

## Supporting Latino Caregivers in Milwaukee County

Milwaukee County has a vision for Milwaukee County that by achieving racial equity Milwaukee County will be the healthiest county in Wisconsin. This vision was formalized in 2020. Since then, the DHHS Dementia Care Specialist (DCS) team, from Milwaukee County, have been purposeful in helping to eliminate racial disparities to improve the lives of people of color, including Latino caregivers that are caring for someone with dementia and other caregivers of diverse backgrounds. The Dementia Care Specialist program is a state program that provides support and services to dementia caregivers that is free and unbiased and allows the individual living with dementia to live their best quality of life and stay living in their home longer. The DCS team in Milwaukee County not only provides bilingual DCS services but can also to provide bicultural services due to having a bilingual and bicultural Dementia Care Specialist. The DCS team understands that working with Latino caregivers may require a different approach than working with White caregivers. Since working with Latino caregivers may require a different approach, the DCS believed that it was important to learn more and understand what dementia related support and services are needed to meet the needs of Latino caregivers.

### **Methods:**

DCS conducted structured interviews with five community partners who have expertise in working with Latino caregivers via one-on-one meetings, outreach events, home visits, etc. The five community partners that DCS interviewed were the United Community Center, the Hispanic Health and Resource Center of Waukesha County, the Wisconsin Alzheimer's Institute-Milwaukee Office, Wisconsin Alzheimer's Institute Assistant professor Maria Mora Pinzon and the Dementia Care Systems Specialist from the Wisconsin Department of Health Services. These expert interviews were completed virtually in October and November of 2023. Each expert interview took about 30-60 minutes to complete. Each community partner was asked the following five discussion questions:

- 1. What do caregivers caring for someone with dementia inform that they need regarding their caregiving journey?*
- 2. Are there any specific methods or delivery of support/services they have told you about that they are looking for?*
- 3. What gaps in dementia programming have caregivers informed you about?*
- 4. What barriers do caregivers caring for someone with dementia express?*
- 5. Any other supports/services they are asking for as part of their caregiving journey?*

DCS also had nonstructured conversations in-person, over the phone, virtually with the following community partners: the United Community Center, the Hispanic

Health and Resource Center of Waukesha County and Alzheimer's Association Wisconsin Chapter.

During August-early December 2023, in partnership with the Alzheimer's Association Wisconsin Chapter, there was a structured survey created for Latino Caregivers via Microsoft Forms. When the opportunity presented itself, DCS or the Alzheimer's Association Wisconsin Chapter conducted the survey via phone call to the Latino Caregivers. DCS specifically conducted the survey with Latino caregivers that DCS worked with in 2022 and early 2023. The survey questions were written and asked in Spanish but have been translated for the purposes of this report. The questions that were on the survey were the following six questions:

1. *Are you caring for a loved one who has dementia?*
2. *What are some of the programs you participate in for your loved one's dementia care?*
3. *How did you hear about these programs?*
4. *Would you be interested in a support group for people caring for someone with dementia?*
5. *Would you be interested in participating in a group and spending time with your loved one and others caring for someone with dementia?*
6. *Aside from the group we talked about, what other types of services would you like to receive?*

During 2023, DCS was able to have one-on-one listening sessions with five Latino caregivers that were on the DCS caseload from August 2023-December 2023. Questions asked during these listening sessions stemmed from DCS consultations while completing the DCS Assessment form. Part of this form gathers current needs of caregiver and the person living with dementia.

### **Results:**

The community partners that were interviewed reported the following themes during the expert interviews: Latino caregivers are in need of knowledge of what services are available to them, and how to access these resources, what respite and/or home health care services are available to them, timely and easy to access/navigate resources, they are looking for information about what is dementia, the progression of dementia and how to approach dementia related behaviors, emotional and mental health support for coping with stress related to caregiving, legal guidance and assistance to advanced care planning, lack of resources for undocumented families, lack of resources due to financial eligibility and cultural and language barrier and Latino caregivers being open to having *Celebraciones*. *Celebraciones* include a time where Latinos come together with food, music and culture and gather.

Community partners informed that Latino caregivers are not aware of where to turn to find out what services and support are available to them as caregivers and for their loved one living with the disease. Since Latino caregivers do not know what support is available to them, they most of the time wait until they are close to or already burnt out to seek support. Since Latino caregivers are not aware of the services/support that are available, they are not aware of respite services, home health agencies, adult day centers, memory cafes, support groups, etc. as an avenue to avoid burn out and for emotional and mental health support. Due to lack of awareness about the available resources and dementia, community partners find themselves informing families about Aging and Disabilities Services, the Alzheimer's Association and the State funded Long-Term Care programs and the qualifications and process of eligibility for the Long-Term Care programs.

Community partners also informed that many caregivers do not know what dementia is and how to manage and approach behaviors that arise from dementia and Latino caregivers do not know what to expect as their loved one's dementia progresses. Since caregivers do not know what to expect or how to approach dementia, they find themselves having trouble coping with stress associated with caregiving. Not only do Latino caregivers have the stress of caregiving but they may find themselves not qualifying for support/services due legal status and/or financial eligibility. In addition, things that can add to Latino caregivers' stressors involve lack of future planning due to stigma and lack of culturally competent staff and/or written material. Lastly, community partners informed that memory cafes and support groups are models that Latino caregivers are not aware of as a resource. Community partners informed that Latino caregivers have *Celebraciones*.

During unstructured conversations, community partners informed that working with Latino caregivers involves professionals spending more than the average time to build rapport. Latino families need more follow-up and hand holding/guidance and need to feel welcomed by organizations that have built trust with them.

Spending more time to build rapport involves agencies having to do more than one contact per outreach site, having more than one home visit and/or phone call before a Latino family begins to open and/or seek support to community organizations. When community partners informed that more follow-up is needed, they provided examples of having numerous phone calls with Latino families for the family to be receptive to suggestions from the professional. Lastly, community partners shared that Latino caregivers need to feel welcomed by professionals that speak their primary language, have handouts that are in their primary language and are culturally appropriate and that the organization is well known in the Latino community.

A total of nine Latino caregivers completed the survey created by the DCS and the Alzheimer's Association Wisconsin Chapter. Surveys were completed between October-December 2023. Latino caregivers that completed the surveys were Latino

caregivers that were on DCS caseload in 2022 and/or currently working with the Alzheimer's Association Wisconsin Chapter. All surveys were completed via phone call.

There were common themes that came about from the surveys. Latino caregivers informed that they are open to being part of a support group and/or memory café but in the evening. Latino caregivers are also interested in education classes about dementia and more paid caregiver support (e.g., get more paid hours through Long-Term Care program and/or from another entity). Latino caregivers also informed that they felt that they needed support in figuring out a secondary caregiver and/or a plan if they as a primary caregiver were not available. It is important to note that when DCS asked caregivers if they were interested in support groups and/or memory cafés, they did not know that these groups existed.

DCS completed listening sessions with Latino caregivers that were on DCS caseload between the months of September-December 2023. A total of five Latino caregivers were part of the one-on-one listening sessions. The listening sessions were conducted via phone call. Four out of the five caregivers were women; the fifth caregiver was a man. Caregivers ranged from 40-55 years old.

Three out of the five caregivers informed that they were interested and needed information about dementia and dementia related behaviors. All three were open to receiving this information via community presentation and/or during one-on-one consultations. Three out of the five caregivers were interested in either a support group and/or a memory café. Three out of the five caregivers informed that they were interested in learning more about what was available for them as a caregiver and about respite.

### **Recommendations:**

After analyzing the information that DCS gathered from community partners that work with Latino caregivers as well as Latino caregivers themselves, DCS believes that the following approaches to DCS work in Milwaukee County would be beneficial and would align with Milwaukee County's vision to achieve racial equity:

1. Build relationships with additional community partners that serve the Latino community.
2. Partner with community organizations that have rapport with the Latino community to provide outreach events that would promote the Milwaukee County ADRC and DCS programs.
3. Be strategic about the coordination of outreach possibly during and/or leading up to Celebraciones.
4. Promoting outreach opportunities in a culturally appropriate way (e.g., using verbal and written language that is culturally appropriate).

5. Partner with community partners that have rapport in the Latino Community to provide presentations.
6. When working one-on-one with Latino caregivers, be flexible by knowing that more follow-up and guidance from professionals will be needed.
7. Validate the stressors that Latino caregivers inform professionals about and provide information about support/services that can help alleviate those stressors.
8. All written material that is provided to Latino families should not only be translated but should also be culturally appropriate.
9. Create a physical space where Latino caregivers can come together to find support from professionals and one another as caregivers (e.g., possibly something like a support group).
10. Create a physical space where Latino caregivers and the person living with the disease can have social time together and feel that they still belong in their community (e.g., possibly something like a Memory Café).
11. Partner with other community partners to advocate for possible change in eligibility criteria for undocumented individuals for public benefits.
12. Partner with other community partners to advocate for possible change in eligibility criteria for financial eligibility for public benefits.
13. Partner with other community partners to advocate for improvement in long wait time for public benefits.
14. Provide education on importance of advance directives and future care planning.

