Unacknowledged caregivers: A review of Young carer research informing programmatic response in the United States

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> ***“if someone says, “How’s your mom doing,” I’ll say, “Oh, she’s doing all right.” But maybe it’d be nice if someone asked me how I was doing. Like, ‘cause I will have an answer.”***

- Female young caregiver, mother with Huntington’s disease

Caregiving in the United States

- Approximately 44 million family caregivers (AARP, 2015)

- Largest provider of care in the United States
  - Approximately 375 billion dollars in unpaid care (NCA, 2007)

- Caregiving research
  - Over 2000 published reports
  - spouses and adult children

- Strain, burden, stress and physical stress (Haley 1997; Stetz and Brown 2004; Schultz and Martine 2006)

State and federal caregiving policies and programs

Federal family medical leave act

Veterans Affairs

National Family support programs

Federal Family Medical leave - 12 weeks of unpaid, job and health benefits protected leave

Paid Family Leave (PFL) provides workers with a maximum of six weeks of partial pay each year while taking time off from work to care for a seriously ill parent, child, spouse or registered domestic partner. Only in a few states.

National Family caregiver support programs - Provide respite, education and support

Focus on adults

None are inclusive of anyone under the age of 18

Young carers in the U.S.

~1.4 million young carers in U.S. between ages of 8-18 (National Alliance for Caregiving, 2005)

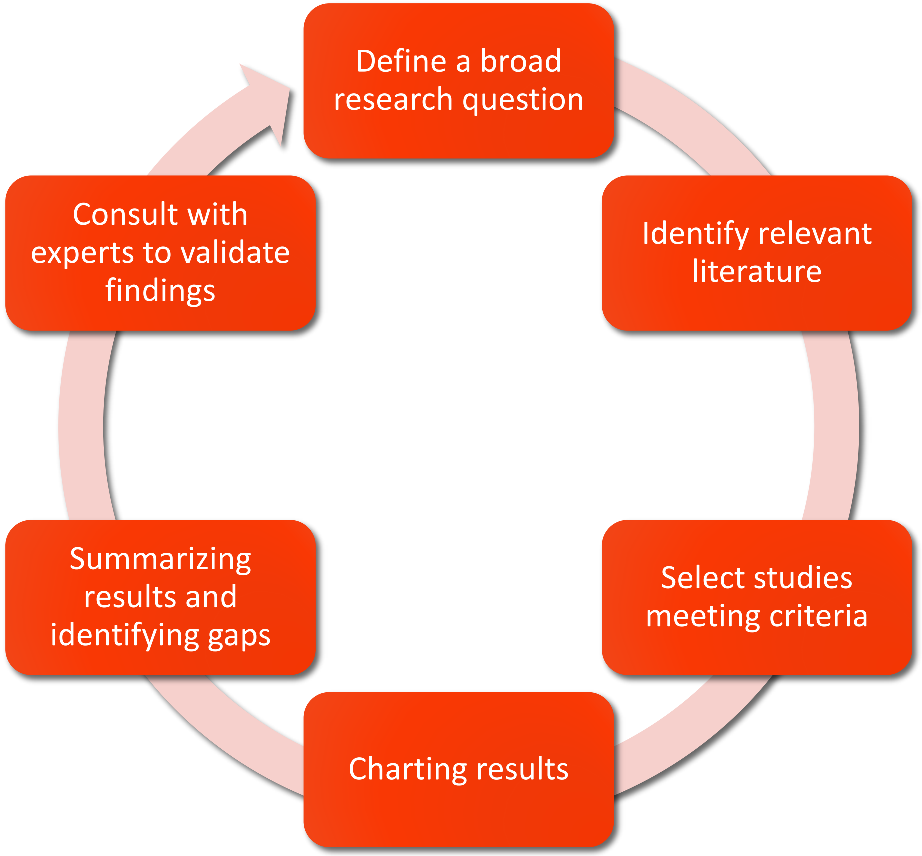
Represent approximately 3.2% of household with children in the U.S.

Rights of young carers in the U.S

- U.S. not ratified the Child Rights Convention
- Numerous potential applications (Kavanaugh, Kalpeni and Stamatopolous, 2016)

No comprehensive review of research and literature of young carers in the US

Current study – Scoping review


Define a broad research question

Identify relevant literature

Select studies meeting criteria

Charting results

Summarizing results and identifying gaps

Consult with experts to validate findings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NARRATIVE REVIEW

Unacknowledged Caregivers: A Scoping Review of Research on Caregiving Youth in the United States

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Abstract With over 43 million family caregivers living in the United States, families are the largest providers of informal care in this country. Despite the extensive caregiving literature about prevalence, characteristics of care providers and care recipients, risks to caregivers' health and well-being, economic costs, impact on personal and family well-being, evidence-based interventions, and model community-based programs and supports for adult caregivers, gaps exist, specifically relating to caregiving youth, i.e., children under the age of 18 years. With no previous comprehensive review to assess what is known about US youth caregivers, a scoping review, focusing on significant knowledge gaps in crucial areas including SES status of families who rely on caregiving youth, the role of race, ethnicity and culture, support across schools, communities and medical professions, and the lack of caregiving programs and polices inclusive of youth under 18. The results underscore the need for further inquiry, including longitudinal study, into the lives and experiences of caregiving youth, informing the development of youth caregiver focused supports and polices across the US.

Keywords Young carer · Young caregiver · Caregiving youth · Scoping review

- Data collected from youth and/or parent and care recipient
- Review found 22 publications
- Predominately small scale descriptive studies

Who are young carers in the U.S.?

- Simply defining is an issue
  - Young carer
  - Young caregiver
  - Caregiving youth
- Age
  - Stopped at 18, others went up to 25
- Gender
- Race/ethnicity
  - Few studies included
- Relationship to care recipient
  - Parent, grandparent, sibling
- Care recipient illness
  - Variations in illness

The caregiving experience


Outcome measures

Caregiving role

Tasks

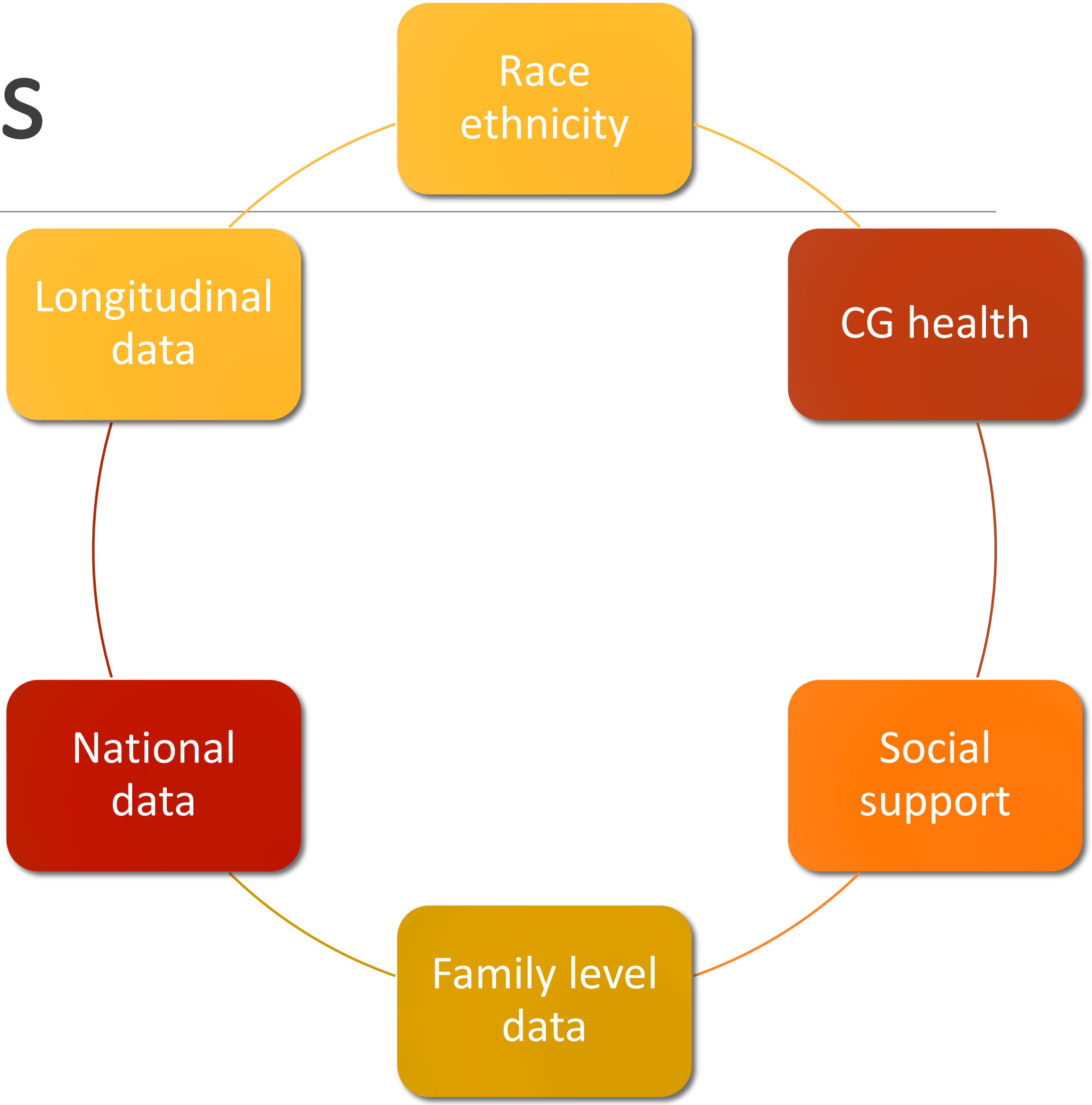
- Often primary caregiver
- Measures included:
  - depressive symptoms
  - parent/child relationship
  - School performance and attendance
- Participate in personal, intimate and companion care
- Variations in disease process

Takeaways and next steps

First and foremost, inclusion and acknowledgement in caregiving policies and programs

Given large variation in the U.S.:

- ☐ Need for more complex analysis
- ☐ Education and support
- ☐ Economic impact
- ☐ Long term complications



Project Collaborators

United Community Center
Centro de la Comunidad Unida

Alzheimer's & Dementia Alliance
OF WISCONSIN

HDYO
HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

ALS
ASSOCIATION

Huntington's Disease
Society of America

Research Projects

Huntington's disease

- N = 40 youth
- Ages 8-19
- Parent with HD

ALS

- N = 57 youth
- Ages 8-18
- 101 parents with ALS

South Africa ALS

- N = 20 youth
- Ages 8-18
- 20 parents with ALS

HDYO Camp

- N = 42 campers
- Ages 15-23
- 39 identified as CG
- Family with HD

Latino students

- N= 200
- 71 identified as CG
- Ages 9 – 14
- Grandparents with Alzh

Youth Caregiving experiences

Huntington's disease (N=40)

(Kavanaugh, 2014)

Caregiving average

- 4.3 years

Caregiving tasks

- Providing company = 34
- Helping parent walk = 31
- Give medication = 12
- Fed parent=18
- Household chores = 36
- Talk to dr for parent = 13
- Toileting =11

Feel they have a lot of responsibility = 36

***Depression -** Mean = 11

ALS (N=57)

Caregiving average

- less than a year

Caregiving tasks

- Dress/undress parent = 44
- Keep them company = 54
- Give medication = 39
- Help them eat = 49
- Use communication equipment = 42
- Help with suction = 12
- Toileting = 28

Feel they have a lot of responsibility = 31

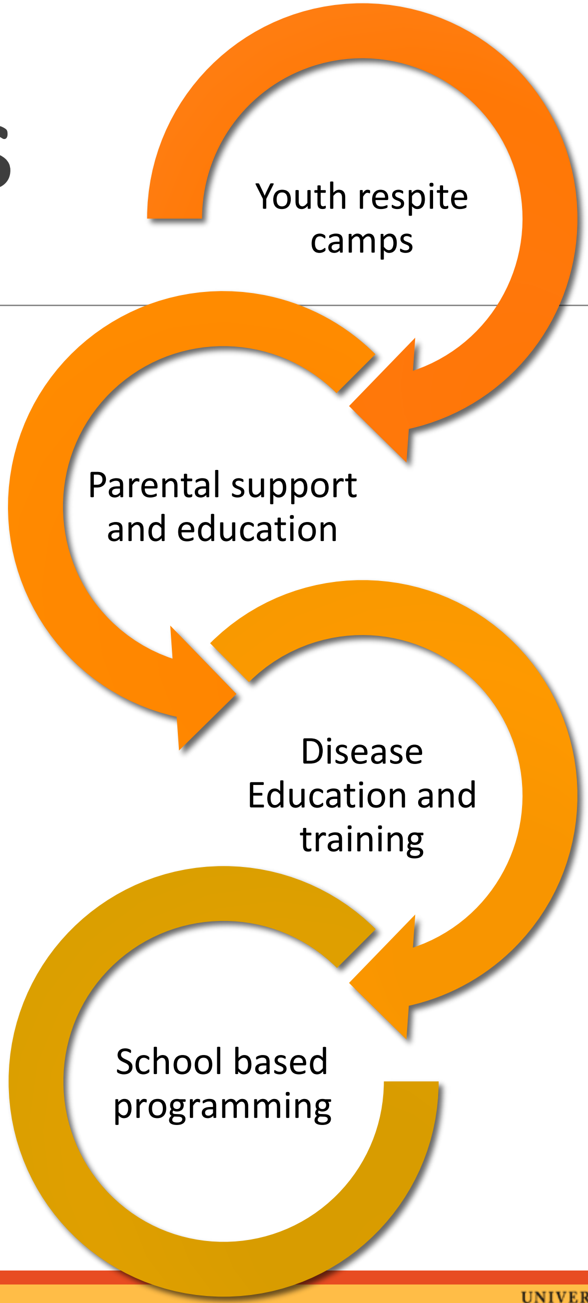
***Depression -** Mean = 7

Developing support interventions

In the absence of national programming -

Need for support for youth and adults across multiple settings

Practice-based interventions



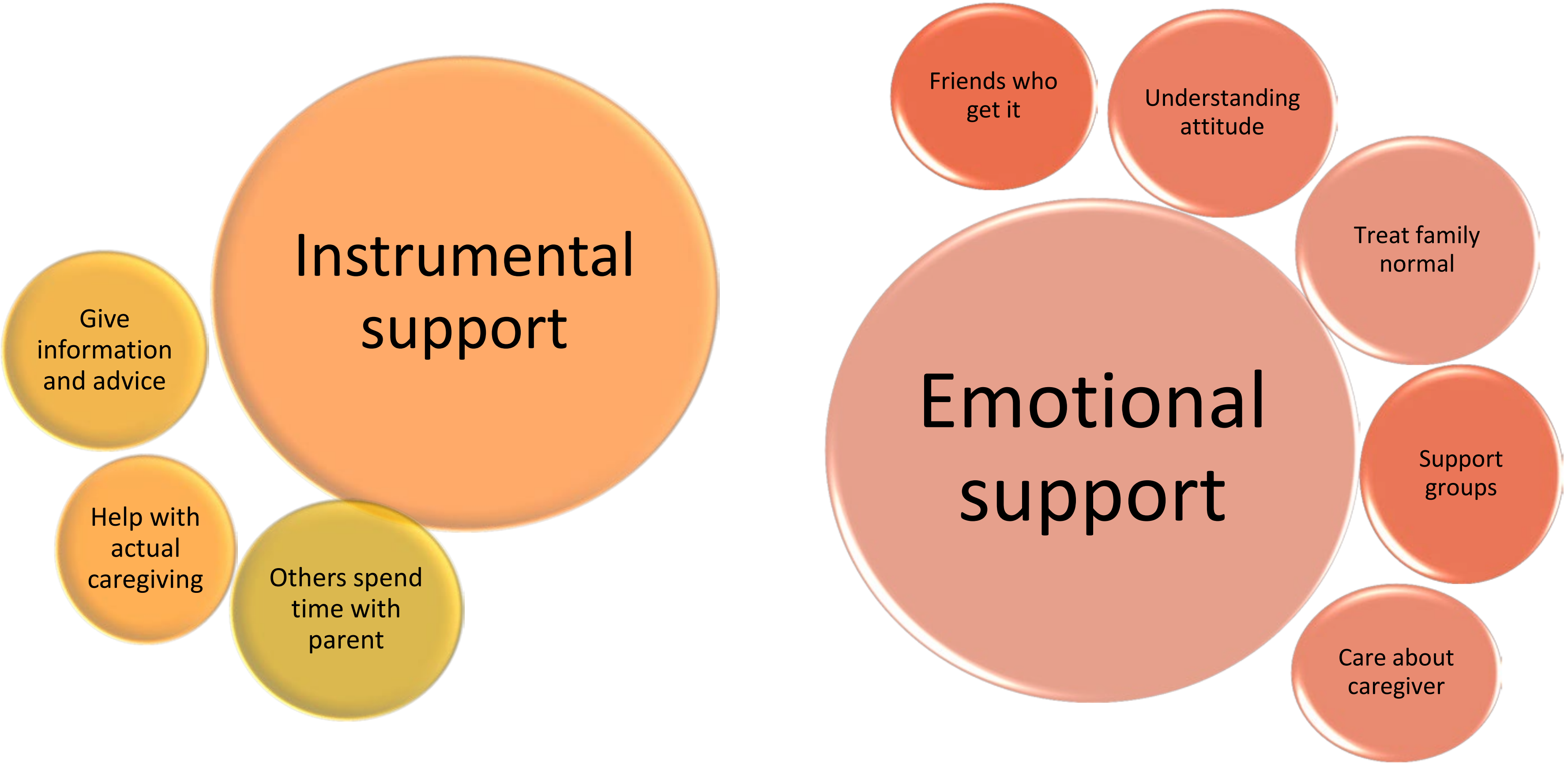
Youth respite camps

Parental support and education

Disease Education and training

School based programming

Caregiver Support needs (Kavanaugh, Noh and Studer, 2015)



Instrumental support

Give information and advice

Help with actual caregiving

Others spend time with parent

Emotional support

Friends who get it

Understanding attitude

Treat family normal

Support groups

Care about caregiver

Youth Respite camp (Kavanaugh et al 2017, under review)

HUNTINGTON'S DISEASE
YOUTH ORGANIZATION

- Mixed method survey administered at four time points (waves), 6 weeks prior to camp, first day of camp, last day of camp and 6 weeks after camp

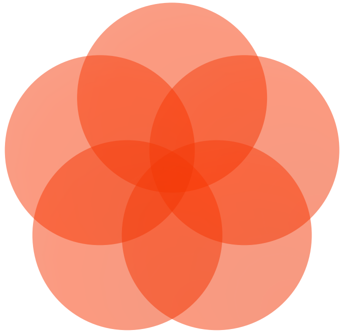
Age		**Gender**		**Race/Ethnicity**	
13-17	15 (43%)	Male	12 (34%)	White	31 (89%)
18-20	12 (34%)	Female	23 (66%)	Black/AA	2 (5%)
21-23	8 (23%)			Hispanic	2 (5%)

- Measures at each time point
  - Self esteem
  - Life satisfaction
  - Social support
  - Resilience

Identify as CG (N=32)

Camp outcomes (Kavanaugh et al, 2017)

Qualitative themes



Information about HD

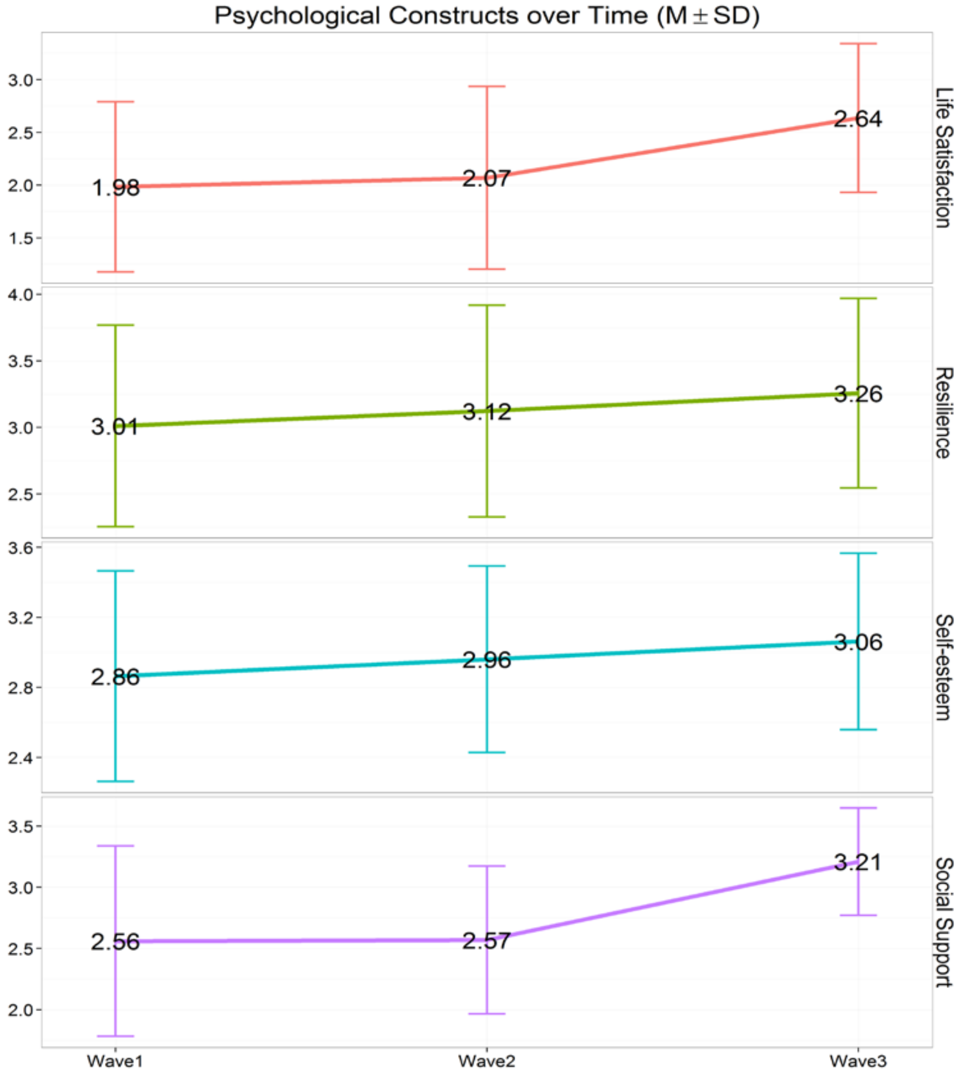
No longer alone

Have the skills to cope

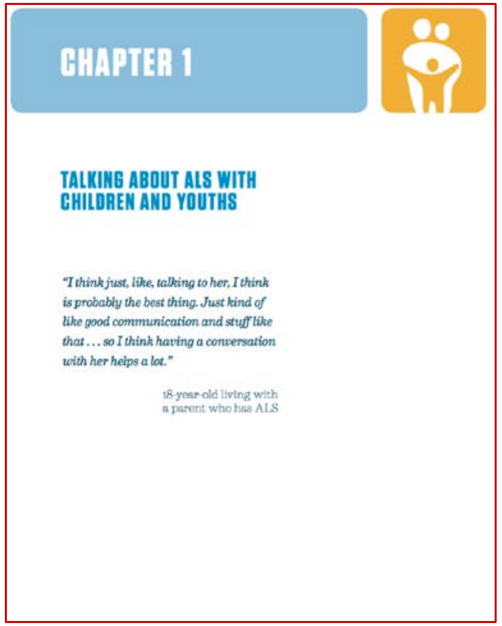
Becoming more positive

“I now know I am not the only one going through this and I know that I am not alone in this fight anymore”

(17-year-old female)



Parent support and education

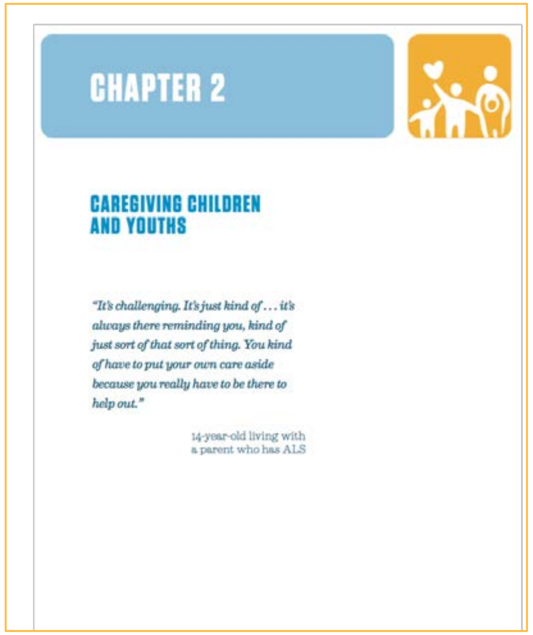


CHAPTER 1

TALKING ABOUT ALS WITH CHILDREN AND YOUTHS

"I think just, like, talking to her, I think is probably the best thing. Just kind of like good communication and stuff like that . . . so I think having a conversation with her helps a lot."

18-year-old living with
a parent who has ALS

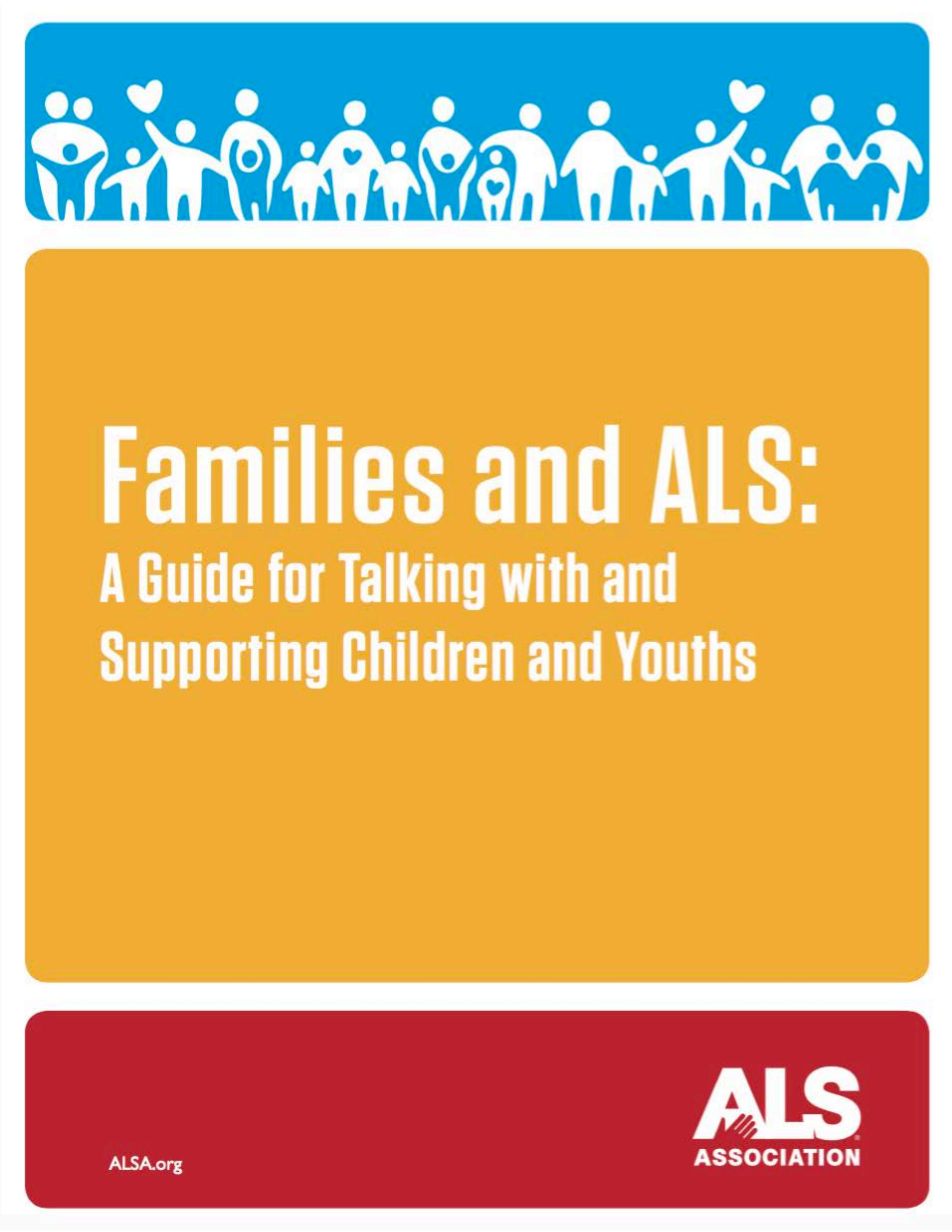


CHAPTER 2

CAREGIVING CHILDREN AND YOUTHS

"It's challenging. It's just kind of . . . it's always there reminding you, kind of just sort of that sort of thing. You kind of have to put your own care aside because you really have to be there to help out."

14-year-old living with
a parent who has ALS



Families and ALS:

A Guide for Talking with and Supporting Children and Youths

ALSA.org

ALS ASSOCIATION

School based support programs

Mission of AACY – to increase awareness and provide support services for youth caregivers and their families by connecting them with Healthcare, education and community resources.

Caregiving youth project

- **In school** - skills-building classes, support groups, and lunch and learn sessions
- **At Home** - linking families with resources, providing computers, tutoring and solutions for special needs
- **Out of School** - overnight camp, fishing, dining, educational and fun activities

Over 700 young caregivers served by the program

American Association of
Caregiving Youth

Thank you

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