and ethical guidelines that required them to respect confidentiality and not create conflicts of interest. Therefore, I asked them to share my contact information with any interested and qualified families instead of giving to me the families’ information. Further, the school psychologists were encouraged to contact me with any ethical concerns that could arise.
One of the two school psychologists was able to identify two families who met the criteria. This school psychologist also suggested I approach and discuss my recruitment efforts with the following: several local Arab American community members, certain local school districts with a higher concentration of Arab Americans, local Arab American community organizations, and a local association of school psychologists. One of these local Arab American community members suggested I also approach and discuss recruitment with specific Arab Americans in local businesses, schools, and religious centers; I met with or spoke on the phone with several of these individuals. In one school district, the Director of Pupil Services agreed to send home a letter to parents identified by school staff as Arab American to request their participation in this study. I sought and obtained approval from Kent State University’s IRB Committee (see Appendix C) to send the letter home to parents. This letter is attached in Appendix D. However, the letter was approved for use too late within the recruitment period and it was never sent.

After one month of active recruitment I was able to locate and interview only two families who were interested in participating. After a second month, I was able to locate an additional four families. As discussed in Chapter 4, participant recruitment was altogether a difficult and slow process for a variety of possible reasons.

As mentioned above, I had originally requested that the referring individuals share my contact information with interested families so they could choose to contact me. However, when the referring individuals spoke with the parents, each of them requested
that their contact information be given directly to me so I could call them. Consequently, I called each referred family and we had an initial phone conversation.

I attempted to engage in face-to-face interaction with the parents—five mothers and one father—as much as possible. This was due to research suggesting Arab American mothers’ tendency to prefer personal communication (Moosa et al., 2001). Therefore, I always gave the participants the option of meeting in person to first discuss the study. However, all parents selected to initially discuss the study over the phone.

During these phone conversations, I introduced myself and explained the following: (a) the goal of the study, (b) the criteria for participation, (c) the potential risks and benefits of participating in the study, (d) confidentiality of the data, (e) the informed consent process, and (f) the sensitive topics that might be discussed. After I explained these topics, I asked each parent if he or she was interested in participating; in all six cases they were interested. Based on the information they shared with me I determined that the parents qualified for the study and I invited each of them to participate.

Thereafter, I described to the parents what would occur during the upcoming interview. I told them we would meet at a location of their choice, where I would present them with the informed consent form that is attached in Appendix E. I explained to the parents that the form would outline the following: (a) the purpose of the study; (b) the risks and benefits of participating; (c) the steps I would take to work toward confidentiality; (d) their rights to stop the interview at any time, which I explained would not upset me; and (e) the sensitive topics that we might discuss during the interviews and that they could choose to avoid. Further, I mentioned that I was conscious of their
potential concerns about confidentiality and that under no circumstances would I communicate to the referring individuals if the parents participated in the study or chose to participate but later withdrew. At that point, I asked the parents again if they would like to participate. After they agreed, we arranged a meeting time and place. Consequently, I believe the parents did not feel coerced or influenced to participate.

Based on Aroian, Katz, and Kulwicki’s (2006) findings of effective recruitment and retention of Arab Muslim mothers in research, I attempted to involve both parents in the interviews. However, in each family the parent with whom I spoke on the phone said the interview needed to be with only one parent: herself or himself. I told each parent to share my information with their spouse in case he or she had any questions or wanted to speak about the study at any point in time; however, no spouses contacted me. Once the participants were recruited, the interviews and data collection began. These steps are described in the next section.

Data Collection Procedures

Researcher Information

I am a Caucasian female in my mid-30s who is enrolled in Kent State University’s School Psychology Ph.D. Program. I have been licensed as a Nationally Certified School Psychologist (NCSP) for nine years, during which time I have practiced as a school psychologist in several U.S. states and also in Kuwait. While there, I worked for two years at a school for students who had been identified by the Kuwaiti government as learning disabled and in need of special education.
It was during this Kuwaiti work experience that I realized that there were no materials for school psychologists working with Arab or Arab American students. My frustration with the lack of research and recommendations in the field is what prompted me to return to the U.S. for a Ph.D., so I could contribute research to the topic. I enrolled at Kent State University in 2007. Coincidentally, this was the publication year for the first introductory article on the topic, *Working with Arab American families: Culturally competent practice for school psychologists* (Haboush, 2007).

Over the years I have had a great amount of professional and personal relationships and experiences with individuals from Arab and Arab American backgrounds. In addition to Kuwait, I have lived in Egypt and Yemen. I have also travelled extensively throughout the Arab world. My Arabic is at a basic to intermediate level; I can understand and speak more than I can read and write. Additionally, my knowledge of Arabic is limited to certain dialects from specific regions: Kuwaiti (Khaliji Arabic), Egyptian Arabic, and Lebanese (Levantine Arabic).

In addition to my professional interests in students with disabilities and their families, I have had relevant personal experiences. One of my brothers was identified with dyslexia during elementary school. As a child, I was never fully aware of the cause of learning difficulties. What I was aware of, though, and have continued to be aware of, is the profound impact of the disability on his daily life.

Living in the Arab world and working in a special education school, as well as living in Germany after college and observing special education there, I have had many opportunities to make international comparisons of special education. Working in several
U.S. regions: the Northeast, the Midwest, and the South, I have also come to appreciate the wide variance in special education services across the U.S. Given the above experiences, I considered it crucial to acknowledge and separate from my biases and prejudgment during this research project. In utilizing a descriptive phenomenological approach, I endeavored to not let these experiences impact my research and to instead reflect on the participants’ experiences as they reported them to me. Therefore, throughout the data collection I engaged in two important components of phenomenological research: bracketing and reflexivity. After the interviews were completed, I also engaged in peer debriefing, which is a crucial component of qualitative research (Lincoln & Guba, 1985). This next section explains the processes of bracketing, reflexivity, phenomenological interviews, and peer debriefing in more detail and it describes how I implemented these techniques to work toward trustworthiness in this study’s analysis. Bracketing is the first process described below.

Bracketing

As explained above, bracketing, or epoché, requires the researcher to place the focus of the research, which is participants’ experiences, within figurative brackets. This allows the researcher to keep the research separate from his or her personal experiences and presuppositions (Bogdan & Biklen, 2003; Creswell, 2013; Moustakas, 1994; Schram, 2006; Wertz, 2005). In this way, the research objective is to collect data that is true to the examined phenomenon rather than to the researcher’s personal traits or experiences (Ahern, 1999; Creswell, 2013).
This phenomenological study required me to empathically enter and understand the world of the participants from their own perspectives (Husserl, 1913/1983). This entry, and the empathy it required, would affect my thoughts and emotions. However, bracketing allowed me to observe and identify my own beliefs and perspectives throughout the process (Creswell, 2013).

The first step of the bracketing process was my own bracketing interview, which serves many purposes, including allowing the researcher to gain a sense of the feeling of being interviewed about the research topic. The researcher is asked the same interview questions and reflects on why he or she is interested in conducting the research (Pollio, Henley, & Thompson, 1997). It ultimately assists in highlighting personal beliefs and assumptions before the data collection begins (DeMarrais, 2004). This insight then allows the researcher to retain a nonjudgmental attitude during data collection and interpretation (Thomas & Pollio, 2002).

My bracketing interview took place two months before I began recruiting participants. I asked a former classmate who had completed his own phenomenological research study to conduct the bracketing interview for me. I believed he would be attuned to the underpinnings of phenomenology and would be able to appreciate the personal and theoretical requirements of a phenomenological researcher.

We met at a local library, which was the type of location I would likely be meeting and interviewing my future participants. I brought along the interview questions that I intended to ask participants and I explained the research questions of this study. He then conducted the bracketing interview, which we recorded. Shortly afterward, I
submitted the interview to the Kent State University’s Research and Evaluation Bureau for transcription, which is what I planned to do with my participants’ interviews. Additionally, I coded my bracketing interview in the same way that I would later do with the participants’ interviews.

Several questions and considerations arose from the bracketing interview. I realized that I was wondering if I might struggle with hearing parents’ potential negative emotions as they recalled their experiences. I was imagining how I would be able to demonstrate the detached empathy required of the researcher. Additionally, I was concerned about families developing intimacy and trust with me during the interviews and then potentially having expectations of me that I could not meet.

The bracketing interview allowed me to get a sense of the feeling of being interviewed by a stranger in a public location about a highly personal and emotionally charged topic. It illustrated for me that I needed to discuss with parents at the beginning their expectations of me and of the interview. Additionally, I was able to make connections between my experiences and my current beliefs that I had not previously considered. In this way, I was able to locate and reflect on my own assumptions from the onset of the study. The interview felt substantial and self-reflective, which then made me appreciate both the interview experience and the interviewer, my former classmate. While it was not therapeutic or confessional, I experienced the interview positively because I appreciated discussing ideas with someone who listened to me and expressed interest in my thoughts.
I did not assume my study’s participants would experience their interviews exactly as I did. However, the bracketing interview allowed me to temporarily take an interviewee’s perspective. I more fully appreciated participants’ generosity in sharing their experiences and I became more aware of their potential vulnerability from sharing their emotions and perspectives with the researcher, a stranger to them. The bracketing interview led me into the practice of reflexivity, which is discussed next.

**Reflexivity**

Reflexivity in qualitative research refers to the researcher’s awareness of his or her preconceptions and personal reactions (Ahern, 1999). Reflexivity is a critical self-inspection or self-reflection that allows the researcher to acknowledge personal emotional connections to the data and the participants (Schwandt, 2001). It also allows the researcher to reflect on his or her place in the research and ultimately on the entire research process itself (Schwandt, 2001). Through reflexive practices, the researcher can bracket personal reactions with less anxiety and discord and can therefore achieve easier neutrality (Ahern, 1999). Interestingly, reflexivity even extends to the researcher’s examination of the data write-up including with which participants he or she most identifies and most often quotes (Ahern, 1999).

These reflexivity issues are considered and documented in a reflexivity journal. This kind of journal is meant to heighten the researcher’s self-awareness and to allow for a type of reflective meditation (Moustakas, 1994). The journal consists of regular entries about methodological and logistical reflections and decisions, as well as personal interests and beliefs. These entries allow the researcher to engage in catharsis, reflection,
and speculation (Lincoln & Guba, 1985). Nolan and Meister (2000) found that a reflexivity journal allowed them to generate questions and ideas, later recall specific feelings about events in the research, and better explain why certain events were meaningful.

My reflexivity journal allowed me to record and consider my reactions. I made entries in it at the following times: (a) as I recruited and screened participants, (b) after I conducted interviews, (c) as I listened to the recordings and read the transcriptions, (d) throughout the data analysis process, and (e) as the core themes emerged. These entries were crucial for me to acknowledge emotional reactions, record immediate and overarching questions, develop theories about connections and themes in the data, and reflect on findings and emerging core themes. Additionally, as I discuss later in this chapter, the journal allowed me to ultimately work toward trustworthiness. Thereafter I was ready to begin the phenomenological interviews, which are discussed next.

**Phenomenological Interviews**

Phenomenological interviews are considered exchanges between two people in a meaningful relationship, with the participant being the expert on the phenomenon (Thomas & Pollio, 2002). It is the researcher’s task to allow himself or herself into the participant’s world (Patton, 2001). Moustakas (1994) referred to the participant in phenomenological research as a *co-researcher*, which indicates how collaborative and cooperative an effort he envisioned phenomenological interviews to be.

Three of the parents opted to meet me and be interviewed in public locations: two parents selected their local library and one chose his place of work, which was quiet and
allowed him ample time to speak freely. At the library I sat with each of the parents on a top floor where there was a good degree of privacy. The participants’ children sometimes came to the two individual library interviews but they stayed downstairs throughout our meetings.

The other three parents invited me to their homes for their interviews. As I discuss in Chapter 4, these three parents were female and *muhajabat* (women who wear *hijab*, or Islamic head coverings). In one of these three interviews, the parents’ children were at home but they remained in another part of the house during the interview.

When I arrived at each of the six interviews I gave the parents a small token of my appreciation: a box of baklava from a local Arab grocery store. I spent a few minutes building rapport with them and engaging in small talk to help them get to know me. I included time for open conversations to allow the participants to become more comfortable with me (Bogdan & Biklen, 2003). This extra time to build relationships and establish rapport is advisable also because of the Arab American cultural preference for personal relationships (Aroian et al., 2006).

After a few minutes, I showed them the informed consent form, which I had reviewed with them on the phone, and gave them their own copy to keep. I allowed them time to silently read the form and then walked them through each section to check for their understanding. We discussed any of their questions. I highlighted for them my contact information on the form in case they needed to speak with me after the interview and I indicated my advisor’s contact information so they could do the same if they had any concerns. They each signed two copies of the form, one of which I took for my
records and one that they kept. Before beginning the actual interviews, I showed the parents the recorder I would use. I demonstrated the red light that would appear when I was recording. I confirmed with each parent that he or she was comfortable being recorded. Additionally, I explained that they would be able to request copies of their recordings, which I would deliver to them a few days later.

Questions in a phenomenological interview can be tailored to each individual and can utilize his or her surroundings to increase the immediacy of the conversation (Patton, 2001). Because each participant in this study was sharing his or her own experiences and my questions flowed from what the individual had shared, each interview was not identical. I asked participants additional or different questions based on what they spontaneously shared and what their comfort level appeared to be with me. While the order of the questions varied, the range of questions about the participants’ experiences with the special education process was constant throughout each interview.

To start the interviews, I had prepared an opening question that would allow for a variety of descriptive responses (Thomas & Pollio, 2002). This question was, “What is your experience with the special education process?” Thereafter, the interview questions were what rather than why questions, which were intended to lead the participants to describe their lived experiences (Thomas & Pollio, 2002). I used words that made sense to the participants, were sensitive to their worldviews, and were succinct and jargon-free. Throughout the interviews, I actively listened and communicated my interest in and respect for their experiences (Kvale, 1996).
The following interview questions are based on Moustakas’ (1994) suggestions for phenomenological research. They are also attached in Appendix F. The questions were adjusted accordingly for different English fluency levels:

- Can you describe for me the special education experience?
- What was most important or memorable to you?
- Which people connected with your experience with the special education process stand out for you?
- How did your experience with the special education process (e.g., referral and/or identification) affect you and your family?
- Looking back on your experience with the special education process, what thoughts stand out for you?
- What feelings and thoughts did you have during the experience?
- How would you describe your child’s educational abilities and needs?
- What are your goals for your child?
- If you were asked the above question before the special education process began, how would you answer?
- Did you have experience with the special education process before this experience with your child?
- How did the experience affect you?
- What changes do you associate with the experience?
- Have your shared all that is significant with reference to the experience?
Stylistically, the participants set the pace of the phenomenological interviews and it is the researcher’s responsibility to closely follow their words, seek clarification when necessary, and confirm that each experience is discussed in detail (Thomas & Pollio, 2002). My intentions were to not interrupt the participants except to clarify or check for understanding, ask for examples of the phenomenon, and summarize at different points during the interview (Thomas & Pollio, 2002). I planned not to ask leading questions (Seidman, 1991). I sought to avoid reinforcing the participants’ responses positively or negatively—such as by saying okay or yes after their statements—because this could unwittingly have served as a controlling mechanism (Seidman, 1991). Additionally, I attempted to make interpretations beginning in the interviews because meanings were then being formed naturally between the participant and myself (Thomas & Pollio, 2002). Whereas I was conscious of my questions and responses throughout the interviews, I know there were a few occasions when I did accidentally lapse by interrupting or by asking a leading question that I tried to correct when I became aware of my error.

During the interviews I began to make some of my own interpretations and I encouraged the participants to do the same. However, I was conscious not to lapse into the role of counselor with them. This was crucial because the open-ended interviewing techniques that I utilized could have been experienced as similar to psychotherapy (Seidman, 1991). If the content of the interviews, including the interpretations that were made, elicited strong emotions in me I later debriefed in my reflexivity journal and with a colleague about my emotional reaction (Thomas & Pollio, 2002).
Throughout the interviews I was mindful of honoring the participants’ experiences as they reported them to me. In one interview that is discussed in Chapter 3, the parent could not recall the name of her son’s identified disability that required special education. She offered to locate and later show me his special education evaluation and IEP so I could verify the information. However, there were several reasons I declined her offer: (a) I wanted to appreciate and hear her narrative of the special education process as she had experienced it, even if that meant appreciating her lack of understanding or memory of the name of her son’s identified disability; (b) I wanted to communicate that her account of her experiences was most important to me; (c) I was not going to see the special education documents of any of the other participants’ children; and (d) I suspected that reviewing the child’s materials might or might not have informed me of other aspects of his special education (e.g., background information, evaluation results, etc.) that I did not want to know unless the mother felt them significant enough to describe as part of her experience.

Another situation arose during the interviews in which I selected to honor the participants’ descriptions of their experiences. This involved two parent participants whose children were receiving special education services as a result of genetic disorders that affected academic performances. These two children could have been receiving special education services under a variety of disability categories (e.g., multiple disabilities, orthopedic impairment, etc.). However, neither parent identified the special education disability category so I chose to present the disabilities as they reported them to me: as genetic disorders.
Immediately after completing each interview, I made an entry in my reflexivity journal to describe the interview setting, communication style, and my personal reactions to the experience (Thomas & Pollio, 2002). Thereafter, I delivered the interviews to Kent State University’s Research and Evaluation Bureau for assistance with transcription. When I received the transcriptions from the Research and Evaluation Bureau, I listened to the recordings and I noted pauses, paralinguistic behaviors, volume level, and other meaningful information from the interviews (Thomas & Pollio, 2002). I also changed people and place names to pseudonyms and I detailed my overall reactions to the data in my reflexivity journal. Thereafter, I listened to the recordings again with the updated transcriptions in front of me and noted any other meaningful information that I could recall (Thomas & Pollio, 2002). After the interviews and transcriptions were complete, I engaged in peer debriefing, which is discussed next.

**Peer Debriefing**

Peer debriefing is a process in which the researcher reveals himself or herself to an impartial peer to explore characteristics of the research and analysis (Lincoln & Guba, 1985). This exploration occurs so the researcher can express and discuss issues that otherwise would exist only in the researcher’s mind (Lincoln & Guba, 1985). Through this process, the researcher explores his or her biases, presuppositions, and personal attitudes toward the data and analysis (Lincoln & Guba, 1985). It is recommended that the researcher engage in peer debriefing before analyzing the data to explore with an impartial peer the plausibility of hypotheses (Lincoln & Guba, 1985).
I engaged in peer debriefing with three individuals before I began data analysis. With these individuals I discussed my reactions to the data collection process and my experiences hearing the participants’ narratives, which were sometimes emotionally charged. We spoke about issues I had written about in my reflexivity journal. These conversations then highlighted further ideas for me to include in the journal. In addition, following initial analysis of the data I engaged in peer debriefing on the content of my analysis. Thereafter, I utilized these discussions as I moved into further analysis. The process of data analysis is discussed in the next section.

**Data Analysis**

As detailed in Chapter 3, phenomenological data analysis includes three main steps: *phenomenological reduction, imaginative variation*, and *synthesis* (Moustakas, 1994). In addition, *epoché* occurs throughout these three steps (Moustakas, 1994). The process of epoché is explained first.

**Epoché**

As explained above in the section on data collection, epoché, or bracketing, is an integral component of phenomenology. The bracketing process occurs throughout both the data collection and the data analysis steps. Based on a Greek word meaning to “abstain” or “stay away from” (Moustakas, 1994, p. 85), this abstinence in epoché relates to the researcher’s avoidance of personal biases relating to the participants or their experiences (Balaban, 2002; Patton, 2001). To accomplish this, the researcher avoids the following: assigning value to any one participant over another, judging participants or
their experiences, and becoming personally involved in the material (Balaban, 2002; Moustakas, 1994; Patton, 2001).

Epoché occurred regularly throughout the data analysis process as I moved from phenomenological reduction to imaginative variation, and later to synthesis. Throughout the process, I was mindful of several issues. First, I remained conscious not to make assumptions about participants’ experiences based on my own experiences with parents of children in special education in the U.S. and parents of students with disabilities in the Arab world. Next, I was careful not to react favorably to one participant over another as a result of interpersonal characteristics or their personal narratives. Additionally, I made no assumptions about the parents’ experiences due to how I imagined I would have felt or have interpreted something in their situation. Altogether, I was cognizant of my reactions—emotions, thoughts, impulses, and questions—as I interacted with the participants, processed their narratives, and analyzed the data. As I noted my reactions, I analyzed their origins and questioned their potential affect on my demeanor or thoughts. In short, as I engaged in epoché throughout the following three data analysis steps, I always referred back to this quote from Moustakas (1994, p. 86):

The challenge of Epoché is to be transparent to ourselves, to allow whatever is before us in consciousness to disclose itself so that we may see with new eyes in a naive and completely open manner. Thus, in the process of being transparent in the viewing of things, we also become transparent to ourselves.
Phenomenological Reduction

Phenomenological reduction is the first step within phenomenological data analysis. It is an analytic step in which the researcher listens with the intent of accepting the phenomena and any personal meanings (Moustakas, 1994). The process of phenomenological reduction is described as a constant “interweaving of person, conscious experience, and phenomenon” (Moustakas, 1994, p. 96). This interweaving is accomplished as the researcher focuses attention on the different experiences of the phenomenon and on “its presence and elucidation” (Moustakas, 1994, p. 91).

The following six steps were followed as part of the phenomenological reduction process.

1. *Collect a full description of the experience and form a verbatim transcript.* I began by receiving transcriptions of the interview recordings from the Research and Evaluation Bureau and by pouring over the transcriptions (Moustakas, 1994).

2. *From the verbatim transcript: consider statements for significance in describing the experience.* I listened to the recordings while reading along with the transcriptions and I considered participants’ individual perspectives. I noted relevant statements within the transcripts and identified them as meaning units (Moustakas, 1994).

3. *Record pertinent statements.* I noted relevant statements from the transcripts and considered their relationship to the participants’ experiences. Thereafter I *horizontalized* the data, which entailed spreading out all of the data for
examination and giving each piece of data equal treatment (Moustakas, 1994; Patton, 2001).

4. List nonoverlapping and nonrepetitive statements to identify invariant meaning units of the experience. I deleted meaning units that were repetitive or overlapping, which allowed me to identify the remaining meaning units as invariant (Moustakas, 1994).

5. Cluster the invariant meaning units into themes. I grouped together the invariant meaning units by topic or theme to examine the data more deeply and form individual participant themes that expressed the gist of their experiences (Moustakas, 1994).

6. Synthesize the invariant meaning units and themes into a textural description of the experience with verbatim examples. I conducted this synthesis to form individual textural descriptions of the participants’ experiences that related to what had occurred and what had formed the essences of their experiences (Moustakas, 1994).

Imaginative Variation

After phenomenological reduction is complete, the researcher engages in imaginative variation. During this process, the researcher details the main structures of the phenomenon, relies on intuition to integrate structures, and considers any perspective as a possibility (Moustakas, 1994). This allows the researcher to identify the phenomenon’s particulars that are bound to specific circumstances and then to separate them to determine the actual essences of the phenomenon (McLeod, 2001). The
researcher also forms structural descriptions, which include his or her reflections on the participants’ experiences of the phenomenon and the dynamics that could account for how the phenomenon was experienced (Creswell, 2013; Moustakas, 1994).

Briefly, the steps of imaginative variation conducted in this study included:

1. *Reflect on the textural description and create a structural description of the experience.* I formed free fantasy variations, which are interpretations from all angles and opposite suppositions that could explain participants’ descriptions of their experiences. This step assists the researcher in ensuring that personal assumptions or perspectives are not injected into the data (Moustakas, 1994). This reflection was the most time-consuming step due to the formation of free fantasy variations, with which I experimented during a long revision cycle.

2. *Construct individual textural-structural descriptions of the essences and meanings of the experience for each of the participants.* I formed these textural-structural descriptions, which encompass the essences and meanings of the participants’ experiences and the perceptions of more complex meanings in the data (Moustakas, 1994; Patton, 2001). After the imaginative variation is complete, the synthesis process occurs.

**Synthesis**

During the final stage of synthesis, the researcher collects the meanings, concepts, and essences of the participants’ experiences and combines them to suggest an overall description of the experiences (Rubin & Rubin, 2005). This reflective study of the
phenomenon culminates as the researcher constructs a textural-structural synthesis of the phenomenon. Essentially, this is accomplished as the researcher integrates the structural and textural descriptions to form a composite textural-structural synthesis description that represents the group’s experiences as a whole (Moustakas, 1994).

The analysis of the data revealed the following four distinct core themes around participants’ experiences with the special education process:

1. Each participant experienced his or her child’s referral for evaluation and identification with a disability as separate steps within the special education process; several parents also had culture-specific concerns about their children’s futures.

2. The special education process included two significant aspects for participants: their children’s special education services and the key relationships the parents built or maintained during the special education process.

3. Parents reflected on many topics related to their children’s disabilities and eligibility for special education: the children’s abilities and difficulties, parents’ own understandings of special needs and of special education, and the importance of some parents’ own advocacy work.

4. Parents reported having unchanged expectations, plans, and goals for their children after experiencing the special education process; parents’ present goals for their children did, however, appear to be impacted by and tailored to their children’s disabilities and abilities.
Throughout the above data collection and data analysis steps, I was mindful of establishing trustworthiness in the research. This process is described next.

Trustworthiness in Qualitative Research

As Lincoln and Guba (1985) explained, quantitative measures of internal and external validity, reliability, and objectivity cannot be used in qualitative research. Instead, they suggested more appropriate techniques to address and establish the rough qualitative equivalent, which they entitled trustworthiness (Lincoln & Guba, 1985). It comprises a combination of truth value, applicability, consistency, and neutrality (Lincoln & Guba, 1985). To establish trustworthiness, Lincoln and Guba instruct qualitative researchers to ask the following four groups of questions about their research:

- Is there truth value or creditability? Can the truth of the findings be established? This is the equivalent of quantitative internal validity and can be established through several techniques that I utilized including: (a) debriefing with an uninvolved peer for analysis, discussion about working hypotheses, and reflection; (b) negative case analysis to revise hypotheses and examine outliers; and (c) a reflexivity journal to record logistics of the study, methodology, and personal reflections (Lincoln & Guba, 1985).

- Is it applicable or transferable? Can the findings be determined to be applicable to other contexts or participants? This is the equivalent of quantitative external validity and can be established through several techniques that I utilized including: (a) a reflexivity journal to record working hypotheses and (b) thick descriptions to assist others in determining if the
conclusions can be transferred to another group of individuals (Lincoln & Guba, 1985).

- Is it consistent or dependable? Could the findings be repeated if the study was replicated with the same or similar subjects or in the same or a similar context? This is the equivalent of quantitative reliability and can be established through the use of a reflexivity journal to track the search for positive and negative data and any shifts in methodology (Lincoln & Guba, 1985).

- Is it neutral or confirmable? Can there be a determination that the findings and data are grounded in the participants’ narratives rather than in the researcher’s biases and personal interests? This is the equivalent of quantitative objectivity and can be established through a review such as the one I conducted of the following: raw data, analytic techniques, and process notes. Thereafter, the findings are reviewed for researcher bias and consideration of negative evidence (Lincoln & Guba, 1985).

The next section discusses trustworthiness in phenomenological research.

**Trustworthiness in Phenomenological Research**

As Thomas and Pollio (2002) explained, “Because phenomenological research aims at meaning and understanding rather than at causality and prediction, the criteria used to evaluate quantitative research must be cast in a different light” (p. 39). Beck (1994) discussed the semantics of the terms *reliability* and *validity* in phenomenological research. She warned that using these terms could cause difficulties because of their
differing definitions cross-paradigmatically (Beck, 1994). Interestingly, even within the three main phenomenological approaches (i.e., Colaizzi, Giorgi, and van Kaam) there are divergent conceptions of the terms (Beck, 1994). Giorgi (1989) explained that utilizing logical-empirical approaches to evaluate validity is inappropriate for the context of phenomenology. Instead, he noted that the phenomenological reduction process satisfies any concerns about validity (Giorgi, 1989).

When comparing Colaizzi, Giorgi, and van Kaam, only in Giorgi’s approach does the phenomenological researcher personally assess the constructs of reliability and validity in the data analysis. In contrast, Colaizzi referred the final validation back to each participant for his or her determination; van Kaam insisted on an intersubjective agreement to be made using expert judges (Beck, 1994). However, Giorgi (1989) argued that phenomenology does not claim to define reality and therefore does not require additional judges.

Giorgi (1989) criticized the use of participants as evaluators of the researcher’s findings, considering it inappropriate to ask participants to appraise a psychological analysis of their own experiences (Giorgi, 1989). He argued that participants are not capable of viewing, nor should they be asked to view, their everyday experiences from a psychological lens (Giorgi, 1989). Asking them to do so requires them to step out of their role of a participant who provides data and into the role of a psychologist or interpreter of their experience (Giorgi, 1989). Participants do not have access to the conceptual framework on which the study was built nor do they have access to the other participants’ experiences, which are what the researcher must combine to conceptualize
and analyze the data (Giorgi, 1989). Instead, the readers of the phenomenological report become the evaluators of the researchers’ interpretation (Giorgi, 1989).

Accordingly, I did not return to the participants for their evaluation or confirmation. Instead, I relied on my own evaluation of the data analysis (Giorgi, 1989). I established trustworthiness with the following methods: keeping a reflexivity journal, bracketing, reflecting on the bracketing interview, peer debriefing, using the phenomenological reduction and imaginative variation steps described above, and relying on my own judgment (Beck, 1994; Giorgi, 1989; Lincoln & Guba, 1985).

**Professional and Ethical Standards for Research**

This section reviews research ethics outlined by professional associations and related to qualitative research, as well as ethical considerations specific to this study. Altogether, these research ethics and considerations led the conceptualization, implementation, and analysis of this study. Professional association research ethics are discussed first.

**Professional Association Research Ethics**

As discussed in Chapter 1, school psychologists are bound by ethical standards detailed by the National Association of School Psychologists (NASP, 2010b) and the American Psychological Association (APA, 2010). These associations also provide ethical standards specific to the area of research. This study abided by such standards including those regarding: institutional approval; informed consent; use of inducements and deception; plagiarism; and the report, publication, and sharing of the research (APA, 2010; NASP, 2010b).
Several aspects of the American Anthropological Association’s *Code of Ethics* (American Anthropological Association [APA], 2009) also informed my ethical standards for this study. These included the need for the researcher to do the following: (a) negotiate the limits of the relationship with participants, (b) uphold informed consent responsibilities, and (c) recognize his or her own debt to the researched communities and personal obligation for reciprocation (AAA, 2009). In addition, I followed standards specific to qualitative research.

**Qualitative Research Ethics**

Qualitative research requires special ethical considerations due to the intimate and meaningful topics being shared by participants and due to the relationships that are built between the participants and researcher (Haverkamp, 2005). From the outset of the study, qualitative researchers must clarify which individuals will have access to the collected data and in what format (Haverkamp, 2005). Such information is detailed in this study’s informed consent form, which is attached in Appendix E. I began every interview by closely reviewing this form with participants.

The informed consent form explained that the interviews in this study were being audio recorded to allow for later transcription of the data. It noted the recordings would be heard only by myself and by the employee of Kent State University’s Research and Evaluation Bureau making the transcriptions. Employees of the Bureau, the form mentioned, are bound by a confidentiality agreement and have completed background checks including fingerprinting. Finally, the informed consent form clarified that at the
conclusion of the research project I would be personally destroying and deleting the audio recordings.

The form also explained the steps I would take, and consequently have taken, toward maintaining confidentiality: I encrypted the data on a removable external hard drive, which is stored in a locked fireproof cabinet in my home. To access the data on the hard drive, one would need my private user account password and the key used in encrypting the data. Furthermore, participants’ names are not associated with the recording or data and immediately after transcription any names that were mentioned were changed to pseudonyms.

I was aware that the issue of confidentiality is often more complicated when conducting qualitative research in small, close-knit communities (Suzuki, Mattis, Ahluwalia, & Quizon, 2005). For example, identifying information—even once changed—might still allow community members to identify each other (Haverkamp, 2005). Therefore, I masked participants’ personally identifying information in the transcripts (e.g., national origin, immigration history, and the birth order of children) without affecting the quality of their experiences.

Qualitative researchers must also consider participants’ experiences of the interviews. For example, there was a chance that the in-depth conversational interviews could have had negative long-term effects on the participants if they were not conducted appropriately or sensitively (Van Manen, 1990). To guard against such negative effects, it was necessary to honor the privacy of participants and to allow them to decide how much information they wanted to reveal (Bogdan & Biklen, 2003). Therefore, I did not
push the participants to share information if they ever appeared uncomfortable and I was attuned to any reluctance to discuss a topic. When parents requested that I stop their recordings so they could discuss sensitive or private topics, I quickly obliged and did not begin recording again until they gave me their explicit permission. Additionally, the participants were invited to skip any questions or stop the interview at any point. I was obligated to revisit the issue of informed consent with participants not just once, but throughout the interviews and during my communication with them (Haverkamp, 2005). In addition to the above ethical considerations related to qualitative research, I also identified considerations specific to this study that are discussed next.

**Ethical Considerations and Safeguards Specific to This Study**

During this study I paid special attention to issues that were specific to the Arab American population and to the sensitive topics we were discussing. These included the following: (a) a potential for heightened parental concern about confidentiality, (b) potential conflict between a parents’ desire to leave this study and the Arab American cultural emphasis on hospitality and obliging one’s guests, and (c) my role as a researcher who has had training as a school psychologist and who can recognize distress in others.

**Confidentiality.** I was correct in anticipating that some participants might be considerably worried about confidentiality, especially due to the intimacy and interconnectedness of the local Arab American community. This was demonstrated to me by the frequent questions several parents asked about the limits of the confidentiality and about my relationships with people in their community. I had already planned to
address these issues with the families. Therefore, I devoted extra time during the initial conversation with each parent and again before the interview to reiterate my dedication to maintaining confidentiality. These conversations sometimes occurred again during the interviews if parents referred to an individual or shared an experience that they wanted to be sure would remain confidential. I explained that I would never refer to their families or divulge their identities through identifying information, nor would I acknowledge their participation in this study. As mentioned earlier, I also reassured them I would not communicate with the referring individual to confirm or deny that they participated in the study.

I also discussed with parents their preferred means of communication and preferred locations for interviews. I did not wish to make the families feel uncomfortable by having to explain my presence or identity to family members or neighbors, so I planned to be flexible in terms of where we met. Some possible meeting locations I suggested were the families’ homes and a private room in a conveniently located public library (Aroian et al., 2006).

**Hospitality.** I anticipated that the cultural emphasis on hospitality in the Arab world and among Arab Americans could complicate social interactions during this research study. To illustrate, I imagined some participants could feel uncomfortable expressing their desire to stop the interview or to withdraw from the study because it could have been perceived as conflicting with the cultural expectation of hospitality or the obligation they had for me as their guest. Therefore, I discussed with all participants that I did not want them to feel obligated to continue with the study or maintain contact
with me and that I would not take their refusal as a sign of rudeness. Additionally, I remained sensitive to the participants’ demeanor during our conversations and interviews and I was flexible regarding their length and scheduling.

**Researcher’s role.** When I spoke with the families about my background and my interest in the research topic, I referred to my training and work experience as a school psychologist. However, I explained to them that in our relationships I would relate to them as a researcher. I mentioned at the start of our communication that I would never consult with their children’s schools in any way. It had occurred to me that parents might try to solicit my help in either understanding their children’s special education evaluations and IEPs or in intervening on their behalf with the schools. Therefore, I was ready to provide the families with contact information for local Arab American school psychologists should such questions or requests arise. However, such a situation never occurred.

In this study, participants discussed issues related to disability and as I anticipated, some parents experienced and discussed strong emotions during the interviews. I had already planned that if parents were to become highly emotional during their interviews I would stay with them until they regained their composure and I would make referrals to a local mental health agency or counselor (Haverkamp, 2005; Thomas & Pollio, 2002). I was prepared to also follow up by phone with any such participants the next day to see if it was necessary to then make another referral. Despite these preparations, I never felt it necessary to make referrals or follow-up calls. Instead, when parents were emotionally distressed during interviews—and only two parents were—their
upsets were momentary. At the end of these two interviews, I followed up with both of the parents on how they were managing their emotions and experiences on a daily basis. Additionally, I verified that they had ready supports to which they could reach out. I also mentioned that I had counseling resources that I could share with them. In both cases the parents declined, saying that they did have ample resources and were emotional during their interviews only because the discussions related to difficult experiences around their children’s disabilities.

Summary

This phenomenological qualitative study explored the experiences of six Arab American families with the special education process and their understandings and beliefs about their children’s identified disabilities. These six participants were recruited through local Arab American school psychologists and their contacts. The study utilized a descriptive phenomenological approach, which requires the researcher to bracket personal experiences and biases while exploring participants’ individual conscious experiences of a shared phenomenon (Polit & Beck, 2008; Spiegelberg, 1975). The descriptive approach was selected because of the need to bracket personal experiences with populations related to this study and because the research had not been researched previously (Giorgi, 1997; Hoepfl, 1997). Data were collected through interviews with parents. Interviews were then analyzed using three main steps: phenomenological reduction, imaginative variation, and synthesis. Additionally, epoché occurred throughout the analytic process. To achieve trustworthiness, a variety of methods were utilized (Lincoln & Guba, 1985). Throughout the study, ethical and professional
standards related to research were maintained. Additional considerations were made as a result of an Arab American and Arab cultural emphasis on hospitality, elevated concerns about confidentiality, and my role as a researcher who possessed training in school psychology. In the following chapter, the data analysis process is detailed and the findings are discussed.
CHAPTER III

FINDINGS

The goal of this phenomenological research study was to explore the experiences of Arab American parents with the special education process. This chapter is divided into four main sections: an overview of the six participants in the study, a review of the research questions and the methods of phenomenological research, an explanation of the phenomenological data analysis conducted in this study, and a detailed discussion of the core themes that emerged from the data regarding the experiences of six Arab American parents. The following section begins with the introduction to the parent participants and their children.

Participants

The six parent participants all met the following criteria for inclusion in this study: (a) they and their spouse identified as Arab American, (b) they had at least one child who had been involved in the special education process within the past five years, (c) at the time of the study the child had been in a grade from early childhood education to sixth grade, and (d) the parent being interviewed was sufficiently fluent in English to avoid the use of an interpreter. When the research was conceptualized I hoped that participants would be balanced in terms of the children’s gender, religion, and generation in the U.S. The recruited sample does reflect diversity in the children’s gender and families’ generation in the U.S. Additionally, the participant group is diverse in the types of disabilities their children had. However, the group is not diverse with regard to religious background: all participants were Muslim although some parents were more
devout than others. Although this homogeneity in participants’ religion did not appear to be significant to the data, this issue is discussed in Chapter 4.

The parent participants included five mothers and one father from a large city in the Midwest. Four parents were born and educated in the Arab world; two were American-born. Four of the six parents had only one child in special education; two parents had multiple children in special education. In total, nine children were discussed: six boys and three girls. Their identified disabilities ranged from visible disabilities (e.g., genetic disorders) to invisible disabilities (e.g., SLDs). Table 1 lists demographic information for each participant including the location of their birth and their children’s names, identified disabilities, and current ages.

The recruitment process and the work to protect confidentiality have been detailed in Chapter 2. As described, pseudonyms replace the names of participants, their children, schools, and towns. Additionally, references to specific home countries and specific genetic disorders have been removed.
Table 1

Participant Characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Location of Participant’s Birth</th>
<th>Children</th>
<th>Child’s Age</th>
<th>Child’s Disability as Reported by Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afaf</td>
<td>Arab world</td>
<td>Ali</td>
<td>10</td>
<td>Specific Learning Disability (SLD)*</td>
</tr>
<tr>
<td>Boshra</td>
<td>Arab world</td>
<td>Bassem</td>
<td>8</td>
<td>Autism</td>
</tr>
<tr>
<td>Camilla</td>
<td>U.S.</td>
<td>Cazem</td>
<td>8</td>
<td>Autism</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Culthum</td>
<td>9</td>
<td>Specific Learning Disability (SLD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Carem</td>
<td>7</td>
<td>Speech or Language Impairment &amp; Specific Learning Disability (SLD)</td>
</tr>
<tr>
<td>Dima</td>
<td>U.S.</td>
<td>Dalal</td>
<td>15</td>
<td>Attention-Deficit/Hyperactivity Disorder (ADHD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dawud</td>
<td>10</td>
<td>Speech or Language Impairment</td>
</tr>
<tr>
<td>Eqbal</td>
<td>Arab world</td>
<td>Ebtisam</td>
<td>9</td>
<td>Genetic Disorder*</td>
</tr>
<tr>
<td>Fawaz</td>
<td>Arab world</td>
<td>Faisal</td>
<td>11</td>
<td>Genetic Disorder*</td>
</tr>
</tbody>
</table>

*Note. These three parents did not refer to the categories of their children’s disabilities that were eligible for special education. Afaf did not remember the name of Ali’s identified disability, which for the purposes of categorization in this study was assumed to be a Specific Learning Disability (SLD). Eqbal and Fawaz did not specify the identified disability categories for their children. For categorization purposes in this study, these disabilities are listed as Genetic Disorders.

Afaf

Afaf was the mother of four children including 10-year-old Ali. Ali had recently been identified with a disability that required special education. For the purposes of classification in this study, Ali’s identified disability was surmised to be an SLD. Afaf and her family had been living in the U.S. for two years. Previously, Ali and his siblings
had been educated in private schools in their home country in the Arab world. When Ali enrolled in school in the U.S., he was identified as having difficulties with reading and writing. His mother asked his teachers to hold him back a year to allow him to improve his English academic skills. However, Ali did not show academic improvement and his teachers referred him for an evaluation for special education eligibility. He was then identified by his school’s evaluation team as having a disability that required special education.

The interview with Afaf occurred in her local public library. Upon meeting, she was reserved and hesitant about her speech in English. She spoke in English with a heavy accent and made several grammatical mistakes that are typical for Arab native speakers learning English (e.g., the use of the present tense when describing an event in the past). Afaf said her husband spoke less English than she did.

**Boshra**

Boshra was the mother of four children including eight-year-old Bassem, who was her third child. Boshra moved to the U.S. with her husband over two decades ago and gave birth to her children in the U.S. Bassem had an ASD that was diagnosed by a medical doctor when he was three years old. Bassem was nonverbal and he was sometimes violent toward others and himself. Boshra wished he could communicate with her. At school Bassem used PECS (Picture Exchange Communication System, which is a type of augmentative and alternative communication used with children with an ASD or other special needs; Bondy & Frost, 1994). However, Boshra chose not to use PECS at home.
Boshra invited me to her home for our interview. She was a *muhajiba*, which is a female who wears a *hijab* [the Islamic head covering] in public or around men not related to her. Boshra discussed her hijab during the interview and it is mentioned in one of her quotes later in this chapter. When we met she seemed quickly at ease. She spoke rapidly and laughed frequently. Boshra broke into tears while discussing certain upsetting memories and concerns she had experienced. During and after her fourth pregnancy she had struggled with Bassem’s violence against her. She shared that her husband had been unsupportive of her decision to have her fourth child. At the time of the interview, which was several months after her delivery, her husband had become supportive of Boshra’s decision and he and the entire family had begun to consider the baby to be a gift from God. Boshra reported Bassem’s behavior had improved at home since the birth of his baby sister and he seemed to be positively affected by her interactions with him.

At the time of the interview Boshra’s husband and some of their children had gone to visit their family in the Arab world for the summer. Boshra was preparing to leave soon with the remaining children once the school year ended. While there, Bassem would attend a boarding school for students with ASD. Boshra said she currently relied on her older children to help her with Bassem. She took comfort in knowing that they would continue to assist her with Bassem even more as they became older.

**Camilla**

Camilla was the mother of four children, three of whom had been enrolled in special education (Culthum, Cazem, and Carem). Camilla was born in the United States; her husband and her parents were born in the Arab world. Nine-year old Culthum had an
SLD; eight-year old Cazem had Asperger’s disorder; and seven-year-old Carem had an SLD. All three children were identified by their schools’ evaluation teams with disabilities that required special education.

Camilla invited me to her home for our interview. She was a muhajiba. At the beginning of the interview, Camilla wanted to establish why this research project was of interest to me and why it was a worthwhile topic to research. She had had experiences with her children in both public schools and private Islamic schools in the U.S. Camilla was the first member of her family to experience special education and she reflected that she had felt isolated as a result. A few years after she began the special education process, some of her cousins’ children were identified with ASDs. At the time of the interview, Camilla had three cousins with children identified with ASDs. Camilla said she spoke often with them about their experiences with their children.

**Dima**

Dima was the mother of five children, two of whom were in special education. Dima was born in the United States; her husband and father were born in the Arab world. Dima’s parents were of Arab descent. Dima’s first child to be identified with a disability requiring special education was Dalal, who was 15 years old and had ADHD that was identified several years earlier. A few years after Dalal’s identification, her younger son Dawud was also identified with a disability requiring special education services. Dawud was 10 years old and had a speech impairment. Both children’s disabilities were identified by their schools’ evaluation teams.
Dima’s interview occurred at her local library. She spoke quickly and loudly and she often punctuated her narrative with my name or a term of endearment such as sweetie. In the beginning of the interview, Dima answered a few questions and then began talking for several minutes without needing another question to prompt her. Dima spoke mostly about Dawud; she talked about her experiences with Dalal only if asked.

Eqbal

Eqbal was the mother of three children including nine-year-old Ebtisam. Eqbal and her family were born in the Arab world and had been living in the U.S. for three years. Ebtisam had a genetic disorder that affected her speech and cognitive abilities. At the age of six she was first diagnosed with a disability by a medical doctor in the Arab world.

Eqbal invited me to her home for our interview. She was a muhajiba. Eqbal was immediately friendly and talkative. She explained that she, her husband, and their children had intended to come to the U.S. only for brief treatment for Ebtisam. Her family planned for her to receive a cure in the U.S. and to then return home. Instead, the U.S. doctors explained that the original diagnosis had been incorrect and Ebtisam actually had a genetic disorder. Realizing that Ebtisam could not be cured, the family recognized she would be unable to receive special education or adequate therapy services in their home country. Therefore, they decided to stay in the U.S. for a longer time. Eqbal’s husband found work and their three children enrolled in local public schools.

During the interview, Eqbal spoke frequently about the Arab world and she contrasted daily life there with her experiences in the U.S. She also spoke frequently
about difficulties she had with her husband, who she explained was ashamed of Ebtisam’s disability, especially within his professional (medical) circles. Eqbal shared that they frequently argued about their stay in the U.S. and about the financial and professional impact it was having on their family.

**Fawaz**

Fawaz was the father of three children including 11-year-old Faisal. Fawaz and his wife had lived in the U.S. for two decades. When Faisal was four years old, a medical doctor diagnosed him with a genetic disorder that affected his gross and fine motor skills. As Fawaz explained, Faisal could still move “until he get like seven or something. Everything getting harder for him. Eight, nine he stopped walking.” Since the age of nine, Faisal’s mobility had continued to decline and he used a wheelchair.

Fawaz was interviewed at his place of work. He worked in a business that allowed him significant free time in which he was able to sit and speak freely. During the interview, Fawaz spoke quickly and without going into much detail. He did not voluntarily offer information beyond answering the questions I asked.

Fawaz expressed gratitude that Faisal could receive such comprehensive services inside and outside of the home in the U.S. As he explained, the living situation for a physically disabled individual in the U.S. was much better than for a physically disabled individual living in the Arab world. To illustrate, Faisal would not be able to attend school in their home country if they lived there, Fawaz said. Fawaz described situations when the family had visited their home country and found no public handicapped accessibility for Faisal. Faisal did not enjoy these trips.
Summary of Participants

All of the parent participants shared their individual experiences with the special education process. Their children’s disabilities included genetic disorders, ADHD, SLDs, ASDs, and speech or language impairments. The parents’ paths through special education were all unique, as were their experiences accepting and understanding their children’s disabilities and needs for special education services. The next section in this chapter reviews the research questions and phenomenological research.

Review of Research Questions and Phenomenological Research

The four research questions in this study were:

1. How do Arab American parents experience the process of their children being referred for special education evaluation and being identified as eligible for special education services?

2. Which aspects of Arab American parents’ experiences with the special education referral, evaluation, and identification process stand out as most significant to them?

3. How do the parents understand and contextualize their children’s identified disabilities and special education eligibility?

4. How have the parents’ expectations or plans for their children changed (if at all) as a result of their special education experiences?

As described in Chapter 2, phenomenological research is recommended when the researcher intends to examine the construction of personal and social worlds (McLeod, 2001). A phenomenological study explores—and seeks an understanding of—the
experiences of a group of individuals who have a shared experience or shared phenomenon. These phenomena can be unusual or they can be general, even mundane, to the participants (Creswell, 2013). In this study, the phenomenon being explored is the experience of having one’s child go through the special education process.

Phenomenological research is a process during which the researcher “learns to see naively and freshly again, to value conscious experience, to respect the evidence of one’s senses, and to move toward an intersubjective knowing of things, people, and everyday experiences” (Moustakas, 1994, p. 101). The phenomenological researcher must remain open for significance in the process of understanding a phenomenon (Giorgi, 1971). In this type of research, reality is considered to be how an individual assigns meaning to an experience (Creswell, 2013).

There are several approaches to phenomenological research (Giorgi & Giorgi, 2007). One approach, descriptive phenomenology, is set apart from other forms of phenomenology because the researcher utilizes epoché, which is also known as bracketing (Spiegelberg, 1965, 1975). In contrast, the interpretive approach to phenomenology requires the opposite: the researcher’s biases are instead “embedded and essential to interpretive process” (Laverty, 2003, p. 28). As described in Chapter 2, the descriptive approach was selected for this study because of its (a) emphasis on the description of the phenomenon without the researcher’s presuppositions and (b) usefulness when exploring un- or under-researched topics such as this study. In the next section, the steps of descriptive phenomenological data analysis are described.
Data Analysis

This section explains the data analysis process utilized in this study. As outlined in Chapter 2, descriptive phenomenological data analysis includes three main steps: *phenomenological reduction, imaginative variation, and synthesis* (Moustakas, 1994). *Epoché* occurs throughout the entire data analysis process (Patton, 1999). Although epoché is presented next as the first component in this data analysis section, it is not a separate step that is ever truly completed. Instead, it is an overarching activity and state of mind required of the phenomenological researcher employing a descriptive approach.

Epoché

The goal of epoché, or bracketing, is to eliminate the researcher’s bias or prejudgment throughout the entire phenomenological data analysis process (Moustakas, 1994). To engage in epoché the researcher avoids the following: assigning value to any one participant over another, judging experiences or participants, and becoming personally involved in the material (Balaban, 2002; Moustakas, 1994; Patton, 2001). The researcher determines nothing in advance of the data analysis and assumes no fixed position (Moustakas, 1994). This allows him or her to fully appreciate the participants’ experiences and to interpret their experiences without any personal bias (Moustakas, 1994). As described in Chapter 2, bracketing interviews round out this process of epoché. These epoché steps allowed me to be value-neutral during the data collection and data analysis.

The data analysis methodology utilized in this study is referred to as the modified Stevick-Colaizzi-Keen method (Moustakas, 1994). This method is endorsed by Creswell
(2013) as being more useful and practical than other versions modified by Moustakas. The three components of this method and their corresponding steps described by Moustakas (1994) are outlined below and then described in detail in the following three sections.

Phenomenological Reduction

1. Collect a full description of the experience and form a verbatim transcript.
2. From the verbatim transcript: consider statements for significance in describing the experience.
3. Record pertinent statements.
4. List nonoverlapping and nonrepetitive statements to identify invariant meaning units of the experience.
5. Cluster the invariant meaning units into themes.
6. Synthesize the invariant meaning units and themes into a textural description of the experience with verbatim examples.

Imaginative Variation

7. Reflect on the textural descriptions and create a structural description of the experience.
8. Construct individual textural-structural descriptions of the essences and meanings of the experience for each of the participants.

Synthesis
9. Combine the individual textural-structural descriptions to form a composite textural-structural synthesis description representing the group’s experiences as a whole.

**Phenomenological Reduction**

The process of phenomenological reduction is described as a constant “interweaving of person, conscious experience, and phenomenon” (Moustakas, 1994, p. 96). This interweaving is accomplished by the researcher focusing attention on the different experiences of the phenomenon and on “its presence and elucidation” (Moustakas, 1994, p. 91). Phenomenological reduction includes the steps listed above in #1 to #6.

The first step entails the researcher collecting a full description of each participant’s experiences of the phenomenon and creating a verbatim transcription (Moustakas, 1994). Within a few weeks of each interview, Kent State University’s Research and Evaluation Bureau had transcribed recordings of each of the six interviews. This allowed me to begin pouring over the transcriptions several times and to begin the next step.

The researcher then considers statements from the verbatim transcripts to identify significance in the participants’ experiences (Moustakas, 1994). In doing so, the researcher takes different perspectives on the narratives and treats each perspective equally while acknowledging the unique contribution each individual’s view makes to the body of research (Moustakas, 1994). Listening to the interviews as I read along with the transcriptions allowed me to better understand the participants’ overall experiences. I
then listened to the recordings and noted any behaviors that occurred during the
interviews that were not captured in the recordings. If new memories of my experiences
during the interviews arose or if I had new thoughts and reactions while reading and
listening to the interviews I reflected on—and bracketed—they in my reflexivity journal.

Next, I noted pertinent statements within the transcripts of the participants’
narratives to identify and consider meaning units related to the participants’ overall
experiences of the special education process (Moustakas, 1994). This overall process of
examining the data, giving equal weight to each piece, and identifying and considering
meaning units is called horizontalization (Moustakas, 1994). This is a “never ending
process and, though we may reach a stopping point and discontinue our perception of
something, the possibility for discovery is unlimited” (Moustakas, 1994, p. 95). Table 2
lists some example meaning units in the middle column. These meaning units come from
statements made by Afaf about her experience at the beginning of the special education
process for her son.

The following step is to list nonoverlapping and nonrepetitive statements to
identify invariant meaning units of the experience (Moustakas, 1994). To do so, I
reviewed the list of meaning units, refined the list by deleting irrelevant and repetitive
expressions and rephrasing vague expressions, and then identified the remaining meaning
units as the invariant meaning units (Moustakas, 1994). Throughout this step I engaged
in epoché by bracketing my emotional reactions, assumptions, and beliefs so I could
completely appreciate the data without my own biases interfering (Moustakas, 1994).
Table 2

*Identification of Invariant Meaning Units From Meaning Units*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Meaning Units</th>
<th>Invariant Meaning Units</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afaf</td>
<td>They say they have a program, you know what they call the program that it’s like ABT or something? OBT? I can’t remember.... They explain for me what this program say and how gonna do to Ali. And I said, “That’s okay.” Because special education—and some [Arab] people say like special education is for people who [have] something in the brain [that is wrong or damaged]. I said, “No, I can’t understand that because like I was teacher in my country. I know like how is, like, not all the kids in the same step. There’s different.” Then they did this [test] for him for everything: how he’s writing, how he’s reading, even how he used the bathroom, how he wash his hands to see if he, like if [when] he done from the bathroom he go to wash his hands or not. How he’s dress, like he took off his shoes he can put it on back . . . Then they called me later to tell me what’s going on and what’s the thing he need . . . [They told me] how like they found him nervous, and how was his attention, how he can understand [material] by TV or by the radio, or by the board, or by the teacher.</td>
<td>Was informed about special education program—with unmemorable name—for son Gave approval Explained general Arab belief: Special education is for people with some kind of brain damage Possessed knowledge about learning processes and different ability levels Special education evaluation included writing, reading, and daily living skills Was told results of evaluation and son’s needs. Results included son’s behavior, attention, comprehension</td>
</tr>
</tbody>
</table>

The right column of Table 2 illustrates the invariant meaning units identified from the meaning units discussed in the previous step.

It should be noted that Giorgi (2010), whose research and methodology has been cited in this research, recommended the researcher not delete repetitive statements. He
argued, “Such a procedure does not follow the phenomenological claim to be faithful to the experienced phenomenon because if there are repetitions in an experience then they belong there and probably have a disciplinary meaning” (Giorgi, 2010, p. 18). However, in this study I chose to closely follow the steps—including the deletion of repetitive statements—outlined by Moustakas (1994) in the modified Stevick-Keen-Colaizzi method. This is because it is through precisely this step in the data analysis process that the phenomenological researcher locates the invariant meaning units of the experience (Moustakas, 1994). I chose to follow Moustakas because I believed that the actual inclusion of the relevant statements was more important than the quantification of the relevant statements.

The next step in phenomenological reduction is the clustering of the invariant meaning units by thematic relationship (Moustakas, 1994). In other words, invariant meaning units that were related by topic or theme were grouped together to examine deeper layers of meaning in the data (Moustakas, 1994). These clustered invariant meaning units became the individual participant’s themes that expressed the spirit of his or her experience (Moustakas, 1994). Throughout this process I also bracketed my assumptions and emotional reactions. The invariant meaning units from Afaf’s experience, which are listed above in Table 2, are now grouped into individual participant themes in Table 3.
Table 3

*Individual Participant Themes*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Individual Participant Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afaf</td>
<td></td>
</tr>
<tr>
<td></td>
<td>I. Referral</td>
</tr>
<tr>
<td></td>
<td>• Being informed by staff about a special education program with an unmemorable name for her son</td>
</tr>
<tr>
<td></td>
<td>• Giving approval</td>
</tr>
<tr>
<td></td>
<td>II. Cultural Belief</td>
</tr>
<tr>
<td></td>
<td>• Knowing some Arabs believe special education is for people with some brain damage</td>
</tr>
<tr>
<td></td>
<td>• Having previous knowledge about the processes of learning and different ability levels</td>
</tr>
<tr>
<td></td>
<td>III. Identification</td>
</tr>
<tr>
<td></td>
<td>• Knowing her son was evaluated in the areas of writing, reading, and daily living skills</td>
</tr>
<tr>
<td></td>
<td>• Hearing her son’s evaluation results including his behavior, attention, comprehension, and what he needed in special education</td>
</tr>
</tbody>
</table>

The final step in phenomenological reduction is the synthesis of the invariant meaning units and individual participant themes into an *individual textural description* of the experiences (Moustakas, 1994). A textural description is a descriptive account of an individual’s experiences that relates to what occurred and what formed the essence of the experience (Creswell, 2013; Moustakas, 1994). Table 4 illustrates the individual textural description that emerged from Afaf’s individual participant themes above.

**Imaginative Variation**

Imaginative variation has its name because the researcher imagines and intuits beyond the surface of the data to understand the underlying contributing, or structural, themes in the phenomenon that account for how it was experienced (Moustakas, 1994).
Table 4

*Individual Textural Description*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Individual Textural Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afaf</td>
<td>The parent’s experience of the referral included learning about the special education program and giving permission for an evaluation. The parent did not remember the acronym name of the special education program. The parent reported not feeling upset during the referral meeting about the prospect of special education for her son because of her professional training in education. However, the parent said she knows other Arabs who believe, “special education is for people who [have] something in the brain [that is wrong or damaged].” At the eligibility determination meeting the parent was told “what’s going on and what’s the thing [her son] need.” This information included the evaluation results of her son’s behavior, attention, and comprehension/information processing, as well as the identification of his special education needs.</td>
</tr>
</tbody>
</table>

In the section above, textural descriptions were defined. It is important to also define structural descriptions and distinguish between the two types of descriptions. *Textural* descriptions relate to how the phenomenon was experienced in terms of what occurred; *structural* descriptions relate to the researcher’s reflections on how the participant’s experience of the phenomenon came to be what it is (Creswell, 2013; Moustakas, 1994). In other words, a structural description explains the dynamics of the participant’s experience that could account for how the phenomenon was experienced (Creswell, 2013; Moustakas, 1994).

During imaginative variation, the researcher engages in two crucial steps: (a) *reflection on the textural descriptions to create structural descriptions* of the experience and (b) *construction of individual textural-structural descriptions* of the essences and meanings of the experience for each of the participants (Moustakas, 1994).
As I began to reflect on textural descriptions to create structural descriptions I followed Moustakas’ (1994) recommendations to not blindly accept a description of a phenomenon at face value. Instead, I considered descriptions from all angles of interpretation and made opposite suppositions (Moustakas, 1994). These angles of interpretation and opposite suppositions are called free fantasy variations (Moustakas, 1994). I was conscious of the possible structural dynamics that could have accounted for the individual’s textural descriptions (Moustakas, 1994). Additionally, I constantly challenged my thoughts and imagined contrasting reasons (Moustakas, 1994). These steps were necessary to ensure I was considering participants’ experiences from all vantage points and not inserting my own assumptions or perspectives into their experiences (Moustakas, 1994). Table 5 illustrates the individual structural description formed from Afaf’s individual textural description above.

Table 5

<table>
<thead>
<tr>
<th>Participant</th>
<th>Individual Structural Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afaf</td>
<td>The referral and identification were separate and significant experiences within the participant’s experience of the special education process. The referral to special education brought up for the parent an awareness of other Arabs’ beliefs about special education being for people with damage to their brain. The parent had had professional training to know this is not accurate. The identification process gave the parent quantifiable knowledge and measurements of her son’s academic abilities, daily living skills, and learning style. She ultimately chose to keep her son’s special education eligibility and enrollment a secret. The implication is that something about his eligibility and enrollment is worth being kept secret or is shameful to her.</td>
</tr>
</tbody>
</table>
The second step of imaginative variation is the *construction of individual textural-structural descriptions* of the essences and meanings of the experience for each of the participants (Moustakas, 1994). During this step I was able to look deeper into the data to perceive more complex meanings for the individual regarding the experience (Patton, 2001). Each participant’s individual textural-structural descriptions included the invariant meaning units and themes identified in the above manner (Moustakas, 1994).

Imaginative variation, as explained above, requires the researcher to intuit and imagine beyond the surface of the data (Moustakas, 1994). Giorgi (1989) argued that this process is imaginative rather than empirical. Due to the imagination required in this process, it is worthwhile to briefly review how the issue of trustworthiness has been considered and addressed during this study. As detailed in Chapter 2, throughout this study I utilized the following techniques to establish trustworthiness: reflexivity journal, époché/bracketing, reflection on the bracketing interview, peer debriefing, the phenomenological reduction and imaginative variation steps described above, and reliance on my own judgment. The next section discusses the final step of summative synthesis and core theme identification.

**Summative Synthesis and Identification of Core Themes**

During this final step of phenomenological data analysis, all of the participants’ individual textural-structural descriptions are combined to form a *composite textural-structural synthesis* representing the group’s experiences as a whole (Moustakas, 1994). This synthesis embodies the collective essences and meanings of the groups’ experiences of the phenomenon (Moustakas, 1994; Polkinghorne, 2005). In describing this final
stage, Moustakas (1994) noted that determining “the essences of any experience are never totally exhausted” (p. 100). Instead, the researcher synthesizes the individual textural-structural descriptions into a composite that “represents the essences at a particular time and place from the vantage point of an individual researcher following an exhaustive imaginative and reflective study of the phenomenon” (Moustakas, 1994, p. 100).

Some qualitative researchers follow van Kaam’s (1966) approach to data analysis, in which an essential structural element must occur in the narratives of at least half of the participants for it to be considered essential to the analysis. If that approach was followed in this study, at least three of the six participants would have been required to form a majority. I believed that following van Kaam’s approach with the six participants would have been dismissive of meaningful data: I would have been prevented from including meaningful themes if they happened to be based on only two participants’ narratives rather than three. Also, requiring a majority would have invalidated and disregarded the natural variation and richness within participants’ individual narratives.

Thomas and Pollio (2002) advised against van Kaam’s approach and instead recommended that the phenomenological researcher should rely “less on quantification and more on reflection about recurring patterns in the data” (p. 37). I followed their advice. Therefore, in this final step of composite textural-structural description synthesis and core theme identification I chose to include essences of experiences that were also unique to one or two participants rather than include only those that were shared by three or more participants.
The analysis of the data identified four distinct core themes around the participants’ experiences with the special education process. The core themes are summarized in this list below and then described in detail in the following section:

1. Each participant experienced his or her child’s referral for evaluation and identification with a disability as separate steps within the special education process; several parents also had culture-specific concerns about their children’s futures.

2. The special education process included two significant aspects for participants: their children’s special education services and the key relationships the parents built or maintained during the special education process.

3. Parents reflected on many topics related to their children’s disabilities and eligibility for special education: the children’s abilities and difficulties, parents’ own understandings of special needs and of special education, and the importance of some parents’ own advocacy work.

4. Parents reported having unchanged expectations, plans, and goals for their children after experiencing the special education process; parents’ present goals for their children did, however, appear to be impacted by and tailored to their children’s disabilities and abilities.

The final section of this chapter details the above core themes that emerged from the data analysis. Table 6 links the research questions with their related core themes. The
core themes are discussed below in detail using illustrations from participants’ narratives, beginning with Core Theme 1.

Table 6

Research Questions and Core Themes

<table>
<thead>
<tr>
<th>Research Questions</th>
<th>Core Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>How do Arab American parents experience the process of their children being referred for special education evaluation and being identified as eligible for special education services?</td>
<td>Each participant experienced his or her child’s referral for evaluation and identification with a disability as separate steps within the special education process; several parents also had culture-specific concerns about their children’s futures.</td>
</tr>
<tr>
<td>Which aspects of Arab American parents’ experiences with the special education referral, evaluation, and identification process stand out as most significant to them?</td>
<td>The special education process included two significant aspects for participants: their children’s special education services and the key relationships the parents built or maintained during the special education process.</td>
</tr>
<tr>
<td>How do the parents understand and contextualize their children’s identified disabilities and special education eligibility?</td>
<td>Parents reflected on many topics related to their children’s disabilities and eligibility for special education: the children’s strengths and difficulties, parents’ own understandings of special needs and of special education, and the importance of some parents’ own advocacy work.</td>
</tr>
<tr>
<td>How have the parents’ expectations or plans for their children changed (if at all) as a result of their special education experiences?</td>
<td>Parents reported having unchanged expectations, plans, and goals for their children after experiencing the special education process; parents’ present goals for their children did, however, appear to be impacted by and tailored to their children’s disabilities and abilities.</td>
</tr>
</tbody>
</table>

Core Theme 1

Each participant experienced his or her child’s referral for evaluation and identification with a disability as separate steps within the special education process; several parents also had culture-specific concerns about their children’s futures.
As discussed in Chapter 1, IDEA was last amended by Congress in 2004 with House Bill 1350 and guarantees services to children with disabilities throughout the U.S. (U.S. Department of Education, 2006). IDEA governs early intervention, special education, and related services to individuals with disabilities between the ages of birth to two and three to 21 (U.S. Department of Education, 2006). IDEA includes a list of the disability categories requiring special education: autism, emotional disturbance, hearing impairment including deafness, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, SLD, speech or language impairment, traumatic brain injury, and visual impairment including blindness (U.S. Department of Education, 2006).

This study’s first research question asks how Arab American parents experience the process of their child being formally or informally referred for special education assessment and identified with a disability requiring special education services. After completing the data analysis steps, Core Theme 1 became clear: parent participants experienced their children’s referrals and identification with disabilities as separate steps within the special education process and many experienced accompanying culture-specific concerns. The next section begins with parents’ experiences of the referral process including the sources of their referrals.

**Referral**

In special education, referrals are requests for an initial evaluation for special education eligibility that come from a parent, school district, or other education agency (ODE/OEC, 2012). Referrals from the school district originate from the school’s
evaluation team who determine eligibility for special education services. This evaluation team includes at least one of the student’s teachers, at least one special education teacher, a representative of the school district, a person such as a school psychologist to explain the effects of the evaluation results on teaching, and any other professional such as related services personnel who has knowledge of the student (ODE/OEC, 2012).

Each of the six parent participants discussed the referral process for their children. The time of their referrals varied: one child was referred for early intervention before her first birthday; others were already in grade school at the time the referrals were first made. The individuals who made referrals were either school personnel or the parent. Five of the six parent participants received a referral from school staff; one parent made the referral on her own.

**Parent.** Eqbal was the only parent to initiate the referral herself. She did so because she noticed delayed and atypical development in Ebtisam. Eqbal became concerned about her daughter’s motor and verbal development when Ebtisam was around nine months old. At that point Eqbal began taking Ebtisam to physiotherapy and speech therapy and later to doctors for a diagnosis. This occurred while Eqbal and her family were living in their home country in the Arab world. Ebtisam’s diagnostic process is detailed in the next section on identification. The remaining five parents received referrals from school staff, which are discussed next.

**School staff.** The majority of the participants received the referral for special education assessment from school personnel. Sometimes these referrals came during involvement in early intervention, which is a program to identify disabilities and to
address developmental delays in children ages birth to three (ODE/OEC, 2012).

Following are the specifics of each of the five parents’ referral experiences from school staff.

Bassem was enrolled in an early intervention program and was receiving speech therapy services in the home. His speech therapist encouraged Boshra to pursue an evaluation for her son. “She told me, ‘Your son this and that’ but she can’t tell me that like he is autistic. Officially she can’t. She said, ‘Just tell the doctor I told you this and that.’” Boshra recalled the speech therapist’s concerns about Bassem’s lack of eye contact, repetitive play, and picky eating. The speech therapist’s encouragement ultimately prompted Boshra to pursue an evaluation for an ASD.

Previous to her interactions with the speech therapist, Boshra had been unfamiliar with what an ASD was. A few years earlier, her sister had suggested to Boshra that she consider getting Bassem evaluated by a doctor. Boshra reported ignoring her sister’s recommendation: “[My sister] saw Bassem and she heard the news about autism in Arabic and she was telling my mom, ‘I’m afraid Bassem is autistic.’ But we were laughing at her.” During Boshra’s interview she said she later regretted not having originally asked her sister for more information about ASDs.

Dima was the second parent who received a referral from an early intervention program. She was born in the U.S. At the time of the interview, she had two children who had received special education services: 15-year-old Dalal and 10-year-old Dawud. Teachers had referred both children for special education evaluations. The first referral for evaluation was for Dalal, who was in an early intervention program and demonstrated
language delays. Dima recalled the teacher saying, “Your daughter, I think she’s not comprehending things that are going on. What I’m talking to her about she’s not understanding.” At the time, Dima suspected that the language delays were because speaking both English and Arabic had confused Dalal. Dima recalled being hesitant and “in denial” about Dalal’s language delays. The teacher pushed Dima further until she agreed to an evaluation. Looking back on the first referral, Dima reflected, “I’m so happy that [the teacher] kind of picked up on it, which I didn’t pick up on it.” Dima’s emotions around Dalal’s referral were doubt, hesitation, and then gratitude.

Years later, Dima experienced less denial when Dawud was referred due to his delays and his need for an evaluation to determine special education eligibility. Dawud had lost his hearing when he was one month old. Doctors had inserted tubes into Dawud’s ears but soon thereafter he began getting ear infections. Dima remembered, “He started getting fluid behind the ear, that’s what they said caused him for his speech to be delayed and for him to lose a little bit of hearing.” At the age of two, Dawud began speech therapy with an early intervention program. During preschool, his teacher encouraged Dima to get Dawud a special education evaluation. Dima said that when the teacher made this recommendation, “I was not hesitant. I was not hesitant. I was with Dalal but not with Dawud. I got over it with Dalal and [with Dawud] I said, ‘No, let me shut up and let me go see this.’” When Dima looked back on Dawud’s referral experience she warmly remembered his preschool teacher’s encouragement and support.

The remaining three participants received a referral immediately upon their children beginning school in the U.S. Fawaz recalled the referral for his son Faisal
occurring when he entered preschool. Faisal had delayed motor skill development and Fawaz recalled, “The teacher notice it right away: he is not moving like other kids.” Upon receiving the referral from school personnel, Fawaz pursued an evaluation with Faisal’s medical doctor to determine the cause of his motor delays. The medical diagnosis of Faisal’s genetic disorder is discussed in the next section on identification.

Camilla had long been aware that her son Cazem had severe speech delays and preferred repetitive play. He was sensitive to any deviation from his routine and threw frequent tantrums when someone disrupted his preferred activities. Well before any of Camilla’s children were evaluated for eligibility for special education services, Camilla’s cousin suggested to Camilla that Cazem might have an ASD. Camilla remembered: “Cazem was still a little child and I guess she spotted [his exceptionality] because she knew.” Camilla noted that her reaction to her cousin’s suggestion was denial; she did not pursue the matter.

A few years later when Cazem started kindergarten his teacher spoke to Camilla about Cazem’s atypical socialization. Camilla recalled, “I was already traumatized that the kid was having problems in general. She just used all the wrong words. She didn’t come at me the right way.” Camilla was still emotional about the encounter when she spoke about it during the interview. She appeared angry and sounded distressed as she described Cazem’s teacher: “She had no heart the way she came at me.”

Ultimately, it was Cazem’s speech pathologist who directly confronted Camilla with the reality that her son might have an ASD. During this pivotal conversation the speech pathologist demonstrated for Camilla that Cazem avoided eye contact: “Cazem
looked everywhere but her eyes. So then that was—I was—I burst into tears. It was obvious. That’s it; there was no changing it. It was so traumatizing for me.” Camilla’s resistance and difficulty accepting Cazem’s referral for an evaluation and eventual identification with a disability are discussed further in Core Theme 3.

Afaf and her family moved to the U.S. when Ali was the age to enroll in third grade. When he entered school, Ali’s teachers noticed he was struggling with reading and writing in English. Therefore, Afaf asked that Ali be placed in second grade so he would not be dramatically behind in comparison to his peers. After Ali continued to struggle, his school’s evaluation team referred him for a special education evaluation, to which Afaf consented.

**Summary.** Altogether, school staff initiated the referral process for the majority of the participants either during early intervention programs or once the child entered school. One parent also made the referral herself. The parents differed in their initial willingness to accept the referrals and their emotions ranged from denial to anger and from gratitude to sadness. Some parents described the referral process as having been emotional; some became emotional in the interviews, exhibiting tears or strong words as they described their experiences of the process.

Once a referral for a special education eligibility evaluation is made and parents give their consent, the evaluation process begins (ODE/OEC, 2012). Every parent participant in this study agreed to proceed with his or her child’s evaluation. As a result of the evaluation process, the participants’ children were determined to be eligible under
IDEA due to their identification with a disability requiring special education. The next section reviews the identification experience for the parent participants.

**Identification**

As discussed in Chapter 1, after a referral the next step in the special education process is an evaluation for special education eligibility. The children in this study experienced two distinct routes to being identified with a disability that was eligible for special education. One set of children was evaluated and identified entirely in the school. Another set of children was initially evaluated by a medical doctor and then was determined to be eligible for special education services within the school setting.

Three participants’ children were referred for special education evaluations by school staff. Afaf, Camilla, and Dima’s children were deemed eligible for special education services after being identified by their schools’ special education evaluation teams as having disabilities under IDEA. The children’s disabilities were determined to be negatively affecting their performances in school, which then made them eligible for special education services.

In contrast, the other three participants’ children were referred for a special education evaluation after they had been evaluated by a medical doctor and diagnosed with a medical disability. Boshra, Eqbal, and Fawaz’s children were deemed eligible for special education services after each was diagnosed with a medical disability by a medical doctor and then evaluated by the schools’ special education evaluation teams to determine if the disabilities were included under IDEA. Their disabilities did not automatically make them eligible for special education services; instead, the evaluation
teams determined that their disabilities were negatively affecting their performance in school and they were deemed eligible for special education services.

As discussed in Chapter 1, it is well established that a parent receiving the news that his or her child has a disability can experience negative emotions (e.g., Hatton et al., 2003). Parents must reconcile the news and sometimes even mourn the loss of the future plans they had for their children (Bowlby, 1980; Leerkes & Burney, 2007; Marvin & Pianta, 1996; Moses, 1987). This can result in denial, which is a common parental reaction (Ho & Keiley, 2003).

This section reviews participants’ experiences related to their children being identified by school evaluation teams or medical doctors as having a disability that caused them to be eligible for special education services. The participants’ experiences are categorized by whether a medical doctor or a school evaluation team identified the disability. All six participants mentioned the identification process. The group of participants was balanced in terms of who identified their children’s disabilities: three parents received a diagnosis from medical doctors outside of school; three parents learned about their children’s identified disabilities and eligibility for special education services from the evaluation team at eligibility determination meetings. The children who were diagnosed with a medical disability by doctors had a genetic disorder or a severe ASD; the children identified by school staff had an SLD, a speech or language impairment, or a less severe ASD. Table 7 outlines the individuals who identified the children’s disabilities to the participants and includes the parents’ reactions to the identification.
The next section reviews the experiences of parents whose children were diagnosed by medical doctors.

Table 7

<table>
<thead>
<tr>
<th>Identification Source</th>
<th>Participant</th>
<th>Parents’ Reactions to Identification</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor</td>
<td>Boshra</td>
<td>Parent struggled with the diagnosis, with child’s behavior in public, and with attention from strangers</td>
</tr>
<tr>
<td></td>
<td>Eqbal</td>
<td>Parents chose to stay in U.S. for treatment and special education services for child</td>
</tr>
<tr>
<td></td>
<td>Fawaz</td>
<td>Parent began therapies for child soon after identification</td>
</tr>
<tr>
<td>School Staff</td>
<td>Afaf</td>
<td>Parent re-read report at home to fully understand language</td>
</tr>
<tr>
<td></td>
<td>Dima</td>
<td>Parent experienced frustration that her first child was not quickly evaluated or identified as eligible for special education</td>
</tr>
<tr>
<td></td>
<td>Camilla</td>
<td>Parent was resistant to school staff’s identification of her child because she imagined him having a limited future</td>
</tr>
</tbody>
</table>

**Doctor.** Boshra, Eqbal, and Fawaz were the three parents who received diagnoses for their children from medical doctors. In Boshra’s case, Bassem’s speech therapist referred Bassem to a specialist who then diagnosed an ASD. Boshra recounted the diagnosis experience as “hard, very hard.” Her difficult experience accepting the diagnosis was closely connected to her awareness of strangers’ attention to and confusion about her son’s peculiar behaviors, such as his tendency to scream in public. During such experiences she felt it was imperative to explain to others about Bassem’s disability and the reason for his behaviors. Her acts of advocacy are discussed in Core Theme 3.
Eqbal’s path to a correct diagnosis for her daughter Ebtisam spanned several years and included medical consultations in her home country and in the U.S. When Ebtisam was an infant, Eqbal noticed her daughter’s developmental delays. At that time, the family was living in the Arab world and the doctors there gave Ebtisam what would later be discovered to be an incorrect diagnosis. When Eqbal and her family came to the U.S. for further medical consultation they believed Ebtisam would receive a quick operation to cure her and “everything would be solved.” However, U.S. doctors diagnosed Ebtisam with a genetic disorder that affected her speech and cognitive skills and that required intensive therapy. Upon hearing the diagnosis, Eqbal and her husband decided to stay in the U.S. with all three of their children so Ebtisam could receive special education and better treatment than was possible in their home country. Therefore, the decisions made as a result of the correct U.S. diagnosis had a direct and immediate effect on all of the family members’ lives. The educational and social implications of the family’s emigration are discussed in the following core theme sections.

As mentioned in the above section on referral, when Fawaz’s son Faisal entered preschool his teachers noticed delays in his gross motor skills. Upon their recommendation, Fawaz took Faisal to his pediatrician. After doing blood work, the doctor reported that Faisal had a genetic disorder that affected his motor skills. Fawaz said that a few months after the diagnosis, special education services began for Faisal: “And then we start [down] the road.” Fawaz’s experience with the diagnostic process was closely connected with the commencement of special education services that will continue for Faisal’s entire educational career. Altogether, the diagnoses that these three
parents received from medical doctors were an ASD and genetic disorders. The next section relates to the identification of disabilities that were made by school staff.

**School staff.** The three parents whose children were identified with disabilities by school staff were Afaf, Dima, and Camilla. Afaf said that each piece of Ali’s evaluation was explained to her at his eligibility determination meeting. She recalled that members of the evaluation team had told her, “They found him nervous, and how was his attention, how he can understand [material] by TV or by the radio, or by the board, or by the teacher.” Afaf was also told that Ali had a disability that qualified him for special education services. She said that the school’s evaluation team explained the evaluation report clearly to her; however, when Afaf was at home about two weeks later she needed to read the report more closely to better understand the language of the evaluation and the disability identification.

It is worth noting that Afaf was the only one of the six participants who did not know the name of her child’s identified disability. She knew Ali was receiving special education services and in which academic areas but when she was asked in her interview about his identified disability she said she did not know its name. For the purposes of classification and based on Afaf’s report of Ali’s areas of weakness and special education services, it will be assumed that he was identified with an SLD.

Dima also went through the identification process with school staff. She experienced frustration during her first experience with the special education process for her daughter Dalal. As Dima reported, the process was not straightforward or quick:
When [Dalal] was three years old [the school psychologist] tested her; she tested real low. They tested her again when she was four; she tested real low. We got her to kindergarten. I begged them, “Please test my daughter. I want to get her an IEP. I want to see where my daughter is at.” They never did.

Finally, Dalal was evaluated in fourth grade and identified with ADHD. Dima recalled a member of the evaluation team sharing the results of the evaluation: “She told me that my daughter would—every kid would sit and focus. My daughter would just space out, wandering off. She wasn’t comprehending and she had a little bit of delay with how she put the words together.” Altogether, Dima experienced frustration around Dalal’s identification process because the evaluation occurred years later than she had hoped it would.

In contrast, Dawud’s evaluation process was experienced by Dima as faster and much more straightforward: “I went through [the process] with my daughter but it was not as well as it is with Dawud . . . We made an appointment for [Dawud] to be tested. They tested him and he qualified for special ed.” Dima’s second experience with the identification process felt less complicated and also less upsetting to her.

Camilla was the third parent who learned of her child’s identified disability from school staff. She recalled feeling concern and dread when she heard that her son Cazem had Asperger’s, an ASD, and qualified for special education services. She remembered what her immediate concern had been when she heard about the daily living skills Cazem would be taught in school: “The first thing that came to my head—you know how they have usually one or two people that work in a supermarket that [are] not normal? That’s
the first thing that came to my head.” Camilla envisioned Cazem’s future being limited to repetitive and menial tasks. She was resistant to some special education services proposed by the school such as PECS (Picture Exchange Communication System). She said she “had a little tantrum” as she fearfully envisioned her son as an adult being unable to socialize and communicate typically. Camilla’s concerns also had a cultural component that is discussed in the next section. Altogether, Afaf, Dima, and Camilla had children who were identified with disabilities by school evaluation teams. The disabilities included an SLD, ADHD, speech or language impairment, and an ASD.

**Summary.** Overall, half of the participants had children who were identified with disabilities by medical doctors and half had children identified by school evaluation teams. When comparing the identification sources, the two children with more medically based disabilities (e.g., genetic disorders) and one nonverbal child with an ASD were diagnosed by medical doctors; those children with SLDs, speech/ language impairments, ADHD, and Asperger’s were identified by school staff.

The identification process can be a highly emotional process for parents (e.g., Singer & Powers, 1993). Parent participants reported experiencing a variety of reactions to the identification of their children’s disabilities including relief, frustration, confusion, and anxiety. The next section relates to the parents’ concerns that can be categorized as culture-specific based on what is known about Arab and Arab American culture.

**Culture-Specific Concerns**

As discussed in Chapter 1, the Arab culture highly values individuals’—and by extension, families’—reputations (El-Aswad, 2006). Additionally, there is a cultural
imperative to marry and have children (Gregg, 2005; Inhorn, 2012). A stigma and strong sense of shame often exist around disabilities for Arabs and Arab Americans (Haboush, 2007; Sharifzadeh, 1998). Therefore, these Arab American parent participants, who were already conscious of their culture’s perspectives and beliefs about disabilities and of the potential impact of a disability on their family’s reputation, were attuned to any negative perceptions of their children’s disabilities. These perceptions could have existed within their culture, communities, and families.

As discussed above in the referral and identification sections, several parents reported experiencing denial during these processes. Another frequent parental reaction was to have concerns and fears about the children’s futures. Although there were no specific interview questions to generate such discussions, four parents (Camilla, Eqbal, Dima, and Afaf) spontaneously shared their concerns connected to their culture’s values and beliefs about disabilities. Their concerns included the potential for limited marriage prospects and generally negative associations with the term special education. Table 8 summarizes the participants’ culture-specific concerns about the future for their children or for Arab and Arab American children in general. Discussed first is the most frequently cited culture-specific concern, which was about the potential for eventual difficulty when searching for a marriage partner.
Table 8

*Parents’ Culture-Specific Concerns for Children*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Parents’ Culture-Specific Concerns for Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Camilla</td>
<td>Parent’s child would later have difficulty finding a marriage partner and therefore having children</td>
</tr>
<tr>
<td>Eqbal</td>
<td>Children in general would later have difficulty finding a marriage partner</td>
</tr>
<tr>
<td>Dima</td>
<td>Children in general would later have difficulty finding a marriage partner; Parent was aware that in the Arab culture special education had a pejorative association</td>
</tr>
<tr>
<td>Afaf</td>
<td>Parent was aware that in the Arab culture special education had a pejorative association</td>
</tr>
</tbody>
</table>

**Marriage.** As discussed above, Arab culture emphasizes marriage and includes the imperative to have children (Gregg, 2005; Inhorn, 2012). Three of the parent participants, Camilla, Eqbal, and Dima, discussed their culture-specific concerns. Concerns included the marriage prospects of an Arab or Arab American individual with an identified disability.

When Camilla recalled her experience with Cazem, her first child to go through the special education process, she described it as “traumatizing.” Her culture-specific concerns began when she first heard Cazem’s diagnosis:

Even with the Arab mentality—you see with anybody else—if I told a White lady, “Well hey, your kid has a problem.” Me: “Is my son going to be able to get married and have children? Am I going to be able to see that?” That’s the first thing that pops into my head.
Camilla’s first concern was for Cazem’s ability to marry and have children. She was not worried about Cazem’s physical capacity to have children but instead about the marriage prospects he would have as an adult with a disability. The news that Cazem required special education evoked Camilla’s immediate worries about his ability in a couple of decades to have his own family.

Eqbal and Dima did not discuss concerns specifically about their own children’s futures. Instead, they considered the general cultural implications for an Arab individual with a disability and the ramifications for that individual’s siblings. In reference to Arab men, Eqbal said, “They don’t marry from these [disabled] girls or the girl’s sisters. Or if there is a man and he has a brother like this they don’t like to marry from him because he can [pass it along].” Dima referred to similar difficulties for Arab girls with a disability: “Especially with the Arabic girls getting married young those men want to see those girls perfect. . . . In the Arabic community you’ve got to be perfect. You can’t have no mistakes.” Thus, these three participants shared their concerns about the potential consequences on the marriage prospects for Arab and Arab American individuals with disabilities as well as for their families. The parents’ second concern was for an Arab American individual to be associated with the term special education.

**Association with special education.** Dima and Afaf discussed the term *special education* and its different cultural associations in English and Arabic. Dima explained that when someone from “the Arabic community” knows a child is enrolled in special education he or she typically says, “Oh, they’re retarded. There’s something wrong with them. They wasn’t born right.” Dima said, “[Arabs] don’t want you to be special ed.
They don’t want you to get those tools.” She related how this negative association around special education had affected her daughter Dalal:

It hurts Dalal when somebody Arabic knows [she is in special education].

Because in her school there is not one Arab person in that school. So she’s confident about that but when [Arab American students] know she’s in special ed they make fun of her. It’s not the American kids; it’s Arabic kids: “Oh, you’re LD [learning disabled]. Oh, you’re this. Oh, you’re that.” That’s how the Arabic community carries themselves when they see a child that needs those services in the special ed: “Oh, they’re LD.”

Dima surmised that because of this negative association several Arab American parents kept their children’s enrollment in special education a secret. She said, “I bet you any amount of money . . . some [Arab American parents enrolled their] kids in those [special education] programs but nobody knows about it. . . . It’s kept secret. It really is.”

Afaf acknowledged similar negative meanings and connotations when *special education* is said in Arabic. As discussed in Chapter 1, the Arabic terminology for special education is pejorative. Afaf noted this when she described the Arabic term for special education. She explained that when it is translated into English it means the individual has “something in the brain [that is wrong or damaged].” Afaf had been trained as a teacher in her country of origin and she explained that because of her higher education she personally did not assign a stigma to students in special education.

As mentioned earlier, Afaf told only her husband about Ali’s identification with a disability and eligibility for special education. She did not tell any other family members
or friends because “maybe they would not understand.” She recalled a recent experience when Ali’s older sisters had seen Afaf reading a document in Arabic about the special education process that had been provided to Afaf by Ali’s school. Ali’s sisters asked their mother why she was reading such a document and instead of telling them about Ali’s enrollment in special education, Afaf lied and said it was training material related to her daycare job.

To further illustrate the offensiveness of the term *special education* to Arabs and Arab Americans, Afaf shared the experience of an Arab American father who was told by the evaluation team at Ali’s school that his own son required special education. Afaf shared, “When they call him to the meeting he was like nervous. He was saying [some] bad words for the teachers, like: ‘My son is not like [that]!!’” Afaf was not surprised by his reaction; instead she thought that it was predictable based on their culture’s beliefs. This cultural belief about special education is summarized below.

**Summary.** Culture-specific concerns arose during interviews with four of the six participants. The four parents spontaneously shared their concerns for their own children and for any Arab or Arab American child within a culture that stigmatizes special education and disabilities. Dalal and Afaf envisioned the far-reaching consequences of attaching the term *special education* to a child and his or her family. These consequences included poor future marriage prospects for the entire family. It also meant that they would be associated with a pejorative and humiliating term.

In summary, the first research question asks how Arab American parents experience the process of their children’s referral for special education evaluation and
identification with a disability that requires special education. Core Theme 1 explains the significance of patterns in participants’ experiences of the referral and identification processes, as well as patterns in their concerns relating to cultural perspectives on special education and disabilities. The next section introduces Core Theme 2, which describes the aspects of the special education experience that were most significant to the parent participants. These significant aspects include the special education services that their children received and the parents’ key relationships during the special education process.

**Core Theme 2**

The special education process included two significant aspects for participants: their children’s special education services and the key relationships parents built or maintained during the special education process.

In the previous core theme’s section, parents recalled their experiences with the referral and identification process. It follows that their recollections would include a review of what was notable to them during these experiences. This section on Core Theme 2 addresses the two significant aspects of the participants’ special education experiences: their children’s special education services and their own key relationships during the special education process. First to be discussed are the children’s special education services.

**Special Education Services**

As discussed in Chapter 1, the individualized educational plan, or IEP, is a written legal document that outlines the educational goals and objectives for a child with a disability as well as the specific special education services and supports the child will
receive to meet the goals and objectives identified for programming (ODE/OEC, 2011).

This plan describes the child’s need for specially designed instruction, related services, and accommodations. Related services assist a child’s success with special education including physical and occupational therapy, speech-language pathology services, and psychological services (ODE/OEC, 2011). Additionally, accommodations can be made in the child’s assessment, presentation of material, response style, location of instruction, and timing and scheduling of instructional activities (ODE/OEC, 2011).

One significant aspect of the parent participants’ experiences with the special education process was their children’s special education services. As discussed in this section, the participants in this study had experiences with the following special education services: (a) specially designed instruction, (b) physical and occupational therapy, (c) speech-language pathology services, and (d) accommodations in assessment, timing, and scheduling. Although the parents did not directly receive the services themselves, they were highly attuned to the provision of the services to their children. During the interviews, participants shared their own perceptions of the services and the interactions they had had relating to the provision of these services. None of the parents were asked specifically about the special education services their children received although they all referred to the services and did so spontaneously. Therefore, some children might have been receiving other services in addition to what their parents mentioned below.

Overall, the parents’ experiences with special education services were important and meaningful to them. Some parents, such as Dima, expressed appreciation that their
children had grown and improved as a result of the services. She explained, “I’m very happy that he is in special ed because if it wasn’t for special ed he would not get the help that he is getting now. It really benefited him and benefited me that my son progressed.” Fawaz’s perspective on his son’s special education services was also positive. He shared, “They help his situation a lot. Without the help you can’t make it.”

All six of the parent participants said their children’s special education services included specially designed instruction that typically was not provided in the general education curriculum. Three of the six parents also described their children’s speech-language pathology services, three parents mentioned physical and occupational therapy, two parents described assistance during assessments, and one parent talked about extended time on work assignments. Table 9 lists the special education services the participants described. The most commonly mentioned special education service was specially designed instruction, which is discussed first.

**Specially designed instruction.** Each of the six parents noted that their children received *specially designed instruction* such as small-group and individual instruction. Four of the six parents—Dima, Afaf, Fawaz, and Camilla—had children who were in general education for the majority of the day. Their children were moved to special education classes for individual instruction or they received special education accommodations within the general education classroom.
Table 9

*Special Education Services Received by Participants’ Children*

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<thead>
<tr>
<th>Participant</th>
<th>Special Education Services Received by Participants’ Children</th>
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<tbody>
<tr>
<td>Afaf</td>
<td>• Specially Designed Instruction</td>
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<tr>
<td>Boshra</td>
<td>• Specially Designed Instruction</td>
</tr>
<tr>
<td></td>
<td>• Speech-Language Pathology Services</td>
</tr>
<tr>
<td></td>
<td>• Physical &amp; Occupational Therapy</td>
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<tr>
<td>Camilla</td>
<td>• Specially Designed Instruction</td>
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<tr>
<td></td>
<td>• Assessment Accommodation</td>
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<tr>
<td>Dima</td>
<td>• Specially Designed Instruction</td>
</tr>
<tr>
<td></td>
<td>• Speech-Language Pathology Services</td>
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<tr>
<td></td>
<td>• Assessment Accommodation</td>
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<tr>
<td>Eqbal</td>
<td>• Specially Designed Instruction</td>
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<tr>
<td></td>
<td>• Speech-Language Pathology Services</td>
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<td></td>
<td>• Physical &amp; Occupational Therapy</td>
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<tr>
<td>Fawaz</td>
<td>• Specially Designed Instruction</td>
</tr>
<tr>
<td></td>
<td>• Physical &amp; Occupational Therapy</td>
</tr>
<tr>
<td></td>
<td>• Timing &amp; Scheduling Accommodation</td>
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Dima’s son and Afaf’s son both received individual tutoring in reading. Afaf described Ali’s specially designed instruction in math, reading, and writing. He received assistance from teachers and they checked for his understanding after he read passages. Afaf reasoned that once Ali improved in reading and writing, other subjects would become easier for him:

> I told them if he know how to read and to write, it’s going to be more easy for him, everything. But like, if he know how to read, to write, the science is going to be easy for him. History easy for him. Anything. That will be easy for him.
Fawaz’s son Faisal experienced physical weakness due to his genetic disorder. For this reason, Faisal received support from a scribe in his class when he was required to write. Fawaz explained the purpose of the scribe: “If [Faisal] cannot even write somebody can write for him.”

Camilla’s children received small-group instruction. She was dissatisfied with the amount of special education instruction on Cazem’s IEP and would have preferred that the amount of time be increased so that there might be a more positive effect from the services: “I think the time they usually give is very little and it needs to be on a certain pace where it’s more [so] he’s actually affected by it.” Altogether, Camilla and the other three parents above had experiences with special education services provided mostly within a general education classroom setting.

The remaining two parents, Boshra and Eqbal, had children who received specially designed instruction mostly or entirely within special education classrooms. Bassem was in a special education classroom for most of his school day. Boshra was pleased with the small ratio of teachers to students in Bassem’s class: “He’s going to be in special class but really Dover very good school because only six kids in the class. Three assistants besides the teacher. Very good, really.”

Eqbal reported her pleasure with the emphasis that Ebtisam’s school placed on inclusion. Ebtisam received a majority of her instruction in a special education classroom but she was also exposed to and integrated with general education students during special classes like art or music. Eqbal explained, “She’s in a completely different class for the whole day but she goes to the typical classroom so she knows how to deal with people.”
She can talk now with all kids; she is not scared anymore.” The students “love to talk with her, they love to deal with her, they love to play with her.” Eqbal attributed Ebtisam’s experiences with inclusion as the reason for her comfort and familiarity with her general education peers and in turn for their comfort with Ebtisam. The next special education service mentioned by some participants was speech-language pathology services.

**Speech-language pathology services.** Speech-language pathology services are considered related special education services within the context of IDEA. Three of the six parent participants reported their children received speech and language therapy: Boshra’s son, whose ASD affected his speech; Dima’s son, whose disability was in speech production; and Eqbal’s daughter, whose genetic disorder affected her speech. After mentioning their children’s involvement in speech and language therapy, neither Boshra nor Dima described the services in detail.

Eqbal, who is described above as having been pleased with Ebtisam’s exposure to and involvement in general education classrooms, was similarly pleased with her inclusion during speech-language pathology services. Eqbal happily explained that Ebtisam’s general education peers were involved in her speech therapy: “When her speech session is there they [say], ‘Pick me, pick me!’ They take a typical child to know how to speak with her. To use her [communication] device we use typical child.” Next, physical and occupational therapy were also provided to some participants’ children in special education.
Physical and occupational therapy. Similar to speech-language pathology services, physical and occupational therapy are considered *related special education services*. The children of three participants were reported to receive physical and occupational therapy: Faisal and Ebtisam, who both had genetic disorders that affected gross motor skills, and Bassem, who had an ASD.

Faisal’s therapy emphasized the strengthening of his muscles. Fawaz explained, “He do physical therapy once a week. They trying to strengthen his muscle a little bit. Not treatment but maybe something help.”

Ebtisam’s physical and occupational therapy was similar to her speech therapy in that it emphasized social skills during therapeutic activities so she was allowed to pick a few children to participate in her therapy sessions. Eqbal described the success of the social emphasis: “When she goes to the physical therapy they pick like three or four children with her. They help her. They talk with her. She has a lot friends there.”

Boshra was also pleased with Bassem’s therapy services. She summarized the success of his services by saying, “Occupation therapy, speech therapy—they helped [Bassem] very well.” Next, some parent participants reported that their children received accommodations during assessments or with timing and scheduling.

Assessment. *Accommodations* with assessment can occur during statewide and district wide achievement testing (ODE/OEC, 2011). Two of the six participants mentioned their children’s IEPs included assessment accommodations. Camilla’s and Dima’s sons both received accommodations to facilitate their completion of state achievement tests.
Camilla noted her pleasure that Cazem received accommodations on state achievement tests: “But the good things about it is that like when he’s doing the [state] tests and whatnot he gets special help on that. So, I mean [the special education services] had its good things about them.”

Dima described Dawud’s accommodations on state achievement testing: “He gets one-on-one when they did their [state] test . . . If [he] can’t read the question the teacher will read it to them. She won’t give them the answer.” Dima noted that these accommodations were helpful in accurately measuring Dawud’s true knowledge: “If he would not have gotten accommodated he would have rushed through it and then got a low score.” These accommodations also allowed Cazem and Dawud to participate in and complete state achievement testing with their peers. Another accommodation, timing and scheduling, is discussed next.

**Timing and scheduling.** The other accommodation mentioned by parents was in timing and scheduling. Fawaz was the only participant to mention such a special education accommodation. Faisal received extended time on testing and academic tasks due to his tendency to tire easily from his genetic disorder. Fawaz explained, “He has [a genetic disorder] so just in case he tired, they extends the time for him.” In this way, Fawaz’s muscle weakness was eliminated as a hindrance so his teachers could more accurately measure his knowledge and skills.

**Summary.** Special education services include any specially designed instruction, related services, and accommodations provided to assist a child’s success in special education (ODE/OEC, 2011). The participants in this study had experience with special
education services including the following: (a) specially designed instruction; (b) the related services of speech-language pathology services and physical and occupational therapy; and (c) accommodations in assessment, timing, and scheduling. These services were experienced positively overall. Parents were generally satisfied with the improvement their children had demonstrated. They also appreciated the individual attention and practical assistance their children received in school and the investment the services were making into their children’s futures. One parent, however, wished that the services were provided more frequently and regularly so that they would be more effective. In addition to discussing their children’s special education services, parent participants discussed their own key relationships during the special education process. These relationships are described next.

**Key Supportive Relationships**

Substantial research has been done on the demands placed on parents of children with disabilities and the difficult emotional effects children’s disabilities can have on their families (Barnett et al., 2003; Birenbaum & Cohen, 1993; Hodapp & Krasner, 1995; Lavin, 2001; Meyerson, 1983; Singer & Powers, 1993). However, Abidin (1990) noted that the parental experience is directly affected by factors such as external support, parental relationships, and the specific demands of the child.

Participants in this study described understandable challenges associated with parenting a child with a disability. Sometimes these challenges were exacerbated by social isolation (e.g., being new in the U.S. or without family nearby) or by cultural differences. However, parents also discussed supportive key relationships they built or
maintained during the special education process. For all six parents, these relationships involved school staff members; two parents also had such relationships with outside professionals from parent education classes, parent advocacy groups, parent support organizations, and respite services. This section explores the parents’ supportive key relationships and the traits that made the relationships positive. Table 10 lists the features of these key supportive relationships. The first type of supportive relationship discussed is that which parents had with school staff.

**School staff.** All parent participants reported having had supportive relationships with school staff. When the participants were viewed as a group, there were commonalities in what they reported enjoying in these relationships. Common traits included: (a) genuine care and concern for their child, (b) helpful communication, (c) moral support, and (d) a team approach. These positive aspects of the relationships made the participants feel closer to the school staff and helped them feel supported in their roles as parents. The open expressions of care and concern from school staff for the participants’ children were the most discussed traits parents valued in these relationships.

**Care and concern.** Verbal expression of care and concern is one way to build an emotional connection with someone. Three participants experienced school staff members extending themselves emotionally as they expressed care and concern for the participants’ children. Such displays of emotion made parents feel supported, welcomed in the school, and involved in the education of their child.
Table 10

Features of Supportive Relationships With School Staff and Outside Professionals

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Participant</th>
<th>Supportive Features</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>School Staff</strong></td>
<td>Eqbal</td>
<td>• Care &amp; Concern</td>
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<tr>
<td></td>
<td></td>
<td>• Communication</td>
</tr>
<tr>
<td></td>
<td>Fawaz</td>
<td>• Care &amp; Concern</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Team Approach</td>
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<tr>
<td></td>
<td>Dima</td>
<td>• Care &amp; Concern</td>
</tr>
<tr>
<td></td>
<td>Boshra</td>
<td>• Communication</td>
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<td></td>
<td></td>
<td>• Moral Support</td>
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<tr>
<td></td>
<td>Afaf</td>
<td>• Communication</td>
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<td></td>
<td></td>
<td>• Team Approach</td>
</tr>
<tr>
<td></td>
<td>Camilla</td>
<td>• Moral Support</td>
</tr>
<tr>
<td><strong>Outside Professionals</strong></td>
<td>Eqbal</td>
<td>• Education</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Advocate</td>
</tr>
<tr>
<td></td>
<td>Boshra</td>
<td>• Support Organization/Respite</td>
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</table>

Eqbal, Fawaz, and Dima recalled this care and concern. Eqbal explained:

“Everyone is helping even if the people they don’t have to. At school for example, the teachers are good but even the people [that] are not related to Ebtisam—they don’t have to do anything [but] they do. They help.” Eqbal believed Ebtisam felt comfortable at the school because she was surrounded by caring and loving people; her comfort in turn reassured Eqbal.

Fawaz echoed a similar sentiment about Faisal’s teachers over the years. He said, “They very, very taking care. It’s great here when you have kids like Faisal’s situation and they very, very do the best.” This statement was one of many that Fawaz made
expressing gratitude and satisfaction with the assistance that his son had received from school staff.

Additionally, Dima experienced similar feelings about the school staff who worked with her children. Dima was pleased that the teachers genuinely held her children in high regard and bolstered their confidence. For example, Dima relayed her experiences with one of Dawud’s teachers: “Everyday she asks me about him, ‘How is he doing?’ When I showed them his report card yesterday that he made merit roll she was so proud: ‘I knew Dawud could do it!’” Dima also attributed Dalal’s confidence to some of her teachers: “I really admire everybody in that school that stood by my daughter that made her be confident.” These three parents experienced care and concern that manifested in outward expressions from school staff through helpful acts, consideration, and encouragement. Communication between parents and school staff was also helpful in building relationships that participants experienced as supportive.

**Communication.** Eqbal, Boshra, and Afaf were the three parents who discussed having had supportive communication with school staff. They described being heard, being supported, and being made to feel comfortable approaching staff. Eqbal provided an example of their supportive communication: “They stop you and say, ‘If you need any help?’” Boshra said that teachers asked her, “What we can do for you?” Similarly, Afaf cited supportive communication with school staff including interpreters provided by the school at meetings and during phone calls. Altogether, these three parents felt communication with staff was supportive and positive when it validated them and
increased their accessibility to school. In the next section, another feature of supportive relationships is discussed: moral support.

**Moral support.** Sometimes school staff expressed moral support for the parents and their parenting efforts. Both Boshra and Camilla discussed the resulting kindred bond and emotional support they received from school personnel. Boshra described her son’s teachers as “like sisters” and said that she felt that she was always “in a good hand.”

Camilla reported feeling supported when she communicated with the teachers regarding Culthum, who had an SLD and processed spoken language slowly. The teachers and speech therapist provided Camilla with suggestions for improved communication with Culthum. They also validated Camilla’s experiences: “When I speak to Culthum’s teacher I’m like, ‘It’s not just me, right? You see that look [on Culthum’s face]?’ And she’s like, ‘Yeah, you see her processing.’ And I’m like, ‘Yeah, it’s so funny!’” This sense of moral support was experienced as a feeling of sisterhood for Boshra; Camilla experienced it as a shared understanding of her daughter’s difficulties. Similarly, the sense of being part of a team and working toward a common goal was another trait of some of the parents’ supportive relationships.

**Team approach.** The support some parents felt from school personnel took the form of working toward a shared goal: the success of the participant’s children. Two parents, Afaf and Fawaz, discussed a collaborative team effort with school staff being helpful in facilitating their children’s success in special education. They reported thinking that as the parents, they alone could not do everything. Afaf described it in this
way: “Me alone, I can do nothing with Ali, you know? [But] maybe me with the school we can go [be successful].” Fawaz explained, “Parents can’t manage without teachers. Without [their] help you cannot make it.” Both parents experienced support and camaraderie from school staff and felt that collaborative group efforts would ensure better results than if they just worked alone. This sense of teamwork meant Afaf and Fawaz experienced their children’s special needs and education as more manageable.

Altogether, supportive relationships with school staff were considered positive because of their obvious care and concern for the participant’s children, sensitive and encouraging communication, moral support, and team approach. These relationships with school personnel were one type frequently cited by parent participants. The other type of supportive relationship parents mentioned was with professionals and service providers outside of school.

**Outside professionals and service providers.** Parent participants benefited from supportive relationships with school staff; they also built supportive relationships with professionals and service providers outside of the schools. These professionals and their services were related to special education but were not included in the children’s IEPs or special education services. Therefore, the professionals and services were optional and not something that every parent experienced. Although some participants spontaneously mentioned such relationships or services, no direct inquiry about them was made during the interviews. Two parents in particular, Eqbal and Boshra, spontaneously reported benefiting from such relationships. Eqbal commented on parent education classes and the services of a parent advocate, while Boshra discussed a parent support organization
and respite services. These services were new to these parents, who were both born and educated in the Arab world, because the services were unavailable in their home countries. The first of the three supportive relationships to be discussed is parent education classes, from which Eqbal benefited.

**Education.** Eqbal reported feeling supported and informed by her experiences with parent education classes. These classes helped her improve her parenting skills with Ebtisam as well as with her other children. Eqbal recalled that there were parent education classes on various topics: mobility issues within the home, developmental issues, parent self-care, special education law, and independent living. She reported benefiting greatly from the classes: “It was very helpful here. I actually go to all of the meetings. I don’t miss any meetings of these meetings because it’s very helpful. It makes you feel better.” Eqbal felt supported by relationships at these classes because she became more informed and empowered in her parenting techniques, in Ebtisam’s education, and in planning for her future. Eqbal also benefited from her relationship with a parent advocate, which is discussed next.

**Advocate.** Parent advocate volunteers attend IEP meetings, case reviews, juvenile court hearings, and treatment team meetings (Ohio Family and Children First [OFCF] Cabinet Council, 2010). They also encourage parents to advocate for their children and their family’s needs (OFCF Cabinet Council, 2010). The OFCF Cabinet Council formed the Parent Advocacy Connection, which connects families with parent advocates (Ohio Legal Rights Services, 2005).
Eqbal was the sole parent who reported interacting with a parent advocate. Because Eqbal was new to the U.S. and its educational system she was connected with a parent advocate when Ebtisam began school. Eqbal was unfamiliar with special education law and with the position of a parent advocate; both did not exist in her home country. The advocate assigned to Eqbal assisted her communication with Ebtisam’s teachers. Additionally, the parent advocate taught Eqbal about special education laws. Eqbal was emboldened and empowered to hear that she could speak her mind and make requests at the IEP meeting:

[The parent advocate] told me my rights. I didn’t know. When I [used to] go to this [IEP] meeting I just sign and go. She told me, “No, you have to see if you like everything. Say everything.” I should say everything.

Eqbal believed that since Ebtisam was already receiving so many beneficial services that it was wrong to ask for more but the advocate encouraged Eqbal to ask for what she thought would benefit her daughter. She learned that she could request more inclusion or any other services that she wanted for Ebtisam. The advocate also told Eqbal to state her goals, regardless of how ambitious they were: “Even if I say I want my daughter to talk you can say that. They would work about it. If it’s not- if it’s not applicable they will tell you but don’t hesitate to say.”

Eqbal cited the parent advocate as the sole source of her special education law knowledge. Her positive experience receiving support, information, and assistance during the special education process was directly related to her relationship with the
parent advocate. The third non-school staff relationship that was cited as supportive involved respite services referred by a parent support organization.

**Support organization and respite services.** The OFCF Cabinet Council, which is affiliated with the National Alliance for Mental Illness-Ohio, coordinates government programs and services for children with special needs and for their parents (Ohio Legal Rights Services, 2005). The OFCF Cabinet Council provides a myriad of parent resources including short-term respite services during short-term crises with one’s child (Ohio Legal Rights Services, 2005).

Boshra reported benefiting immensely from such services as she went through a particularly difficult experience with her family living in the Arab world. At the time of the family’s crisis, Bassem’s behaviors were also becoming increasingly challenging and violent. Boshra contacted a local parent support organization she knew from his early intervention services and she told them, “Bassem did this to me. He hits me. I feel like I don’t want to do something back to me or to anybody. I feel I’m depressed.” The parent support organization then located a local respite center where Bassem was able to stay on the weekends and after school while Boshra cared for herself and managed her family’s affairs. She explained, “They help me for two months. They paid for it even. This until I feel like he’s fine. Thanks God, thank you. It was very helpful for me.” These respite services and the referral from the parent support organization were crucial in allowing Boshra to work through her family’s crisis and return with the strength she needed to care for Bassem and her other children.
Altogether, two parents cited meaningful and supportive relationships with professionals and service providers outside of their children’s schools. These important connections assisted the parents emotionally, educationally, and physically (e.g., respite services taking care of Bassem outside of the home). The relationships were directly related to their children’s disabilities but were focused on the parents’ knowledge, empowerment, and well-being. These supportive relationships with school staff and outside professionals assisted and comforted parents during the special education process.

**Summary.** In addition to special education services, each parent cited supportive relationships as being significant to his or her experience with the special education process. All six participants reflected on some positive relationships they experienced with school staff members; three of these parents benefited also from supportive relationships with outside professionals. The next section discusses relationships that were not as supportive and that were experienced negatively by some participants.

**Key Unsupportive Relationships**

As mentioned above, it is well established that raising a child with a disability can be stressful (Barnett et al., 2003; Birenbaum & Cohen, 1993; Hodapp & Krasner, 1995; Lavin, 2001; Meyerson, 1983; Singer & Powers, 1993). However, this stress could be affected by the quality of parental relationships and external supports available (Abidin, 1990). This section reviews key relationships that were significant for negative reasons in four parents’ experiences with the special education process. These unsupportive relationships were with some participants’ husbands and with school staff. Table 11 lists the features of these negative relationships.
Husband. As previously discussed, the Arab American family is a cohesive unit that highly values family relationships and collectivity (Dwairy, 2006). It follows that the Arab American participants’ experiences with the special education process would frequently refer to family relationships. When parents sought support during the special education process they frequently considered family first. In some situations, family provided such assistance; in several cases discussed above, parent participants received support from their children’s schools or from outside service providers. A strong parental relationship can help alleviate stress from parenting a child with a disability (Abidin, 1990). However, such spousal support was sometimes not available to three female participants who reported feeling burdened by and isolated from their spouses during the special education process. This lack of support manifested as the husbands’ minimal involvement in the special education process or denial of their children’s disabilities.
Each of the three participants’ experiences was different although these two themes repeatedly surfaced during their interviews. The first theme to be discussed is the husbands’ minimal involvement.

**Minimal involvement.** Eqbal and Boshra said that their husbands showed some lack of involvement throughout the special education process and that this had negative effects on their experiences. Eqbal’s husband was largely uninvolved as Eqbal attended all of the IEP meetings and communicated with the school. Similarly, Boshra felt unsupported by her husband with responsibilities at home and with the children. Her husband’s work schedule was busy so she assumed most household and childcare responsibilities. Boshra sensed her husband’s lack of understanding about the challenges she faced and she resented his minimal involvement. She reported that they frequently fought and “he doesn’t understand me because of Bassem.” As a result, their relationship suffered. Overall, both Eqbal and Boshra did not feel supported by their husbands’ involvement and felt it necessary to singularly shoulder most of the emotional and logistical concerns related to special education.

**Denial.** Eqbal and Camilla experienced denial from their husbands about their children’s disabilities. Both of their husbands had received medical training; the husbands cited this as the source of their knowledge that nothing was “wrong” with their children. Eqbal explained that before moving to the U.S. her husband had denied that Ebtisam had a disability. He had not allowed Eqbal to take their daughter to the doctor to receive a diagnosis and he said, “I am a doctor. I know there is nothing wrong with her. You are dreaming.” For a year, Eqbal secretly went to doctors for a diagnosis and
therapy for Ebtisam. At that point her husband became convinced and said, “Yes, something wrong with her.” He agreed to travel to the U.S. for treatment although he continued to deny the disability.

In the same manner, Camilla’s husband believed that there was nothing “wrong” with their son Cazem and relied on his medical training to substantiate his belief. Camilla said that because she spent more time with Cazem than her husband did she recognized Cazem’s developmental delay. Camilla recalled an experience when she and her husband had visited a neurologist for Cazem: The neurologist did an intake of the family history and when she heard that Camilla’s husband was a doctor she asked him for his professional opinion. He replied that he did not think Cazem had any traits of an ASD and so the doctor “didn’t check [Cazem]. She completely minus-ed [a diagnosis of ASD] out.” Without the support of her husband, Camilla felt isolated and invalidated. She explained the negative effect it had on her: “You keep it in and it chews you up. At nighttime you think about it.” Altogether, these three mothers experienced unsupportive relationships with their husbands in significant ways: lack of involvement in the special education process and denial that their child had a disability. These traits negatively affected their relationships with their husbands. In addition to unsupportive spousal relationships, some parents reported unsupportive relationships with school staff.

**School staff.** Both Dima and Camilla reported having had unsupportive relationships with school personnel. As is discussed in Chapter 4, there could be many reasons why it was these two U.S.-born, native English-speaking parents who had such
experiences. Poor communication and judgment featured in their negative relationships; communication is discussed first.

**Communication.** Dima and Camilla both experienced negative communication with school staff and as a result they each chose to transfer their children to new schools. Dima was frustrated by painful communication that she and Dalal had had with some teachers over the years. Dima’s most memorable negative experience was with one of Dalal’s middle school teachers who had insulted Dalal in front of her class when she had asked to use the restroom. At the time, Dalal was taking medication for ADHD and she was suffering from kidney stones. Dima explained:

> In her records [it] says that she can go to the bathroom as needed because my daughter has kidney stones. So this [teacher] took it upon himself to tell my daughter that she was crazy. He told this to my daughter in front of the whole entire class. That she was crazy, she needed not only two pills, she needed to be on four pills and she needed to be sedated.

As a result of the incident, Dima complained to the school and the teacher about this experience. She explained, “Me being from a tough family—we don’t cry. But I cried. I broke down when he told that to my daughter and I went up there and I cursed him out. I said, ‘How dare you!’” Dima was not satisfied with their response so she transferred Dalal to another school. Years later during her interview for this study, Dima’s emotions from the experience were still fresh. She became visibly upset when recounting the story and she referred to Dalal’s teacher as a “bastard.” Dima reflected,
“That experience with Dalal, I would never want to go back to that place ever again, ever.”

Camilla also experienced a lack of support from school staff when she communicated with Cazem’s first elementary school teacher. As mentioned in Core Theme 1, Cazem was Camilla’s first child referred to special education and she was already feeling denial and resistance toward the referral. When Cazem’s kindergarten teacher shared with Camilla some concerns about Cazem having a disability, Camilla experienced the teacher’s communication as cold and blunt during the especially painful interaction described earlier. Camilla explained, “I didn’t even give it a second—I just pulled him out.” The teachers’ direct and abrasive communication soured Camilla’s relationship with her and prompted Camilla to immediately change Cazem’s school placement. In addition to insensitive communication, Dima and Camilla also experienced judgment in some of their relationships with Arab American school staff.

Judgment. Both Dima and Camilla had experienced judgment from Arab American school staff. Camilla had early experiences with judgment from her children’s Arab American teachers. Later, when she enrolled her children in an Islamic school and learned that they would again have Arab American teachers she anticipated their judgment. Therefore, she did not initially tell them that Cazem had an ASD. She recalled, “What I did was I didn’t tell his second grade teacher. I knew it but I didn’t want her to judge him for it. So I told them [when] it was like the second semester.” Similarly, Dima’s experiences with Arab American teachers’ judgments made her concerned that she would face criticism again from other Arab American teachers.
Summary. One significant aspect of participants’ experiences with the special education process was key relationships, both supportive and unsupportive. Unsupportive relationships were experienced by four of the six participants. Three of these four parents recalled feeling burdened by their husbands’ lack of involvement and denial of disability. Two of the four parents had been upset by poor communication from American school staff and by judgment from Arab American teachers. These unsupportive relationships contributed negatively to the four parents’ experiences of the already-stressful process of special education and raising children with disabilities.

Overall, the second research question asks which aspects of the special education experience stood out to parent participants as most significant. In Core Theme 2, parent participants had memorable and significant experiences with the special education services their children received. Additionally, the relationships they built or maintained during the special education process were significant and could be described as supportive or unsupportive. Core Theme 3 builds on the significant features of the special education process to look at how the parents considered their children’s identified disabilities and special education eligibility.

Core Theme 3

Parents reflected on many topics related to their children’s disabilities and eligibility for special education: the children’s strengths and difficulties, parents’ own understandings of special needs and of special education, and the importance of some parents’ own advocacy work.
This core theme relates to the study’s third research question, which asks how parents understood and conceptualized their children’s identification with a disability requiring special education. Parents referred to their children’s strengths and difficulties, which helped them to consider their children’s involvement and needs in special education. This section begins with the parents’ discussions of their children’s skill sets.

**Children’s Strengths**

Each parent referred to at least one area of strength in his or her child(ren). The strengths could be clustered into three main areas: daily living skills, academics, and hobbies. The most-cited area was daily living skills, which is discussed first.

**Daily living skills.** Daily living skills are described as activities such as dressing, eating, communicating, behaving appropriately, making friends, and walking (ODE/OEC, 2011). Five parents mentioned their children’s daily living skills as areas of strength. For example, Boshra explained that Bassem has a level of independence at home: “When he wants to eat, he goes to fridge. He goes to the bathroom by himself.” Camilla shared that Culthum was competent in tasks related to “living.” She said, “When I told her, ‘Culthum, get the broom. Let’s sweep.’ She did certain things. She was okay with living. She was okay.” Additionally, Eqbal described her pleasure with Ebtisam’s latest abilities:

Now she can eat and she know how to eat by herself and this is lunch and she have to sit and she have to eat. . . . She knows how to go to the computer, turn it on, and how to pick what she likes and how to click on it. I was thinking that this was dream, you know?
Afaf described Ali’s maturity and communication skills. She said Ali “like to talk and
discuss with the person who older than him. Like to sit with his cousins or the
neighbors.” Finally, Dima noted Dawud’s large social circle and said that she was proud
of his appropriate behavior: “His teacher told me he is so well mannered. He’s so well
mannered his behavior is off the charts.” These five parent participants cited various
daily living skills that included self-care tasks, activities within the home, and social
interactions. A second skill area discussed by parents was academics.

Academics. Four participants mentioned their children’s skills in specific
academic subject areas or in overall academic performance. Afaf noted that Ali is strong
in math especially as it relates to counting money, calculating change, and tallying his
purchases. Dima mentioned Dawud’s strong math and reading skills and she shared that
Dalal had done well enough in middle school to be accepted into a secondary school that
required a high GPA for admission. Fawaz said that Faisal made top grades in school
and always completed his homework. Eqbal also noted Ebtisam’s abilities: “Now she
knows her E’s. She knows all of the letters of her name.” The third area of strength
mentioned by participants was hobbies.

Hobbies. Hobbies are leisure activities that an individual enjoys during one’s
free time. Four parents discussed their children’s strengths in relation to hobbies and
interests outside of school. Afaf and Dima described each of their sons’ abilities in
sports. Fawaz’s son showed skill in stationary hobbies such as watching wrestling,
playing with toys, and spending time with animals. Bassem was talented in repetitive
activities such as swimming, swinging, jumping on a trampoline, bouncing on a large
ball, playing video games, and memorizing schedules. The leisure activities shared by these four parents were connected with their children’s interests and physical and intellectual abilities.

**Summary.** Each of the six parent participants mentioned at least one area of strength for their children and some of the parents referenced multiple skill areas. The children’s skills were in the areas of daily living, academics, or hobbies. The following section discusses participants’ references to their children’s areas of difficulty.

**Children’s Difficulties**

As mentioned above, parents easily reflected a balanced view of their children’s strengths and difficulties. Core Theme 3 explains that parents conceptualized their children’s identified disabilities along with the children’s strengths and difficulties. Each of the parents mentioned at least one area of difficulty for their children. The areas included verbal communication, academics, behavior, and motor skills. The most commonly cited area of weakness was verbal communication, which is discussed next.

**Verbal communication.** As Buckley (2012) explained, human communication includes verbal and nonverbal communication and incorporates a combination of language skills, mental processes, and physical movement. Verbal communication refers to spoken and written language such as speech, writing, and sign language (Buckley, 2012). Four participants in this study—Boshra, Eqbal, Dima, and Camilla—cited their children’s difficulties with the *production* of verbal communication; Camilla also discussed her other children’s difficulties with the *comprehension* of verbal communication.
Boshra and Eqbal explained that their children, Bassem and Ebtisam respectively, required augmentative and alternative communication (AAC) materials or devices to assist them in producing verbal communication. Both children required these supports to communicate verbally because they were unable to utilize speech, writing, or sign language to express themselves. Bassem utilized PECS at school and Ebtisam used a device that produced speech for her.

Eqbal discussed Ebtisam’s difficulty in speech production, saying her daughter would like to speak with words but was unable to do so:

She cannot talk. She feels a little frustrated so she can like—she grabbed the children to make them look at her and they think that she will harm them. I have to go and explain for the child and for the parents when we go to [home country].

. . . She cannot express herself. And now with this device, alhamdulillah [thank God], she feels much better. She can go and express herself.

Similarly, Boshra said Bassem is nonverbal: “He can’t speak—apraxia. For now, nothing—no words. He can’t nothing. No words, no—not even anything. Just bah he can say now. Bah or ah. That’s it.” When not utilizing these AAC materials or devices, Ebtisam and Bassem both communicated nonverbally using noises and gestures.

In contrast, Dima’s son Dawud and Camilla’s son Carem had speech impairments that negatively affected their production of speech. However, the boys’ impairments were not to the extent that they required AAC devices to communicate. Dawud’s and Carem’s speech impairments negatively affected their speech although they remained
fully capable of spoken communication. Both boys received speech and language therapy services at school.

Camilla’s two other children, Cazem and Culthum, were also in special education and had difficulties with the comprehension of verbal communication. Cazem had Asperger’s disorder and interpreted language literally. Culthum had an SLD and struggled with processing verbal communication, both spoken and written. She was forgetful regarding multi-step commands and needed to receive verbal instructions multiple times before understanding what she was being asked to do. Culthum was also unable to process what she read. The next section addresses academic difficulties for the participants’ children.

Academics. Four participants mentioned their children had academic difficulties in reading and writing. Boshra explained Bassem’s academic abilities: “So, now he’s going to be in second grade but he doesn’t know how to write, how to read, nothing.” Afaf said that despite Ali repeating the second grade, he struggled with reading and writing so much that there was a significant difference in ability between him and his classmates. The academic performance of Camilla’s daughter, Culthum, was also negatively affected by her reading comprehension difficulties. Dima said her daughter often wrote in reverse and this negatively impacted Dalal’s performance in several subjects. The next area of difficulty that parents discussed is behavior.

Behavior. Camilla and Eqbal said that their children displayed age-inappropriate behaviors. Camilla described her son, Carem, as unusually hyperactive and fidgety, which she called “running around.” Ebtisam had some cognitive delays due to her
genetic disorder and she tended to eat materials or non-food substances like paper. She was stimulated by spreading soft, creamy substances on walls and objects in a way that a much younger child might be. Eqbal described Ebtisam’s behaviors and some possible reasons for them:

She cannot play with everything like everyone and this is the other thing that she feels like all of her energy are done. . . . She still eat some papers. It’s a very big problem I have from the beginning but now she eats much less and she knows. What makes me happy that she knows that she is doing something wrong, “This is not food. This is paper and I shouldn’t eat it.” . . . Before she didn’t know. She could eat like the whole thing. If you gave her like chocolate or something she would eat the chocolate and the paper.

Carem and Ebtisam demonstrated immature or inappropriate behaviors; their mothers hoped the children would grow out of the behaviors. The next area of difficulty that parents discussed is motor skills.

**Motor skills.** Fawaz was the sole parent to refer to motor skills as an area of difficulty for his child. The motor skill weaknesses that Faisal had would be life-long because they were symptoms of his genetic disorder. Fawaz explained, “He cannot do anything [physical]. Especially the last three years he sit in wheelchair. So we have to help with everything because he cannot.” Fawaz’s emotional reaction to Faisal’s motor difficulties will be discussed in the following section on empathy.

**Summary.** Each participant mentioned at least one area of difficulty for his or her child including speech and language, academics, behavior, and motor skills. The
most common areas were speech and academics. Overall, parent participants were able to easily recognize areas of strength and difficulty including academic and non-academic domains. This balanced recognition of abilities assisted the parents as they considered their children’s disabilities and eligibility for special education. The next section explores the second component of Core Theme 3: participants’ reflections on their own understandings of special needs and special education when considering their children’s disabilities and special education eligibility.

**Parental Understanding**

During the interviews, participants reflected on what their understandings of special needs and special education had been prior to their children’s referrals for special education. Of the six parents, four reported that before their children’s special education experiences they did not know that it even existed. Therefore, these parents learned about their children’s disabilities and the special education process simultaneously.

Participants also discussed their emotional and intellectual reactions to their children’s referrals for evaluation and identification with disabilities requiring special education. Some parents reported struggling with the acceptance of their children’s identification and some shared their feelings of empathy for their children. Of the group of six, two parents reported having difficulty accepting their children’s limitations and needs for special education. Another two parents discussed the empathy they felt for their children during particularly difficult tasks.

Two of the participants were educated in the U.S.; the remaining four received their education in the Arab world. This information is included in Table 12 along with
the parents’ reactions to their children’s identification with disabilities requiring special education. The next section begins with a discussion of the four participants who had no previous knowledge of special education.

Table 12

Parents’ Previous Knowledge of Special Education, Location of Parents’ Education, and Reaction to Identification and Disabilities

<table>
<thead>
<tr>
<th>Participant</th>
<th>Previous Knowledge of Special Education?</th>
<th>Location of Parents’ Education</th>
<th>Reaction to Identification and Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dima</td>
<td>No</td>
<td>U.S.</td>
<td>Difficulty Accepting (for first child)</td>
</tr>
<tr>
<td>Eqbal</td>
<td>No</td>
<td>Arab world</td>
<td>Empathy</td>
</tr>
<tr>
<td>Boshra</td>
<td>No</td>
<td>Arab world</td>
<td>Difficulty Accepting</td>
</tr>
<tr>
<td>Fawaz</td>
<td>No</td>
<td>Arab world</td>
<td>Empathy</td>
</tr>
<tr>
<td>Afaf</td>
<td>Yes</td>
<td>Arab world</td>
<td>Stated Acceptance (however kept identification secret)</td>
</tr>
<tr>
<td>Camilla</td>
<td>Yes</td>
<td>U.S.</td>
<td>Difficulty Accepting</td>
</tr>
</tbody>
</table>

No previous knowledge. An individual’s knowledge of different styles of education is based largely on how, where, and when one was educated. All participants in this study were previously unfamiliar with the process of special education; four of them were also completely unaware of the existence of special education before their experiences with their children. These four parents were Dima, Eqbal, Boshra, and Fawaz.
Dima was the only U.S.-born participant without any previous knowledge of special education. She explained, “I didn’t know anything about special ed until my two kids. I never heard about special ed until my two kids.”

The other three participants—Eqbal, Boshra, and Fawaz—were born and educated in the Arab world and likely had not experienced inclusion in their own schools. As discussed in Chapter 1, students with disabilities in the Arab world are often not educated due to a lack of special education and the tendency of schools to refuse admission. For the minority of disabled students who do get an education, it is often in residential institutions or separate schools (Amr, 2011; Bradshaw et al., 2004; Thomas & Lakkis, 2003). Eqbal’s recollection of her understanding and experiences before coming to the U.S. reflects such a separation for disabled individuals:

I didn’t know that there is cases, there is levels, there is something called autism [or] something called like Ebtisam . . . [I believed that] these people have to go to some private place and be locked there and have nurses to deal with them and that’s it. So they don’t have the right to live like everyone else. It was my idea about people who are different, you know? My own idea before getting Ebtisam. Because I didn’t see—I’ve never seen [in] my life in the street or in anywhere someone like this. . . . I didn’t see a lot of special needs cases in [home country], why? Because they are all at home, they are locked in a room for their whole life, even if they life for twenty years. You can be a very close friend to the family and you don’t know they have a special needs kids or anyone at home because
they locked him [in], they considered him like a chair or something at home. He eats and does his stuff. He never go out.

In addition to having no prior knowledge of special education, Eqbal and Boshra both had no prior knowledge of the specific disabilities with which their children were later identified. Eqbal heard about her daughter’s type of genetic disorder for the first time only when Ebtisam was properly diagnosed in the U.S. Boshra’s sister, as discussed above in the section on identification, was the first person to suggest to Boshra that Bassem might have an ASD. However, at the time of her sister’s suggestion Boshra did not know what an ASD was. Boshra shared that after Bassem’s diagnosis, “It took me a while to understand what is [ASD]. It took me two years maybe or more to understand what they talking about: why, what is it?” Altogether, these four parents had no previous knowledge about special education. The other two parents had some limited previous knowledge about the existence of special education.

**Previous knowledge.** Two parents, Afaf and Camilla, possessed limited information about special education before their children’s identification with disabilities. Afaf heard about special education in her home country and Camilla knew about it from her U.S. school attendance. Afaf had been trained as a teacher in the Arab world and had been taught about differences in students’ abilities. As described earlier, there she had heard negative connotations about special education students. Already aware of the concept of special education, Afaf reported being agreeable to Ali receiving services. However, she did not share his academic placement with anyone aside from her husband.
In contrast to Afaf, Camilla struggled significantly with the decision to enroll Cazem in special education:

I didn’t want him in special ed. Just the name of it: *special ed.* Every time I think about it it’s not special ed, it’s just the *IEP.* You literally try to get around saying—you don’t want to say it’s special ed. A lot of people that told me, “Don’t put him in special ed. He’ll get the hang of it.”

Afaf and Camilla both had previous knowledge of special education and yet had different initial reactions to the option of special education for their children. Afaf reported being comfortable with Ali’s participation in special education (although she kept it a secret) and Camilla struggled with the social stigma around the term *special ed.*

Despite different reactions, Camilla and Afaf were both in agreement that they wanted their children to receive special education services sooner than later. They believed delaying services would result in their children being stigmatized or too delayed to catch up with peers. Afaf explained, “I didn’t want [Ali] to go in fourth grade, third grade. Then other student can read, write, and he can’t. This is going to be a big problem for him. More than now, you know?” Camilla echoed, “I really don’t want [Cazem] to be [in special education but] I’d rather him get the help now than be when he gets older and he really does get picked on for whatever reason he is in [special education] now.” She rationalized, “Better now, the first couple years of the school, than later down the line in high school when you have kids entering high school [who] are still at fourth grade level.” These two mothers were more concerned about their children later being stigmatized and having more significant academic delays than about discrimination...
their children could face during special education services in the early grades. The next section addresses the difficulty that some parents experienced accepting their children’s special needs.

**Acceptance.** As discussed in the earlier section on identification, initially accepting that one’s child has a disability can be an emotionally difficult experience (e.g., Bowlby, 1980; Leerkes & Burney, 2007; Marvin & Pianta, 1996; Moses, 1987). Significant literature exists about the process of parental acceptance, or parental resolution, of the diagnosis of a chronic illness or disability for one’s child (e.g., Oppenheim et al., 2011; Pianta et al., 1996). In this study, *acceptance* relates to the parents’ own descriptions of their emotional and behavioral reactions to the identification of their children’s disabilities requiring special education.

Three of the parent participants—Camilla, Boshra, and Dima—discussed their initial difficulties accepting their children’s limitations and needs for special education. First, Camilla struggled with acknowledging the existence of two of her children’s special needs. She often felt frustration from having to frequently repeat her words when she spoke with Culthum. For example, Camilla explained that teachers are professionally trained to be patient but she had no such training and felt like yelling at Culthum at times. Additionally, she was frustrated when she realized her own lack of control over Culthum’s learning difficulties: “No matter how much I study with her, she’s always going to be a little lower.” As mentioned in Core Theme 1, Camilla also experienced difficulty accepting the reality of Cazem’s delays: “I think it’s the hardest for a mother to say, ‘Yeah, my son has a problem.’ It’s very sensitive.” Camilla compared a parent’s
stages of acceptance of his or her child’s disability as similar to an alcoholic needing to first admit to having a problem: “[First] you have to say, ‘He has a problem.’ Then you start with the help.”

Next, Boshra also struggled with accepting Bassem’s identification with an ASD. After Bassem was identified, Boshra avoided parent support groups; she did not want to hear other parents discuss their children who might have had more severe symptoms than Bassem. Boshra feared that doing so would cause her to believe Bassem would develop in the same way. At the time of the interview, Boshra had changed her opinion of these support groups and was willing to speak with other parents of children with an ASD:

“Now I feel: ‘No, I can hear even if it’s bad. I will accept anything.’ I’m more mature now I feel.” Boshra believed that if she were social with other such parents she would learn more about Bassem’s needs and about ASDs. Both mothers ultimately reflected on the evolution of their acceptance: Camilla had to first acknowledge her children’s difficulties and Boshra needed to feel ready before choosing to learn more about her son’s ASD.

Finally, Dima discussed her reticence with accepting Dalal’s identified disability and eligibility for special education. However, she reported feeling differently when Dawud later went through the process. The following section reviews parents’ empathy for their children’s struggles.

**Empathy.** Empathy is the ability to understand or experience the feelings of someone else. Fawaz and Eqbal described feeling empathy when they observed their children struggling from physical or intellectual limitations. Fawaz discussed having an
empathic reaction when Faisal was clearly being affected by his physical limitations and mobility difficulties. Fawaz shared that he and the family felt “bad” for Faisal at those times.

Eqbal felt empathy for Ebtisam when she was unable to use speech to communicate. Eqbal reported doing a great deal of introspection and imagining the state of mind and emotions of her daughter. Specifically, Eqbal sensed Ebtisam’s frustration and attributed some of her behaviors to that frustration. For example, she imagined Ebtisam’s drive to make frequent messes: “She cannot stop this and I can understand that. It’s like a need. She cannot play with everything like everyone and this is the other thing [that she can do] that she feels like all of her energy are [expended].” When Eqbal was asked how she understood Ebtisam’s emotions without using spoken language she responded, “From her eyes. She comes to me. We have like our special language.” The parents’ empathy was a reaction to their children’s limitations and it served a purpose: Fawaz’s empathy helped him appreciate Faisal’s challenges and Eqbal’s empathy facilitated her understanding of Ebtisam’s needs.

Summary. All six parents discussed what their understandings of special education and special needs had been prior to their children’s evaluation referrals. Four of the parents were previously uninformed about special education; two of these four also did not previously know about the existence of the disability with which their children were later diagnosed. Some parents struggled to accept their children’s special needs and eligibility for special education; others felt empathy when their children struggled with difficult tasks. For some parents, the experiences with their children’s special education
process and the feelings of empathy for their children’s struggles led them into informal advocacy work. The next section reviews this advocacy.

**Parental Advocacy**

Some parents spontaneously reflected on their beliefs in the equality of their children and their children’s rights to enjoy life as others could. These beliefs had prompted the participants to do informal advocacy work. Whereas they never used the word *advocacy*, many parents described situations that could be described as such: they had spoken up for their children to receive equal treatment and to be allowed to live without others’ judgment.

Half of the six participants discussed acts of advocacy and the importance they assigned to these interactions. These three parents hoped and believed that such advocacy would improve their children’s qualities of life in the present and future and would also create change in society in the treatment of individuals with disabilities. Each of these three parents discussed experiences of advocacy with strangers. Additionally, a couple of participants discussed advocacy work with other parents of children with special needs, with their extended family, or with their own children. Table 13 lists participants’ experiences with advocacy. This section begins with parents’ advocacy with strangers, which was the most frequently reported type of advocacy experience.
Table 13

*Parent Advocacy Experiences*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Advocacy with:</th>
<th>Parent Advocacy Experiences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dima</td>
<td>Strangers</td>
<td>Promoted special education</td>
</tr>
<tr>
<td></td>
<td>Arab American</td>
<td>Advised them to have their children evaluated and to ask questions, and not to feel embarrassed or delay special education evaluation or services</td>
</tr>
<tr>
<td></td>
<td>Parents</td>
<td>Advised them not to believe they were disabled, otherwise their self-esteem and self-expectations would be lowered</td>
</tr>
<tr>
<td></td>
<td>Own Children</td>
<td></td>
</tr>
<tr>
<td>Eqbal</td>
<td>Strangers</td>
<td>Argued that her daughter deserved to be accepted and not to be stigmatized</td>
</tr>
<tr>
<td></td>
<td>Arab Parents</td>
<td>Advised them not to feel ashamed about their children’s disabilities</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>Advocated to continue her daughter’s treatment and special education in the U.S. rather than return to the Arab world</td>
</tr>
<tr>
<td>Boshra</td>
<td>Strangers</td>
<td>Dressed child in a shirt that stated his identified disability</td>
</tr>
</tbody>
</table>

*Strangers.* All three parents referred to their experiences when they had advocated for their children’s equality and rights to strangers. Dima advocated with American parents who were unfamiliar to her, Eqbal spoke with unknown Americans in the U.S. and Arabs in the Arab world, and Boshra communicated with American strangers in the U.S. Their experiences are described below.

During Dima’s interview, she frequently shared her belief in the equality of students in special education. She recalled advocating with American parents for such equality: “Sometimes people say, ‘Oh, special ed. They’re LD. They’re not normal
Eqbal shared her belief with strangers in the U.S. and the Arab world: “I know my daughter is a special needs. I don’t care about people. This is my daughter. You can accept her!” Eqbal was driven especially by the worry that Ebtisam would become aware of people’s negativity and eventually feel “like she has something wrong.” Eqbal shared, “Sometimes I want to have a sign: ‘What about looking? Please, because a lot of people are different and you keep looking and you keep watching like this. It is not nice.’” As Eqbal reflected on her advocacy she said she spoke to “everyone” and “it’s not easy at all.”

Boshra’s advocacy with American strangers in the U.S. involved informing them about the reason for her son’s atypical behaviors. She noticed that strangers were perplexed when Bassem screamed in public and she reasoned that their confusion stemmed from his appearance, “He looks fine; he’s so cute.” However, she worried that someone who could not recognize traits of an ASD would think Bassem was misbehaving. As a result, Boshra settled on something similar to Eqbal’s idea of holding up a sign: during public outings Boshra dressed Bassem in a purchased shirt that said roughly, “I got autism. I am autistic. Be patient with me. Understand me.” Boshra summarized the message of the shirt being, “‘I’m like your kids but I’m autistic.’ Something like this, just: ‘Shut up, people. This is my son.’” Boshra felt more comfortable after she began dressing Bassem in this shirt because it communicated to
strangers the reasons for his behavior and she no longer worried about their judgment or confusion. Boshra noted that eventually she had developed this mindset:

I don’t know what they are thinking but no, I don’t care. I’m like this. I’m wearing my hijab. My son is autistic, that’s it. “You wanna look? I look back to you. You wanna talk? I will talk back to you.”

These three mothers advocated with the individuals they encountered most often in public: strangers who were confused about or intolerant of children with special needs. The next section relates to the experiences of some parents advocating to their Arab and Arab American peers.

**Arab and Arab American parents of children with special needs.** Two of the three parents advocated with other Arab or Arab American parents of children with special needs. Eqbal and Dima discussed this advocacy work, which sometimes took the form of telling parents about their own experiences. Eqbal spoke of conversations in her home country in which she had encouraged Arab parents of children with special needs not to feel ashamed of their children’s disabilities. She remembered telling them, “I don’t have to be ashamed of something like this. Everyone should understand: the one [who doesn’t] understand it’s their fault. And it’s not my kids fault.”

Dima encouraged other Arab American parents to have their children assessed, start an IEP, and begin special education services while remembering to “always ask questions.” As mentioned earlier in Core Theme 3, Camilla and Afaf believed that it was better to get special education for children earlier than later. Dima also had this belief and remembered how she expressed this sentiment to Arab American parents:
When your child needs the services please speak up before it’s too late. Do not say, “No, oh my daughter—there is nothing wrong with my daughter or my son!” and be embarrassed to get services. Because while he’s sitting there and not doing nothing they’re going to not progress when they get older.

During these advocacy experiences, Eqbal and Dima spoke to their Arab and Arab American peers and advocated for the rights and equality of their peers’ disabled children. In effect, they were able to communicate with people very much like themselves about other children similar to their own.

These experiences advocating with strangers in the U.S. and the Arab world were so meaningful to Dima and Eqbal that they considered whether they could do so on a professional basis. Dima noted with excitement, “I wish I could be a speaker and tell them about these [special education] programs!” Eqbal hoped to do professional advocacy work when she returned to her home country: “I was planning to go to any school here to learn and when I go back to [home country] I would make this.” Eqbal also advocated within her own family, which is discussed next.

**Family.** Eqbal, her husband, and their three children had been living in the U.S. for three years. As detailed earlier, they initially planned to come to the U.S. to receive brief treatment for Ebtisam and then to return to their home country. However, a valid diagnosis from U.S. doctors and the reality of very limited educational and treatment options for Ebtisam in their home country prompted the family to stay in the U.S.

At the time of Eqbal’s interview, Ebtisam had been in special education classes for three years and Eqbal believed that she had developed significantly. However, she
said that “no one is seeing it” in her family. Eqbal’s husband had begun telling her that it was unfair to keep the entire family in the U.S. for the sake of just one child, especially because he doubted Ebtisam’s improvement. He had said to Eqbal, “What is your point? Why are we here? She’s not talking. It’s three years and she goes to the physical therapist. She walks the same way. Nothing is better.” In addition to Eqbal’s husband, her parents and in-laws also were encouraging her to return to their home country because there she had a job and “a life.” As a result of her belief in Ebtisam’s growth and potential, Eqbal advocated for her daughter’s rights with her husband, parents, and in-laws. She urged her husband to recognize the growth that she had seen in Ebtisam and to agree to stay longer in the U.S. so Ebtisam could remain in school. In their home country, Eqbal argued, the schools would not be able to educate Ebtisam and she would likely have to stay at home.

Earlier, Eqbal’s advocacy experiences with other Arab parents in the Arab world were discussed. She said that she had told them that when someone does not understand or respect a child’s special needs it is that person who has a problem and not the child with a disability. Eqbal mentioned to the parents that this is true even if the disrespectful person is from one’s “own family,” is one’s “own parents,” or “Even it’s your brother. Even your children. Even if it’s someone close. If he doesn’t accept the fact that you have this kid he should go and accept it. It’s not your problem.” Eqbal did this advocacy work with her peers in the Arab world about the value of Ebtisam’s peers who had disabilities. Given Eqbal’s advocacy experiences with her family mentioned above, one
can wonder if Eqbal might have been encouraging these parents in a way that she also wanted or needed to hear. Next, Dima’s advocacy with her own children is discussed.

**Children.** Dima believed that Dalal and Dawud risked having lower self-esteem and self-expectations because of their special education placements. To combat this, Dima frequently reminded her own children that they were “normal kids” and that their special education enrollment did not mean that they were inferior. Dima explained that she did not consider them to be disabled and taught them not to think of themselves as such. Otherwise, she said that they might pity themselves, have low self-esteem, and not be “able to do what they want to do.” Dima prepared her children with advice such as, “You can do anything in life that you put your mind to. Nothing’s going to come to you free. Everything you have to work for.” Dima provided a specific example of this advocacy: when Dalal was considering withdrawing from special education due to social pressure, Dima reminded her to see herself positively. Dima told her, “Just because you’re in special ed, Dalal, it doesn’t mean that you’re dumb. You’re not. Don’t let anybody tell you that you’re dumb.” In this vein, Dima tried to instill confidence in her children and make them believe that they were equal to their peers in general education and in special education.

**Summary.** The advocacy activities of Dima, Eqbal, and Boshra involved specific groups: strangers, Arab or Arab American parents with children with disabilities, their family, and their children. The parents spontaneously mentioned this advocacy during their interviews. They recalled meaningful experiences helping their children receive respect and encouraging attitudes of equality and self-confidence. Although they never
labeled these interactions as advocacy, two of the parents had considered a future professional advocacy role to help and encourage other parents like themselves.

Altogether, parent participants were well aware of their children’s strengths and difficulties. They tended to be previously unfamiliar with special education. Several of them struggled with accepting their children’s special needs and special education placements. Some parents mentioned having feelings of empathy for their children and some parents described participating in informal advocacy experiences. They hoped that such advocacy efforts would ultimately improve their children’s experiences in the present and future. The next and final core theme section in this chapter explores parents’ goals for their children’s futures.

Core Theme 4

Parents reported having unchanged expectations, plans, and goals for their children after experiencing the special education process; parents’ present goals for their children did, however, appear to be impacted by and tailored to their children’s disabilities and abilities.

Core Theme 4 builds on the previous core theme’s examination of both parental understandings of their children’s disabilities and parental advocacy. This section reviews the participants’ expectations or goals for their children and whether these goals changed as a result of the parents’ experiences with the special education process. It has been noted that the disclosure process can be highly emotional and upsetting for parents of children with special needs (e.g., Hatton et al., 2003; Singer & Powers, 1993). Additionally, during the process parents might struggle with the need to create a new set
of future plans for their children (e.g., Bowlby, 1980; Leerkes & Burney, 2007; Marvin & Pianta, 1996; Moses, 1987).

In this study, the parents responded overwhelmingly that their goals for their children had not been changed by their experiences with the special education process, which included the identification of their children with disabilities that required special education services. However, the goals shared by the six parents appeared to accurately reflect their children’s disabilities and current ability levels. As discussed in Chapter 4, there was a disconnect between the parents reporting to have unchanged goals and yet tailoring their goals to their children’s actual ability levels—presumably as a result of the knowledge gained at least partly through the special education identification process. Table 14 lists the participants’ goal areas for their children.

Each of the six parent participants mentioned their goals for their children. These goals appeared to be appropriate for the children’s levels of functioning and areas of need at the time of the interviews. For example, four parents had children with disabilities that impacted aspects of daily life to a marked degree: these parents referred to goals related to their children’s daily living skills. In contrast, the other two parents had children whose daily living skills were not greatly impacted by their disabilities: these parents emphasized academic and professional goals for their children. Altogether, the most frequently cited goal area was daily living skills, which is discussed next.
Table 14

Parents’ Goals for Children

<table>
<thead>
<tr>
<th>Goal Area</th>
<th>Participant</th>
<th>Parents’ Goals for Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Living Skills</td>
<td>Eqbal</td>
<td>To communicate better, to comprehend more speech, and to follow directions</td>
</tr>
<tr>
<td></td>
<td>Boshra</td>
<td>To simply express feelings and needs; To take care of himself</td>
</tr>
<tr>
<td></td>
<td>Fawaz</td>
<td>To maintain independent mobility as long as possible</td>
</tr>
<tr>
<td></td>
<td>Camilla</td>
<td>To “catch on” socially and not be limited by social difficulties</td>
</tr>
<tr>
<td>Academic &amp; Professional</td>
<td>Afaf</td>
<td>To complete school and find appropriate career, perhaps working with child’s father</td>
</tr>
<tr>
<td></td>
<td>Dima</td>
<td>To complete school, to find appropriate career, and to “make it somewhere in life”; To not be like child’s father</td>
</tr>
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</table>

Daily Living Skills

As previously mentioned, daily living skills are activities such as communicating, making friends, behaving appropriately, walking, dressing, and eating (ODE/OEC, 2011). Four parents—Eqbal, Boshra, Fawaz, and Camilla—had children who demonstrated difficulties with daily living skills. These parents’ daily living skill goals for their children related to communication, independence, or socialization.

Eqbal and Boshra noted communication goals for their nonverbal children. Eqbal hoped that nonverbal Ebtisam would improve in her self-expression and eventually be able to comprehend speech and follow directions. She explained, “First [Ebtisam] would not understand. Now she understand but she will not listen. I hope that she understand
and she listen.” Boshra hoped that Bassem’s communication would eventually include some simple speech: “I wish he can tell me he’s happy or ‘Mom, I’m happy. Mom, happy.’” Boshra wished that he would be able to express if he was in pain or being hurt by someone. While she was realistic in understanding that he would likely not talk “like us,” Boshra said she did “wish he can say any word.” Both Eqbal and Boshra wanted their nonverbal children to be able to communicate their needs, desires, and sensations as well as be able to participate more actively in the world around them.

Fawaz and Boshra discussed having daily living skill goals for their children related to independence. Fawaz’s goals for Faisal related to independent physical mobility because he had difficulty moving and controlling his muscles. Faisal’s genetic disorder would continue to cause physical deterioration in a progressive but unpredictable way. Fawaz hoped Faisal would continue to have some degree of independent mobility for as long as possible. He said, “I’m thank God he can write [now] but who knows because the progress for that disease is very bad.” Boshra’s independence goals for Bassem included the hope that when he became an adult, “He’s going to be he can take care of himself. I want him just to take care of himself.” She was also pragmatic: “I know he won’t be able to go by himself alone or drive maybe or [get] married. But that’s okay.”

Camilla’s daily living skill goal for Cazem related to socialization. She was optimistic that when Cazem became an adult he would blend in and strangers might think only, “That guy is a little weird.” Camilla hoped Cazem would “catch on” in the social realm and not “be held back in life” by his social difficulties. Like Eqbal, Boshra, and
Fawaz, Camilla’s goals for her child were linked to the daily living skill area in which his disability most affected him. The remaining two parents cited their academic or professional goals.

**Academics and Career**

Afaf and Dima discussed their academic and professional goals for their sons. Ali and Dawud each had a disability—SLD and speech language impairment, respectively—that did not significantly affect their ability to complete daily living tasks; this was in contrast to the other four participants’ children. When Afaf and Dima looked ahead in their children’s lives they envisioned academic and professional success.

Afaf said she always envisioned her son becoming an engineer. Ali hoped to join the military or work in his father’s business. Afaf was hesitant when thinking about allowing Ali to join the military “because he’s the only one [boy] I have.” She was confident that Ali would complete school but she hoped he would settle in a career that was well matched to his interests and abilities.

Dima mentioned only her goals for Dawud. She believed that if he stayed at his current school and continued making academic growth and speech improvements he would “make it somewhere in life.” Dawud’s ideas for his future included being a chef or building houses; Dima said she would be happy with either career. However, Dima felt especially strongly about Dawud not “working in a corner store like his dad.” Her husband had been working in such stores for the 25 years he had lived in the U.S. and he had never received an education. Dima said she wanted her son to work in a different business than his father and “have something that he says, ‘Look, I did it myself because..."
I got the help I need.” Altogether, Afaf and Dima hoped their sons would continue making academic progress and achieve professional success.

Summary

Core Theme 4 relates to parents’ goals for their children and whether the goals changed as a result of the parents’ experiences with the special education process. Overwhelmingly, parents reported that their goals had not changed. As explored next in Chapter 4, these reported goals appeared to have been developed after considering their children’s disabilities. Therefore, one could argue that the goals had been influenced by the parents’ experiences with the special education process. In the following section the four core themes are summarized and related back to the original research questions as well as to the overarching inquiry that guided this study.

Summary of Core Themes and Chapter

The purpose of this study was to examine the experiences of Arab American parents with the special education process. The research questions asked about parents’ experiences with the special education process and its significant aspects, the parents’ understandings of their children’s identified disabilities, and their expectations or goals for their children. A descriptive phenomenological data analysis was undertaken, during which epoché was utilized to bracket personal beliefs and attitudes and to appreciate and hear the participants’ experiences as individual narratives. This analysis revealed core themes related to the following issues for the parents: (a) introductions to special education, (b) culture-specific concerns, (c) children’s special education services, (d) relationships during the process, (e) children’s strengths and difficulties, (f) understandings of special
education and special needs, (g) advocacy experiences, and (h) goals for their children’s futures.

Chapter 3 detailed the results of this phenomenological exploration of Arab American parents’ experiences with the special education process. The next chapter situates these core themes in relation to current literature about Arab American culture, Arab American students, and parents of children with disabilities. Also discussed in the next chapter are this study’s limitations, researcher reflections, future research considerations, and implications of the findings for the field.
CHAPTER IV

DISCUSSION

In this final chapter, the findings of this research study are reviewed and situated within the current body of research literature that was discussed in Chapter 1. Limitations of this study, reflections on the research experience, and suggestions for future research are considered. Additionally, recommendations are provided for school psychology training and professional practice.

Review of Research Questions and Core Themes

This qualitative study explored the experiences of Arab American parents with the special education process. The intent of the study was to understand Arab American parents’ experiences, their understandings of their children’s disabilities and needs, and their goals for their children. Qualitative methods, although uncommon in the field of school psychology, are recommended for several reasons including when there is a small body of research on a specific topic (Giorgi, 1997; Leech & Onwuegbuzie, 2007). Researchers might also select qualitative methods to learn about nuances in the meanings attributed by participants to a research topic (Creswell, 2013).

There are several approaches to qualitative research including phenomenology, which seeks to identify the essence of experiences or phenomena that are shared by individuals (Creswell, 2013). Phenomenology also has several different frameworks (Giorgi & Giorgi, 2007). Generally, it emphasizes an open, empathic, and exhaustive description of a shared experience (Giorgi, 1971; McLeod, 2001). Researchers engage in horizontalization, form thorough descriptions, and seek the essence of a phenomenon
(McLeod, 2001). In descriptive phenomenology, which is one of five main approaches to phenomenology, the researcher brackets previous assumptions during a thorough process of intuition, analysis, and description (Giorgi & Giorgi, 2007; Spiegelberg, 1965, 1975).

Only two introductory articles (Goforth, 2011; Haboush, 2007) have been published regarding school psychology practice with Arab American students in special education and their parents. These articles provide similar content, including: the definition and demographics of Arab Americans, the importance of school psychologists possessing cultural competence with this population due to its increasing size, and the lack of information available to school psychologists because of the absence of empirical studies in the field (Goforth, 2011; Haboush, 2007). Both articles referred to the Arab American culture and traditions that are important for school psychologists to consider, including the centrality of religion, which is most often Islam or Christianity, and the importance of family, which is patriarchal and collectivist (Goforth, 2011; Haboush, 2007). Additionally, Haboush (2007) detailed historical and political issues in the Arab world, attitudes toward education in general, and potential parental reluctance to enroll children in special education. Brief recommendations are made to school psychologists evaluating and counseling Arab American students and families (Goforth, 2011; Haboush, 2007).

Despite these two articles, school psychologists require more extensive information about Arab American students and families, including: cultural beliefs about special education and disabilities, potential parental attitudes toward disability identification and special education, parent-school communication, parent supports,
goal-setting for students, and overall parental experiences with special education. This study begins to fill the significant void in the literature and to work toward increased cultural competence for school psychologists. Such competence is crucial as school psychologists strive to provide culturally sensitive services to Arab American students and their families.

As detailed in Chapter 3, four core themes regarding parental experiences emerged from the data analysis. These themes relate to the following: (a) distinct aspects of the special education process and culture-specific concerns; (b) special education services and significant relationships; (c) understandings of special education, awareness of their children’s abilities and needs, and advocacy work; and (d) goals for their children’s futures.

These findings are significant for developing an appreciation and understanding of the Arab American parent participants’ experiences with the special education process. In this final chapter, the four core themes are assembled into five activities in which the parents engaged during the special education process. This organization moves the findings past the lateral connections with the original research questions and onto a summary of patterns in the significant activities engaged in during the special education process. In the following section, these activity patterns are discussed and illustrated by some participant narratives.

**Discussion of Findings: Parental Experiences**

This section clusters the participants’ special education experiences into five activity patterns of the group. The parents’ activities included the following: (a) learned
about special education, (b) reacted to the process, (c) interacted with the Arab American culture, (d) compared geographical locations, and (e) reflected on their children. These activities are summarized and illustrated below, beginning with the parents’ experience of acquiring knowledge about the special education process.

**Learned About Special Education**

During the interviews, participants reflected on their own evolving understanding of special education and special needs. All six parents discussed what their understandings had been prior to their children’s referrals for a special education evaluation. Each of them had been previously unfamiliar with special education’s procedures and services. Four participants had been unaware that special education even existed until their children were referred for an evaluation for eligibility.

As the participants discussed their experiences with the special education process and the services that their children received, they acknowledged the benefits and purpose of the services. For example, Dima and Faisal shared their pleasure that because of special education accommodations their children had been able to accurately demonstrate their academic knowledge and abilities. Eqbal and Boshra remarked on the positive influence of their children’s special education in the areas of communication and independence skills. Camilla and Afaf opted for their children to receive services so they could improve academically. The parents’ knowledge and understandings of special education, as well as their individual reasons for enrolling their children in it, were discussed in their narratives. Discussed next are the parents’ reactions to the special education process.
Reacted to the Special Education Process

Parents described their reactions to the special education process, which included the formation or maintenance of relationships with school staff and the maintenance of spousal relationships. Additionally, they shared their emotional reactions to the process. These reactions are discussed below, beginning with the relationships parents formed or sustained with school staff members.

**Relationship with school staff.** Each of the participants reflected on their relationships with staff at their children’s schools. All six parents discussed positive aspects of their interactions, including school personnel’s concern, communication, moral support, and team approach. For example, parents were positively impacted by staff’s concern, which was evident in their helpful behaviors, encouragement, and consideration. Participants felt supported and encouraged when the personnel’s communication increased parents’ accessibility to the school and provided validation. Staff’s moral support was evident to parents when there was a feeling of sisterhood and a shared understanding of their children. Additionally, parents experienced a team approach during successful collaborations with school personnel.

Two of the six parents also described negative aspects of their communication with school staff. Dima and Camilla both discussed a lack of compassion during their communication with non-Arab American teachers at their children’s schools. For example, Dima recalled unsympathetic and cruel words that her daughter’s teacher had used toward Dalal in front of her class. Camilla reflected on a previous conversation with her son’s teacher, during which the teacher “had no heart” and spoke bluntly about
Cazem’s difficulties. Additionally, Dima and Camilla had felt they were being judged by Arab American teachers and consequently worried about future experiences of judgment.

It could have been a coincidence that it was only the two American-born mothers in this study who experienced negative encounters with teachers. There could, however, also be reasons for the similarities that relate back to their native-English speaking abilities and their familiarity with the cultures of their children’s schools. For example, it is possible that the two mothers’ shared traits (i.e., their own educations in U.S. schools and their abilities to communicate with teachers without the use of an interpreter) could have prompted them to visit their children’s schools more often and seek out more interactions with teachers than a non-native English speaking parent would have done. If so, it could be argued that there were more opportunities for Dima and Camilla to communicate with staff members, thus increasing their chances of being offended. Similarly, their language skills could have allowed them to interpret and become offended by nuances in English communication with teachers. Whether their shared experiences can be attributed to anything other than coincidence will never be known. Their similar experiences, however, do bring up questions about factors in parents’ relationships, and their interpretations of those relationships, with school staff.

**Relationship with husband.** Three parents—in this case all mothers—reported that the special education process had affected their relationships with their husbands. They revealed that they did not feel supported enough by their husbands. Altogether, the mothers felt burdened by the special education process, isolated from and unsupported by
their husbands, and—as discussed in the synthesis section—hurt when the husbands denied their children’s disabilities.

**Emotional reactions.** Parents clearly recalled their emotions from different periods of the special education process. They reported having felt: denial, overwhelmed, frustrated, hurt, confused, anxious, lonely, unprepared, and reluctant, as well as proud, optimistic, enlightened, determined, relieved, analytical, empathic, and more mature. They discussed the emotional impact of their relationships with school staff and family members. Additionally, participants referred to their emotional experiences of parenting a child with a disability. Their discussions of the Arab American culture are discussed in the next section.

**Interacted With the Arab American Culture**

Parents described and analyzed their interactions with their Arab American culture. Within their narratives they discussed Arabic terminology related to special education and its stigma. These discussions were closely connected to their emphases on the importance of confidentiality and parent advocacy. These interactions are discussed below, beginning with the terminology of special education.

**Terminology, meaning, and stigma.** Several parents referred to the term *special education* and its different associations in English and Arabic. One parent explained that the meaning of a *special education student* in Arabic is an individual who has “something [wrong] in the brain.” Similar pejorative terms exist in Arabic to describe *disability* and *mental illness*. Some of these Arabic terms are linked etymologically with evil spirits (Dwairy, 2006; Gharaibeh, 2009). The lack of less devastating terms in the language
means that someone who attempts to describe these terms in Arabic—or translate the English terms into Arabic—can only utilize such disparaging terminology.

It should come as no surprise, therefore, that four of the six participants referred to the pejorative cultural associations with the terms *special education* and *disability.* These parents discussed their very real concerns about the short-term and long-term implications for children and children’s families when disabilities are identified. Camilla described the “traumatizing” experience of her son’s identification and she stated that non-Arab Americans cannot appreciate the social impact that disabilities have on Arab American children and their families.

**Confidentiality.** Given this cultural sensitivity to disabilities and special education, as well as the various strong emotions such topics can evoke in Arab Americans and Arabs, it is understandable that parent participants were very concerned about maintaining their confidentiality in this study. This was evident in the narratives of four participants. During the interviews with two of those four parents, in fact, I was instructed at multiple times to stop recording when the conversations turned to personally sensitive topics such as family discord and secrets. Although I understood their concerns, had already discussed confidentiality with them, and expressed no hesitancy to stop recording, I considered it as an outward reflection of their culture’s sensitivity to special education and disabilities.

During the interviews with the remaining two concerned parents, they were also sensitive to confidentiality. First, Afaf explained that she had kept Ali’s special education enrollment a secret from his siblings and extended family. Additionally,
Camilla noted that because of her concerns that Cazem’s Arab American teachers would judge him for his disability, she did not tell them about it until the second half of the school year. Altogether, the parents’ concerns, their descriptions of other Arab Americans’ responses, and their analyses of their culture’s general attitudes all reinforced the cultural sensitivity and stigma around special education and disabilities.

**Advocacy.** Given this cultural stigma and sensitivity, participants’ experiences with advocacy were important to them. Without being asked, three parents discussed the importance of their informal advocacy work in the U.S. and in the Arab world, with strangers and with people close to them. These three participants shared their perceptions of the importance of advocacy and they talked about the feeling of empowerment that they hoped their children would eventually experience.

The three parents believed their advocacy work was important for several reasons: (a) to educate others about their children’s strengths and difficulties, (b) to stand up for their children’s rights, and (c) to encourage other Arab and Arab American parents to feel unapologetic about their own children’s disabilities and to seek out special education services. Two of the three parents discussed their interests in continuing the advocacy work: Eqbal wanted to pursue training to become a professional advocate for parents in the Arab world and Dima wanted to work as a community advocate for special education programs in the U.S. Throughout parents’ descriptions of their interactions with their Arab American culture, they often referred to the Arab world and contrasted their home countries with the U.S. In the next section, these comparisons between the two locations are reviewed.
Compared Geographical Locations

During interviews, parents frequently compared the U.S. and the Arab world. They discussed the differences in special education services and in quality of life for individuals with disabilities. There were no specific interview questions on this topic so these discussions were initiated entirely by the parents.

Special education. Of the six participants, four were born and educated in the Arab world. These four parents each referred to the differences between special education in the U.S. and the Arab world. Some of the parents imagined the limited educational options that would be available for their children if they lived in their home countries. For example, Fawaz explained that because of difficulties with wheelchair accessibility in his home country, which is discussed in the next section, Faisal would not be able to attend school if he lived there.

Similarly, Eqbal recognized that Ebtisam would likely not be able to attend school in their home country, but if she did, the school would not be of high quality and would be “just to make the parents get rid of the children for a time, for a while. It’s not as good. She would not never learn anything.”

Additionally, Afaf compared the Arab world to the U.S. when she noted that she had a 17-year-old niece who lived in Afaf’s home country, where there was no option for special education. Her niece was unable to read or write. Afaf believed that if her niece had lived in the U.S., she would have been able to receive special education services and become literate. Afaf said, “If she was here, maybe she got the chance to learn.”
Finally, Boshra’s experiences in her home country illustrate the lack of quality special education services in the Arab world. She spoke about a private residential school that was “number one” in her home country for children with an ASD. At the time of the interview, Boshra was preparing to enroll Bassem for the summer vacation in that school in their home country. The school offered services to its students and advice for their parents that would be considered questionable in the U.S. For example, Boshra explained that in the school Bassem would be receiving oxygen therapy to help his ASD. He would also be placed on a restricted diet because the school had said that the foods Bassem ate were the cause of his severe behaviors. In addition to comparing special education in the two regions, parents compared the quality of life for individuals with disabilities. This is discussed next.

**Quality of life.** Three parents imagined their children’s overall well-being if they were to reside in the Arab world instead of the U.S. The first parent, Boshra, worried that children in her home country would “be mean” to Bassem if they knew that he had an ASD. Therefore, she did not tell strangers about his disability when they were visiting the country.

The second parent to make such comparisons was Fawaz, who described the difficulties Faisal would have in moving around in his wheelchair in the Arab world. During annual trips to visit family in his home country, Fawaz had to hire drivers to transport Faisal and his wheelchair. The drivers had to move Faisal’s wheelchair in and out of the car each time they would arrive at a destination. Without ramps on the sidewalks and into buildings, Faisal’s wheelchair had to be carried everywhere.
Additionally, within the family’s apartment, the bathrooms were not wheelchair accessible. In contrast, Fawaz described his house in the U.S. as being equipped with a special lift to move Faisal up to the second floor and with a wheelchair-accessible bathroom. Fawaz summarized the comparison of countries by explaining that Faisal “wish he stay here but because here is the best country for handicapped people.”

The third parent to compare quality of life was Eqbal, who explained in a similar manner that daily life in the Arab world for an individual with disabilities could be problematic due to mobility difficulties. Like Fawaz, she discussed the problems faced by individuals in wheelchairs:

If you have a wheelchair or something handicap he cannot go outside this easy you know. Not the streets, not the nothing! So, it would be like if I am a mother how I would carry my child with the wheelchair everywhere like this? Some people are suffering and doing this . . . I will tell you it’s impossible if you want to have a normal life with a special need kid back in [home country]. It’s almost impossible.

Eqbal also spoke at length about the impact of negative attitudes in her home country toward individuals with disabilities. She provided several examples of individuals with disabilities whose families hid them at home for years to keep them secret. Altogether, Eqbal presented many reasons why the quality of life in the U.S. was better for Ebtisam. Eqbal also made this stark summary: “Here she is alive; there she is dead.” In addition to considering the differences between geographical regions, parents reflected on their children. These parental reflections are discussed in the next section.
Reflected on Their Children

While describing their experiences with the special education process, parents often reflected on their children’s past development, current abilities, and futures. When parents spoke about their children’s development, they discussed developmental stages and sometimes referred to early indicators of atypicality. Parents also spoke about the process of their children’s identification with disabilities.

In reference to their children’s current strengths and difficulties, parents easily offered examples of both. Areas of strength included daily living skills, academics, and hobbies. Areas of difficulty included speech and language, academics, behavior, and motor skills.

Participants’ reflections on their children’s futures included the parents’ goals, which will be reviewed later in this chapter. These goals closely related to the children’s different ability levels. Therefore, some parents’ goals referred to academic and professional success while others referred to improved daily living skills.

Summary

Altogether, the findings from this study demonstrate the depth of parents’ involvement in their children’s special education process and in their children’s lives. Participants learned about the process and reacted to it in different ways. They also had interactions with their Arab American culture, which prompted them to analyze cultural mores and attitudes. They compared how their children’s lives would look if they lived in the Arab world rather than in the U.S. Finally, the parents reflected on their children’s
paths through life and the parents’ hopes for future accomplishments. In the next section, this study’s findings are located in relationship to previous research on related topics.

**Synthesis of Current Study and Previous Research on Related Topics**

This study is the first of its kind. As mentioned, school psychology research on the experiences of Arab American parents is nonexistent. Therefore, it is difficult to situate this study’s findings within the existing literature. Nevertheless, it is important to relate the findings in some way to published research.

This section synthesizes the previous related research that was discussed in Chapter 1 with this study’s findings that were described in Chapter 3. The focus is on the following three topics that have been researched: Arab American culture, Arab American students, and parents of children with disabilities. In the paragraphs that follow, the findings from this study are related to these three topics to illustrate how they reinforce or contribute to the body of published research. It is explained that this study does the following: (a) reinforces current literature related to Arab American cultural commonalities, (b) contributes to research on Arab American students by illustrating the importance of knowledge about the stigma around disabilities and about the status of special education in the Arab world, and (c) contributes most significantly on the topic of Arab American parents of children with disabilities. The first section below describes how the participants’ narratives support the related literature on the Arab American culture.
Arab American Culture

Previous research on the Arab American culture tends to highlight the heterogeneity of Arabs and Arab Americans (e.g., Kira et al., 2012; Wingfield, 2006). In this study, Camilla acknowledged this heterogeneity when she compared two countries in the Arab world: “It’s so different from Yemen to Egypt: the living, the people, the mentality.” She explained that the different acculturation levels and lifestyles among Arab Americans are due to the large geographical region. She described emigrants from Yemen living in the U.S.: “They’re completely different [from other Arab Americans].” This heterogeneity is also evident in the Arabic language, which includes many different dialects (Moradi & Hasan, 2004). Camilla explained, “Even our language is completely different. Like I would never be able to understand [Yemenis]. Even though Arabic is Arabic, but Yemen is completely different.” Due to such heterogeneity in the population, generalizations are difficult to make (Moradi & Hasan, 2004). Some cultural commonalities in the Arab American culture can be highlighted, however (Wilson, 1996). These relate to the following: (a) family structure, (b) beliefs on child development, and (c) attitudes toward disabilities as reflected in terminology, stigma, and etiological beliefs.

Family structure. Arab and Arab American families are frequently described as patriarchal, with women responsible for rearing the children (Bouhdiba, 1997). These responsibilities were reflected in the composition of the participant group in this study: five of the six parents were female. These mothers reported that they were more involved in their children’s educations than their children’s fathers were. As will be discussed in
the following section on this study’s limitations, the gender imbalance in the participant group could be related to cultural expectations of mothers or to a variety of individual factors.

**Child development beliefs.** As described in Chapter 1, interdependence between mother and child is emphasized in the Arab world (Gregg, 2005). Self-help skills are not introduced to children as early as they are in the U.S. (Wilson, 1996). Similarly, independence and responsibility are not promoted as much as they are in the U.S. (Abu-Hilal & Bahri, 2000).

An emphasis on interdependence was reflected in two parents’ narratives. Eqbal was the sole parent in this study to compare cultural perspectives on child development in the U.S. and the Arab world. In her home country, she said, parents intentionally keep their children dependent on them to a much greater degree than do parents in the U.S. She was critical of the approach in the Arab world and said, “They make the typical kids dependent and go to be a special needs, a real special needs. Here [in the U.S.] they make the special needs independent and go to be like a typical child.” To illustrate, Eqbal explained that when a “typical” child in her home country “goes to school and comes back [home], he has to depend on his mom for everything. He cannot do anything. He is like—they don’t teach him how to live.”

Boshra also referred to interdependence, however, she did not describe it as a broad cultural value or as an outcome of an educational system. Instead, Boshra highlighted its benefits and importance in her own family. To illustrate, after she described her goals for Bassem and the future challenges he would likely face, Boshra
relayed an important conversation she had recently had with Bassem’s older brother. She remembered telling him, “You’re the only one here. Bassem—maybe he needs your help when you grow up. You have to take him. You have to help your dad . . . we need money. He has to work. So you have to be support.” Boshra said that she had also told her teenage son to do well in school so he would later be able to assist his father and provide support to the family. In this way, Boshra demonstrated how she reinforced interdependent values to her children for the benefit of the entire family.

**Attitudes toward disabilities.** Cultural attitudes toward disabilities can be examined through the language and terminology used to describe them. In Arabic, language regarding disability is extremely pejorative and can include negative associations with evil spirits (Dwairy, 2006; Gharaibeh, 2009). Terminology for students in special education is also highly offensive. In general, there tends to be a cultural hierarchy of disabilities: intellectual and developmental disabilities are the most disdained, followed in decreasing order by mental illness, physical and sensory disabilities, and lastly visual impairments and blindness (Gharaibeh, 2009).

This disparaging Arabic terminology was referred to by some participants as they described the negative connotations of the term *special education* among Arab Americans and Arabs. As explained in Chapter 3, four of the parents referenced their concerns about their own children, or other Arab American children, with disabilities that required special education. The parents’ concerns related to the children being known in their community as having disabilities or receiving special education services. Their concerns also related to the difficulties the children and their siblings would likely
encounter in the future when seeking a marriage partner. One example of these concerned parents is Afaf, who despite asserting that she understood Ali’s needs and accepted the term *special education*, chose not to share his identified disability with anyone aside from her husband. Afaf might have feared that Arabs would misunderstand Ali’s abilities and assume he had some sort of brain damage. While she never explained her reasoning, one might ask if Afaf had hoped that by keeping Ali’s special education enrollment a secret she would not jeopardize the future marriage prospects for him or his sisters. Afaf understood her culture’s resistance to the term *special education* and perhaps might also have been resisting the term through her own conscious omission.

The stigma around disabilities in the Arab world is frequently discussed in the literature. As Gregg (2005) explained, adults in the Arab world are expected to marry and have children. If they do not, they can be stigmatized (Inhorn, 2012). Several researchers have discussed the negative implications of disabilities on the marriage prospects for an individual with a disability and for his or her family members (Al-Kandari & Al-Qashan, 2010; Boukhari, 1997; Crabtree, 2007b; Turmusani, 2003; Young, 1997). As a result of this stigma, individuals with disabilities are generally not seen in public in the Arab world (Crabtree, 2007b). As Reilly (2011) explained, this results in a general disregard for them. It also results in a lack of knowledge and misunderstandings about disabilities.

One example of this lack of knowledge is the perception of disabilities in the Arab world. Although the medical model is sometimes subscribed to, evil spirits, the evil eye, God, and contagion are often suspected as the causes of disabilities (Atshan, 1997;
Crabtree, 2007c; Dorsky, 1986; Naggar Gaad, 2004). Crabtree’s (2007b) research with parents of children with disabilities in the U.A.E. was described in Chapter 1. She found participants could recall several instances of their children being ostracized by strangers in public (Crabtree, 2007b). In this study, Eqbal described her own similar experiences in the Arab world. For example, when Ebtisam was three years old and tried to play with another little girl who was a stranger, the girl’s mother noticed Ebtisam’s “little tiny difference.” In front of Ebtisam and Eqbal, she talked to her child about Ebtisam and said, “Don’t play with her. Keep yourself away from her.” Eqbal said it was “like if [Ebtisam] touches her or something [the girl] will be harmed in any way.”

This lack of knowledge about disabilities is also evident in schools in the Arab world. Bazna and Reid (2009) researched teaching assistants in Kuwait, where inclusion is rare and where there are no teacher education programs on learning disabilities. These teaching assistants worked in the only school in the country that educated children with learning disabilities (Bazna & Reid, 2009). The researchers found that the assistants had had no knowledge of learning disabilities before they began their current employment (Bazna & Reid, 2009). Instead, they had been familiar only with physical disabilities (Bazna & Reid, 2009). In this study, Eqbal discussed the negative implications in society of this lack of knowledge. She said,

[People] don’t get it, you know. They need to get how to deal with people like this . . . At home they are locked all the time, no one sees them. So [society] don’t know how to do deal with them.
Eqbal said that she had not previously seen individuals with disabilities when she lived in the Arab world. In fact, she was unaware before Ebtisam was born that there were even different types of disabilities. Similarly, Boshra had been unaware of the existence of ASDs until Bassem was diagnosed with one.

The issue of inferior or unavailable special education services in the Arab world was often mentioned by parent participants in this study. Afaf, Eqbal, and Faisal each referred to the difficulties for their children or children in the Arab world to receive a special education similar to what is available in the U.S. This supports findings from two studies (Jegatheesan, 2009; K. Kim et al., 2007) in which parent participants referenced inadequate services for individuals with disabilities in their home countries and reported feeling lucky that their children could be educated in the U.S. Special education for Arab American students, which is a largely under-researched topic, is described in the next section.

**Arab American Students**

The few studies on Arab American students (Abu El-Haj, 2006, 2007; Adeeb & Smith, 1995; Al-Hazza & Bucher, 2008; Al-Khatab, 1999; Ayish, 2003; Ghaffar-Kucher, 2009; Ibish, 2003; Mastrilli & Sardo-Brown, 2002; Park et al., 2007; Salaita, 2005; M. F. Suleiman, 1996, 2001; Tabbah et al., 2012) focused on the students’ functioning within the schools or their self-perceptions. School psychologists require more resources to increase their cultural competency with Arab American students and parents (Goforth, 2011; Haboush, 2007). This competence is especially important in the area of special education. Specifically, it is important for school psychologists to be aware of the stigma
and shame that often exist around disabilities for Arabs and Arab Americans (Haboush, 2007). In this study, more than half of the participants referred to this stigma. They also considered its effects on their own children and on other Arab American children enrolled in special education or identified with disabilities.

In the Arab world, students with disabilities are often not educated or are educated in residential institutions and separate schools (Amr, 2011; Bradshaw et al., 2004; Thomas & Lakkis, 2003). When special education is offered in the region, inclusion is uncommon and sometimes disdained (Alghazo & Naggar Gaad, 2004; Gaad, 2004). Therefore, parents who recently emigrated from the Arab world, as well as those who have been in the U.S. for generations, could be unfamiliar with the practice of special education in the U.S. and could have expectations based on their knowledge of special education in the Arab world. Such unfamiliarity was evident in every participant in this study. The majority of the parents were not only uninformed about special education but they were also unaware of its existence. All of the parents learned a great deal about U.S. special education as their children went through the process and began receiving services. In the next section, the participants’ experiences are related to existing literature on parents of children with disabilities.

Parents of Children With Disabilities

As described in Chapter 1, previous research has studied parents of children with disabilities in the U.S. and internationally (e.g., Barnett et al., 2003; Hwa-Froelich & Westby, 2003; Nespor & Hicks, 2010; Skinner et al., 1999). There is currently no literature regarding Arab American parents of children with disabilities. In this section,
the findings from this study are connected to previous research. However, due to the current lack of literature with Arab American parents regarding special education, connections are made to research with parents in general. This study’s findings relate to the following important issues for all parents: (a) the identification of their children’s disabilities, (b) perceptions of their children’s disabilities, (c) supports and school communication, (d) advocacy, and (e) goals and expectations for their children.

**Identification of children’s disabilities.** The moment in which a parent learns about his or her child’s disability and specific needs has been termed disclosure (Hatton et al., 2003). It has been described as a time of crisis (Hatton et al., 2003). Common parental reactions during this experience are denial, the feeling of being overwhelmed, fear, frustration, isolation, and guilt (Graungaard & Skov, 2006; Hatton et al., 2003; Hess et al., 2006; Ho & Keiley, 2003). The parents in this study discussed their emotional reactions, which commonly included denial and difficulty accepting their children’s disabilities. Additionally, some parents reported feeling empathy for their children after they observed the significant difficulties caused by the disabilities. Parents also reflected on their children’s actual disabilities, which are discussed next.

**Perceptions of children’s disabilities.** Some qualitative research has explored cultural patterns in parental beliefs on the etiology of their children’s disabilities (Dennis & Giangreco, 1996; Groce, 1999). Parents’ beliefs are reported to affect their coping reactions and help-seeking behaviors (Ingstad & Whyte, 1995). Limited research on this topic has been conducted with non-Arab Muslim families in the United Kingdom and with Arab families in the Arab world. For example, one of the findings from Fatimilehin
and Nadirshaw’s (1994) research in the U.K. was that Muslim Asian-British parents were less likely to know the English names of their children’s disabilities. In this study, this is similar to Afaf’s lack of knowledge about the name of Ali’s identified disability. While it is unknown why Afaf did not know the name of the identified disability, it can be asked: Was her English level a factor and was the disability a word or phrase that was difficult for her to remember or that seemed to hold no meaning for her? Afaf ultimately decided to keep Ali’s identified disability a secret from everyone except her husband. Therefore, it can also be asked: Did its name seem unimportant to remember because Afaf knew she would not be sharing or discussing it with anyone else?

Other research has explored Arab parents’ perceptions of their children with developmental disabilities in the U.A.E. (Crabtree, 2007b). The study found several fathers denied their children’s disabilities, which was evident in the refusal to accept the existence of the disabilities or to seek medical confirmation (Crabtree, 2007b). This is similar to the experiences of two parents in this study, Eqbal and Camilla, whose husbands actively denied their children had disabilities. In both cases, their husbands had professional medical training that they relied on to substantiate their conclusions that their children did not have disabilities. Even at the time of Eqbal’s interview, which was three years after Ebtisam’s correct diagnosis of a genetic disorder, Eqbal’s husband continued to keep the disability a secret from others. Ultimately, Eqbal and Camilla experienced their husbands’ denials as a significant lack of support. In the next section, some positive parental supports are reviewed.
Supports and school relationships. Parents’ experiences of their children’s disabilities are directly affected by factors such as external support, parental relationships, and the specific demands of the child (Abidin, 1990). The literature reviews different forms of support for parents, including respite care, parent education, and teachers. Respite care has been cited as providing parents with direct relief, stability, relaxation, time off, and family unit preservation (NICHY, 1996). In this study, Boshra noted how crucial Bassem’s respite care had been for her during a difficult episode when she required extra support.

Parent education has been described positively when it increases parenting skills and knowledge, allows parents to address their children’s needs, and minimizes family stress (Mahoney et al., 1999; McIntyre & Phaneuf, 2007; Shumow, 1998). Unfortunately, there is very little research related to parent education with culturally diverse families (Santarelli et al., 2001). In this study, Eqbal recalled the benefits she received from parent education classes. There she learned about raising a child with a disability and she experienced emotional support. Eqbal summarized the classes: “It makes you feel better.”

Finally, school staff has been cited in the literature to be most supportive when they communicate concern and assist parents in understanding their children’s disabilities (Hess et al., 2006). Morrow and Malin (2004) noted the effectiveness of these relationships when they are actual partnerships. In this study, each of the six parents recalled the positive support they received from school staff. The parents reported benefiting from school staff’s genuine care and concern, helpful communication, moral
support, and team approach. Some parents also benefited from advocacy experiences, which are described next.

**Advocacy.** Around the world, research has been conducted on the advocacy activities of parents of children with special needs (e.g., Dawson & Osterling, 1997; Jegatheesan et al., 2010; K. Kim et al., 2007; McCabe, 2007; Nespor & Hicks, 2010; Phillips, 2008; Ryan & Cole, 2009; Shapiro et al., 2004; Wang et al., 2004). In this study, three parents spoke about their advocacy work. There were no specific questions asked about such experiences so there is a possibility that more than the three parents engaged in advocacy in some way. Participants spoke about their advocacy with the following groups: strangers in the U.S. and the Arab world, Arab and Arab American parents with children with special needs, their families, and their children. The parents’ experiences were described as very meaningful to them. In fact, two of the three participants were thinking about continuing the advocacy in a more formal role so they could help and encourage other parents like themselves. In the next section, parents’ goals for their children are discussed.

**Goals and expectations.** Significant research has explored parents’ shifting goals for their children once disabilities have been identified (Bowlby, 1980; Leerkes & Burney, 2007; Marvin & Pianta, 1996; Moses, 1987). This study explored whether Arab American parents’ goals for their children shifted as a result of the special education process. Not one of the parent participants reported that their goals had shifted.

Despite the parents’ assertions, their goals appeared to be appropriate for their children’s current levels of functioning and types of disabilities. Specifically, four
parents reported goals related to their children’s daily living skills. These children had disabilities that significantly impacted aspects of their daily lives. The other two parents, whose children’s daily living skills were not significantly impacted by their disabilities, held academic and professional goals for their children. Such findings would suggest a shift in goals, presumably as a result of the knowledge the parents gained at least partly through the special education identification process.

To explain the discrepancy between parents’ reports and their seemingly shifted goals, one could take any of the following three perspectives. First, the parents with children with more severe disabilities were made aware of the disabilities from an earlier age so they had more time to tailor their goals, such that special education experiences did not suddenly or drastically cause them to change their goals. Second, parents might not have been able to refer back to their previous goals to remember actually making changes. Third, they might not have even realized that their goals had shifted over time.

Two main methodological considerations, however, make it impossible to argue that their goals had actually changed at all. First, parents were not asked about their goals before they began the special education process. Such questions would have helped establish and record parents’ original goals. Parents were asked about any shifts in their goals only at the time of this study’s interviews. At that point, the participants’ children had already begun or concluded the special education process. Therefore, any shift in parents’ goals could not be accurately documented. Second, several parents made significant grammatical mistakes in English that are typical of native Arabic speakers learning English. For example, many did not show mastery of the past tense and used
only the present tense (e.g., “Last year, I go to the school,” or “Yesterday, he reads a book”). As a result, their abilities to process past tenses during interview questions could have been compromised. This could also have impacted their abilities to answer questions in a way that delineated any shifts in thoughts or goals from the past to the present.

As a result of the possible explanations and methodological considerations explained above, the parents’ reports of their unchanged goals were presented in the findings in Chapter 3. In this study, parents’ experiences were accepted as they reported them rather than contested or verified by any outside measures. This includes the parents’ statements of their unchanged goals. Further research could explore this question in more depth and could address the above methodological considerations. In the next section, the limitations of this study are considered.

**Limitations**

This section begins with a review of several considerations specific to qualitative and phenomenological research. Thereafter, the section transitions into an exploration of this research study’s limitations, including traits of the researcher and the participant group. Finally, the significance and potential impact of these limitations are examined.

Qualitative research is appropriate for establishing variables in areas that are typically difficult to measure (Creswell, 2013). This research study explored an under-researched population’s experiences of a sensitive and sometimes stigmatizing process. Due to the cultural stigma around special education, the research topic was sensitive to explore with Arab Americans. Participants might have held back sensitive
emotions, recollections, or opinions because they were being interviewed by a stranger. In hindsight, participant interviews on this topic might have yielded deeper or more personal data if parents were interviewed during second or third meetings. Although I believe participants were very open with me about their experiences, it is possible that they would have felt more comfortable and open after additional meetings.

In qualitative data collection that includes interviews, researchers pose open-ended questions to explore the nuances of participants’ individual understandings and experiences (Nastasi & Schensul, 2005; Patton, 2001). If a different qualitative researcher had conducted this study, different open-ended questions would likely have been asked or different responses and follow-up questions would have been presented. In other words, the interview and follow-up questions that I selected, the responses that I made, and the nonverbal behavior that I demonstrated all are specific to me as an individual. Therefore, although participants’ experiences of the special education process would not have changed if a different qualitative researcher collected them, their experiences would likely have been solicited and reported in a somewhat different style.

In phenomenological research, the researcher must identify and separate from personal assumptions, biases, and experiences using a bracketing process (McLeod, 2001; Moustakas, 1994; Wertz, 2005). He or she is required to utilize intuition, description, and reflection (Giorgi, 1971). Although different several methods to ensure trustworthiness have been employed in this study, the process of phenomenological data analysis is intrinsically an individual process during which some biases might invariably surface. Other researchers could have intuited, described, and reflected on the data
differently. While I am confident that my methods were trustworthy, I cannot assume that a different phenomenological researcher would not have reached different conclusions or interpretations from the data. A discussion of my own personal limitations in the research is next.

Some of my personal knowledge could be construed as a limitation in this study. For example, my experiences in the Arab world as well as with Arab and Arab American individuals mean that I am familiar with the culture. While that familiarity could be seen as an advantage (e.g., I was able to easily build rapport with participants and demonstrate my long-standing interest in their culture), it could also be seen as a limitation. For example, participants might not have explained certain experiences or might not have detailed cultural attitudes because they could have believed that I already understood the cultural context. Therefore, if I had not explained my experiences and communicated a familiarity with their cultural background—or if I had not had the experiences in the first place—the participants’ narratives might have been richer with more explanations or analyses of their culture.

Another personal limitation could be my limited ability to speak Arabic. My restricted fluency allows me to speak and understand some dialects of Arabic although I am not bilingual. This meant that participants were obligated to express themselves in English to me even if they would have felt more comfortable speaking in Arabic. This limitation is discussed below in the context of participants’ traits.

Several traits of the participant group could be construed as limitations in this study. The group was comprised of six parents who were homogenous in several aspects:
religion, gender, geographical location, and the decision to enroll their children in special education. Additionally, a majority of the participants were born in the Arab world and spoke English as a second language. These participant traits are discussed below, beginning with the participants’ shared religion.

AAI (2002a) estimated that only 24% of Arab Americans are Muslim. However, all of the participants in this study were Muslim. The parent participants were referred to me almost entirely by individuals working in secular public schools. It is therefore unknown why the referred parents all happened to share the same minority religion. This coincidence could relate to a variety of unknown factors, including a potential preponderance of Arab American Muslims in the area in which I recruited. Although all of the participants were Muslim, it is my belief that their special education experiences would be consistent with those of Arab American parents of the Christian, Jewish, or Baha’i faiths. This is conjecture, however, until it can be established by further research.

Fathers were under-represented in the parent group: five mothers and one father participated. Like the parents’ religion, the gender imbalance also reflects the referrals that I received during the recruitment period. This disproportion could relate to the cultural tendency for Arab mothers to be responsible for their children’s education (Bouhdiba, 1997). It could, however, stem from other more individual factors such as parents’ English fluency, personal interests, or time commitments. In future research, an equal number of fathers and mothers could be recruited and gender differences in experiences could be explored.
For the ease of scheduling and conducting in-person interviews, the parent participants were recruited from the same Midwestern metropolitan area. The parents descended from different countries in the Arab world and had distinct immigration histories. Some participants had grown up in the U.S.; others had moved there as adults with their families. However, because all of the participants resided in the same metropolitan area at the time of the interview, there could be geographical limitations to this study. For example, it is possible that the public schools in the area had similar special education practices or had distinct practices of communicating with parents that might have differed from other areas of the U.S. Therefore, further research could involve Arab American parents from other regions of the country to explore differences in special education experiences.

As explained in Chapter 2, the parent participants in this study were required to have had some experience with special education. This meant that one of the following situations would be true for each participant: (a) his or her child was referred for a special education evaluation but the parent refused permission for the child’s evaluation, (b) his or her child was identified with a disability requiring special education but the parent chose not to enroll the child, or (c) his or her child was identified with a disability requiring special education and the parent chose to enroll the child. Parents from only the third group were referred to me. Therefore, only participants with this specific type of special education experience were recruited to participate in this study. The findings of this study could have been different if parents from the first two groups had also
participated. These two groups are worth exploring in future research with Arab American parents.

Another criterion of participation was that parents possessed enough English language fluency to allow them to communicate during interviews without the use of an interpreter. This decision was based on two potential issues: participants could have concerns about confidentiality and the dynamics between the researcher and participants could change because of the presence of an interpreter in the interviews. Parents with low English skills, therefore, were not recruited for this study. As a result of this criterion, four of the participants who had been born in the Arab world and who spoke Arabic as a first language could have felt obstacles to communicating in English during the interviews. As mentioned above and illustrated by excerpts from the interviews, those four parents spoke English with several grammatical and vocabulary mistakes. It is possible that they would have selected to share different or more complex memories and experiences if they had been interviewed in Arabic. This should be considered in future research, which could involve a bilingual researcher fluent in Arabic to conduct the interviews in the parents’ language of choice.

In summary, qualitative research involves participants who are not evenly selected from the general population; they are chosen based on who can describe and reflect on the experience being investigated (Polkinghorne, 2005). The parents who participated in this study were referred by others who knew that they had had special education experiences. The group of participants was homogenous in several significant areas, which could be regarded as a limitation in this study. Additionally, my existing
cultural knowledge and limited Arabic abilities could be perceived as limitations.
Ultimately, the goal of this phenomenological study was to look in detail at the parent
participants’ experiences with the special education process rather than to generalize the
study’s findings to all Arab American parents. This study could be considered a success
in that regard despite any limitations that exist. In the next section, my reflections from
the research process are described.

**Researcher’s Reflections**

My interest in this topic is longstanding. As discussed in Chapter 2, my personal
and professional experiences prompted my interest in Arab American families involved
with special education. It has been very satisfying to conduct this important research and
to contribute to the field.

As a result of my bracketing interview, which occurred before I began recruitment
and data collection, I realized that I was thinking a great deal about the concept of *visible*
versus *invisible* disabilities. Specifically, I wondered if Arab American parents’
experiences of the special education process might differ based on the degree of visibility
of their children’s disabilities. Participants, however, did not mention this issue during
the interviews.

This study intentionally included a small number of participants so I could
explore in depth each individual’s experiences. As I optimistically set out to recruit a
small group of Arab American parents, I did not anticipate just how difficult the process
would be. In looking back, I would have gone about recruitment differently so the
process could be more efficient and less stressful. For example, I would have asked
families who had been referred to me to share my contact information with other suitable families they knew who might also be interested. Additionally, I would have planned for a significantly longer recruitment period, such as six months.

In looking back at interviews, I wonder if the locations of the meetings might have factored into the data collection process or might have affected participants’ comfort levels. It was my intention that the participants would choose to be interviewed where they felt most comfortable and I believe they each did select the most appropriate location for themselves. For example, three of the parents invited me to their homes for the interview; they all happened to be *muhajibat* (women wearing hijab). I do not know if this was a coincidence or if the mothers chose to be interviewed at home because they anticipated feeling more comfortable there than in public, where it is likely they would have received more attention. Regardless, I suspect that these three interviews might have proceeded differently if they had occurred in public (e.g., interviews of shorter/longer duration, fewer/more emotional displays, less/more disclosure). Of the remaining three participants, it is likely that two of them would not have felt comfortable being interviewed by me in their homes. For example, it would not have been culturally appropriate for me to suggest or to agree to interview Fawaz in his home because of our opposite genders. Additionally, it would not have been possible for me to interview Afaf in her home because her daughters did not even know about Ali’s special education enrollment.

Overall, I continue to be very touched by and appreciative of how much the parent participants shared with me. They took enormous risks in disclosing to a stranger
such personal information about their inner lives, their experiences, and their families. I learned so much from them and will always be grateful for their generosity.

**Future Research**

As discussed in Chapter 2, topics that do not have an already-established body of research are best researched with qualitative methods (Giorgi, 1997). These methods can assist researchers in forming theories on a topic when current theories are inadequate or incomplete (Creswell, 2013). Qualitative research also allows researchers to appreciate and focus on the meanings assigned by the participants to the topic (Creswell, 2013). One of the reasons that qualitative methods were the most appropriate for this study is that this is an unexamined topic. Before this study, there was no other research—qualitative or quantitative—with Arab Americans regarding the special education process.

This study only begins to explore this important topic; further research is necessary. Such investigations would allow school psychologists to increase their cultural competence, which would then result in positive outcomes for students and parents. In initial subsequent research with Arab American parents and students, qualitative research is recommended for a thorough and sensitive exploration of several important topics. These suggested topics are listed below (with examples of possible qualitative research approaches):

- Students’ experiences of special education (narrative inquiry),
- Home-school collaboration (ethnography or case studies),
• Parents’ interpretations of and beliefs regarding their children’s disabilities (phenomenology or grounded theory),

• Successful and appropriate supports for parents of children with disabilities (case studies or phenomenology),

• The process of drafting IEPs and setting goals when parents have an interdependent orientation (narrative inquiry or ethnography).

In the next section, the implications of this study are discussed and recommendations are made for the transfer of this study’s findings to the field of school psychology.

**Implications of Findings for the Field of School Psychology**

Despite Arab Americans being a sizable population in this country, few recommendations are available for school psychologists working with Arab American students and families. Consequently, more recommendations are necessary, including recommendations specific to Arab American parents involved with the special education process. In this section, recommendations are made based on the findings from this study and on the most recent related literature.

The core themes that emerged from this study form the recommendations that are presented below. The recommendations relate to the parents’ experiences, which are discussed in the core themes: (a) reactions to and understandings of the special education process; (b) interactions with the Arab American culture regarding disability terminology, confidentiality concerns, and advocacy experiences; (c) comparisons of the Arab world to the U.S. in special education options and quality of life for individuals with disabilities; and (d) reflections on their own children.
Additionally, the recommendations incorporate the most recent related literature. This includes the following: (a) the stigma in Arab American culture associated with disabilities and special education, (b) the general lack of special education services across the Arab world, (c) the significance parents in general assign to the identification and disclosure of their children’s disabilities, and (d) the positive impact school staff relationships and various support programs can provide to parents in general.

The recommendations are divided into two sections. The first section specifies necessary professional knowledge of Arab Americans in the areas of parent communication, cultural perspectives on disabilities, and heterogeneity of parents’ backgrounds and experiences. The second section specifies professional practice considerations with Arab Americans related to confidentiality and the identification of disabilities, parental reactions to and interpretations of the special education process, and supports for parents.

**Professional Knowledge**

Graduate students in school psychology training programs and current school psychologists can benefit from the following recommendations. They are designed to increase cultural competence and professional knowledge of the Arab American population. The recommendations relate to communication, perspectives on disabilities, and diversity in experiences.

**Work toward sensitive communication with parents.** Within the Arab American culture, there is a preference for in-person and personal communication (Moosa et al., 2001). Therefore, parents should be allowed to visit the school
psychologist’s office and call on the phone if it is preferred. When reaching out to parents, this personal approach should be utilized.

**Create a welcoming environment.** In the Arab and Arab American culture, hospitality is very important (Al-Krenawi & Graham, 2000). When parents visit the school psychologist’s office, time for informal conversation should be allowed before discussing professional content. The cultural tendency for indirect communication should be appreciated by school psychologists; parents should not be approached immediately in a direct and confrontational manner.

**Seek information on cultural perspectives and beliefs on disabilities.** School psychologists should understand how a parent’s perspectives, beliefs, and orientation could impact his or her perspectives on child development. These factors can also affect his or her priorities during the process of setting goals for individuals with disabilities.

**Understand heterogeneity in backgrounds and experiences.** Arab Americans are a very diverse group with different religions, acculturation levels, immigration histories, and dialects (Moradi & Hasan, 2004). It is important to seek out information on the Arab world’s different religions, as well as the history, politics, and socio-economic levels of different Arab countries. If appropriate, school psychologists can express an interest in parents’ backgrounds to learn more about their specific experiences and perspectives.

**Professional Practice Considerations**

School psychologists can utilize the following recommendations to develop and sustain respectful and informed relationships with Arab American parents and students.
Such relationships can improve the families’ experiences with the special education process and the school. The recommendations relate to three areas: (a) outreach and communication, (b) interactions during the referral and identification processes, and (c) resource and support provision.

**Assure confidentiality.** During outreach and communication, school psychologists should respect and understand parents’ and students’ concerns regarding confidentiality. A parent might worry that school staff could share private information regarding his or her child and family. Instead, parents should be reminded frequently about confidentiality laws. They should hear why certain information is solicited, how their private information will be used, and who will be able to review it. If a student is being evaluated for special education eligibility, parents should be provided with an explanation of the evaluation process and prepared for what will be required for the team to make an eligibility determination.

**Be prepared for parental reactions to the referral and identification.** The moment in which parents learn about their children’s disabilities can be highly emotional (e.g., Graungaard & Skov, 2006; Hatton et al., 2003). For Arab Americans, their sensitivity to the experience could be multiplied due to the cultural stigma related to disabilities and special education. Therefore, they might respond with strong emotion to any discussion of special education or reference to disabilities. Additionally, they could react strongly to the referral and identification of disabilities that require special education. To sensitively navigate this process, school psychologists may avoid the use of terminology related to disabilities and special education. Instead, they should focus on
the children’s strengths and emphasize the difference in their learning needs compared to other students.

**Be prepared for different reactions in one family.** During the referral and identification processes, one parent might respond with denial or anger while the other might be relieved and accept the situation. If this occurs, the school psychologist should speak with each parent differently and try to understand their perspectives without assigning value judgments. In this way, the school psychologist maintains relationships with both parents and does not create or contribute to a divisive situation. If only one parent attends school meetings, he or she may be asked how the other parent will likely respond and if the school psychologist should be in touch with him or her.

**Solicit and seek to understand parents’ beliefs, knowledge, and experiences.** School psychologists should understand parents’ conceptions of the following topics: disabilities, their etiology and impact, special education services, special education law, and parents’ rights including advocacy. School psychologists should not make assumptions about parents’ knowledge. Parents should be asked about their special education experiences and knowledge. When inquiring, it is important to be sensitive and explain that the questions are being asked to better understand the parents and their experiences.

**As always, disclose and identify disabilities with sensitivity.** When possible, school psychologists should meet with parents alone to allow them to ask questions away from the larger and sometimes intimidating evaluation team. The evaluation results should be presented to parents without jargon; some parents might also prefer a verbal
explanation rather than a written one. They may be asked if the strengths and weaknesses found by the evaluation team match what they observe at home. Parents’ perceptions of the implications of the disability on the student and the family should be discussed. Parents should be presented with options related to special education and should be allowed to review them. The importance of early intervention and the goals of special education should be explained. Parents should hear descriptions about how special education services are provided. Finally, they should be reminded of their rights, including their power to make the final decisions about their children’s education.

**Recognize their difficult decisions.** Parents should be encouraged to discuss the rationale for their decisions regarding their children’s special education. School psychologists should inquire about the opinions of other family members and appreciate any difficulties parents might be experiencing in deciding whose wishes to follow. Parents should be encouraged to share their short-term and long-term goals for their children. If parents refuse special education services it does not necessarily mean that they do not care for their children; instead, culture-specific concerns or beliefs could have persuaded them not to accept the services.

**Expect and incorporate different goals.** If parents do agree to special education services, they should be asked for their input in drafting the IEP and hear why it is being solicited. Parents should be asked to share their goals for their children for school and home. Suggestions should be offered to parents so they can help their children work at home toward academic and non-academic goals.
Empathize with parents about challenges and help arrange supports. In some situations, the school staff will be the only adults with whom parents might be able to discuss their children’s disabilities and special needs. Therefore, school psychologists should inquire about parents’ available supports and resources. Parents should be asked to imagine what sorts of supports they would prefer and could envision utilizing (e.g., literature, web sites, parent groups, community organizations, parent education classes, and mental health counseling). They should also be asked if they would like assistance in finding more resources. Additionally, parents may require assistance explaining evaluation findings and special education services to other family members, including the student. If parents do opt for special education services, they and the student should be reminded how confidentiality will be addressed within the school environment.

Conclusion

In this final chapter, the findings of this descriptive phenomenological research are reviewed and discussed in the context of existing current literature. Findings of this study revealed that during the Arab American parents’ experiences with the special education process they engaged in the following significant activities: (a) learned about special education, (b) reacted to the process, (c) interacted with the Arab American culture, (d) compared geographical locations, and (e) reflected on their children. Relevant recommendations have been provided for school psychologists.

This is the first study to explore this topic. The findings include detailed and concrete experiences of Arab American parents involved in the special education process for their children. The parents’ narratives provide informative perspectives on the
following experiences: (a) being introduced to special education, (b) having culture-specific concerns, (c) reflecting on their children’s special education services, (d) forming and maintaining significant relationships, (e) reviewing their children’s strengths and difficulties, (f) evaluating their understandings of special education and special needs, (g) engaging in advocacy, and (h) considering their goals for their children. Future research should continue to explore Arab American students’ and parents’ interactions with special education.
APPENDICES
APPENDIX A

INSTITUTIONAL REVIEW BOARD APPROVAL FOR STUDY
Appendix A

Institutional Review Board Approval for Study

From: "KIEHL, LAUREN" <sien1@kent.edu>
Subject: IRB approval for protocol #11-184 - retain this email for your records
Date: April 22, 2011 8:06:14 AM CD
To: "ANHALT, KARLA" <karla@kent.edu>, "KIESZ, TRICIA" <dnesz@kent.edu>

RE: IRB #11-184 entitled "A Phenomenological Exploration of the Experiences of the Special Education Process for Arab American Parents:

Hello,

I am pleased to inform you that the Kent State University Institutional Review Board reviewed and approved your Application for Approval to Use Human Research Participants. Approval is effective for a twelve-month period:

April 20, 2011 through April 19, 2012

"A copy of the IRB approved consent form is attached to this email. This "stamped" copy is the consent form that you must use for your research participants. It is important for you to also keep an unstamped text copy (i.e., Microsoft Word version) of your consent form for subsequent submissions.

Federal regulations and Kent State University IRB policy require that research be reviewed at intervals appropriate to the degree of risk, but not less than once per year. The IRB has determined that this protocol requires an annual review and progress report. The IRB tries to send you annual review reminder notices by email as a courtesy. However, please note that it is the responsibility of the principal investigator to be aware of the study expiration date and submit the required materials. Please submit revised materials (annual review form and copy of current consent form) one month prior to the expiration date.

HHS regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design, or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB must also be informed of any adverse events associated with the study. The IRB further requires a final report at the conclusion of the study.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protections (OHRP); FWA Number 0000165.

If you have any questions or concerns, please contact me at 330-672-2104 or pmkashio@kent.edu.

Respectfully,
Kent State University Office of Research Compliance
137 Cartwright Hall | fax 330.672.2658

Kevin McGraw | Research Compliance Coordinator | 330.672.8058 | kmcgraw@kent.edu
Laurie Kiehl | Research Compliance Assistant | 330.672.0857 | liiehl@kent.edu
Paulette Washko | Manager, Research Compliance | 330.672.2704 | pwashko@kent.edu
APPENDIX B

RECRUITMENT SCRIPT AND MATERIALS
Appendix B
Recruitment Script and Materials

The following text is the content of the e-mail that I will send to school psychologists I know to ask for their help in locating Arab American families who might be interested in participating in the study.

Dear ________,

I am recruiting Arab American families to interview for my dissertation about Arab American parents’ experiences with the process of special education for their child. I feel this is an important topic to research because there is minimal literature for school psychologists working with Arab American families and none that describe the individual experiences of Arab American parents.

I will be seeking six to twelve families, each with at least one child who has been referred for a special education evaluation. It is not necessary that the child has been identified as eligible for special education or received special education services. Instead, I am interested in families that have any experience with the process, even if it is only in the beginning stages (e.g., they eventually refused assessment or services).

Participants will need to fit the following criteria:
• Parents or primary caregivers (hereafter referred to as parents) identify as Arab American.
• Parents have a child who has been involved in the special education process in the United States (i.e., anywhere along in the process from the initial referral for assessment to the diagnosis and determination of services).
• Parents have had these special education experiences within the last five years.
• At the time of the experience, the child was in a grade from pre-school to sixth grade.
• At least one of the parents speaks English fluently and the services of a translator are not needed to collect interview information from the parent(s).

Before I continue, I must point out that I am aware of your need as a school psychologist to maintain confidentiality and sound professional ethics. Should you refer families to me, I do not want this to cause you a conflict of interest or other ethical/confidentiality concerns. Please bring any such concerns to my attention.

During the initial phone conversation with the parent, I will describe to them the potential risks and benefits of participating in the study, as well as the steps that I will take to maintain confidentiality (see below). I will tell them that if they decide to participate and we meet for the interview, I will then give them an informed consent form to sign. Also, I will explain that they will have the option to stop the interview and/or withdraw from the study at any point.

Securing and maintaining confidentiality of the data will be of utmost concern during this study. I will begin the interviews by explaining the procedures I am taking to maintain confidentiality. For example, I will be using aliases in my transcriptions and notes and I will be “scrambling” personally identifying information in the transcripts, such as national
origin, and personal details (e.g., time of arrival in the United States, neighborhood of residence).

Potential risks to the participants include negative long-term psychological effects due to recalling and describing experiences that might be emotionally upsetting to them. Additionally, they could experience upsetting emotions if the interviews are not conducted sensitively.

Therefore, I will conduct the interviews with the highest level of sensitivity to the participants’ reactions to questions and I will respect their privacy, allowing them to decide how much information they would like to reveal. I will not push them to share information and I will be attuned to any reluctance to discuss a topic. Additionally, I will provide all participants with referrals for psychological support in the community that they can call or visit should they choose to. If an interview results in the participant experiencing emotional distress, I will follow-up with them by phone the next day to encourage them to contact one of the psychological referrals.

There are no expected direct benefits to individual subjects, except for any psychological benefits that they might experience from sharing their experiences. However, this project intends to contribute to the field of school psychology regarding Arab Americans and their experiences with the special education process. There will be no compensation offered to the participants. A small token of appreciation will be given to participants at the conclusion of their interview but it will have no significant financial value (e.g., a box of Middle Eastern pastries, etc.). I will not communicate to you whether specific parents have contacted me about participating in the study or if I eventually interview them. Therefore, the parents should not feel coerced or influenced to participate in the study.

You are welcome to share my contact information with any parents who you think fit eligibility criteria and might be interested in participating. The best way for you or them to reach me is by phone at 475.201.6888 or by e-mail at edonovan1@kent.edu.

Please let me know if you have any questions. You are also free to contact my advisor, Dr. Karla Anhalt, at 330.672.6582. This project has been approved by the Kent State University Institutional Review Board. If you have questions about Kent State University’s rules for research, please call Dr. Sonia Alemagno, Interim Vice President for Research, Division of Research and Sponsored Programs at 330.672.3704.

Warmly,

Elizabeth Donovan, M.S., NCSP
Doctoral Candidate
Kent State University
School Psychology Ph.D. Program
APPENDIX C

INSTITUTIONAL REVIEW BOARD APPROVAL FOR LETTER TO PARENTS
Appendix C

Institutional Review Board Approval for Letter to Parents

From: "WIEHL, LAUREN" <lauraw@kent.edu>
Subject: IRB approval for MODIFICATION(S) (protocol #11-184) - retain this email for your records
Date: June 7, 2011 13:56:18 AM CDT
To: edonov01@kent.edu <edonov01@kent.edu>
CC: "ANNALI, KAPSLA" <dunhall@kent.edu>

RE: IRB #11-184 entitled "A Phenomenological Exploration of the Experiences of the Special Education Process for Arab American Parents."

Hi,
The Kent State University Institutional Review Board (IRB) has reviewed and approved your protocol modification request. It is understood that the research is continuing with modifications including providing the school district with a letter signed by the advisor that states that "the school district and its employees are not participating in or endorsing the study." The modification to this protocol was approved on June 7, 2011.

"If applicable, a copy of the IRB approved consent form is attached to this email. This "stamped" copy is the consent form that you must use for your research participants. It is important for you to also keep an unstamped/test copy (i.e., Microsoft Word version) of your consent form for subsequent submissions. Note that if you are conducting an online study, the stamped consent form is only for record keeping purposes.

Federal regulations and Kent State University IRB policy requires that research be reviewed at intervals appropriate to the degree of risk, but not less than once per year.

HHS regulations and Kent State University Institutional Review Board guidelines require that any changes in research methodology, protocol design, or principal investigator have the prior approval of the IRB before implementation and continuation of the protocol. The IRB must also be informed of any adverse events associated with the study. The IRB further requires a final report at the conclusion of the study.

Kent State University has a Federal Wide Assurance on file with the Office for Human Research Protections (OHRP; OWA Number 0001182).

If you have any questions or concerns, please contact me at 330-672-2704 or lwashko@kent.edu.

Respectfully,
Kent State University Office of Research Compliance
137 Cartwright Hall | Fax 330.672.2658

Kevin McCreary | Research Compliance Coordinator | 330.672.8058 | kmccrea@kent.edu
Laurie Kiel | Research Compliance Assistant | 330.672.0837 | lkiel@kent.edu
Paulette Washko | Manager, Research Compliance | 330.672.1704 | pwashko@kent.edu

For link to obtain general information, access forms, and complete required training, visit our website at www.kent.edu/research.
APPENDIX D

LETTER TO PARENTS
Appendix D

Letter to Parents

May 26, 2011

Dear Parents,

Asalamu alaykum! Greetings! I am a doctoral candidate in school psychology at Kent State University and my dissertation is about the experiences of Arab American parents who have been involved in or participated in any way in the special education process on behalf of their child. I am doing this research because there is not much published school psychology literature on working with Arab American students and families, and I hope my dissertation project will shed light on the needs and experiences of Arab American students and families taking part in the special education process.

I am seeking six to twelve families who will speak with me individually for a confidential and respectful interview about their experiences. The interview will be in English so at least one parent in the family should speak English. My dissertation study has been approved by my doctoral committee and I have received Kent State Institutional Review Board (IRB) approval for this study. To participate in the study, parents must be Arab American, their experience with special education should be within the last five years, and at the time of the experience their child was in a grade from pre-school to sixth grade.

Please contact me if you would like to learn more about my study or if you would like to participate. I would be happy to give you more information in person or over the phone. I can be reached at: (478) 201-6288 or edonov3@kent.edu Please know that Strongsville City Schools and its employees are not participating in or endorsing this project.

Shukran wa ma'salama! Thank you and goodbye!

Elizabeth Donovan
Doctoral Candidate
School Psychology Program
Kent State University

Karla Anhalt, Ph.D.
Associate Professor & Co-Coordinator
School Psychology Program
Kent State University

School of Lifespan Development and Educational Sciences
Counseling and Human Development Services • Educational Psychology • Gerontology
Human Development and Family Studies • Instructional Technology
Rehabilitation Counseling • School Psychology • Special Education
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330-672-2294 • Fax 330-672-2512 • www.edhs.kent.edu/ldes/
APPENDIX E

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY
Appendix E

Informed Consent to Participate in a Research Study

Study Title: A Phenomenological Exploration of the Experiences of Special Education for Arab American Parents

Principal Investigator: Elizabeth Donovan

You are being invited to participate in a research study. This consent form will provide you with information on the research project, what you will need to do, and the associated risks and benefits of the research. Your participation is voluntary. Please read this form carefully. It is important that you ask questions and fully understand the research in order to make an informed decision. This form will include some things we have already discussed. You will receive an extra copy of this document to take with you.

Purpose:
I am researching the experiences of Arab American parents with the process of special education for their child. I feel this is an important topic to research because there is minimal literature for school psychologists working with Arab American families and none that describe the individual experiences of Arab American parents with special education in the United States.

Participation Criteria:
This study will include six to twelve families, each with at least one child who has been referred for a special education evaluation. It is not necessary that the child has been identified as eligible for special education or received special education services. Instead, each family should have some experience with the process, even if it is only in the beginning stages (e.g., they eventually refused assessment or services). Additionally, participants should fit the following criteria:

- Parents or primary caregivers (hereafter referred to as parents) identify as Arab American.
- Parents have a child who has been involved in the special education process in the United States (i.e., anywhere along in the process from the initial referral for assessment to the diagnosis and determination of services).
- Parents have had these special education experiences within the last five years.
- At the time of the experience, the child was in a grade from preschool to sixth grade.
- At least one of the parents speaks English fluently, and the services of a translator are not needed to collect interview information from the parent(s).

Procedures:
If you choose to participate, I will interview you in person to discuss your experiences with the special education process. During the interview, I will ask you to verbally share your experiences. You will be able to skip any questions or stop the interview at any point. The interview should last between one and two hours. We will arrange to meet for the interview either in your home or a private location (e.g., room in the public library, etc.).
Audio Recording
The interview will be audio recorded to allow me to transcribe the information you share with me. You will have the choice to listen to the recording after we have finished the interview. The recording will be heard by only myself, my two research advisors, and perhaps an employee of Kent State University’s Research and Evaluation Bureau. If they assist with transcriptions. (Note: These employees are bound by confidentiality agreements and have completed background checks, including fingerprinting.) Additionally, I will be personally delivering the recording to the supervisor of the Research and Evaluation Bureau for transcription. Finally, at the conclusion of the research project, I will be personally destroying and deleting the audio recordings.

Benefits
This research will not benefit you directly, except for any benefits that you might experience from sharing your experiences. However, your participation in this study will help us to better understand the individual experiences of Arab American parents with the special education process in the United States.

Risks and Discomforts
Although I do not anticipate it happening, the biggest risk of this project is that you could feel emotionally upset during or after the interview about sensitive topics that you share with me. Some of the questions I ask are of a personal nature and may be upsetting or you may feel uncomfortable answering them. If you do not wish to answer a question, you may skip it or stop the interview at any point. At the conclusion of the interview, I will provide you with contact information for counseling assistance if you find it necessary.

Privacy and Confidentiality
Confidentiality will be maintained to the limits of the law. Securing and maintaining confidentiality of the data will be of utmost concern. I will be encrypting the data on a removable external hard drive, which will be stored in a locked fireproof cabinet in my home. To access the data on the hard drive, one would need my private user account password. Furthermore, your name will not be associated with the recording or data, and immediately after they have been transcribed I will be changing any names mentioned in the recording to aliases. I will also be "scrubbing" personally identifying information from the transcripts, such as national origin, and personal details (e.g., time of arrival in the United States, neighborhood of residence). If the results of this study are published or presented at scientific meetings, no information will be presented that could possibly identify individuals or families. Finally, confidentiality may not be maintained if you indicate that you may do harm to yourself or others.

Voluntary Participation
Taking part in this research study is entirely up to you. If you choose to participate, you may withdraw from the study at any time.

Contact Information
If you have any questions or concerns about this research, please call me at 412.717.1398 or my advisor, Dr. Kurla Anhalt at 330.672.6582. This project has been approved by the Kent State University Institutional Review Board. If you have questions about Kent State University's role in research, please call Dr. Sonja Alemagno, Interim Vice President for Research, Division of Research and Sponsored Programs at 330.672.2704.
Consent Statement and Signature
I have read this consent form and have had the opportunity to have my questions answered to my satisfaction. I voluntarily agree to participate in this study. I understand that a copy of this consent will be provided to me for future reference.

Participant Signature ____________________ Date ______________

Participant Name, Printed ____________________

Audio Recording Consent
I agree to be audio recorded for the research project described above. The researchers may use the audio recordings for the research and any reports and publications that are produced from the research.

I have been told that I have the right to a copy of the audio recording before it is used. I have decided that I:

___ do want a copy of the recording

___ do not want a copy of the recording

If so, where shall I send the digital recording file? [e-mail / postal mail] ____________________

Participant Signature ____________________ Date ______________
Appendix F

Interview Questions

Phenomenological interviews are considered exchanges between two people in a meaningful relationship, with the participant being the expert on the phenomenon (Thomas & Pollio, 2002). Questions can be tailored to each individual and can utilize the individual’s surroundings to increase the immediacy of the conversation (Patton, 1990). Because each individual will be sharing his or her own experiences and my questions will flow from what the individual has shared, each interview will not be identical and some questions will be specific to the individual. There will not be a standard structured format for each interview. I will ask different questions of the participants based on what they spontaneously share, and what their comfort level is with me. While the order of the questions might vary, the range of questions about the participants' experiences with the special education process will be constant throughout. Therefore, while I am not able to predict all of my follow-up questions, what follows are questions that I intend to ask at some point during each interview:

• What is your experience with the special education process?
• Can you walk me through the experience and point out what incidents were most important or memorable to you?
• Which people intimately connected with your experience with the special education process stand out for you?
• How did your experience with the special education process (e.g., referral and/or identification) affect you and significant others in your life?
• Looking back on your experience with the special education process, what thoughts stood out for you?
• What feelings were generated by the experience?
• How would you describe your child’s educational abilities and needs?
• If you were asked this question before the special education process began, how would you answer?
• What did you observe of your child’s experiences during this process?
• Did you have experience with the special education process before this experience with your child?
• What dimensions, incidents, and people intimately connected with the experience stand out for you?
• How did the experience affect you? What changes do you associate with the experience?
• What thoughts stood out for you?
• Have your shared all that is significant with reference to the experience?
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