



# System Navigation Committee

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FAMILY CAREGIVER SURVEY – PRELIMINARY ANALYSIS

# Purpose of System Navigation Workgroup

The goal of the System Navigation Workgroup is to collect feedback from diverse groups of families, caregivers and professionals to identify gaps in resources and service provision in order to improve access and navigation to essential supports, information and resources.

# Initial Strategy of the System Navigation Workgroup

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Improve access and navigation to essential supports, information and resources for family caregivers, self-directed consumers, and professionals.

We broke it down into 3 key steps.

1. Survey professionals throughout the state who provide support and information to family caregivers and self-directed persons with disabilities.
2. Survey family caregivers and self-directed consumers throughout the state who are seeking supports and information based on their individual needs.
3. Compare and contrast results of both surveys to identify where things are working well, identify gaps, and make recommendations for improvement.

# Strategy: Step 1

- In 2018 the System Navigation Workgroup conducted a statewide survey to collect specific information from professionals who support individuals with disabilities and their families.
- We had 216 respondents.
- We presented on the results of this survey at the WFACSA Caregiver Summit in 2018. (you can download the survey results by going to our website at <http://wisconsin caregiver.org/system-navigation-and-access-workgroup>)



# Strategy: Step 2

- In 2019 the System Navigation Workgroup conducted a statewide survey to collect specific information from family caregivers and self-directed persons with disabilities.
- We had over 500 respondents.
- Today we present to you the results of this survey.



# Survey Overview

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# Demographics – who took the survey?

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Mostly white, non-Hispanic women

- 91% female
- 89% white (non-Hispanic)

Caring for:

- Son/daughter (41%)
- Parent/in-law (28%)
- Spouse/partner (16%)

With:

- I/DD (46% total; 86% for younger, 20% for older)
- Physical disability (33%)
- Alzheimer's/dementia (20%)

Caregivers spanned the life course

Caregiver age

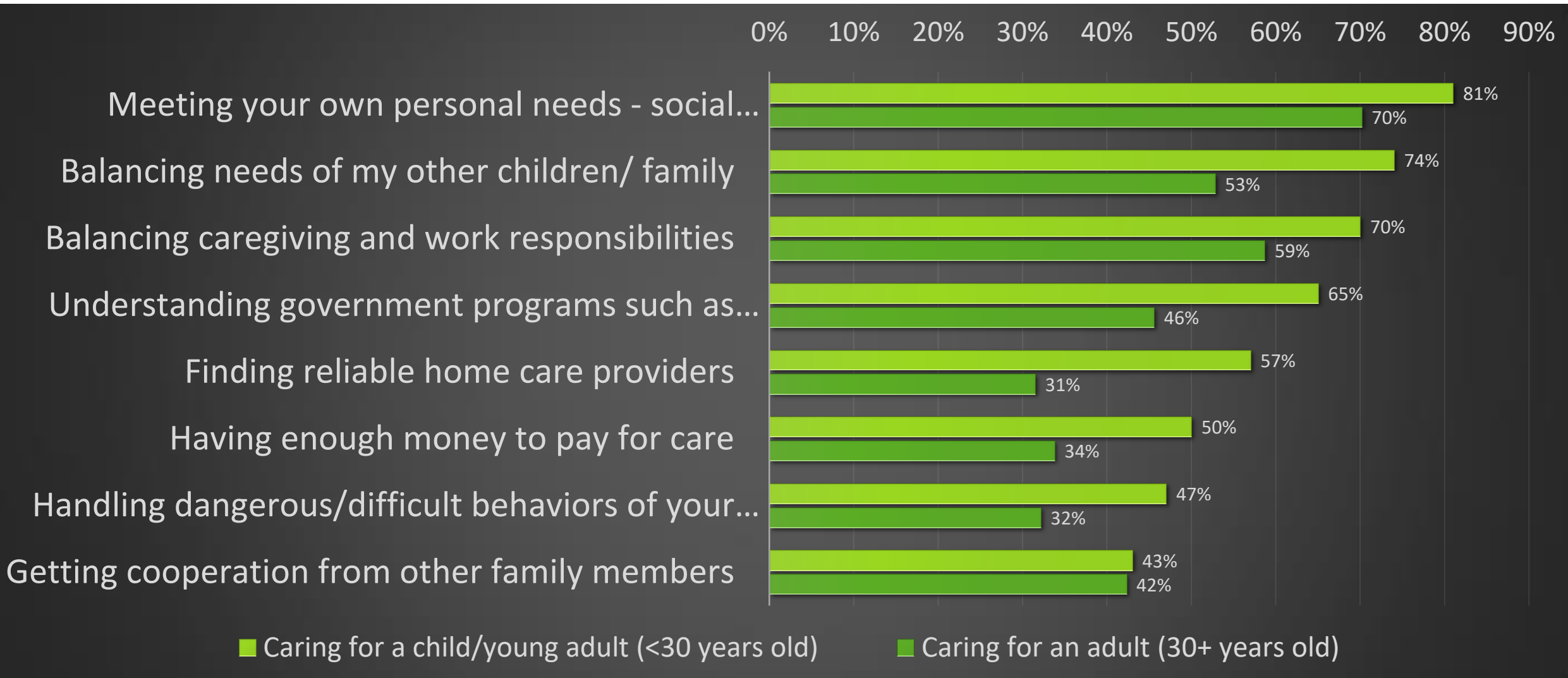
Caring for a child/  
young adult



Caring for an  
adult/older adult



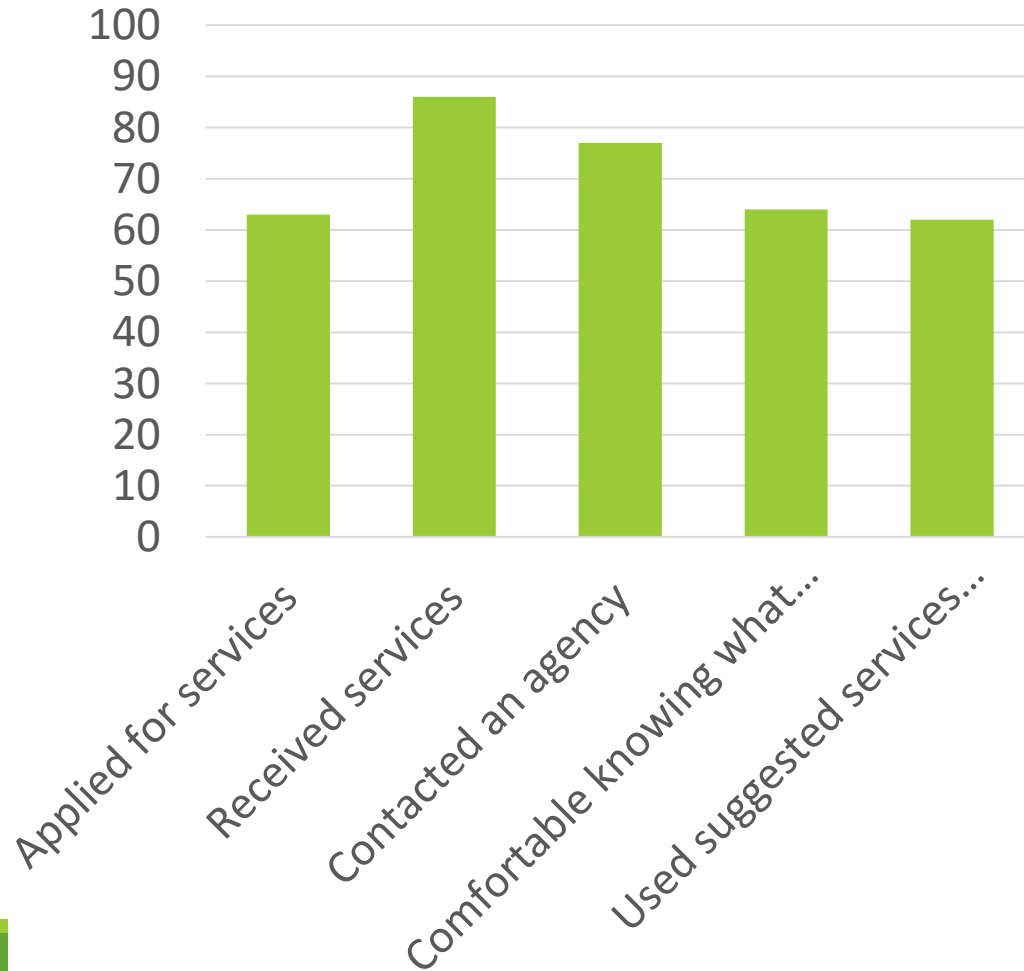
# Caregiving Difficulties



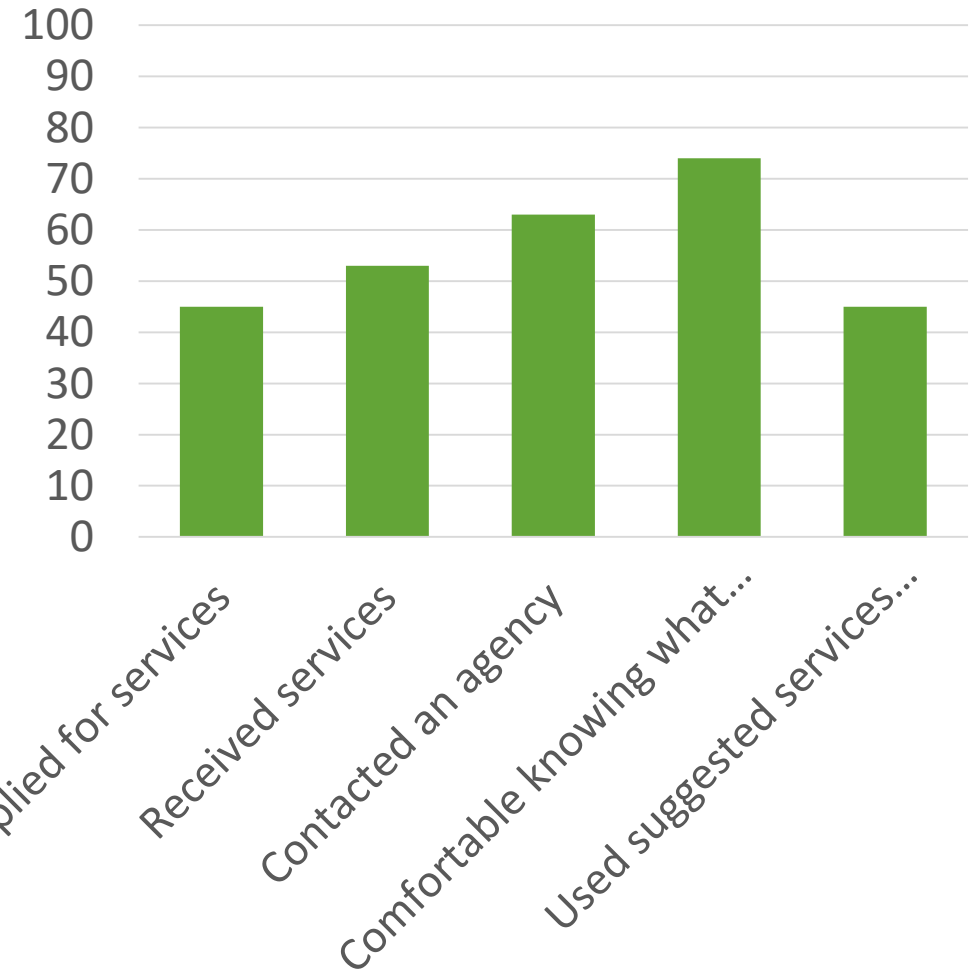


# Service Use

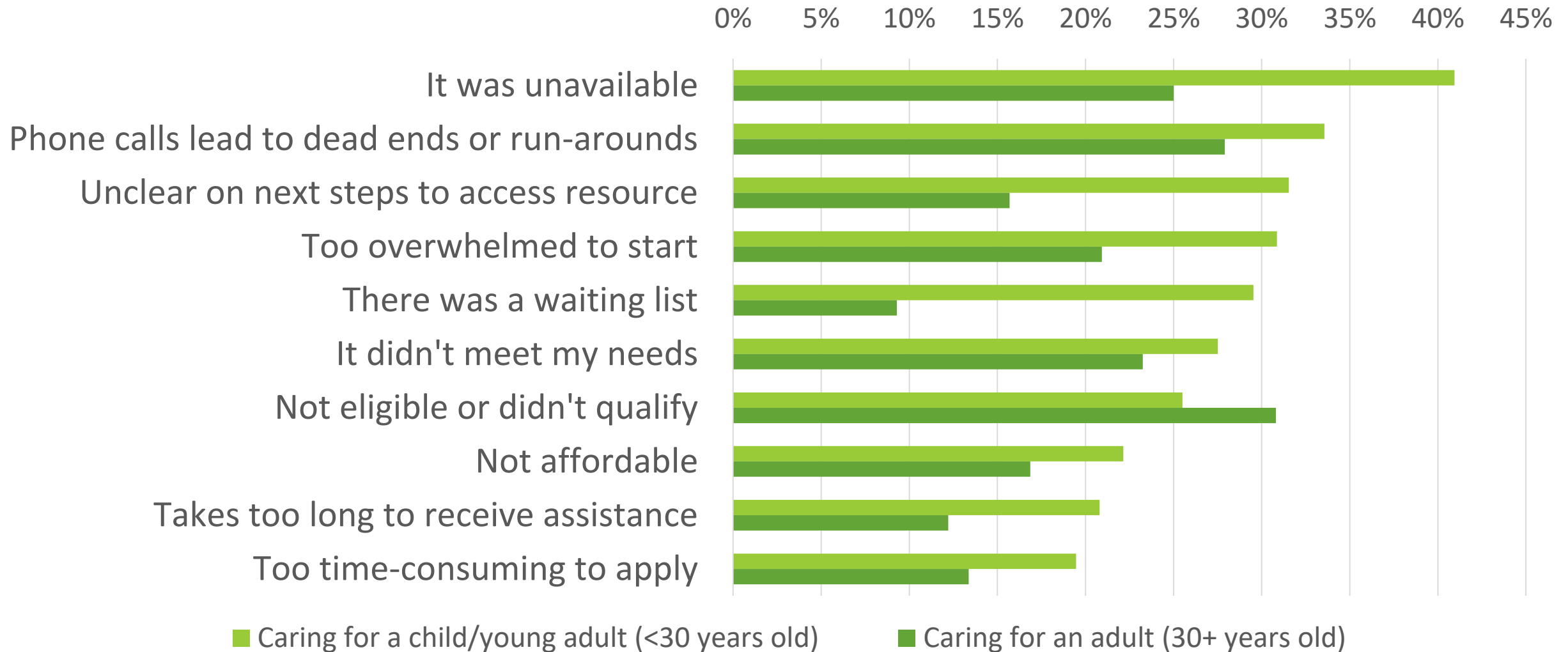
Caring for a child/young adult (<30 years old)



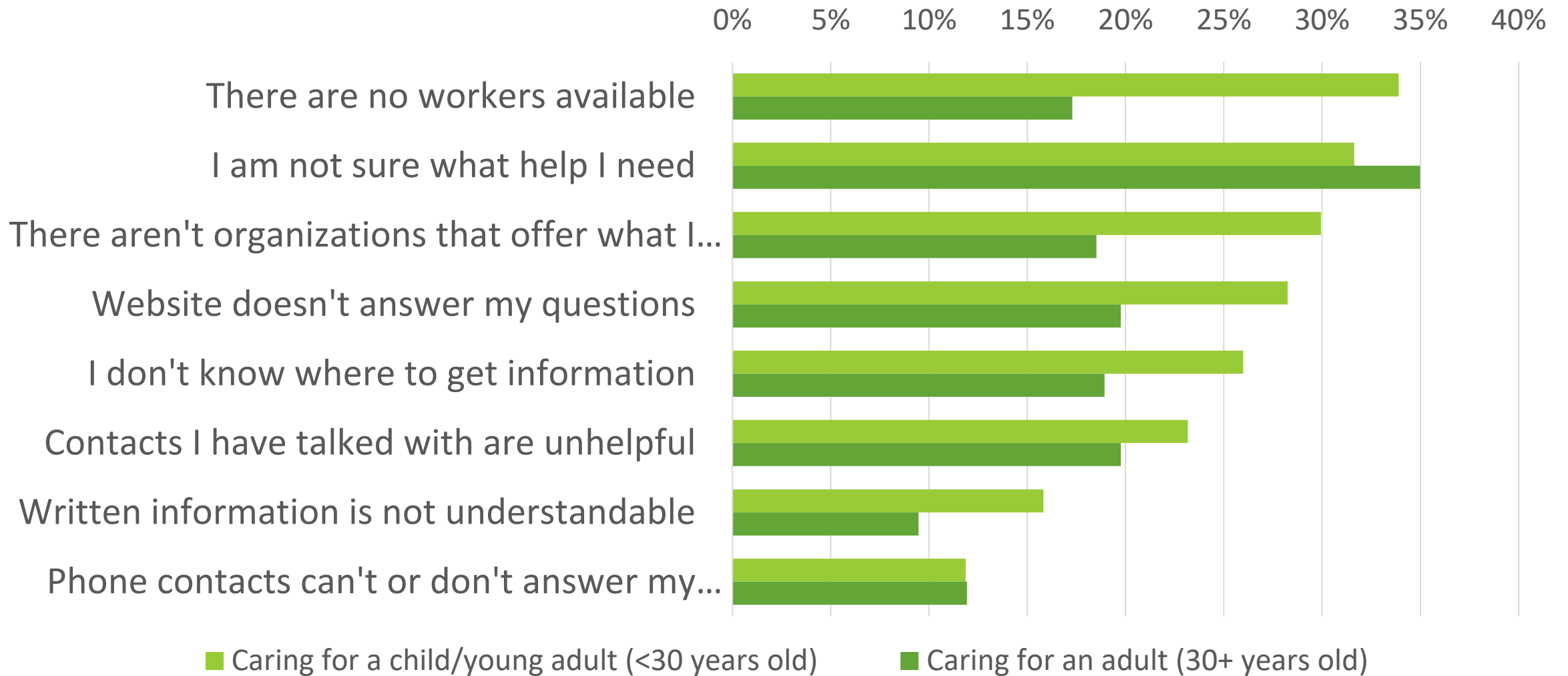
Caring for an adult (30+ years old)



# Reasons for not using services



# Challenges finding help



# Respite Care Use

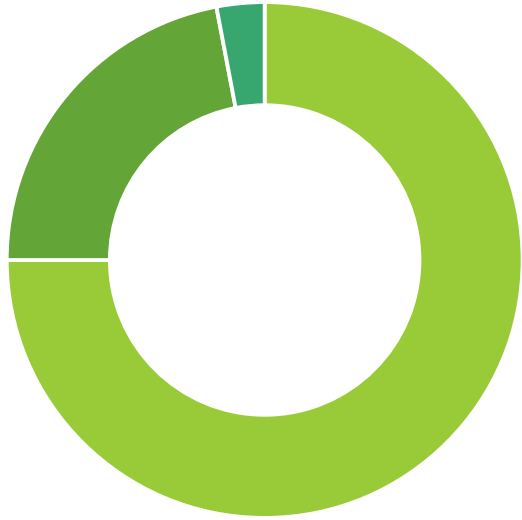
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Caring for a child/young adult (<30 years old)



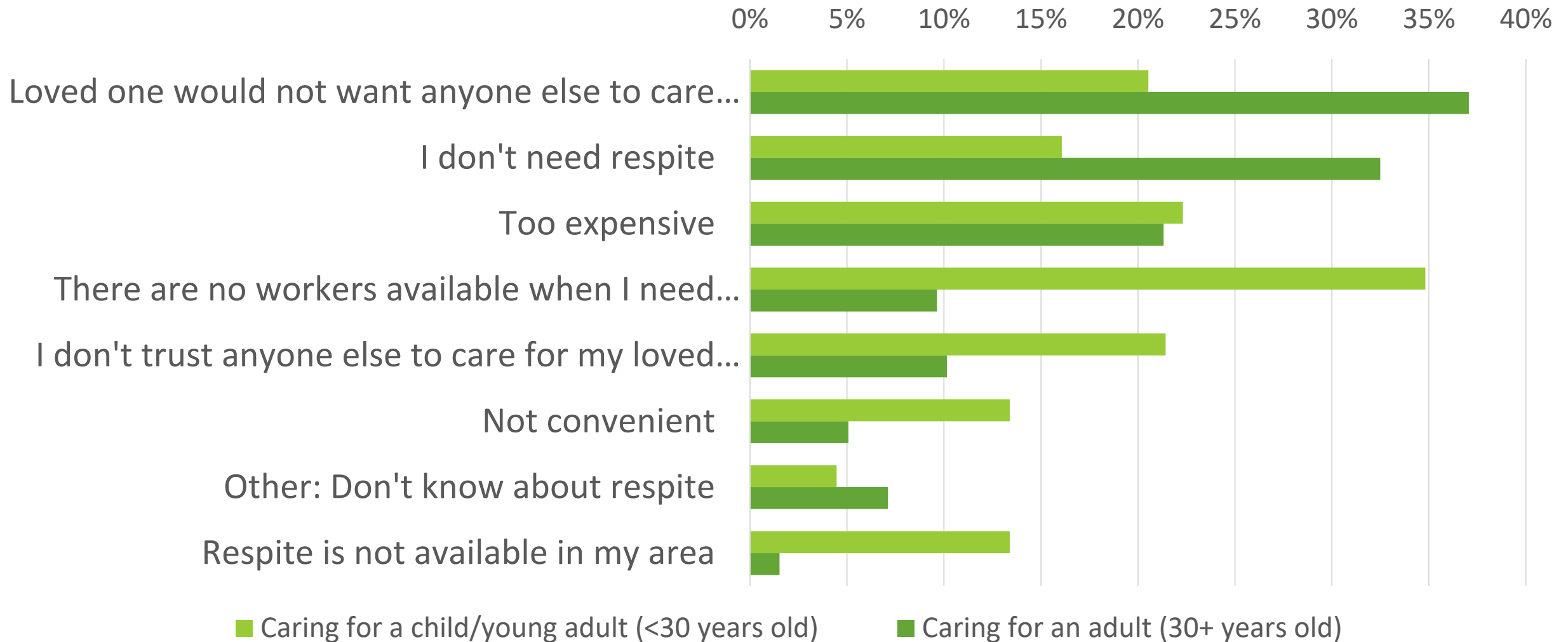
■ No ■ Yes ■ Unsure

Caring for an adult (30+ years old)

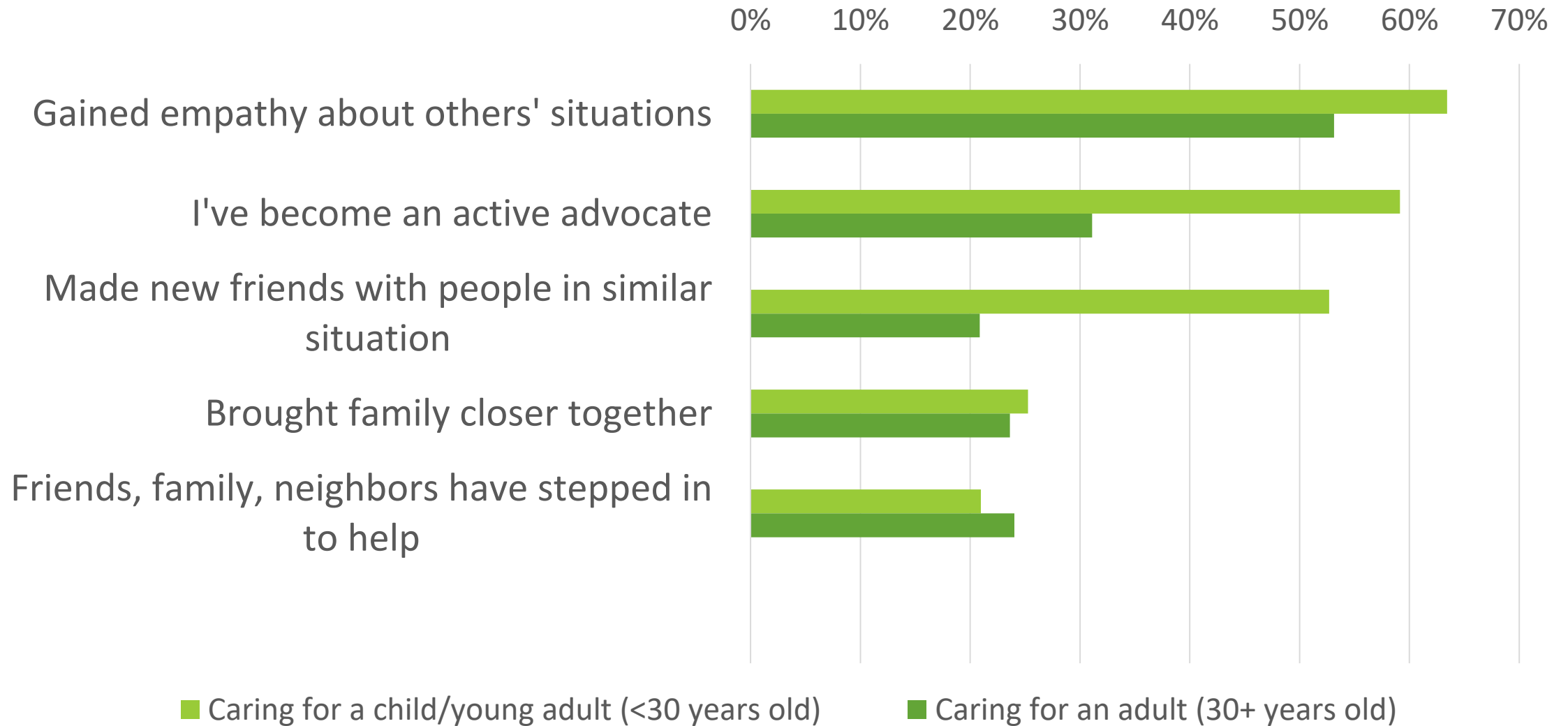


■ No ■ Yes ■ Unsure

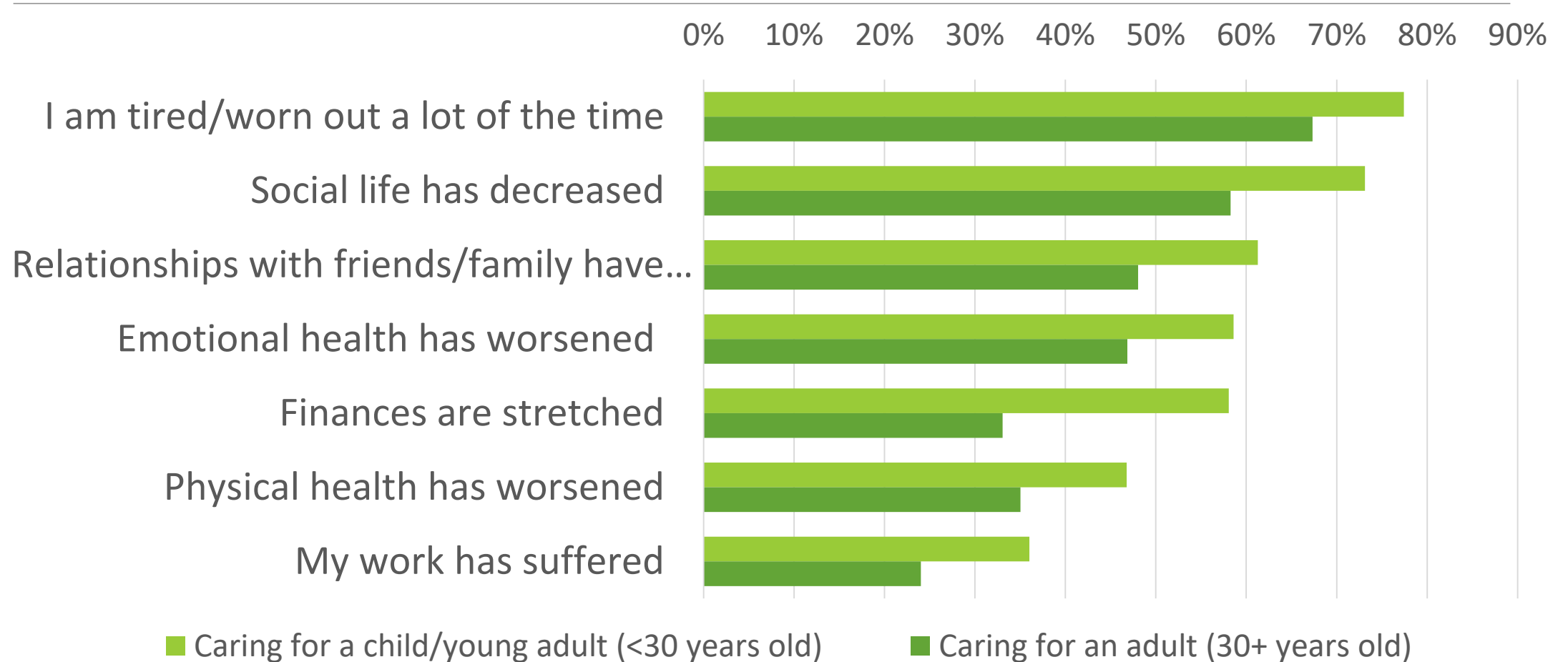
# Reasons for not using respite care



# Impacts of caregiving: Positive



# Impacts of caregiving: Negative



# Comparison with provider survey

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## DO CAREGIVERS FOLLOW-UP ON RESOURCES?

Caregivers:

- Sometimes: 39%
- Frequently/always: 54%

Providers:

- Sometimes: 38%
- Frequently or always: 43%
- **Unsure: 19%**

## ...ASK ABOUT SERVICES THAT AREN'T AVAILABLE?

Caregivers:

- Sometimes or more: 78%

Providers:

- Sometimes or more: 71%

*Quantifies a known issues that is likely frustrating for both caregivers and providers*



# Comparison continued (2)

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## GOOD MATCH BETWEEN INFORMATION AND RESOURCES?

### Providers:

- Sometimes: 35%
- Most of the time/always: 63%

### Caregivers:

- 3 in 4 report that agencies don't have a service they asked about
- When asked why they didn't follow-through on a recommended service, 25% said it didn't meet their needs

*Providers may need more information about the instances where not a fit*

## WHEN CAREGIVERS DON'T FOLLOW-THROUGH, WHY?

### Caregivers:

- Resource unavailable (32% vs 16% in the provider survey)
- Difficulty navigating the system
- Not eligible/didn't qualify

### Providers:

- Overwhelmed
- Financial constraints
- **Don't know (31%)**

# Comparison continued (3)

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## COORDINATION OF SERVICES

### Providers:

- 61% feel knowledgeable or very knowledgeable about other resources available in the community

### Caregivers:

- Report that they aren't always being referred to other services (21% said "never" referred)
- Some caregivers specifically noted lack of coordination and centralization as a key challenge and source of frustration

## BIGGEST CHALLENGES?

### Providers:

- Don't ask for help
- Don't know they need help
- Not aware of where to access information
- No service or funding available

### Caregivers:

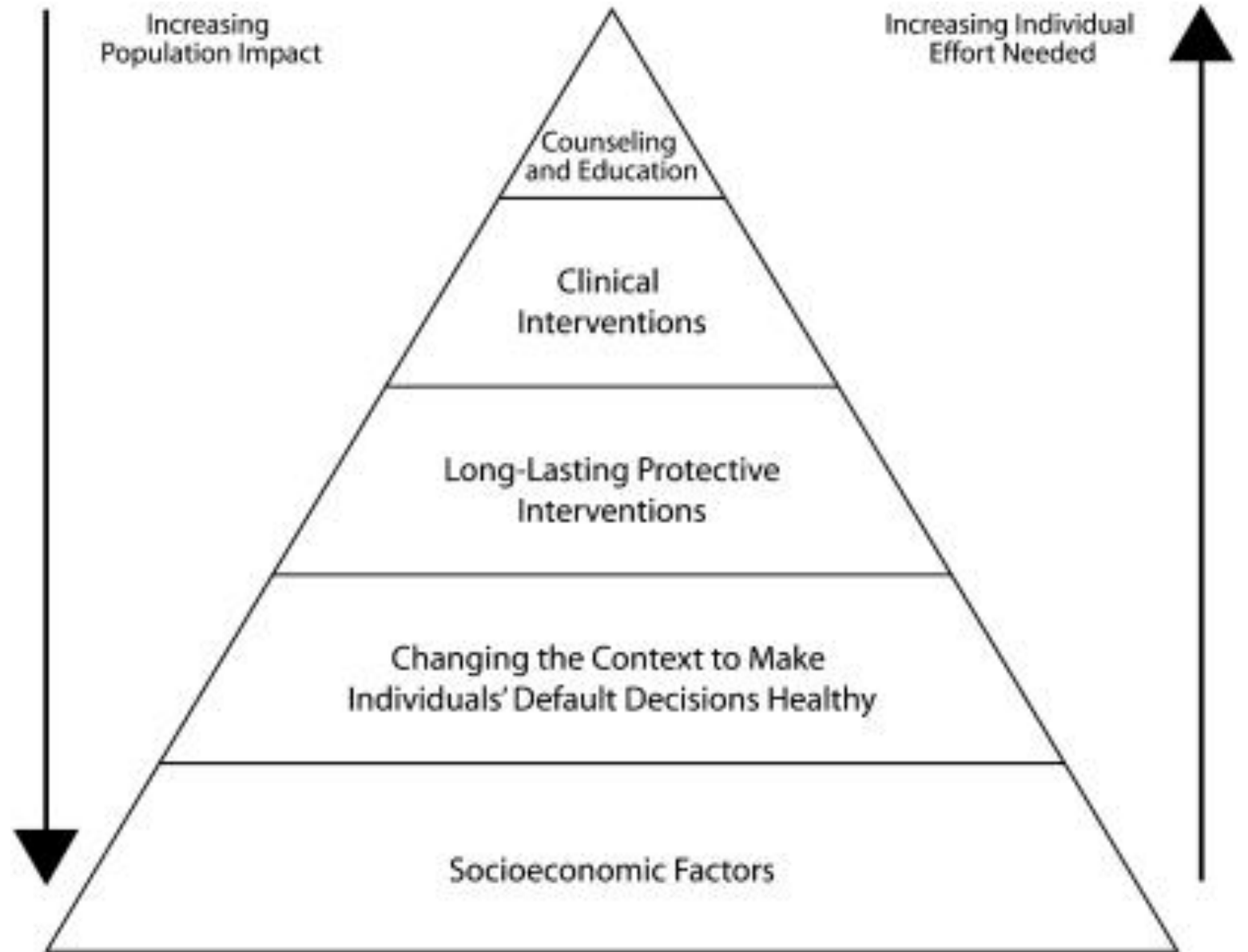
- Unsure what help they need/Don't know where to get information
- No workers available
- Organizations don't offer what they need
- Don't have good information/contacts aren't helpful

# What Works?

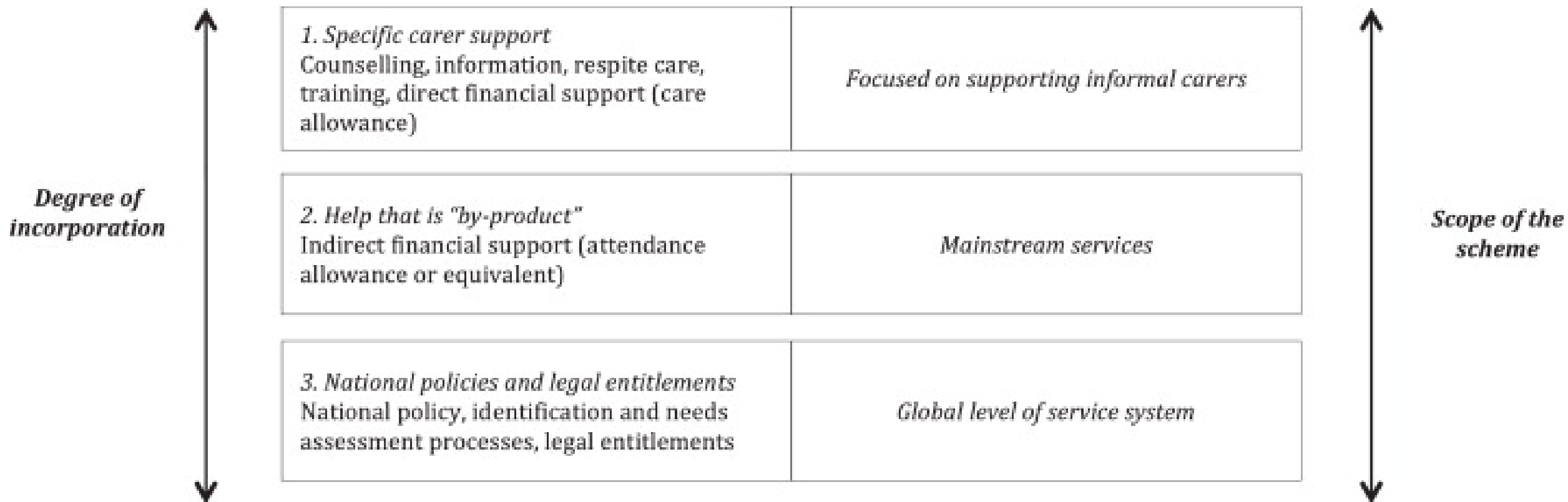
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# Health Impact Pyramid

Frieden, Thomas R. "A framework for public health action: the health impact pyramid." *American journal of public health* 100.4 (2010): 590-595.



# Levels of caregiver support



# How does the US match up?

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Financial support: direct or indirect payments	Some – depends on state and employment history
Bereavement leave	Some – depends on state
Employment protections	Yes – FMLA
Pension/tax credits (e.g., Belgium)	No
Help with out-of-pocket costs (e.g., home modifications, travel)	Some – if quality for NFCSP
Help with other OOP costs (e.g., energy, housing, food)	No
Costs related to patient's healthcare	Yes – if Medicaid/Medicare Hospice Benefit

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# “Voltage drops” to receipt of supports

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Potential to  
receive needed  
services

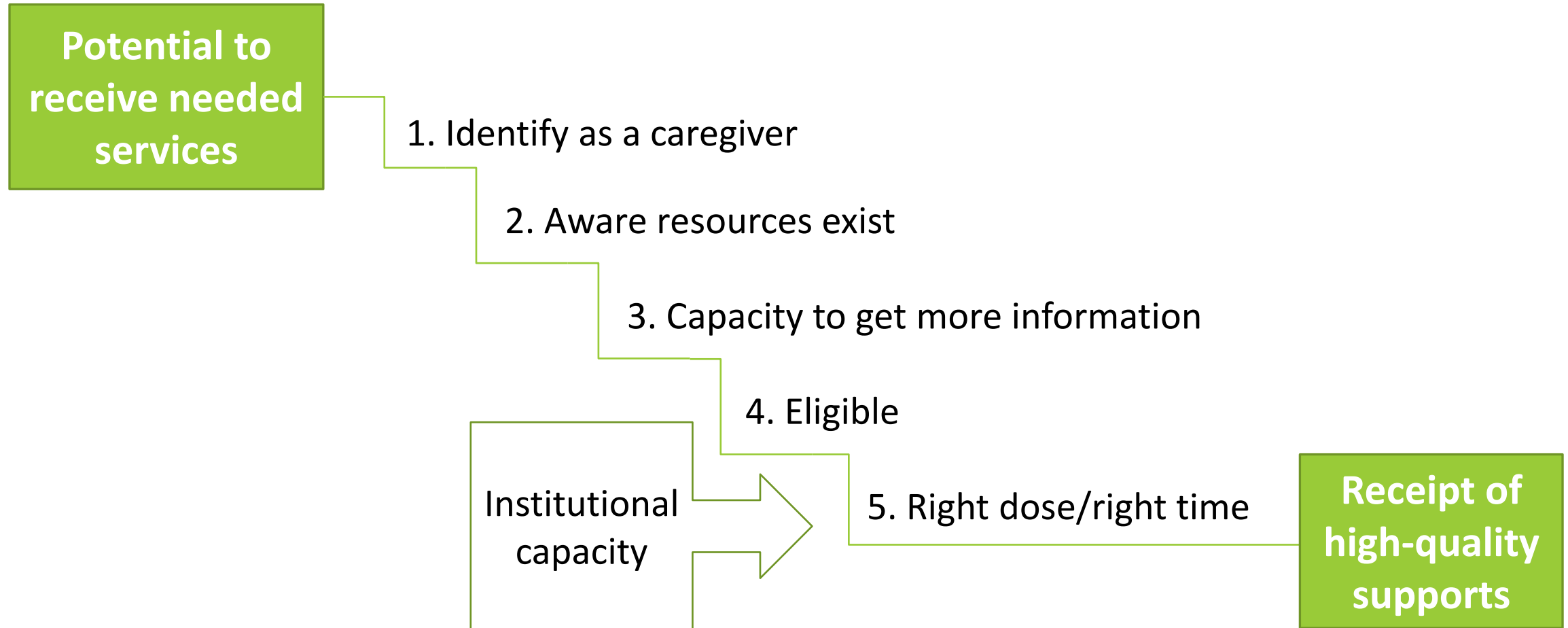


Availability of:

- Financial supports
- Psychosocial/emotional supports
- Logistical supports/training

Receipt of  
high-quality  
supports

# “Voltage drops” to receipt of supports





# Innovation in other states

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Hawaii	Kupuna Caregivers Program: Financial support for working caregivers (up to \$70/day for, e.g, adult day care, chores and meal services, transportation)
Maine	Prioritizes access assistance (i.e., helping people get information about resources available to them) and meal services
Minnesota	Campaign to increase awareness of family caregiving; Incubate caregiver programs via grants
Tennessee	Mandates standardized family caregiver assessment
Washington	Paid leave for family caregiving

# Lessons for policy-makers

From: Afill, Jennifer, Julia Burgdorf, and Jennifer Wolff. "In Support of Family Caregivers: A Snapshot of Five States." (2019).



**Take time to test new approaches; there is value in sustained incrementalism.**

Innovations in services such as transportation, educational webinars, or help at work require flexible funding and iterative development, refinement, and pilot testing.



**Assess caregivers' experience.**

Services should be tailored to the individual.



**Increase awareness and visibility of caregivers.**

Caregivers may not identify themselves as people who need services.



**Harness the potential of the aging network.**

Composed of state and local agencies, the network provides services and supports to older adults.



**Support cross-sector integration at the local level, while recognizing challenges.**

It is important to integrate financing, information systems, and service delivery to coordinate across health plans and service providers.

# Reading List

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Aufill, Jennifer, Julia Burgdorf, and Jennifer Wolff. "In Support of Family Caregivers: A Snapshot of Five States." (2019).

National Academies of Sciences, Engineering, and Medicine. 2016. Recommendations to Support Family Caregivers of Older Adults. In *Families caring for an aging America*. Washington, DC: The National Academies Press.

Meyer, K., Kaiser, N., Benton, D., Fitzpatrick, S. Gassoumis, Z., Wilber, K., & the California Task Force on Family Caregiving (2018, July). Picking Up the Pace of Change for California's Family Caregivers: A Report from the California Task Force on Family Caregiving. Los Angeles, CA: USC Leonard Davis School of Gerontology

Gardiner, Clare, et al. "Comparison of financial support for family caregivers of people at the end of life across six countries: A descriptive study." *Palliative medicine* 33.9 (2019): 1189-1211.

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# Questions?

# A big THANK YOU to the System Navigation Workgroup Members

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Lisa  
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Kristin  
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