



The national resource for the support of children who are caring for chronically ill, injured, elderly, or disabled family members.

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Prevalence of Caregiving Youth in Florida

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BACKGROUND

- "Caregiving youth" are children and adolescents under the age of 18 who provide regular care for someone at home who has a medical condition or is experiencing functional decline with aging
- A 2020 AARP/NAC report estimates at least 3.4 million children in the US under age 18 who provide care to an adult recipient¹
- Youth may assist with ADLs (such as mobility and feeding) and IADLs (such as cooking and assisting with medications)²
- Studies have shown that caregiving youth tend to have difficulty with learning³, higher levels of anxiety, and increased resilience⁴
- There is a lack of data describing the prevalence and characteristics of caregiving youth in the US

Figure 1: Question on youth caregiving in the YRBS

During an average week, on how many days do you provide care for someone in your family or household who is chronically ill (lasts 3 months or more), elderly, or disabled with activities they would have difficulty doing on their own?

1. There is no one in my family or home who is chronically ill, elderly, or disabled who needs care
2. 0 days per week
3. 1 or 2 days per week
4. 3 to 5 days per week
5. 6 or 7 days per week

Figure 3: Responses to YRBS question on days per week spent providing care among middle and high school students

The American Association of Caregiving Youth (AACY) is a non-profit organization in Boca Raton, FL that supports caregiving youth and their families

STUDY OBJECTIVES

Analyzing data from the 2019 FL YRBS, this study aims to

1. Estimate the prevalence of caregiving youth in Florida
2. Examine the demographic characteristics of this population

RESULTS

Figure 2: Prevalence of caregiving among middle school (N = 5,177) and high school (N = 5,703) youth by grade

- 23.6% of middle school students and 16.4% of high school students provide regular care during the week
- 6th grade boys have the highest prevalence of youth caregiving at 27%
- Children in lower grades are more likely to provide care ($r = -.05, p = .00$)
- Among high schoolers, boys are more likely to provide care than girls ($t = 2.33, p = .02$)
- Among high schoolers, Native American and Hispanic youth are more likely to provide care than white youth [$F(3357) = 6.37, p = .000$]

DISCUSSION & CONCLUSION

- This study reveals a high prevalence of caregiving that, extrapolated across Florida, reflects more than 790,000 youth who provide care
- Caregiving youth needs to be recognized as a potentially vulnerable population of children in need of support
- Pediatricians can help by screening their patients for caregiver status, providing guidance to caregivers, and advocating for policy that supports caregiving youth
- Future research should aim to determine a national prevalence of youth caregiving and identify correlations between providing care and other YRBS risk factors

METHODS

Youth Risk Behavior Survey (YRBS)

- YRBS was created by the CDC to monitor the prevalence of common risk factors contributing to morbidity and mortality among high school youth (grade 9-12)⁵
- The Middle School Health Behavior Survey (MSHBS) is administered to middle school students (grade 6-8)
- The 2019 YRBS and MSHBS were distributed to a random sample of classrooms in public schools from 61/67 FL counties
- A question on time spent providing care was introduced into both surveys (Fig. 1)

Data Analysis

- Simple descriptive statistics of high school and middle school study samples were used to calculate prevalence
- Samples were divided into a dichotomous variable of caregiver vs. non-caregiver and independent T-tests were used to identify differences by gender/age; ANOVA was used to identify differences by race/ethnicity

REFERENCES

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Welcome to The Advisory Council

As we enter into a new quarter, we are immensely excited to announce the growth of our National Advisory Council! This council is vital to the organization as it brings together individuals who are leaders in their respective fields and allows them to share their expertise and knowledge with our organization to enhance our ability to spread awareness and caregiving youth's concerns.

We are excited for Richard W. Lindsay, MD, and Jodi O'Donnell-Ames to have joined our already esteemed list of Advisory Council Members.

National Listening Project



As the national conversation regarding youth caregiving continues



Richard W. Lindsay, MD is Emeritus Professor of Internal Medicine and Family Practice and former Head of the Section of Geriatric Medicine at the University of Virginia Health Sciences Center in Charlottesville. Dr. Lindsay grew up in upstate New York, where his father was a family physician. He attended Cornell University and New York Medical College from which he received his M.D. degree and where he was a member of Alpha Omega Alpha.

Dr. Lindsay was a co-founder of the Institute for Innovations in Caregiving, which is now a part of Virginia's Senior Navigator. Recently Dr. Lindsay was honored by having the Institute renamed the Lindsay Institute for Innovations in Caregiving.



Jodi O'Donnell-Ames is a certified teacher, writer, member of Union Fire Co. and Rescue Squad, and tireless advocate for Lou Gehrig's disease, or ALS (Amyotrophic Lateral Sclerosis). She is also the founder and Community Outreach Director of Hope Loves Company, a non-profit organization committed to providing educational and emotional support to children and young adults who have had or have a loved one battling ALS in their lives. She lives with her husband Benton in Titusville, NJ. Their children, all young adults, have lost a parent to ALS before the age of 11. Jodi is the author of two books, *The Stars that Shine* and *Someone I Love has ALS*. She was chosen as *People Magazine's* "Hero Among Us" and is the recipient of many awards including the Russ Berrie Making a Difference Award, the AFP (Association of Fundraising Professionals) Founder's Award, the TIAA Difference Maker Award, the New Jersey Governors Jefferson Award, the TCNJ Alumni Humanitarian Award and the Princeton Mercer Chamber of Commerce Women in Achievement Award. In addition, she was invited to give a TedX talk on *Leading a Life with Purpose*.

Tutor Pool

One of our current projects is to recruit additional tutors as the grade of many of our youth slipped during the final weeks of the last academic school year. We are focusing first on those who are entering high school along with those beginning their senior year to ensure that their overall grade averages can be address, and when needed improved. This past year our high school senior graduation was 100% bringing our six-year average to 98.3%! If you are or know of anyone interested in entering our tutor pool please feel free to email us at Info@acy.org.

to grow, we are excited to announce that seven of our youth had the opportunity to participate in the RAISE Family Advisory Council Listening Project. This was a fantastic opportunity because it allowed our youth tell their stories directly to the decision-makers who will be creating a national strategy that will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers

In The News & Raising Awareness

AACY, has made significant progress in bringing awareness of the organization and our cause and most recently we had two major articles conducted on youth caregivers, as well as our two of our youth had the opportunity to participate in a radio interview.

[Forbes: The Youngest Family Caregivers](#)

[More Than 3 Million Youth Play a Caregiving Role. They Need Our Support.](#)

[WLRN Radio Interview](#)

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Thank You!

During this time of limited in-person fundraising, we extend our special appreciation to five foundations whose recent grants are helping AACY accomplish its goal of improving the lives of caregiving youth and their families. They are:

- Boca Raton Regional Hospital Foundation
- The Cornelia T. Bailey Foundation
- Leslie L. Alexander Foundation
- United Way of Town Palm Beach

We are equally grateful for all of our individual donors and while we know we are important to you, we want to remind you that are important to us!

