Youth Caregiver Research

General Systems Fall 2019
Livanta
Project Team

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Agenda

- Youth Caregivers: *In their Shoes*
- Project Value Proposition
- Research Findings
  1. Education & Identifying Youth Caregivers
  2. Supporting Youth Caregivers
  3. Advocacy
- Recommendations & Next Steps
- Outstanding Questions
Youth Caregivers: *In their Shoes*
Stressful
Lonely
Overwhelming
Nobody Understands
Rewarding
Loving
Mature
Important
Youth Caregiving
Prevalence

Single parent, low income families
True number is unknown

1.4 mil*
Youth between 8 and 18 that have caregiving responsibilities

*This is known to be an underestimate

Source: 2005 study conducted by the National Alliance for Caregiving
Potential Negative Consequences on YCGs

- Decrease in school performance – **22% dropout rate**
- Inability to participate in after-school activities
- Physical injuries or fatigue from lifting a family member
- Behavioral problems
- Emotional strain like worry, guilt, isolation, and loss.
Project Scope & Value Proposition
Livanta & Youth Caregivers

- Livanta came across a group of youth caregivers at a symposium unexpectedly, which brought their attention to this hidden population.
- They grew interested in growing awareness and further researching the Youth Caregiver population.
- Livanta is eager to better understand the Youth Caregiver population, advocate for them, and impact policy surrounding Youth Caregivers.
Value Proposition

The Problem

There is very little research or understanding of caregiving youth today, leaving this population largely unidentified and unsupported.

Value Proposition

By identifying gaps in research and understanding as well as necessary support agencies and stakeholders, we can create advocacy to inform Livanta, CMS, and other key stakeholders who can take action to support youth caregivers.
Research Findings & Recommendations
Our Research Approach

Provide an informative analysis about what is currently known about Youth Caregiving and what gaps exist in current research and knowledge by diving into the following topic areas:

Personal Support for Youth Caregivers
Identifying where YCGs go to for support, current support systems in place, and where there are opportunities for support

Research
What gaps exist in current research? Potential new themes for research?

Policy Making
Assess policies that could be used as a model and what information would helpful to effectively advocate for YCGs

Engagement with the Health Care System
Which organizations and institutions are engaged with YCGs?

Community Building
Understanding current community programming and federal initiatives

Youth Caregivers (YCGs)
Research Findings

Findings & Recommendations

- Identification of YCG
- Advocacy & Policy Making
- Supporting YCG

Research Topic Areas

- Engagement with the Health Care System
- Personal Support for Youth Caregivers
- Community Building
- Research
- Policy Making

Additional Research

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Identifying Youth Caregivers

“Then I realized the level of responsibility...before that, I thought it was the norm”

Current State Assessment of Youth Caregiver Identification

Youth Caregiver Terminology
Multiple terms being used to describe YCG: young carer, child caregiver, young caregiver, caregiving youth

Common misconception
Common assumption is children require support, not adults – inhibits true understanding of caregivers

Hidden Population
Children under 17 need consent to participate in surveys, family fears judgment and embarrassment

Unknown Interactions
Hard to measure engagement between teachers, doctors, community members and YCGs

Partnerships among community organizations and schools could alleviate gaps by:
• Utilizing common language when referring to Youth Caregivers
• Identifying where in each community Youth Caregivers can be found
• Educating Stakeholders on who Youth Caregivers are and the right questions to ask
• Educating Youth Caregivers on what support currently exists
Supporting Youth Caregivers

Care Coordination

Limited Support
Learning health conditions, medications, insurance, and finances

Shifted Priorities
From school and friends to providing care to their loved one and ensuring bills are paid – takes a toll on the youth caregiver

Medication Management
Need to understand implications of incorrect medication management by Youth

Youth Social Support

Hospitals & Health Orgs
Leading the way in addressing implications of youth violence

Partnership Opportunities
Leveraging partnerships to share resources, networks, and advocacy

Youth Violence & Poverty
Utilizing shared resources that address overlapping needs

Adult Social Support

Current Caregiving Resources
Resources through AARP that are targeting adult caregivers

Whole Family Approach
Disease Management orgs, such as MS Society, look for young carers while providing support to adults

Increasing Awareness
Educating organizations that provide caregiving resources on the prevalence of youth caregivers
AACY’s Vision
Every youth caring for chronically ill, injured, elderly or disabled family members will achieve success in school and life.

Educational Support
- Provides laptops, tutors, college prep, overnight camps, etc.

Professional Growth
- Skill building classes, lunch and learns

Social Work
- At Home visits, access to resources

Best Practices From Dr. Siskowski
- Storytelling is key – best way to spread awareness of youth caregiving and provide support for YCGs
- Funding is always best: money goes to providing services, little left for resources and administrative support
- Creating formal agreements with schools to help identify Youth Caregivers
Connect youth caregivers to support resources that build a community and provide respite from caring duties.

Connect

Increasing awareness and understanding of youth caregiving through grass-roots marketing

Partnering with community organizations that engage with youth and caregivers including hospitals, schools, community organizations, disease support groups.

“I think it’s just a whole experience of being around people who understand and aren’t judgmental.”

“You can act your age; you don’t have to be a grownup.”
Scaling Support through Policy

Legislation targeting youth caregivers needs to address both of these areas:

1. **Identify Caregivers**
   A holistic approach should include local authorities working together to identify youth caregivers and connect them with resources for support.

2. **Support Caregivers**
   Create a framework for establishing and funding agencies dedicated to supporting youth caregivers.

**The UK: Setting a Global Example**

The United Kingdom is a leading example of addressing and supporting youth caregivers through legislation:

- Care Act of 2014
- Children and Families Act of 2014

However, gaps remain in their processes and dedicated YCG support organizations still lack proper funding.
Recommendations
Research Opportunities

Strides have been made to understand Youth Caregivers, though many gaps exists in understanding youth caregivers

**Identification**

- The last study on Youth Caregivers in the US was 15 years ago in 2005
- What is the best way to locate current Youth Caregivers?
- What is the best way to educate communities and stakeholders on Youth Caregivers?
- Are there child caregivers under the age of eight? Current studies focus on the age group between eight and 18.

**Support**

- What current support services exist for Youth Caregivers? How are these currently communicated to this populated? How can this existing support be expanded to reach more Youth Caregivers?
- What, if any, are the adverse effects of medication administration by child caregivers?
- Are any healthcare stakeholders (like pediatricians) able to provide insight into the Youth Caregiving experience?

**Advocacy**

Through better identification and support of Youth Caregivers, stakeholders will be able to effectively advocate for and create policies in support of youth caregivers.
**Recommendations**

1. **Identify** youth caregivers across the system
   - Identify most common conditions that result in a child in a caring role & target these for high impact
   - Educate Stakeholders on the right questions to ask and equip with the right resources
   - Utilize common language when referring to Youth Caregivers

2. **Support** youth caregivers through dedicated programs
   - Model support after the AACY or UK programs that are dedicated to YCGs
   - Relieve burden of care by identifying proper support for the adult
   - Existing orgs should actively acknowledge YCGs and provider resources

3. **Advocate** for youth caregivers through policy
   - Comprehensive approach for identification & support of YCGs
   - Framework for establishing & funding new orgs, or expansion of existing
   - Measure the impact and re-assess the needs of youth caregivers, and continue to learn from the UK as an example

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"It’s life changing…I don’t know what my life would be without them"
It was a pleasure to work with you.

Livanta
Ellen Evans, MD
Jack Militello

American Association of Caregiving Youth
Connie Siskowski

General Systems Team
Michael Hamilton
Nicholas Eagon
GS Faculty and Coordinators
Research Recommendations

**Identifying Youth Caregivers: Recommendations**

- Utilize common language when referring to Youth Caregivers. The most common terms in literature today are young caregiver and caregiving youth. In the United Kingdom, the single most common term is “Young Carer”.
- Identify where youth caregivers can be found in each community.
- Educate stakeholders on who youth caregivers are and the right questions to ask a child when they believe they might be taking responsibilities as a caregiver.
- Educate youth caregivers on what support currently exists.
- Partner with academic institutions (particularly anthropology departments) that are doing research, or may be willing to do research on youth caregivers. Start with the Universities that have partnered with the AACY.

**Supporting Youth Caregivers: Recommendations**

- Conduct additional research to understand how organizations that address youth violence (and other difficult experiences) provide support to young people.
- Partner with organizations that currently serve youth in some capacity and increase their awareness and understanding of youth caregiving.
- Leverage resources from current organizations that can also be used to support youth caregivers.
- Existing national caregiver programs should expand support to include youth caregivers.
- Investigate what steps and measures the MS society took to integrate acknowledgement and support for youth caregivers into their model. Share this information with other.
- Identify 1) What are the most common conditions affecting the people who youth caregivers are caring for and 2) What organizations exist to support people with those conditions. Start by focusing on partnership with those organizations for the highest impact.
- Adult social support programs that support the cared-for patient should be educated on youth caregivers. They may also be leveraged to expand their support to youth caregivers by taking a whole-family approach.

**Advocating for Youth Caregivers: Recommendations**

- To better advocate for and inform policy needs, there is a need for additional research on youth caregivers, particularly around demographics.
- Legislation should clearly identify what agencies should have responsibility for not only making reasonable effort to identify young caregivers through assessments, but to also connect them with available resources that can provide support.
- It should also include a framework for establishing and funding organizations dedicated to providing support for youth caregivers, or funding the expanding existing organizations to include youth caregivers.
- There should be continued assessment of legislation to understand efficacy, and identify opportunities for continued improvement to policy.
References: Youth Caregiver Stories

Quotes throughout this presentation were gathered from actual youth caregivers who shared their stories in the resources below.

Help for Young Carers

Barnardo's | Young Carers | #LifeStory - Caitlin
https://www.youtube.com/watch?v=wxyL8_VRY-E

Barnardo's | Young Carers | #LifeStory - Laura
https://www.youtube.com/watch?v=VGOpUC9O77o

What it's like to take care of multiple family members at age 15
References

Alexander, Chloë, and Bennett, Laura. “Know Your Rights: Support for Young Carers and Young Adult Carers in England.” Carers Trust, 2015.


Hunt, Gail, et al. Young Caregivers in the US. National Alliance of Caregiving, 2005, pp. 1–66, Young Caregivers in the US.


“Know Your Rights: Support for Young Carers and Young Adult Carers In.” Carers Trust, 2015, carers.org/know-your-rights-support-young-carers-and-young-adult-carers-england.


“NAC.” National Alliance for Caregiving, www.caregiving.org/resources/.


