

YOUTH CAREGIVERS IN WISCONSIN

July 15, 2026, Statewide Caregiver
Coordinator Meeting

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Overview of Objectives

Define who youth caregivers are and understand their caregiving roles

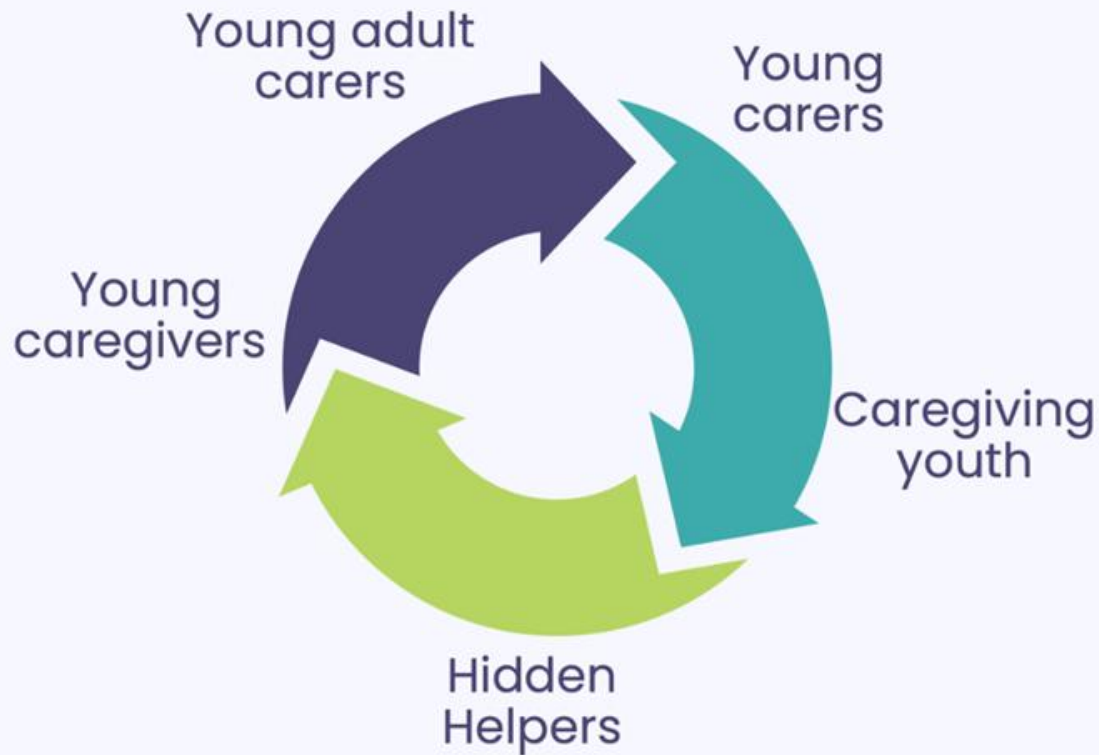
Recognize the impact caregiving can have on children and adolescents

Identify opportunities to screen and support youth caregivers

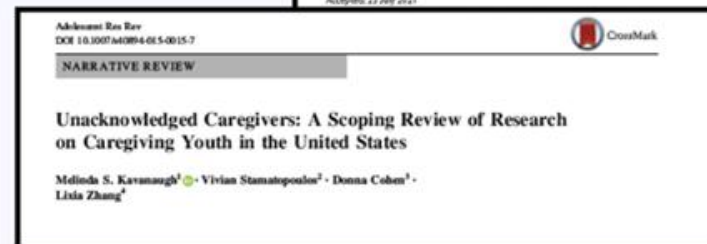
Connect youth caregivers and their families to Wisconsin resources

Understand how caregiver programs and community partnerships can help reduce caregiver burden

Children, Youth, and Young Adult Carers

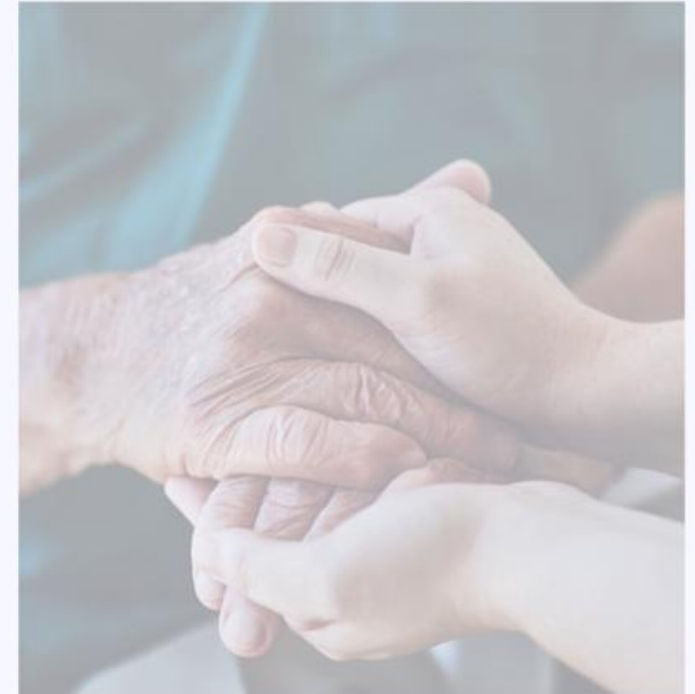


- Ages 6–25
- Between 5–22% of college students are currently or were caregivers^{1,2,3}
- ~5 million young carers in the US, with an estimate of 3 million in veteran homes⁴
- Care for Parents, grandparents and siblings
- **Across race, ethnicity, culture and geographic location**



Care across disability, illness and injury

- **Spinal cord injury, traumatic brain injury and PTSD¹**
 - Feeding, transferring, managing behaviors, emotions and family communication
- **Neurological conditions²**
 - Feeding/choking, transferring, communication, Cognitive and emotional care
- **Mental health and substance abuse³**
 - Emotional support, sibling care, ADL's IADL's
- **Alzheimer's and related Dementias⁴**
 - Managing behaviors, family communication, cognitive impairment
- **Siblings with illness, injury or developmental disabilities⁵**
 - Managing behaviors, daily care tasks, cognitive impairment



Young Carer Mental Health

Young carers report significantly more depression than normative peers²

Youth caregivers living with care recipients at the highest risk for anxiety and depression³

More caregiving was associated with higher levels of emotional challenges (e.g., suicidality, hopelessness, self-harm)⁴

Critical to address – intensity of care, age, ethnicity, location of care and the care recipient illness – all significant for potential increased mental health issues

Caregiving impacts on school performance and attendance



Too worried to
concentrate



Missed school
assignments



Did not attend
after school
activities



Late to class

But – many young carers feel school as a refuge, a place where they get to be a student and have friends, and not talk about or deal with care

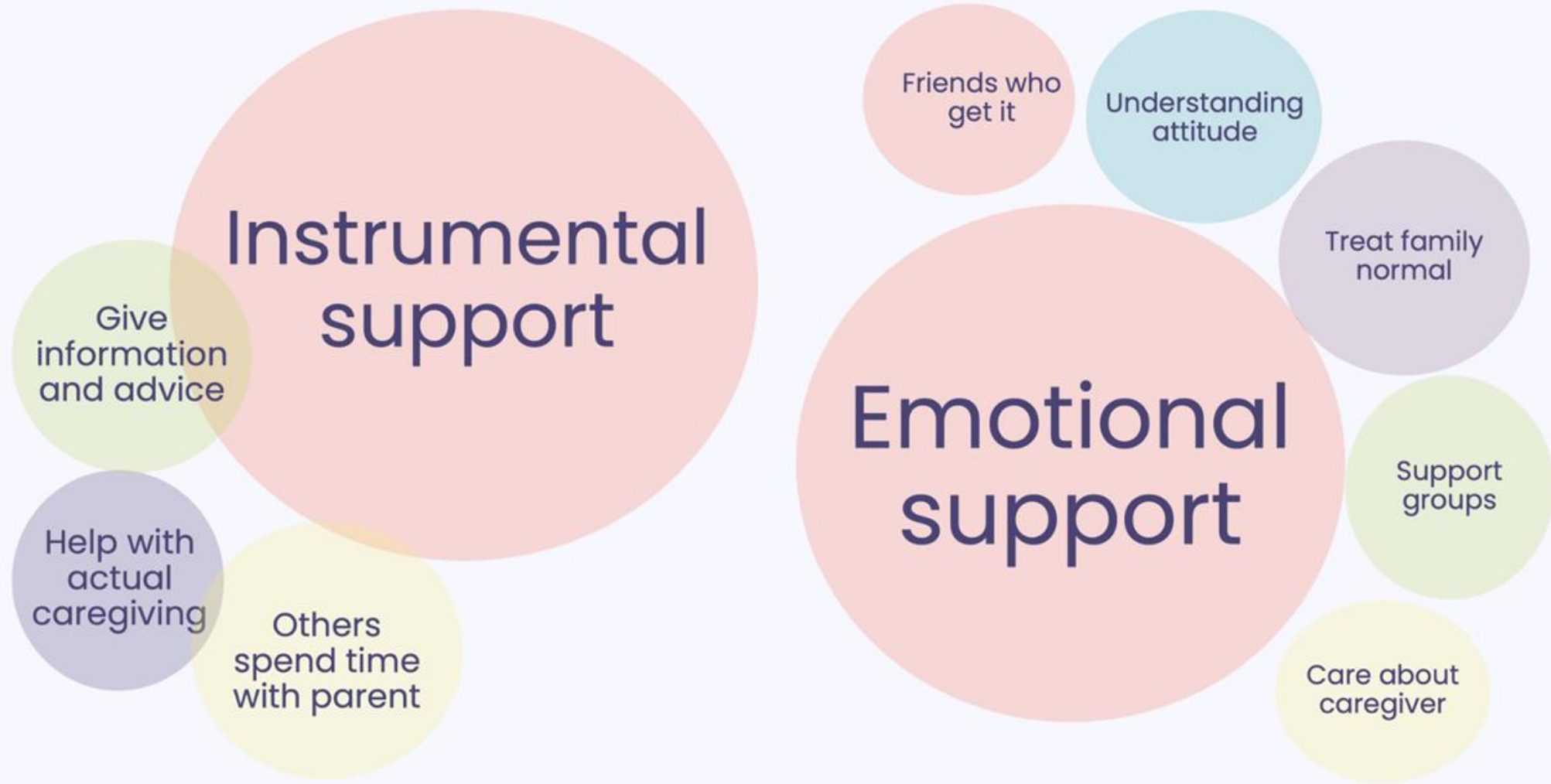


Peers and social isolation

- Overall, young carers have fewer peers and experience social isolation¹
- Many want more peer support and to be seen as just a normal kid²
- Higher risk for lack of peer engagement across all caregiver groups³

Young carers want to be seen and need the support of others – they want to feel like they have a “normal” life

Caregiver Support needs



University programming

- Support groups on campus, between class times
- Dedicated library space for family – can bring care recipient
- Late assignment policy
- Caregiver excused absence form

UWM Student Health and Wellness Center

**Student Caregiver
Support Group**

UNIVERSITY OF WISCONSIN

MILWAUKEE



Center for Young Carer Research and Innovation

- **Developing and conducting research to inform evidence-based programs**
- **Engaging community partnerships**
- **Professional training programs**
 - **Caregiving symposium**
 - **Webinars**
 - **CHE opportunities**
- **Program evaluation**



Helen Bader School
of Social Welfare

Barriers to identifying young carers in the U.S.

The only nation that has not ratified the United Nations Convention on the Rights of the Child

to young carers in the United States: US policies in international context

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- Perceptions of disability in the home
- 42 State laws or policies that included disability-related grounds for the termination of parental rights (TPR), including on the basis of physical disability alone
- How many of these families had a child or youth involved in care is unknown



HHS Public Access

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The challenge of identifying young carers in the US: how state laws put families at risk for separation

Young carers in policy – *Lifespan Respite Care Reauthorization Act of 2025*

- Change to “unpaid individual” – no longer adults only
- This removes the 'adult' limitation in the definition of “family caregiver” and now may include young carers.
- No explicit mention of young carer, caregiving youth
- The bill reauthorizes funding for existing Lifespan Respite Care Programs, extending support through FY 2030.

What does this mean for young carers and for your organization?

Professional Next Steps

Using the data and information as a professional:

- Recognize
- Acknowledge
- Assess
- Connect
- Follow-up

Screening & Identification Tools

- Current screening efforts
 - Using the young carer screening tool
- Where screening can occur:
 - Schools
 - Healthcare settings
 - VA
 - Community organizations
- Why data collection matters

Join the UWM *Identifying & Supporting Young Carers* webinar next week to find out more about the screening tool and how to use it across organizations and settings



What's Coming Next?

- Professional survey
- Additional research
- Grant opportunities
- Using the young carer toolkit
- Wisconsin-specific implementation efforts – partnering with the UWM Young Carer center

Wisconsin Family Caregiver Programs

When the care recipient or adult caregiver qualifies for services, supports may reduce caregiving burden on youth.

Examples:

- Respite services
- Personal care assistance
- Homemaker services
- Transportation
- Caregiver training
- Home-delivered meals
- Supplemental services

MEET EMMA (15)



High school student



Helps care for grandmother with dementia



Mom works full-time



EMMA'S RESPONSIBILITIES



Medication reminders



Meal preparation



Supervision after school



Household chores



SUPPORTS ADDED



Weekly or Monthly Medication Set Up & Medication Machine



Homemaker Services 5 hours/week



Respite Care 5 hours/week



Caregiver education for Mom



RESULTS



More time for school activities



Reduced stress



Family remains safely together at home



Improved quality of life for everyone

Additional Wisconsin Resources

- [Young Carer Support Toolkit](#)
- [Ycare](#) program and resources
 - Free online materials
 - YCare across the state and populations
- [Lorenzo's House](#)
 - Online peer support
 - Youth and young adult programming
- WisconSibs now [SOAR Fox Cities](#)
 - Sibling support and education
- Local schools and community supports

Respite Care Association of Wisconsin Resources

Grants for Family Caregivers:

- [Caregiver Respite Care Grant](#)
- [Supplemental Respite Grant](#)
- [Healthy Meals, Healthy Mind](#)

Eligibility:

- Applicant is the primary caregiver or family caregiver for a child or adult with special needs or disabilities.
- Applicant is unable to access adequate long-term care or respite services due to ineligibility, denial, delays, exhausted funding, or gaps in covered supports.

Reminder: While funds cannot pay youth caregivers directly, they may help reduce caregiving strain experienced by youth caregivers within the family.



Questions & Discussion

What are you seeing locally?

What barriers exist?

What opportunities exist?

How can Wisconsin improve identification and support?