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Family Caregivers Share Challenges and Rewards of Caregiving in November 1 Kick-Off

Madison, WI --Family caregivers from across Wisconsin are sharing their stories in the State Capitol today as a kick-off to National Family Caregiver Month. The Governor's office has issued a formal proclamation declaring November as the month to recognize the value of caregivers who contribute nearly 588 million hours of unpaid care in Wisconsin annually, valued at \$6 billion.

Nancy Gapinski of Glendale who is speaking at the event says people often ask her how she does it when caring for both her two children and her 85-year-old mom who lives with their family.

"I remember the moment that I joined the 'Sandwich Generation' in 2006 when I was pregnant with our first child and my mom had an unexpected double bypass surgery and then inpatient cardiac rehab," says Gapinski. "Her needs have increased over the years. I've adjusted my employment to meet my mom's needs and that of our children. I changed employment, reduced work hours, worked from home, and recently quit my part-time job because of my mom's needs, but I wouldn't have it any other way."

A recent survey of caregivers of people with disabilities in Wisconsin revealed that 98% report some level of stress; 50% are very or extremely stressed. 92% of caregivers reported that caregiving responsibilities affected their employment with 52% giving up on outside employment entirely.¹

The Governor's proclamation being presented to family caregivers today indicates that 80% of Wisconsin residents including older adults who need care receive that support from family and friends at home instead of in nursing homes or other facilities. Due to a significant direct care worker shortage, 85% of Wisconsin residents who rely on paid caregivers indicate they cannot find staff to meet their daily needs². 91% of personal care agencies statewide report they have had to turn away clients because of lack of workers.³

The newly formed <u>Wisconsin Family and Caregiver Support Alliance</u> of aging and disability groups says both in Wisconsin and nationally families are the backbone of the CareForce.

¹ Family & Individual Needs for Disability Support Report 2017 (Inst. on Community Integration and The Arc of the United States)

² Survival Coalition of Wisconsin Disability Organizations

³ Wisconsin Personal Services Association.

"Our mission is to raise awareness of family and caregiver support needs and increase the 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," says Lisa Pugh, co-chair of the Alliance.

Deb Notstad of Stoughton who cares for her 27-year-old son Adam with developmental disabilities and is speaking at today's event says caregiving for her family has been both rewarding and challenging.

"It affects everyone in the household. I have lost hundreds of hours of work time at my job, not only providing direct care but also consulting with medical doctors, nutritionists, therapists and others. It limits the amount of time we can spend outside the home," says Notstad. "We are committed to ensure that Adam has a full, engaging life."

"I am glad that the caregiving relationship is being celebrated this month," says Gapinski. "We are so grateful that Wisconsin values and invests in programs that help people stay in their homes and out of nursing homes," says Gapinski.

Family caregivers and supporters are invited to join the <u>Wisconsin Family and Caregiver Support Alliance</u> (WFACSA) in celebrating caregivers all month long through a "You Might Be a Caregiver If..." campaign. Bi-partisan legislators who spoke at today's event - Rep. Mike Rohrkaste, R-Neenah and Rep. Deb Kolste, D-Janesville - added their own personal reflections about caregiving and the need for statewide solutions. WFACSA is asking caregivers to contact their legislators this month to share their caregiver experience.

All Wisconsin caregivers are also encouraged to fill in the blank for "You Might be a Caregiver If..." and share their stories throughout November. Wisconsin caregivers will be featured on social media all month long. Share stories here: http://wisconsincaregiver.org/family-caregiver-month

Today's Celebration Details:

- Thursday, November 1 at 10 AM
- Governor's Conference Room State Capitol, Madison
- Stories from Caregivers from across the state; presentation of Governor's Proclamation; Remarks by bi-partisan legislators