

What do you wish to sustain?

Implications of Covid-19 on Lifespan Respite Sustainability Planning

Preliminary findings from The Break Exchange survey of respite providers on how Covid-19 has impacted respite services.

1. Alternative/Adapted Services

The majority of programs adapted services, or provide alternative services, along a continuum.

Check In/ Assessment	Resource Referral	Self-Care Guidance/ Support	Emotional Support	Practical Support
<p>Programs reach out to caregivers via telephone or email to proactively maintain a connection.</p> <p>Some programs do risk assessments or Telehealth wellness checks.</p>	<p>Programs seek to reduce the caregiver burden by helping caregivers connect to a variety of community resources. This is accomplished via written lists, social media and individual referrals.</p>	<p>Programs provide anticipatory guidance and support related to creating space, taking time, using technology, doing activities (some provided by programs), and navigating services.</p>	<p>Programs are creating support groups, referring to mental health professionals, providing virtual resources for coping, and organizing weekly caregiver webinars.</p>	<p>Programs are delivering and/or providing groceries, meals, pharmacy, “Basic Needs” baskets.</p>

Compare these services with those identified in the Outcome Evaluation of the National Family Caregiver Support Program (2018).

Through the NFCSP, states and territories offer the following five core services for caregivers, in partnership with Area Agencies on Aging (AAAs) and local service providers:

- **Information for Caregivers about Available Services.** Caregivers can learn about a range of supports, resources, and services available.
- **Assistance to Caregivers in Gaining Access to Services.** Access assistance helps connect caregivers with services offered by private and voluntary agencies.
- **Caregiver Education/Training, Individual Counseling, and Support Groups.** These services help caregivers better manage their responsibilities and cope with the stress of caregiving.
- **Respite Care.** Trained caregivers provide care for individuals, either at

home or at adult day care facilities, so that caregivers can rest or attend to their own needs.

- **Supplemental Services.** Additional services may include transportation, home modifications, and medical equipment.

Sustainability Questions:

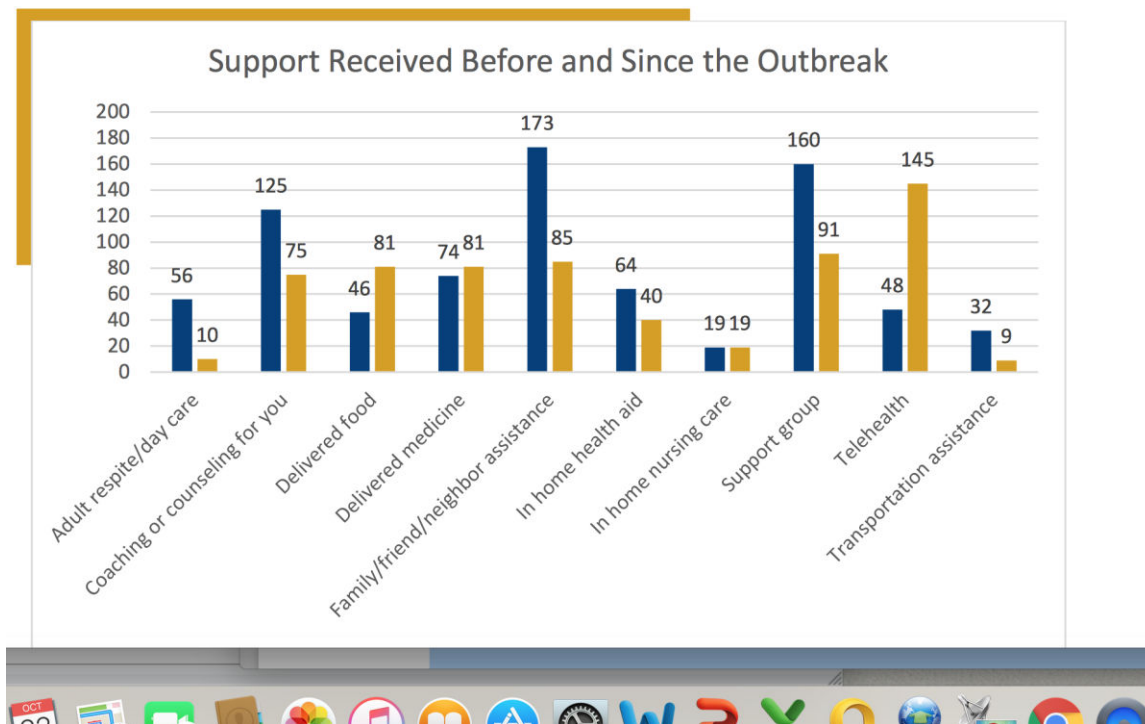
- Have your programs made these adaptations or offered these alternative respite services?
- Of the adaptations you have made to services, will you maintain any of them after the pandemic has subsided?
 - ↳ Why, or why not?

Excerpt from:

Caregivers in Crisis: Caregiving in the Time of Covid-19 (October, 2020). The Rosalynn Carter Institute for Caregiving.

<https://www.rosalynncarter.org/wp-content/uploads/2020/10/Caregivers-in-Crisis-Report-October-2020-10-22-20.pdf>

- While research shows the *need* for support is greater for caregivers during the pandemic, caregivers have actually *received* less support in their role since the onset of COVID-19. The table below shows support before and since the outbreak



Caregivers surveyed shared a statistically significant decline in support received from family and friends, adult respite/day care, coaching or counseling, support

groups, and transportation. By contrast they reported a statistically significant increase in support received for delivery of food and telehealth.

Caregivers expressed a need for more support than they are getting, particularly naming the following:

- Respite and daycare
- Social interaction
- Peer support and self-care
- Financial assistance
- Clinical and in-home care services

There is no single solution that is sufficient in helping caregivers weather this storm. Research in the field has identified many of the challenges and stressors identified in this report but clearly there is a mental health crisis that has been exacerbated and amplified by the COVID-19 pandemic.

2. Stress

This code appeared often, and it appeared that that programs are socially and emotionally close enough to caregivers that they are aware not only that caregiver stress has increased, programs are also aware of the level and sources of stress -- (psychological uncertainty [the unknown future] as well as practical uncertainty [how do I cope today?], lack of guidance about safety and services, social isolation).

Not being able to adequately address caregiver/family stress likely creates stress among providers. There is some evidence of this, but the preponderance of evidence seems to indicate that providers are more concerned about the well being of the caregivers and families they serve than they are concerned about themselves.

Sustainability Questions:

- What guidance and support are you offering to caregivers in your program with regard to safety?
 - ↳ Support services?
 - ↳ Social isolation?
- What guidance and support are you offering to volunteers and staff on work-related stress and/or compassion fatigue?
- Are work-related stress and compassion fatigue something you thought about before Covid-19? If so, did you incorporate ways to address these in your program/services?

3. Technology

Technology stands out as the key vehicle for reaching and supporting caregivers and families—for better or worse. Both programs and bureaucracies struggled to adapt rapidly with technology. Programs were notable in their creativity, resourcefulness (including finding equipment and providing support and training), and inventiveness in using technology to soothe, distract, entertain, educate, etc.

Questions:

- Is technology satisfying socially and emotionally for caregivers/families? For staff/volunteers?
- Will you (*how will you*) continue to use technology after the pandemic subsides?