



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.¹ Although the Aging and Disability Resource Center (ADRC) system in Wisconsin offers a one-stop connection to supports in every county that keep people living in their own homes and communities, underserved families and caregivers are faced with barriers to receiving access to these supports.²

Community members with substantial knowledge and experience with underserved families attended a Wisconsin's Family Support Coalition gathering at the Johnson foundation at Wingspread, August, 2017. They described the *significant barriers* impacting access to Family Caregiver Support Programs including *isolation, privacy, trust, language and culture, technology, transportation, immigration, and background checks.*

The Need

Nationally, more than one third of households are engaging in caregiving. In Wisconsin, 85% of individuals with disabilities who require direct care for some or all their support needs cannot find help.³ 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.⁴ 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.

1/3

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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.⁵ Hispanic families have the highest reported prevalence of 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.⁴ 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.⁵

Strategies to Consider when providing Caregiving Supports to Underserved Families

- 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.

Potential Solutions



- Multicultural caregiving intervention literature has mainly focused on group or technological education of caregivers in order to relieve stress or problem solve. The intervention is focused on modifying the behavior of the caregiver. This has shown modest short-term and questionable long-term results.^{5,6}
- Family Peer Advocates⁷ and the Parent to Parent Program^{8,9} have been shown to better facilitate engagement and increase access to support. A Family Advocate Program¹⁰ supporting Wisconsin families around employment for youth with disabilities in Wisconsin has shown great promise.



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.”

The chart below outlines various models of family or peer advocate support and their efficacy in addressing the needs of diverse caregiver populations. The populations receiving caregiving span children and young adults with disabilities, and older adults with Alzheimer’s Disease.

Caregiver Support Intervention	Description	Outcomes	Economics and Ease of Implementation	Impact on Equity
Individual or group Education (Savvy Caregiver Program) ⁶ <i>Caregivers of older adults with Alzheimer’s</i>	Building internal caregiver skills, knowledge and self-confidence, building external resources. Two hour sessions over 6 weeks.	Moderate Improvements with feelings of competence, depression, problem solving and management. Questionable sustained results.	High Resource Need paid staff, curriculum, physical space, computers, audiovisual, transportation, multiple language opportunities.	Low Equity Ignores barriers of privacy, trust, language, culture, immigration, transportation and technology.
Family Peer Advocate (FPA) Model ⁷ <i>Caregivers of children with Autism Spectrum Disorder</i>	FPA’s have 10 hours of training and additional consultation with social work and psychology. FPA’s meet with other family caregivers in person or by telephone, 12 meetings over 6 months. Identify caregiver needs; provide education, provide support and identify resources.	High Improvement in caregiver stress with additional improvements in knowledge and caregiver strain.	Moderate Resources Ten hours of FPA training, FPA transport, social work and psychology consultation.	Moderate Equity FPA was bilingual and a caregiver themselves but wasn’t a member of the ethnic community. This may have an effect on privacy, trust and immigration fears. Convenient and low expenses to caregiver.
Parent to Parent Program (p2pwi) ^{8,9} <i>Caregivers of children and youth with disabilities</i>	Parent supporters have 8-10 hours training and provide care with 4 phone calls over 2 month period. Match between trained supporting parents and parents who request assistance. Matched according to challenges parent is experiencing. Information and referral to local health resources and support.	High Improvement in ability to cope with situation, ability to view their family situation in a positive light, ability to make positive progress on the goals that are important to them.	Minimal Resources Ten hours of training for volunteer parent supporters, phone	Moderate Equity Trained supporting parents are caregivers of children with disabilities themselves and this may assist with trust. Limited research on how language or cultural barriers are addressed. Care is provided only through phone calls. Convenient and low expense to caregiver.
Family Advocacy Network of Wisconsin Promise ¹⁰ <i>Families of young adults with disabilities</i>	Parent supporters with lived experience have 8-10 hours training, provide at least 4 phone calls over 2 month period. Match between trained supporting parents and parents who request assistance. Matched according to challenges parent is experiencing. Help with navigating the system.	High Satisfaction Families expressing a high satisfaction with the delivery of services. Families report raised expectations, connections to essential services.	Minimal Resources Paid advocates, transportation costs, advocate training.	High Equity Low expense and convenient to families. Advocate has experience with disability as well as lives in the area they serve. Meet in family’s home. Culturally sensitive. Act as mediators to resolve communication difficulties.

RECOMMENDATIONS

- Create and support across various systems a Family Caregiver Advocacy Position combining promising elements of the Family Advocacy Network, Family Peer Advocate and Parent to Parent Models.
- Hire advocates 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.
- Provide caregiver advocates with training and eliminate barriers due to background checks and professional credentials when culturally appropriate.
- Support additional research to determine the efficacy of new family caregiver support models in meeting the needs of underserved families.



Steering Committee Stakeholders

The Arc Wisconsin, Family Voices of Wisconsin, Greater Wisconsin Agency on Aging Resources, Parent University, Respite Care Association of Wisconsin, Wisconsin Board for People with Developmental Disabilities, Wisconsin Bureau of Aging and Disability Resources, WisconSibs, Inc..

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