



Family and Caregiver Supports

Reaching Underserved Families in Wisconsin

Essential supports for Wisconsin family members who are providing care to a loved one are not reaching everyone, particularly the State’s underserved families, including Black, Hispanic, Tribal Communities and Hmong populations. Underserved families and caregivers often face additional barriers to receiving access to typical caregiver supports available in Wisconsin communities.

Community members with substantial knowledge and experience with underserved families attended a Family Support Coalition gathering at the Johnson foundation at Wingspread in Racine, August, 2017. They described the *significant barriers* impacting access to supports for family caregivers including *isolation, privacy, trust, language and culture, technology, transportation, immigration, and background checks.*

The Need

Nationally, 43.5 million adults provide unpaid care to an adult or child according to the National Alliance for Caregiving 2015 Report on Caregiving in the U.S.. In Wisconsin, 85% of individuals with disabilities who require direct care for some or all their support needs cannot find help.¹ Wisconsin families have become the backbone of Wisconsin’s caregiving by providing an estimated 538 million hours of unpaid care to adults with disabilities and older adults.² Caregiving consists of diverse activities such as personal care, medical and nursing tasks, financial assistance as well as emotional and social support for children, adults and seniors with disabilities.

43.5

MILLION ADULTS PROVIDE UNPAID CARE TO AN ADULT OR CHILD

85%

OF PERSONS REQUIRING DIRECT CARE CANNOT FIND HELP

538

MILLION HOURS OF UNPAID CARE ANNUALLY

Barriers to Caregiving Support Identified at Wingspread

Isolation

“We have parents who have been in the house so long that they don’t go anywhere except to pay their bills.”

Privacy

“It’s hard for families to welcome anybody into their home. It’s kind of private, and a lot of Hispanics want that privacy. They especially want to keep their privacy if they have a child with special needs. They don’t want anyone else to know that.”

Trust

“When I go to someone’s home, they size me up to see where I’m coming from, if I’m from Child Protective Services or something. So I go in and tell them who I am, how I live, and where I come from. I tell them I’m not from CPS, I’m not bringing any papers, and I’m not recording. We’re just talking.”

The prevalence of caregiving in the home is increasing as more people are living with chronic conditions, there are shorter hospital stays, and limited access to health services.³ Hispanic families have the highest reported prevalence of unpaid caregiving in the U.S. at 21%, followed closely by African-American: 20.3% and Asian-American: 19.7%. Hispanic and African-American caregivers experience higher burdens and spend more time caregiving on average than their White or Asian-American peers.² In a systematic review of thirty years of caregiving literature, there has been little attention given to multi-cultural issues or how to best address the unique needs of Tribal Communities, Black, Hispanic and Asian American populations.³

Strategies to Consider when providing Caregiving Supports to Underserved Families: Input from Wingspread

- Build trust through a one to one peer match who has experience in caregiving.
- Consider the community culture and language.
- Be sensitive to issues related to immigration status.
- Be aware of skills such as computer, reading/writing.
- Explore the possibility for making culturally necessary exceptions to background checks and professional credentials.
- Offer increased flexibility of funding sources and programs.

Promising Practices in Wisconsin



Powerful Tools for Caregivers

Powerful Tools for Caregivers is an educational program for caregivers designed to reduce caregiver stress, in part by promoting self-care. The model has recently been updated to include Powerful Tools for Caregivers: For Parents of Children with Special Needs.

The program has shown significant improvement in self-care behaviors, including exercise and use of relaxation techniques; increased ability to manage difficult emotions, including reduced anger, guilt, and depression; increased self-efficacy in coping with caregiving demands; and increased use of community services.⁴

These positive outcomes have been demonstrated across a diverse group of caregivers, including ethnic minorities.⁵



Language and Culture

“It’s very important to have someone in your agency who speaks the language, someone who can make a quick call or stop by someone’s house and make the connection. Having someone from your culture who speaks your language is a big step toward trust.”

Technology

“They don’t want to look dumb or say, ‘I don’t have the Internet’.

Transportation

“It turns out she didn’t have any way to get there. She walked all the way from her house and that took 2 hours.”

Immigration

“Immigration is also a barrier. Hispanic families are concerned about the information they give out because a lot of those families are going through the immigration process. That’s one of the things they ask me: ‘Is this going to affect my immigration status?’”

Background Checks

“Caregivers are taught to do a job and passing a background check is a big thing. We need to look at how this is affecting families.”

Parent to Parent Program



Parent to Parent of Wisconsin provides support to parents of children with special needs through a one-to-one connection with another parent who has similar experience and who knows firsthand about the feelings and realities that come with having a child with special needs.⁶

Parent supporters have 8-10 hours training and provide care with 4 phone calls over a 2-month period. Matches are made between trained supporting parents and parents who request assistance. Parents are matched according to challenges the parent is experiencing. The program offers information and referral to local health resources and support.

Participants show high improvement in ability to cope with their situation, ability to view their family situation in a positive light, ability to make positive progress on the goals that are important to them.⁷

Trained supporting parents are caregivers of children with disabilities themselves.

Family Advocacy Network of Wisconsin Promise



The Family Advocacy Network, developed for the Wisconsin Promise project⁸, is an innovative and culturally relevant approach to engage families, share important disability-related information with them, and support them to take action and advocate effectively for their families.

Family advocates have:

- Lived experience with disability; during hiring, this is prioritized over professional experience.
- Local experience in the areas they serve; they are familiar with communities and local services.
- The ability to meet families in their homes.
- Flexibility to focus on what the family identifies as their greatest need.

Diverse family populations express a high satisfaction with the delivery of Family Advocate services. The program has resulted in families raising their expectations for their son or daughter with a disability, connecting families to essential resources and families learning how to speak up for their needs.



RECOMMENDATIONS

- Promote the hiring of advocates (“a Family Navigator”) who have family caregiving experience, who live in the community and belong to the culture to provide one on one caregiver advocacy services. Emphasize face to face connection.
- Educate caregiver advocates about the unique needs of underserved cultures.
- Eliminate barriers due to background checks and professional credentials when culturally appropriate.
- Evaluate how family and caregiver support strategies are meeting the needs of underserved families.



wisconsincaregiver.org/alliance

Mission Statement

Our mission is to raise awareness of family and caregiver support needs and increase availability of and access to services and supports (both paid and unpaid) which will keep people across the lifespan engaged in their community as long as they desire.

1. Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>
2. National Alliance for Caregiving (NAC) and AARP. 2015. *Caregiving in the U.S.* Bethesda, MD:NAC. Washington, DC: AARP Public Policy Institute. http://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf
3. Apesoa-Varano, E.A., et al. 2015-16. “Multi-Cultural Caregiving and Caregiver Interventions: A Look Back and a Call for Future Action.” *Journal of the American Society on Aging* 39 (4): 39-48.
4. The National Alliance for Caregiving & MetLife Foundation National Family Caregiving Awards Report; 2007. <http://www.caregiving.org/data/NACAwardsBookFINAL.pdf>
5. Evaluation of the Powerful Tools for Caregivers Diversity Program: Dissemination Successes and Challenges; Orom, H, & Gage, E.; State University of New York at Buffalo Department of Community Health and Health Behavior; 2013. https://hfwny.org/hfwny-content/uploads/Powerful_Tools_for_Caregivers_Evaluation_2013.pdf
6. S., George H., et al. “A Multi-Site Evaluation of Parent to Parent Programs for Parents of Children with Disabilities.” *KU ScholarWorks, Journal of Early Intervention*, 1 Jan. 1999, kuscholarworks.ku.edu/handle/1808/6070.
7. “Parent 2 Parent of Wisconsin.” *Parent 2 Parent of Wisconsin*, p2pwi.org/.
8. *Wisconsin Promise*, promisewi.com/family-advocates/.