

System Navigation Committee

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



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 <u>http://wisconsincaregiver.org/system-navigation-and-</u> <u>access-workgroup</u>)



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

Demographics – who took the survey?

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

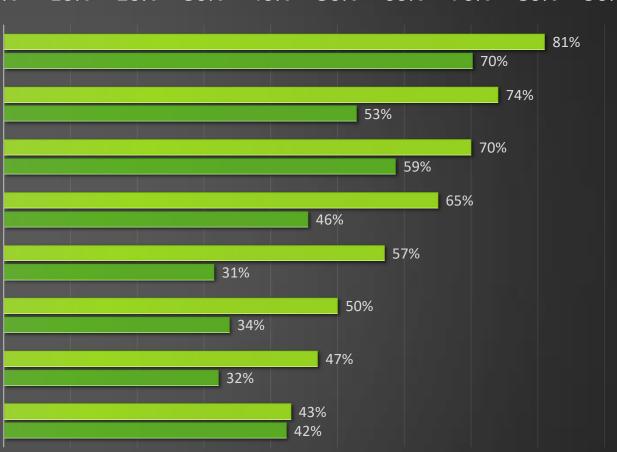
Caring for a child/ young adult Caring for an adult/older adult



Caregiving Difficulties

Meeting your own personal needs - social... Balancing needs of my other children/ family Balancing caregiving and work responsibilities Understanding government programs such as... Finding reliable home care providers Having enough money to pay for care Handling dangerous/difficult behaviors of your... Getting cooperation from other family members

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



30%

0%

10%

20%

40%

50%

60%

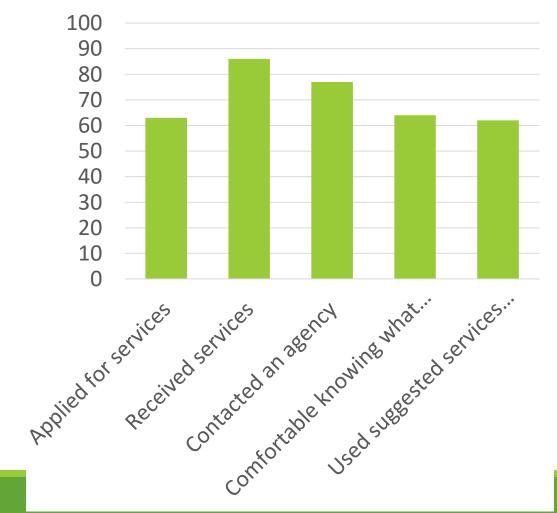
70%

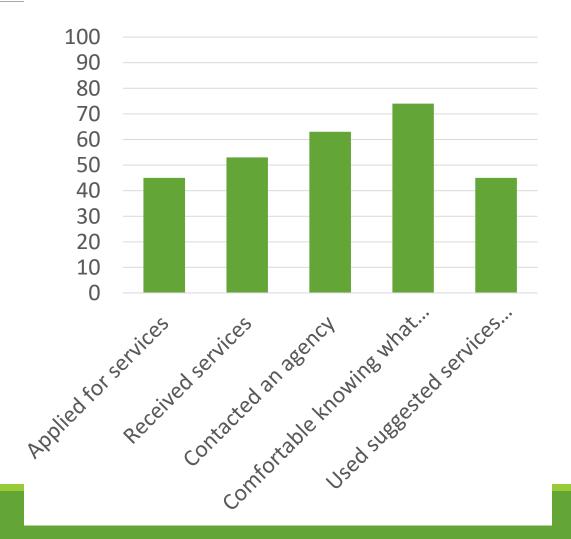
80%

90%

Service Use

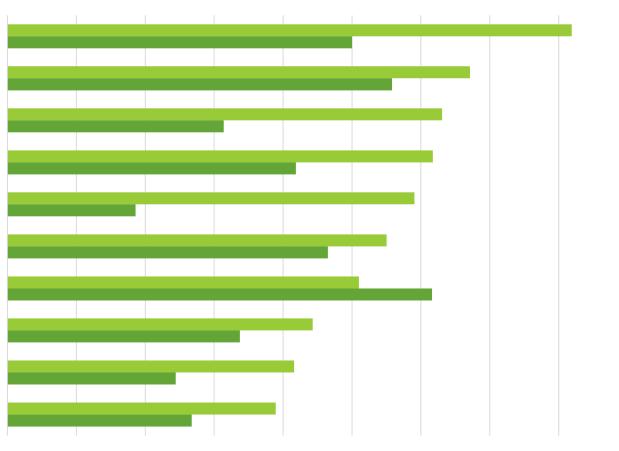
Caring for a child/young adult (<30 years old)





Reasons for not using services

0% 5% 10% 15% 20% 25% 30% 35% 40% 45%



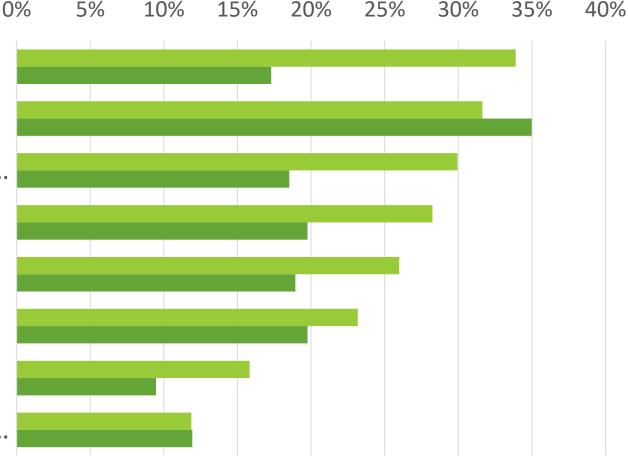
lt was unavailable

Phone calls lead to dead ends or run-arounds Unclear on next steps to access resource Too overwhelmed to start There was a waiting list It didn't meet my needs Not eligible or didn't qualify Not affordable Takes too long to receive assistance Too time-consuming to apply

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

Challenges finding help

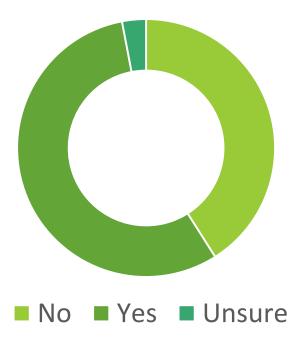
There are no workers available I am not sure what help I need There aren't organizations that offer what I... Website doesn't answer my questions I don't know where to get information Contacts I have talked with are unhelpful Written information is not understandable Phone contacts can't or don't answer my...

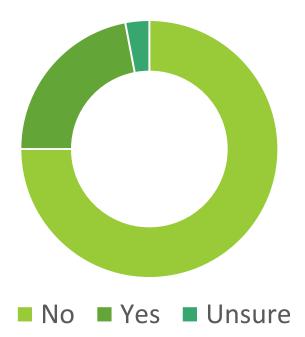


Caring for a child/young adult (<30 years old)</p>

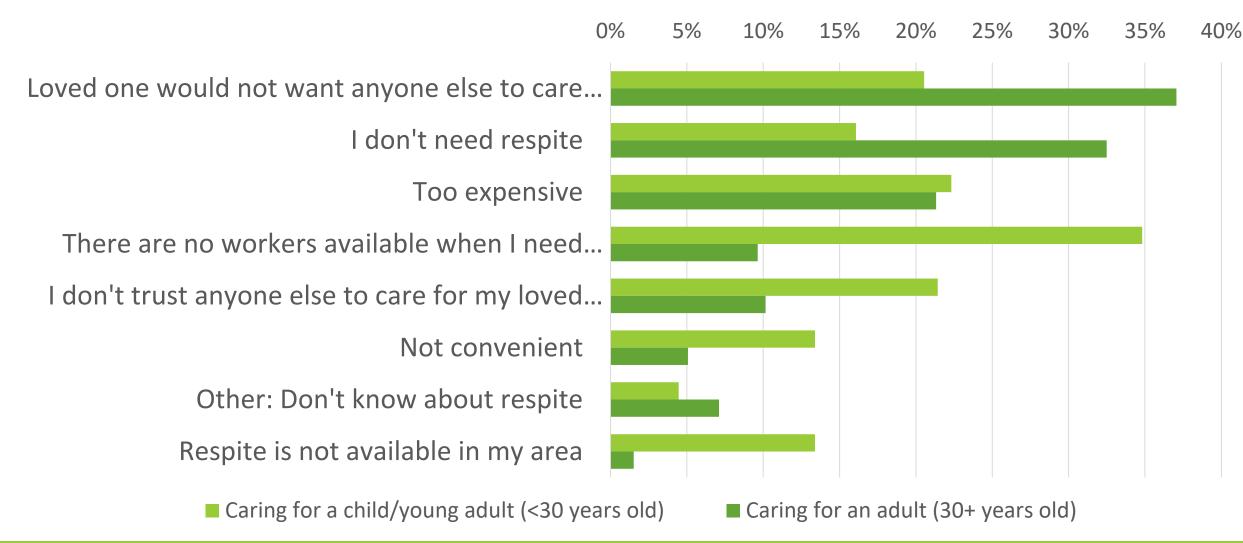
Respite Care Use

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





Reasons for not using respite care



Impacts of caregiving: Positive

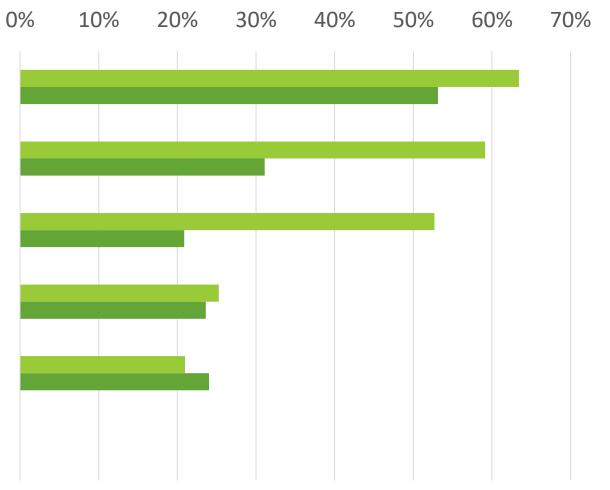
Gained empathy about others' situations

I've become an active advocate

Made new friends with people in similar situation

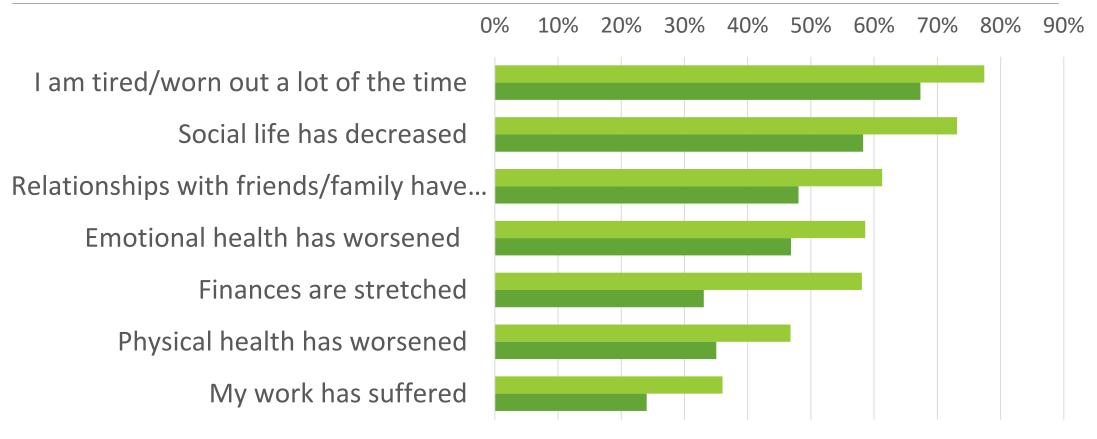
Brought family closer together

Friends, family, neighbors have stepped in to help



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

Impacts of caregiving: Negative



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

Comparison with provider survey

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)

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 followthrough 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-THOUGH, 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)

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

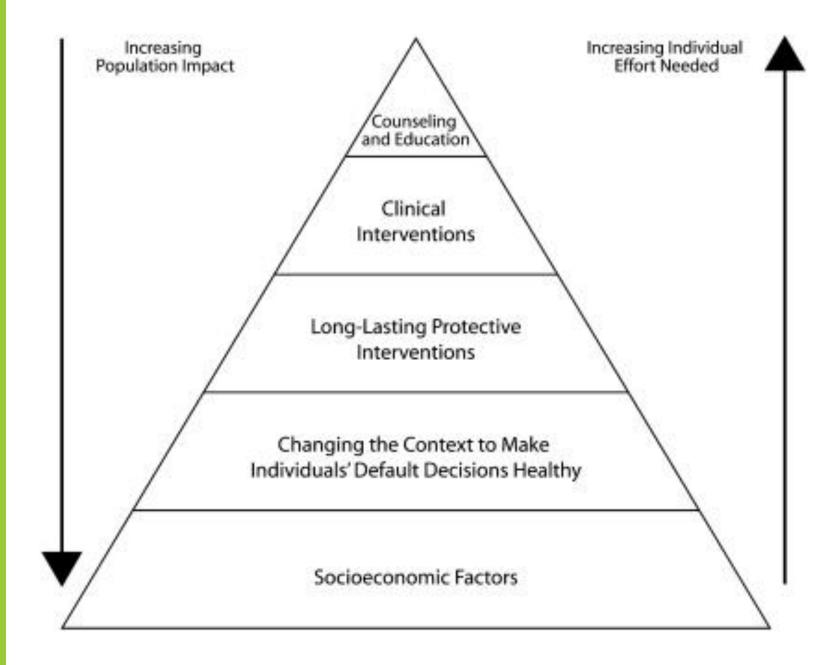
Caregivers:

- 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?

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

1	1. Specific carer support Counselling, information, respite care, training, direct financial support (care allowance)	Focused on supporting informal carers	1
Degree of incorporation	2. Help that is "by-product" Indirect financial support (attendance allowance or equivalent)	Mainstream services	Scope of the scheme
	3. National policies and legal entitlements National policy, identification and needs assessment processes, legal entitlements	Global level of service system	

From: Courtin, Emilie, Nadia Jemiai, and Elias Mossialos. "Mapping support policies for informal carers across the European Union." *Health policy* 118.1 (2014): 84-94.

How does the US match up?

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

"Voltage drops" to receipt of supports



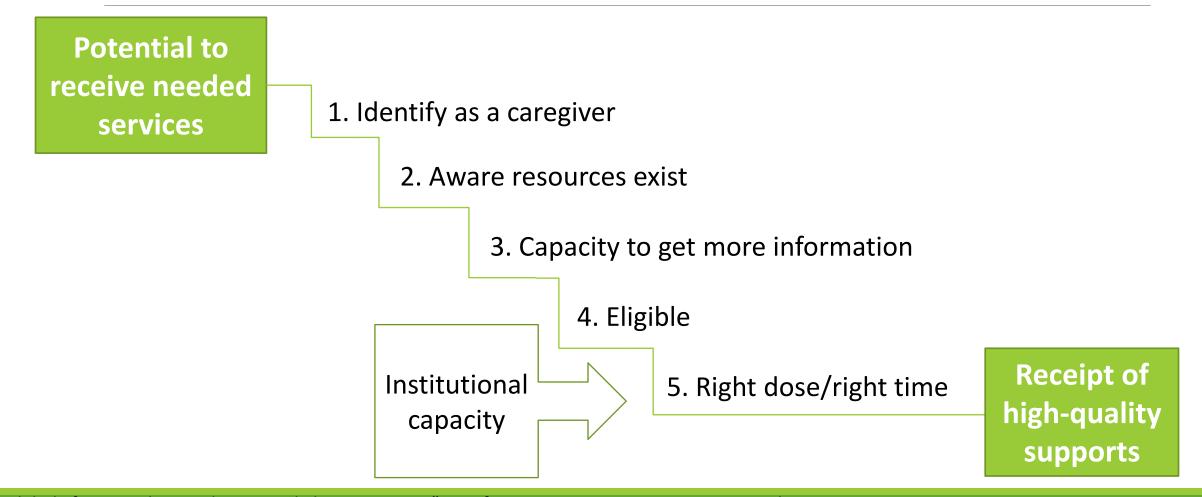
Availability of:

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

Receipt of high-quality supports

Modeled after Eisenberg, John M., and Elaine J. Power. "Transforming insurance coverage into quality health care: voltage drops from potential to delivered quality." *Jama* 284.16 (2000): 2100-2107.

"Voltage drops" to receipt of supports



Modeled after Eisenberg, John M., and Elaine J. Power. "Transforming insurance coverage into quality health care: voltage drops from potential to delivered quality." *Jama* 284.16 (2000): 2100-2107.

Innovation in other states

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

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

Lessons for policy-makers

From: Aufill, 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

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.

Questions?

A big THANK YOU to the System Navigation Workgroup Members

