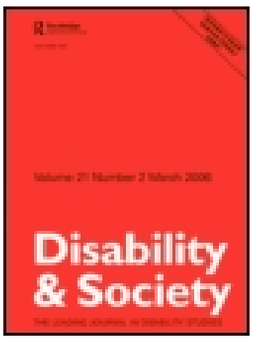

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The gap between theory and practice: using cultural brokering to serve culturally diverse families of children with disabilities

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ABSTRACT

Cultural brokering is one promising approach to support culturally diverse families and their children with disabilities who have divergent identities and needs. This qualitative case study examined the application of a cultural brokering model in a statewide family support program in the United States serving culturally diverse families of children with disabilities. Interviews with cultural brokers and key informants in the disability field were utilized to identify the critical roles of cultural brokers, challenges in cultural brokering and strategies for being effective cultural brokers. Gaps between theory and practice were uncovered in the understanding of cultural brokering as well as the design of a cultural broker program. Implications for community human service providers are discussed to help them effectively implement cultural brokering in community services.

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Cultural brokering; culturally diverse families; intersectionality; disabilities; family support

Points of interest

- Different identities, such as race, gender, country origin, social class, disability and family structure, can create challenges for culturally diverse families of children with disabilities accessing and using services that meet their needs.
- Parents of children with disabilities need support for navigating services that are responsive to their changing needs.
- Cultural brokering is shown in this research as a promising approach for addressing challenges and meeting the different needs of culturally diverse families of children with disabilities.

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- This research found discrepancies between theory and practice when using cultural brokers for parent support with culturally diverse families who have children with disabilities.
- Clearly defining cultural brokers' roles is important for organizations to successfully operate cultural broker programs.

Introduction

There is almost no country today where only natives reside. The acceleration of international migration, 258 million people migrating from one end of the world to the other in 2017 compared to 173 million in 2000, creates increasing diversity as well as complexity in host societies across the globe (United Nations 2017). Each of these societies has their own culture. Culture is the learned and shared knowledge that specific groups use to generate their behavior and interpret their experience of the world (Nieto 2010; Robinson and Weng 2014). Culture includes, but is not limited to, languages, values, beliefs, customs, practices, rituals, communication, roles, relationships and expected behaviors (Gilbert, Goode, and Dunne 2007). Bhugra (2004) noted that racial, cultural and ethnic identities form part of one's identity, and identity will change with development at a personal level as well as at a social level along with migration and acculturation. Cultural identities include a wide range of factors such as race, ethnicity, religion, socioeconomic status, gender, disability and sexuality, to name a few (Nieto 2010).

Disability is a growing culture that impacts people's life experiences as well as service delivery systems around the world (Groce 2004). It is estimated that the number of children with disabilities (aged 0–18 years) worldwide are between 93 million and 150 million, and approximately 5.1% (93 million) of all children (aged 0–14 years) have a moderate or severe disability, of which about 14% (13 million) live with severe difficulties (UNICEF 2013). Children with disabilities are one of the most marginalized and poorest youth groups whose common needs are largely unmet (UNICEF 2013).

For multicultural families, addressing the needs of their children with disabilities can be even more difficult due to complex interactions among a range of factors including cultural identities and family structures (Lindsay et al. 2012). Issues such as divergent perspectives on disability, different understandings of service systems, communication barriers and unique family circumstances can be obstacles for accessing quality support and can cause discrimination and exclusion in services (for example, Hanson and Lynch 1992; Harry and Kalyanpur 1994; Runhare 2004). Disorientation and anxiety, or 'culture shock', can be common when a person experiences an unfamiliar way of life or changing personal and family values and role

expectations following immigration to a new country (Groce 2005; Milstein 2005; Weaver 1994).

In addition, how people conceptualize disability has shifted over time, especially in western developed countries such as the United Kingdom, Canada, Australia and the United States (Jennings, Khanlou, and Su 2014; Moore and Larkin 2005; Strock-Lynskey and Keller 2007; Shakespeare and Watson 2002). Historically, disability was viewed through a medical lens, with 'physical impairment' as the defining characteristic and a focus on finding ways to ameliorate impairment through medical treatment (Barton 2009; Lawrence 1994). In contrast, the social model of disability which emerged in the early 1970s focused on how societies create barriers for people with disabilities and how discriminatory structures limit people with disabilities rather than the disability itself (Barnes 2012; Finkelstein 1980; Oliver 1996). More recently, scholars have advocated for a broader definition of disability that better recognizes the diversity of experiences and perspectives within disability communities and among people with disabilities as individuals (for example, Corker 1999; Corker and Shakespeare 2002; Owens 2015; Shakespeare and Watson 2002).

Research suggests that approaches that support service access for people with disabilities and their families can be improved by adopting models or interventions that acknowledge human diversity and in turn are responsive and flexible for families' divergent and changing identities and needs (Owens 2015; Teo, Kennedy-Behr, and Lowe 2018; Dodd, Saggers, and Wildy 2009). Scholars have proposed different individualized approaches that can provide culturally responsive support to, and better meet the needs of, families and their children with disabilities who have complex and intersecting cultural identities (for example, Achola and Greene 2016; Green et al. 2018; Kahn, Achola, and Povenmire-Kirk 2018; Strock-Lynskey and Keller 2007). For example, Achola and Greene (2016) present a person–family interdependent approach that takes into account both the individual needs of the youth with disabilities and the family interdependence to better assist the transition for culturally diverse youth with disabilities. Green et al. (2018) advocate for a community-led model of support that acknowledges multiple intersecting identities and oppressions of Aboriginal caregivers to improve service access for their children with disabilities. Holloway, Cohen, and Domínguez-Pareto (2018) outline a critical sociocultural approach to work with culturally diverse families and emphasize culture as a system of meaning that is constructed and evolves over time as individuals engage in common activities. In this article, we describe how cultural brokering shows particular promise for addressing challenges and meeting the divergent needs of culturally diverse parents who have children with disabilities.

Culturally diverse families and barriers in accessing disability services

In this research, 'culturally diverse' families refer to families who have a culture that is not dominant in the host country. Research has documented that culturally diverse families are more likely to suffer from isolation, stress and anxiety because they are living within two cultures, the original culture from their home country and the new culture of the host country (LaFromboise, Coleman, and Gerton 1993). This experience can be impacted by factors such as languages, cultural traditions, religious practices, stigma, social status, community contexts and different or even conflicting beliefs and values about disability and service systems (Heer, Rose, and Larkin 2012; Sue and Sue 1999). These views on disability, varying between and even within cultures, in turn create potential barriers for families accessing and responding to disability service systems in a host country (Banks and Banks 2012; Groce 2005; Liu 2005).

In some cultures, people may feel shame for having a family member with disability (Groce 2005; Liu 2005). Social stigmas and biases can isolate people with disabilities and their families, impeding them from reaching out for help and accessing services. Differing perspectives on responsibilities and independence can also be potential barriers. Within some cultures, families may feel it is their role to 'take care' of a person with disabilities for his or her life rather than fostering a person's self-sufficiency or getting assistive services to help the person live independently (Boughtwood et al. 2011). Families may feel guilty and experience criticism from their ethnic community if they do not take on the role of caretaking (Gannotti and Handwerker 2002; Ingstad 1990).

Moreover, lack of awareness and knowledge of the disability service system in a host country can be a significant obstacle for people of different cultural backgrounds in accessing disability services (Jezewski and Sotnik 2005; Zhou 2016). For example, new arrivals in the United States who are originally from areas with limited services may not be aware of the disability system, may have difficulty in locating services and carrying out procedures to access services or may encounter discrimination when accessing or utilizing services (Mirza and Heinemann 2012; Runhare 2004).

In addition to these divergent perspectives on disability and service systems between cultures, other identities and dimensions such as ethnicity, social class, gender, family life stages and language proficiency can also form subcultures that impact how families access, experience and respond to service systems (for example, Dunst, Trivette, and Cross 1986; Smith, Oliver, and Innocenti 2001; Turnbull and Turnbull 1990; Zhou 2016). The disability perspectives of one subcultural group may not be generalized to others in spite of the fact that they are labeled under one big cultural group (Huang 1993).

For example, Parette, Chuang, and Huer (2004) found that not all Asian American families share the same perspectives on disability. They found that Chinese American parents in general are positive toward their children's disabilities and actively engaged in decision-making process, which was not the same view expressed by Asian American parents in prior studies (for example, Chan and Chen 2011; Hanson, Lynch, and Wayman 1990; Parette 1998). Furthermore, even within a subcultural group, other facets of families, such as family structure and size, parents' education background and the severity of the child's disability, may also influence how families access disability services (Hanson and Lynch 1992).

In general, the overall cultural identity of an individual or a family is structured in the reflection and interactions of multiple and complex dimensions of differences related to race, ethnicity, country origin, gender, disability, social class, family structure and more that are constructed in both macrocultural and microcultural contexts (Kustatscher, Konstantoni, and Emejulu 2018; Banks and Banks 2012). The complexity of and divergence in families' cultural identity and perspectives require professionals to not only consider the macrocultural and social context in which families are situated, but also understand specific family contexts and work closely with parents to clearly identify barriers and the appropriate needs of the children with disabilities (Dodd, Saggers, and Wildy 2009; Harry 2002; Parette, Huer, and Brotherson 2001).

Intersectionality theory

The concept of intersectionality provides a theoretical framework for understanding the multiplicity and complexity of cultural identities of and oppressions experienced by diverse families with children with disabilities. The theory has found a home as a practical tool for human service professionals, such as social workers, to work effectively with diverse communities of people with disabilities (for example, Green et al. 2018; Holloway, Cohen, and Domínguez-Pareto 2018). The term intersectionality was first coined by Kimberlé Crenshaw (1989) to posit that professionals need to take all intersecting identities and experiences into consideration when providing support to culturally diverse groups instead of only focusing on one single factor such as race or sex. According to intersectionality theory, the identity of a person is collectively constructed by one's various cultural identities and their interactions (Brah and Phonenix 2004; Garran and Rozas 2013). Teasing apart these social components or ignoring the social constructs one interacts with will lead to superficial and partial understanding of the individual as well as the discrimination and oppression that a person may encounter (Crenshaw 1989).

Intersectionality theory suggests new ways to understand discrimination and social injustice facing culturally diverse populations with disabilities. People with disabilities and their families can be linked with diverse identities such as gender, race, ethnic background, religion, disability, language, sexual orientation and social class (Banks 2018). Perceiving them as different by magnifying the power of some of these identities, such as race and disability, or ignoring the interplay of multiple identities can increase the chances of discrimination (Azzopardi and McNeill 2016). Evidence in the literature demonstrates that people with minority status or a minority identity experience higher rates of discrimination in accessing healthcare services, education and other social services compared to dominant groups (Haight, Kayama, and Gibson 2016; Kattari et al. 2017; Wilkinson and Pickett 2009).

In fact, intersectionality theory – increasingly used in childhood and disability studies today – not only facilitates the comprehension of intersectional identities, power and inequality facing marginalized populations in diverse cultural contexts (Davis 2008; Morrow and Connolly 2006), but also goes beyond this scope to challenge and transform practices that exclude and discriminate marginalized populations (Cho, Crenshaw, and McCall 2013; Konstantoni and Emejulu 2017). Intersectionality deconstructs the uniform identity that is usually dominant by one conspicuous category, such as childhood or disability, and attaches importance to the diverse experiences and power differences based on intertwining social identities and relationships (Kustatscher, Konstantoni, and Emejulu 2018). However, few studies explore the operationalization of intersectionality theory in childhood and disability service practice and use intersectionality as praxis for social justice (Konstantoni et al. 2014; Konstantoni and Emejulu 2017; Liasidou 2013).

Cultural brokering practice

Cultural brokering interventions, increasingly used in healthcare and education fields, have been shown effective in helping culturally diverse families navigate the service system (Brar 2010; Rotich and Kaya 2014; Yohani 2013). While studies recognize the importance of cultural brokering in service delivery, the definitions, ways and role-takers of cultural brokering are inconsistent and can be conflicting (for example, Arvizu 1984; Yohani 2013; Rotich and Kaya 2014). The term cultural broker was first introduced in anthropology, referring to someone acting as a middleman between local communities and governments (Wolf 1956). It was later adopted by the healthcare and education industries to meet the needs of people with different cultural backgrounds (for example, Gentemann and Whitehead 1983; Jezewski and Sotnik 2001; Willis 1999). Specifically, cultural brokers take on different roles such as intermediator between two different cultures (Gentemann and

Whitehead 1983; Jezewski 1995), facilitator of cultural transmissions and innovations (Arvizu 1984), liaison linking between communities and service institutions (Willis 1999) and trainer for service providers (Rotich and Kaya 2014).

Roles in cultural brokerage also vary. Cultural brokers can be family members (for example, youth and parents), community members, teachers, school administrators and professionals (Cooper 2014; Lazarevic 2017; Weiss 1994). Despite the positive outcomes of cultural brokering (Bailie 2010; Brar 2010) and benefits of being a cultural broker (Hua and Costigan 2012; Wu and Kim 2009), some research identified that the complexity of the brokering experience can depress and stress individuals who serve as cultural brokers, especially those with little training and support, and negatively impact their psychological well-being (Lazarevic 2017; Weisskirch 2013). Furthermore, cultural brokering can be increasingly challenging for culturally diverse families of children with disabilities whose needs may involve professional knowledge in various fields such as special education, early intervention, healthcare, resettlement and employment.

Today, cultural brokering is an emerging practice in the disability field that acknowledges the interacting effects of multiple cultural identities and inequities facing multicultural people with disabilities (Lindsay et al. 2014b). Jezewski and Sotnik (2001) adapted the cultural brokering model formulated within the healthcare industry to the disability field. They retained the definition of cultural brokering as the 'act of bridging, linking or mediating between groups or persons of differing cultural systems for the purpose of reducing conflict or producing change' (Jezewski 1995, 20). This cultural brokering model considers cultural brokers as problem-solvers and cultural brokering as a framework for resolving conflicts and problems (Jezewski and Sotnik 2001). Cultural brokers identify and analyze the intersection of intervening components, including social context factors such as economics, bureaucracy and stigma, and individual factors such as type of disability, age and cultural background in the brokering process, and use a wide range of strategies such as mediation, advocating and networking to establish connections and maintain facilitation across systems (Jezewski and Sotnik 2001).

While there is a growing body of literature documenting the positive outcomes of using cultural brokering in therapy, rehabilitation, resettlement and special education when working with multicultural populations (Bailie 2010; Gregory 1993; National Center for Cultural Competence 2011; Wenger 1995), scholarship on using cultural brokers for parent support with culturally diverse families who have children with disabilities is still emerging (Lindsay et al. 2014a). There is no uniform understanding of cultural brokers or cultural brokering approaches for serving culturally diverse families of children

with disabilities. Using a statewide cultural broker initiative in the United States as a case, this study identified key roles of cultural brokers and critical components of cultural brokering for culturally diverse families of children with disabilities, and explored discrepancies between theory and ground-level practice in an effort to help community providers effectively implement cultural brokering to empower culturally diverse families of children with disabilities.

Methodology

Research design

This research used a case study to examine the application of cultural brokering. Case studies can be defined as a method for learning based on a comprehensive understanding of a phenomenon gained by extensive description and analysis to develop or test explanations (George and Bennett 2005). As stated by Yin (2003, 1), the case-study approach is best used when 'how or why questions are being posed, when the investigator has little control over events, and when the focus is on contemporary phenomena within some real-life context'.

This case study was based on a qualitative research design using semi-structured interviews with cultural brokers who directly interact with culturally diverse families of children with disabilities in a statewide family support program in the United States. The statewide family support program's cultural broker initiative serving as the case study for this research is housed within a university center of excellence in developmental disabilities. Established in 2009, the program currently has five cultural brokers working 20 hours per week to provide one-to-one emotional, informational and systems navigational services to families from African American, Refugee, Immigrant, Latinex and Arabic communities who have children with disabilities.

To identify critical components and key steps of cultural brokerage in the disability field so that we could make comparisons between cultural brokering theory and ground-level practice, we also interviewed national key informants/experts in cultural brokering models that support people with disabilities. Qualitative research methods based on semi-structured interviews are identified as a flexible and effective way to obtain more accurate and detailed information from participants and gain a deeper understanding of participants' perspectives (Gill et al. 2008; King and Horrocks 2010). They have been widely used by research on culture and disability (for example, Daudji et al. 2011; Lindsay 2014a, 2014b; Yohani 2013). The research design was approved by the sponsoring university's Institutional Review Board.

Sample

Participants were identified in this study using a purposeful sampling technique. The inclusion criteria for key informants/experts included: being scholars and/or professionals who have worked in the disability field for at least 10 years; having professional and/or research experience on cultural brokerage, cultural competency and other culture issues related to disabilities; and being knowledgeable about cultural brokering in the disability field. Inclusion criteria for cultural brokers included: working at least one year as a cultural broker; having experience working with families raising child(ren) with disabilities; and being previously or currently employed by the case-study family support program. Scholars and cultural brokers who met the inclusion criteria were sent an email with detailed introductions about our research and an invitation for an interview.

The interview sample included five national key informants/experts. All of them are female with races of Black, White and Asian, and included immigrants and US citizens. Two of them have worked in the disability field (related to cultural brokering) for more than 30 years, one for about 17 years and two for longer than 10 years. Six cultural brokers were interviewed. Five of them are currently working in the family support program and one is a previous employee. They are from African American, Asian, White, African and Latinex cultural backgrounds, and three hold immigrant visa or refugee status. One is male; the rest are female. Five are parents of children with intellectual or developmental disabilities and one is a person with a developmental disability.

Data collection and analysis

The primary data source for this study is qualitative data from interviews. These interviews were conducted either in person or by telephone, with an average of 50 minutes for key informants/experts and 70 minutes for cultural brokers. Key informants/experts were asked about their understanding of cultural brokering and the application of this framework in disability field. Cultural brokers were asked to reflect on and share their experience working with culturally diverse families of children with disabilities in order to generate a detailed description of their roles and brokering process. All interviews were recorded and transcribed for thematic content analysis using Dedoose software. The data analysis used both inductive and deductive coding to generate research findings.

Research findings

The following research findings include responses from both key informants and cultural brokers' understanding of cultural brokering and cultural

brokers' roles. It also includes information on the challenges facing cultural brokers and strategies to be an effective cultural broker that emerged in this study.

Definitions and roles of cultural brokers

Key informants all agreed that the term 'cultural broker' is not easy to define. In general, key informants' conceptualization of cultural brokering was quite close to the definition of Jezewski and Sotnik's (2001) cultural brokering theory, which identifies cultural brokers as a bridge between two different groups, agents or cultures with goals of providing support, increasing opportunities and reducing inequity. As one informant stated:

> A cultural broker is someone who plays the role of serving as an in-between, liaison between the person with disability and a provider, or a third person who is trying to bridge the connection to support a person with a disability in accessing opportunity, services of whatever that might be of interest.

Consistent with the broad concept, key informants listed a wide range of roles for cultural brokers, and emphasized the variation of these roles due to different cultural brokering levels and different organization settings. In particular, all key informants mentioned advocating as one of the most important roles for cultural brokers. Other important roles for cultural brokers include acting as liaisons, educators and mediators. As one key informant commented:

> As a cultural broker, you have to provide the information, training and support for your own community … you have to educate others who work with that community … you can be the advocate … the change agent … the mediator. You can be all sort of roles that you can play.

Different from the key informants, cultural brokers in the family support program offered a much shorter list of roles, primarily focusing on acting as a liaison and an educator. A cultural broker shared:

> I have special responsibilities for immigrant families … I have to give them orientation into the services, and help them understand the system … how to go to school and have intervention … Also, I have to draw their attention to the resources that are available to them.

Some cultural brokers emphasized that they were not advocates for families, and other cultural brokers did not even mention 'advocacy' as their role and responsibility. This differed from key informants, who posited being an advocate as a very important role for cultural brokers. For example, one cultural broker commented: 'My role is not an advocate for these families, I'll let them know their rights, where to get information and resources [that] are available to them, so they can advocate for their children'.

Common challenges facing cultural brokers

Culture and language barriers

Key informants identified cultural difference as one of the major challenges for cultural brokers serving culturally diverse families of children with disabilities. They proposed that cultural difference could create barriers for communication, understanding of needs and trust-building with families. Even though key informants agreed that language could be an obstacle for cultural brokers, they emphasized that knowing the language was not enough to remove the barriers created by cultural difference. As one key informant commented:

> Many times when we think that family who could speak English who are from different cultures, they are good to go. No, we dismiss the whole cultural difference from this community that we don't address at all …

Different from key informants, cultural brokers believed language to be the biggest barrier in serving families of different cultural backgrounds. One cultural broker expressed her frustration in a situation where language created great difficulties for understanding evaluation results shared with the family:

> The dad spoke English, but the mom spoke absolutely none. So, it was a really, really hard case and again because of the language barriers. It was just really hard to get across to them, exactly what I could do for them … that was my hardest, hardest case.

Another cultural broker reinforced that challenge:

> Well, if the person can't speak the language, it is difficult. If the cultural broker has the language, it can be a way to speak to them and begin digging in what interests and needs they have.

Difficulty in building rapport

Key informants considered building rapport with families as a major challenge for cultural brokers. They pointed out specifically that it usually takes much longer for cultural brokers to build rapport with families from another culture because families may not have trust in cultural brokers and may be faced with social pressure. As a key informant stated: 'In order for you [cultural brokers] to have trusting relationship so that they [families] can share with you their situation, you need time to figure that out'.

Consistent with key informants, cultural brokers also rated building rapport as a big challenge in their work and agreed that it was a time-consuming process. One cultural broker commented:

> It took weeks and weeks. So, some of the families that I worked with is not like one day or two days. It can be weeks, months. Some of them I've worked with two years as other issues arise. It takes time to build the relationship.

Complexity of cultural brokerage

Key informants believed that the multiple layers and roles of cultural brokering pose a great challenge for both organizations and cultural brokers. When asked about challenges for cultural brokers, one key informant highlighted:

> It gets back to the role of cultural broker as defined by the organization … it needs to be very clear what the expectation is for the cultural broker. Is that a service at a family level? Is it at a higher level, in terms of looking at policy?

Another key informant commented about the complexity of cultural brokering and how it challenges cultural brokers' work:

> For the family with disability, you have to interact not just with the health care issue. You have to interact with the special education field … interact with the human social service people and agencies … even with legal people as well. So, that is really a lot and it is very challenging to work as the effective cultural broker.

Cultural brokers did not talk about the challenges from an organization perspective or from having multiple roles and layers, but they did say that they had difficulties in understanding the concept of cultural brokering and figuring out the roles of cultural brokers when they started their job.

Considerations for being an effective cultural broker

Both key informants and cultural brokers reported that an effective cultural broker should be familiar with the culture of the particular community they support, such as where they are from, the language they speak, their identities and how they view disabilities. For example, one key informant proposed:

> They [cultural brokers] have to have the knowledge, the values, the beliefs, norms and traditions of particular cultural groups. They should have an understanding of the traditional and the indigenous concept … how disabilities are viewed within different contexts.

Being aware of personal biases and respecting difference are considered critical to learn about families' culture by both key informants and cultural brokers. One cultural broker suggested:

> Make sure you are not comparing their experiences to your own, and assuming that yours is the norm … Do not lump each culture altogether as one, like not all Muslims experience the same thing … there are cultural considerations.

Although key informants highly emphasized the importance of knowing the culture of a community, they did not think cultural brokers have to share

all identities with the person or within the community to be successful. They explained that even though the cultural broker comes from the same community, speaks the language and shares the same race and ethnicity, it does not mean that she/he is an effective cultural broker and the best cultural broker for that community. For example, based on our interviews in the case-study program, a white woman has been an effective cultural broker for several refugee communities and an African American cultural broker has worked very successfully with Ethiopian families.

Key informants and cultural brokers also indicated that connecting and collaborating with service agencies and professionals in local communities was very critical in effective cultural brokering for culturally diverse families of children with disabilities. Each reported that this helps cultural brokers to learn about the community and also helps connect them with available, potential resources that families may need. One cultural broker emphasized the benefits of connecting to school resources:

> Some school divisions have a resource centre that has employees [who are] parents or family member of children with disabilities and who are special educators in the school system … So you get both sides … that is really helpful to connect to that kind of resource.

Other important components identified by key informants and cultural brokers for being an effective cultural broker were having knowledge about disability systems and processes as well as first-hand experience working with families of children with disabilities. As one key informant outlined:

> In the special education or disability field, it is very important for you to [work with] somebody who walks the walk, who has already been there, who already has experience in navigating the system either for somebody they love or somebody else …

Discussions and implications

This study addresses gaps in the literature by focusing on cultural brokering, a service delivery model that addresses intersections between cultural, disability and other aspects of individual identity when supporting families who have children with disabilities. As highlighted by scholars across many disciplines, including disability and multicultural studies, there is a great deal of complexity when considering any one aspect of a person's identity (e.g. disability), but it can get increasing complex when considering multiple aspects concurrently (e.g. gender, culture, sexuality, race, etc.) (see Kustatscher, Konstantoni, and Emejulu 2018; Banks and Banks 2012; Lindsay et al. 2012).

In the case study presented, complexity can also be seen in different interpretations between cultural brokering theory and practice. One of the key differences that emerged in the research was how cultural brokers attached

more importance to language than to the particulars of culture (e.g. worldview on disability, trust in government, religious beliefs), while key informants and the literature stated that understanding and addressing nuances of culture is primary for effective cultural brokering (Groce 2005; Jezewski and Sotnik 2005). While more research is warranted to understand this issue in greater detail, it was clear from the perspective of cultural brokers that families had immediate concerns that they wanted to resolve as expediently as possible. They found that a common language that enabled basic communication was foundational in getting these critical situations addressed as quickly as possible. In later research, it will be important to follow families over time to see if and how, once urgent issues are addressed, culture becomes more dominant in influencing the role of cultural brokers and how cultural understanding supports the development of a sustained relationship with families.

The role of a cultural broker as an advocate was another area where there were differences in the perspectives of key informants and cultural brokers. Consistent with the cultural brokering model espoused by Jezewski and Sotnik (2001), all key informants considered 'advocating' a major role for cultural brokers, while cultural brokers in the case-study program did not think advocacy was a primary component of their job. When probing this issue in detail, it became apparent that the word 'advocate/advocacy' was a broad term with somewhat divergent meanings. In the disability field, 'advocacy' is understood as 'the act of informing and supporting people with disabilities so that they can make decisions that serve their needs' as well as 'the responsibility to take appropriate action regarding instances of incompetence or unethical or illegal practices by a member of the service provider team' (Jezewski and Sotnik 2005, 41). Therefore, advocacy can mean micro-level work such as daily support for individuals or groups, but can also mean macro-level work such as trying to change political or social systems through lobbying, campaigns, publications and/or public speaking. In our case example, the cultural brokers did not operationalize their role as advocacy. In fact, some cultural brokers explicitly stated that their role was not to advocate, but instead to support families in advocating for themselves.

Likewise, key informants defined cultural brokering as having different levels and incorporated many more roles for cultural brokers than identified in the case-study program. According to the literature and key informants, cultural brokers could focus on the individual level of brokering (e.g. providing one-to-one direct service to families) (Brar 2010; Shomaker 1995), organization change (e.g. working on behalf of a community or a group to help service providers become culturally sensitive) (Weiss 1994; Willis 1999) and/or policy work (e.g. influencing policy-making and advocating for system change) (Arvizu 1984; Cockburn 2016). In the case-study program, the

cultural brokers identified primarily with the individual-level role with less attention paid to organizational-level or policy work.

Apart from these discrepancies, one other issue that emerged in the literature and among key informants was the issue of cultural brokers sharing identities such as race, ethnicity, language and experiences with an individual or groups that they support (Gentemann 1978; Wyatt 1978). Currently, there is no consensus on which is the best practice. Some scholars state that sharing common language and culture does not guarantee an effective rapport with families (Lewis 2004) and that cultural brokers could be effective if they have high cultural sensitivity, enough knowledge about the culture and rich experiences working with the community (Singh, McKay, and Singh 1999). Other literature emphasizes the need for cultural brokers to be well versed in the norms, customs and practices of these communities (for example, Liu 2005; Miller 2005). Within the case example for this study, cultural brokers reported that they can be successful whether or not they share identities with the community they support. Four cultural brokers in this program reported that they are from the communities they support, and two cultural brokers stated they do not always share the identities such as race, ethnicity or language with families they support, but they all felt that they successfully built rapport with and supported families seeking help.

Some core practices emerged from the study that could assist practitioners working with culturally diverse families of children with disabilities. As outlined in both the disability and multicultural studies literature, trying to understand what identities define a person's particular community and working with that person to best learn about their needs and preferences are fundamental to building partnerships with families (Achola and Greene 2016; Strock-Lynskey and Keller 2007, Lindsay et al. 2014b; Jezewski and Sotnik 2001). Also, the selection of who could and should serve as a cultural broker is very important when developing and supporting a cultural broker program. As described in the literature and seen in the case-study model, cultural brokers can be of similar cultural communities or not, can be family members or professionals, or can focus on direct one-to-one services with service recipients or work at the community level (Cooper 2014; Gentemann and Whitehead 1983; Lazarevic 2017; Weiss 1994; Wolf 1956). While there is no consensus on 'the' way a program should be structured, programs should thoughtfully approach these decisions, weighting the relative strengths and weakness of the various models and what has been learned from emerging research on cultural brokering initiatives. Finally, as the practice of cultural brokering is evolving and various models are being used in practice, it is of critical importance to conduct extensive program evaluation on both the process of cultural brokering and the outcomes for families of program planning.

While, at one level, ambiguities about the role of advocacy, the levels of cultural brokering and the sharing of cultures did not impact the day-to-day functioning of cultural brokers in the case study, they do have broader implications for operating cultural broker programs. It is critical that the work of cultural brokers is clearly defined to the broker and for the organization. This is important because it enables the cultural broker to understand the expectations and boundaries of their role. It is also essential for organizations to clearly define the role of the cultural broker so that they can effectively evaluate the outcomes of the intervention for families and for their organization.

There are limitations in this study. Our research focused on one case study, which limits the generalization of the results. In addition, the case study had a small sample size of cultural brokers and there was also a relatively small pool of people to serve as key informants who have expertise in both developmental disabilities and cultural brokering. Further, the focus of this inquiry was on the perspectives and experiences of cultural brokers and opinions from key informants. Future study should consider the views, experiences and outcomes of families as well as their family member with a disability.

Conclusion

Disability is complex and so are issues related to culture. The increase of diverse populations in countries across the world makes providing culturally responsive services a forefront issue (Czaika and de Haas 2014; Keating and Karklis 2016). Intersectionality provides a useful theoretical framework for recognizing, understanding and addressing the complexity, variability and dynamics for culturally diverse families of children with disabilities, and suggests there is not a fixed formula that can be universally applicable for all problems facing these communities. Cultural brokering is a promising tool that is highly responsive and dynamic for providing culturally sensitive support. However, in order to implement an effective cultural brokering initiative, this study implies that service providers should have a clear definition of cultural brokering, work with communities to select effective cultural brokers, provide strong organizational support for cultural brokers, strengthen collaborations with other organizations and professionals, and offer continuous culture-related training to both cultural brokers and other staff to improve positive outcomes and magnify systematic impacts of the cultural brokering practice.

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