

RELEASE | More than 100 Michiganders attend caregiving roundtable to map change

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[EXTERNAL]**For immediate release:** Tuesday, Aug. 30, 2022Contact: Mandy Culbertson, mandy@caringacross.org | 913.709.9515**Roundtable Discussion Reveals Major Care Infrastructure Needs In Michigan***More than 100 people showcased need to provide support for families
and improve care workforce pay*

LANSING, Mich.—U.S. Representative Debbie Dingell (D-MI 12th District) and Michigan state representatives Padma Kuppa (D-41st Michigan House District) and Stephanie Young (D-16th Michigan House District) joined more than 100 caregivers and caregiving advocates for a roundtable discussion to chart a path forward for addressing Michigan’s urgent unmet care needs for families and for care workers.

The discussion highlighted how, due to the lack of strong and well-funded care infrastructure in the U.S., there is an over-reliance on unpaid family caregivers, who provide the majority of care in this country.

U.S. Rep. Dingell and Michigan Rep. Young both shared stories of how these families often have little support, receive few services and can lose jobs and income as they try to meet their family members’ needs.

“Caregiving allows for all other work to be possible. It’s the foundation of our economy — no one can do their job if their loved ones aren’t cared for,” said **U.S. Rep. Dingell**. “It’s simple: Seniors and people with disabilities deserve to live with dignity and in safety. And care workers deserve adequate benefits and pay for the work they do. Currently, our nation’s long-term care system simply does not meet those unique needs. We have a responsibility to take care of our seniors, our workers and to fight for better home- and community-based services (HCBS).”

“Home health care and community based workers are not alone in the fight for fair wages and benefits,” said **Rep. Young**. “Home healthcare and community-based workers are not alone in the fight for fair wages and benefits. I am grateful the legislature was able to secure an additional \$2.35 an hour for them, but we won’t stop fighting until all care workers receive wages and benefits equitable to their important role of caregiving for our loved ones.”

Conversation centered on how individuals and families are left to fill the gaps in the system, often sacrificing their ability to work and losing all they own as they struggle to afford needed care.

"Having been active in the long-term care and disability spaces through my state legislative efforts and work as co-chair of the Michigan Legislative Care Caucus and member of the Disability Caucus, I recognize the need for additional federal resources to improve our care infrastructure for seniors, those with disabilities and care providers,” said **Rep. Kuppa**. “Care accessibility and quality are vital to the health of our state, and I was thrilled to join this discussion to share ideas on improving care outcomes for all Michiganders.”

"We need an investment in our care infrastructure that will strengthen our direct care workforce and support our families," said **Ai-jen Poo, executive director of Caring Across Generations and president of the National Domestic Workers Alliance**. "We must strengthen our systems of care so that no one has to make the impossible choice between the health and safety of our loved ones and going to work. That's why we came together today, to continue to push for funding so that all Michiganders can access home and community based services, and to ensure that we achieve better pay and stronger benefits for Michigan's care workers."

Advocates from Michigan care organizations showcased the lack of access to necessary supports throughout the state for people to age with dignity in their homes and for disabled people to live the life they choose.

"HCBS support persons with disabilities so they can receive services in the most integrated setting," said **Angela Martin, senior associate director at Michigan Developmental Disabilities Institute**. "These services ensure people with disabilities can go to work, go to school and volunteer in their community. Our communities are richer when all of its members contribute. Delivering quality community support is not only the right approach for people, it reduces the need for emergency services and hospitalization."

"Without HCBS, people can't age at home. This means higher costs and worse outcomes," said **Nicole Shannon, systemic advocacy attorney at Michigan Elder Justice Initiative**. "When HCBS isn't there, people live in dangerous situations. Living in a dangerous situation can look to outsiders like the adult lacks capacity to make decisions--leading to the guardianship system. In reality, people have full mental capacity and are making impossible choices with impossible tradeoffs."

"Quality HCBS supports are highly dependent on the federal funding to Michigan's Medicaid program," said **Sherri Boyd, executive director at The Arc Michigan**. "This includes prioritizing wages for direct care workers. Quality HCBS cannot be delivered without sustained, livable wages and benefits for direct care workers."

The lawmakers lauded the value of paid direct care workers, and highlighted how care work makes all other work possible, noting that better supporting family caregivers and paid care workers will boost the care economy.

"Caregivers, disabled people and elders are not mutually exclusive groups," said **Kaci Messeder, policy analyst with Detroit Disability Power**. "Oftentimes caregivers, including direct care workers, are disabled and/or elders themselves. We all encounter disability naturally at some point in our lives, and we're all care providers and receivers in our day-to-day lives without naming it as such. Supporting our direct care workforce protects all of us — now and for our futures together."

"I was glad to participate today to ensure that caregivers are being heard," said **Christina Potts, a direct care advocate and care worker with more than 30 years experience**. "The current state of the direct care worker is a job with low wages and no time off. I would like to see a living wage and investments in benefits, including time off and training, that would allow me to have a better quality of life and have more time with my family. If these steps are taken, Michigan's direct care workforce will be stronger and can care for the people of our state for the long term."

The roundtable included representatives from a coalition of caregiving focused organizations including Care Can't Wait Michigan, Alzheimer's Association of Michigan, Area Agencies on Aging Association of Michigan, Caring Across Generations, Detroit Disability Power, Michigan Developmental Disabilities Institute, Michigan Elder Justice Initiative, Mothering Justice, National Domestic Workers Alliance and The Arc Michigan.

BACKGROUND: The Gaps in the Michigan Home and Community-Based Care Infrastructure

The Problem: Families all over the country are facing difficult decisions about supporting family members as they age and/or have a disability. In Michigan alone, it is estimated that 1.3 million family caregivers have provided 1.1 billion hours to loved ones above the age of 18, filling the gaps that the system leaves behind. These numbers have been further exacerbated by the COVID-19 pandemic so the limits of our current service system, funded by the Medicaid program through Home and Community-Based Services(HCBS), have long been surpassed. Nationally, upward of 850,000 elderly and/or disabled Americans are on waiting lists for these essential services, waiting up to five years. While there are no formal waiting lists in Michigan, there are thousands of people who are not receiving the services that they need due to the lack of capacity in the system, and the lack of direct care workers.

Within Michigan, 106,700 individuals currently receive these Medicaid HCBS services, with an expected growth in need. The system will need to create 118,000 direct care jobs by 2028 to meet the growing number of beneficiaries. Without more funding and support, direct care jobs will be left unfilled and capacity will continue to fail to meet the need. Left unaddressed, more and more Michigan families will have to face difficult care decisions and will have nowhere to turn to for help.

The Solution: The Better Care Better Jobs Act (BCBJA) would go far in making the desperately needed investments in the crumbling service system that supports people with disabilities and/or aging adults. The act would provide funding to expand access to these services, create the infrastructure needed to support those currently going without the services that they need, and provide funding for states to address the direct care workforce crisis in Michigan. Additionally, the Better Care Better Jobs Act also will improve the quality of the direct care workforce by increasing the wages for home care workers, which will directly increase additional annual income for these workers and their families by \$498.5 million.

The Financial Case: The investment of funds included in the BCBJA will be significant and is needed after decades of lack of investment. Funding is required for states to build the infrastructure and capacity that they need to move people with disabilities and aging adults off of the waiting lists, hire the workforce needed to provide care, improve conditions for the workforce and streamline the system. Developing long term infrastructure and sustainably creating thousands of “living wage” care jobs would bolster to Michigan’s economy in the coming years as it recovers from COVID-19.

Definitions

LTSS: People with disabilities and aging adults often require some assistance to live independently in their homes and communities. Broadly, these services are called long-term services and supports or LTSS. They include a broad range of health-related and social services; including assistance with activities of daily living (ADLs); such as bathing, dressing, eating, toileting and personal hygiene and instrumental activities of daily living (IADLs); such as meal preparation, money management, house cleaning, medication management, shopping and communication support. The main program that pays for LTSS for people with disabilities and aging adults is Medicaid.

Medicaid: Medicaid is a state and federal partnership, governed by a federal law, in which the costs are shared between the federal government and the states. Because it is a state run program, Medicaid requirements vary by state, including the amount and type of income and assets eligibility requirements. Services are also based on “medical necessity,” so not all Medicaid-eligible individuals receive LTSS. There is a lack of consistency of services, so what is available in one state is often not available in another. Not only do the types of services and quality of services vary from state to state, but the access to services can also vary due to waiting lists.

Waiting Lists: Because of what is referred to as the *Institutional Bias* of the Medicaid program, state Medicaid programs are required to fund LTSS in institutions with no enrollment limits, but are not required to fund Home and Community-based Services (HCBS) and can cap enrollment for HCBS programs. This creates long waiting lists for participation in Medicaid-funded HCBS, which are the services that more people with disabilities and aging adults want. In some states, wait times for services can be years or even a decade.

Caregiving/ Workforce: Many disabled people and aging adults rely on support that is provided by informal caregivers, such as friends or family members. Caregiving can result in difficult financial, physical and emotional obstacles. And informal caregivers usually have little to no training and have little access to information or support in navigating the complicated Medicaid system. In order to support people with disabilities and aging adults, there is an extreme need to improve the supply, retention, pay and career trajectory for the workforce that supports people with disabilities and aging adults. This workforce that plays the critical role of supporting people with disabilities and aging adults is made up of mostly women—particularly women of color — and the BCBJA would ensure that the vital role of this workforce is recognized by ensuring that care jobs are good jobs.

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Caring Across Generations is a national campaign of family caregivers, care workers, people with disabilities and aging adults working to transform care so it's accessible, affordable and equitable—and enables everyone to live and age with dignity. To achieve our vision, we transform cultural norms and narratives about aging, disability and care; win federal and state-level policies; and build power amongst the people touched by care.

Caring Across Generations is a fiscally sponsored project of the National Domestic Workers Alliance, Inc. The National Domestic Workers Alliance, Inc. does not endorse, support or oppose any candidate or party for public office.

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