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Lessons Learned: Providing Peer Support to Culturally Diverse Families of Children with Disabilities or Special Health Care Needs

Robin L. Dodds, Dana V. Yarbrough, and Nubia Quick

Effective peer support is important to the promotion of well-being in parents of children with disabilities or special health care needs, who may suffer from higher levels of stress due to increased caretaking burden and difficulty navigating systems of care (White & Hastings, 2004). Parents from culturally and linguistically diverse (CLD) communities may bear the effects of additional stressors, such as economic instability, language barriers, limited access to disability-related information, the aftereffects of trauma, and lack of social support (Khanlou, Haque, Sheehan, & Jones, 2015). Unfortunately, when CLD families of children with disabilities reach out, the support they receive may not be culturally sensitive or culturally appropriate (Fellin, Desmarais, & Lindsay, 2015). In this Practice Update we describe Parent to Parent (P2P), a peer support program for parents of children with disabilities, discuss barriers to serving families from diverse communities, and detail promising practices that have improved their ability to provide culturally agile support.

P2P

P2P is a peer support program that trains parents of children with disabilities to provide informational and emotional support to other parents who are seeking support through a one-to-one match. The volunteer parents who provide support receive extensive training in communication, systems navigation, and cultural competence. P2P matches are driven by the concerns, needs, and priorities of the help-seeking parent and may include assistance in navigating school, social services, and medical systems of care (Wood, 2016).

Virginia's P2P program provides one example of the challenges in identifying and supporting CLD

families. Immigration to, and refuge in, the United States has increased the diversity of our communities. For example, in 1970, one in 100 Virginians were born in another country; by 2012, it was one in nine (Sen, 2014). In addition to this rise in the percentage of foreign-born people within the state, there has also been a large shift in the composition of the immigrant and refugee populations. These changes necessitate building diversity sensitivity and competence across Virginia P2P initiatives to provide supports and services that address the needs of children and families within the context of their respective cultures.

Prior to 2009, the staff of the P2P program in Virginia all identified as white and 70 percent of the families they supported were white. With the addition of five CLD cultural brokers, Virginia's P2P program staff now reports the racial and ethnic backgrounds of the over 2,800 families supported annually as 41 percent white, 20 percent African American, 12 percent Hispanic, 8 percent Asian, and 19 percent some other race or unknown. In the following sections we present barriers to engagement of CLD families in P2P, followed by promising practices for their inclusion culled from our experiences in P2P of Virginia.

BARRIERS TO PROGRAM DIVERSITY

Not Enough Diverse Trained Support Parents

The first barrier to serving CLD parents in P2P is a dearth of volunteer supporting parents from diverse communities. If a parent from a community that is underrepresented in the pool of trained volunteer supporting parents calls in to P2P to request support, the coordinator cannot guarantee that the match will be close enough for the parents to bond over their

shared experience. According to a mixed-methods evaluation of the P2P program, when parents were too different, the help-seeking parent did not benefit emotionally from the support relationship (Singer et al., 1999). Without suitable matches for parents seeking support it becomes imperative for a P2P organization to provide opportunities to identify and train more diverse parents.

Conflicting Views and Beliefs

The CLD recruitment deficit may be explained in part by a mismatch of views and beliefs around disability and support preferences between cultures. Parents who originate from a more collectivist culture may initially feel more comfortable in a group support setting because over time they may become “like family,” making the receipt of support and advice more acceptable and trustworthy (Mueller, Milian, & Lopez, 2009). Parents from cultures that place high value on the family as a unit may have different perspectives around topics such as independence and advocacy than those in the dominant culture (Fisher et al., 2014; Steidel & Contreras, 2003). These views and preferences may not align with those presented in a P2P training.

Overworked Volunteers

Help-seeking parents who are new to the country may also require more intense support around issues of acculturation, food and housing security, and systems navigation (Nicholas, Fleming-Carroll, Durrant, & Hellmann, 2017) in addition to the emotional support common to all P2P matches. This may put their supporting parents at increased risk for health consequences such as fatigue, decreased immune function, and depression associated with caregiver fatigue (Murphy, Christian, Caplin, & Young, 2007).

Refugees and Undocumented Immigrant Wariness

Refugees and undocumented immigrants are not reaching out to disability programs for support. Possible reasons for this include a lack of knowledge of services available, paucity of translated materials, and lower levels of acculturation. Refugee communities may also carry considerable distrust for health care professionals and disability organizations so that it may be difficult to gain their trust (Johnson, Ali, & Shipp, 2009). In addition, they may find the idea of being matched with someone from their home country threatening due to the issues they fled when

they left their country of origin. Furthermore, families who are undocumented immigrants may not want to call attention to themselves for fear of judgment or the involvement of Immigration and Customs Enforcement.

PROMISING PRACTICES FOR CULTURAL INCLUSIVITY

There are a number of initial steps a P2P program can take toward serving the needs of CLD communities: conducting community mapping to identify prevalent CLD communities in their region or state, assessing whether their database of trained volunteers and help-seeking parent demographics matches with the mapping findings, writing a language access plan to align staffing and budget considerations to devote resources to CLD communities, and begin dialoguing with key leaders in CLD communities to build trust and support for the P2P program. If this is not practical, the P2P can identify at least one CLD group not currently served and begin to make plans to engage with members of that group.

Go into the Community

P2P programs have had success engaging underserved communities by volunteering for and creating coalitions with institutions that already serve that group, such as relief organizations and houses of worship (Dorsher, Kim, Krzyska, Perna, & Wolfish, 2014). This approach to engagement helps a P2P program assess unmet support needs and facilitates making connections with influential people within the community. This kind of networking has proved to be beneficial in reducing the stigma associated with disability in marginalized communities and increasing the capacity for disability advocacy (Miles, Fefoame, Mulligan, & Haque, 2012).

Communicate Messages Effectively

Scheduling “meet and greets,” where families from a cultural group are invited to have a meal and gather to introduce them to disability-related rights and services has also been successful for engaging CLD families in P2P. Having informational materials prepared in the native language of the group can improve communication and contribute to trust by showing a commitment to partnership. An evidence-informed practice the Virginia P2P program uses to produce materials and resources that meet the needs of CLD families is localization. *Localization* involves analyzing the semantics in a

language to make sure that the right thing is said that the product works functionally and linguistically in the intended culture. Furthermore, localization takes into account the customs, traditions, and preferred formats of the group for which the information is intended (Sajan, 2017).

Create Culture-Specific Groups

Once a group of families has been introduced to the P2P organization, the program can begin to provide support by hosting a culturally specific support group in the primary language of the community. Parents of children with a disability or special health care need will then have the opportunity to share their experiences with other parents of their culture. This group model of social support can be beneficial to attendees who have not had the opportunity to talk to other parents with similar experiences. Support group members who successfully navigate health and education systems and exhibit good communication skills can later be recruited to be trained as support parents to improve the diversity of the program's roster of volunteers available for matching.

Employ Cultural Brokers

P2P organizations that do not have the diversity in their program to adequately serve the community may also make use of paid cultural brokers. *Cultural brokers* are individuals who understand the values and beliefs of their culture toward health and education and also have had successful experiences with assimilation and navigation of health and education systems in the United States. Because they provide a more intensive level of support than a P2P volunteer and have a professional skill set not required of P2P support parents, they are hired as paid employees. Employing a cultural broker can reduce the amount of time P2P support parents spend providing instrumental support and allow them to give the kind of emotional support that only another parent can.

DISCUSSION AND RECOMMENDATIONS

The promising practices identified in this article have helped P2P of Virginia reach its goal of providing culturally agile peer support to parents of children with disabilities throughout the state; however, it is important to recognize that each program will have its own challenges. Regions will

vary in their demographic makeup, resources, and organizational structure for systems of care and, as such, interventions to improve the cultural responsiveness of a program will have to be approached in a way that is specific to the needs of the locale. Focus-group and survey research will need to be conducted with stakeholders, including parents, community members, P2P coordinators, social workers, and medical and school professionals to learn how to more effectively match the needs and preferences of families from different CLD communities with culturally informed evidence-based models of peer support. **SW**

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