Future of Respite in a Post-pandemic Environment
Breakout Room Discussion Notes
July 14, 2021
Facilitator: Susan Summers

Questions centered on participants' ideas about supporting the respite goal cited in the RAISE recommendations; and participants' response to questions in their thinking and their services post-pandemic.

RAISE goal 3.2: Increase the availability of high-quality, setting appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities

Responses to Questions — RAISE	Observations/Comments
Cheryl Dinnell (NV) described their state's pilot program for self-directed care, and spoke about the importance of caregivers defining appropriateness and quality with regard to respite. Cheryl said they used the "good enough" measure as defined by caregivers.	These comments related to quality and caregiver-defined portions of the RAISE respite goal.
Deana Prest (NY) spoke about her state's Caregiver Plan (2015) for in-home services and how they are expanding that model to include out-of-home and voucher services. In addition to convening a workgroup comprised of 25 AAAs in partnership with the coalition to develop requirements and program instructions to expand models, they facilitated two caregiver focus groups (with 8 caregivers and 11 caregivers in each group). An important finding from the focus groups was that caregivers believed training should be required even when the care provider was a family member. (Deana also mentioned the importance of including male caregivers in the focus group.)	These comments related to quality, setting and caregiver-defined portions of the RAISE respite goal, and the role training plays in quality.
Rosalyn Alber (WA) observed that kinship caregivers may be hesitant to participate in respite because care recipients have behavioral challenges.	This comment is related to quality (a fit between the provider's skills and care recipient's needs).
Cheryl Dinnell (NV) spoke about the importance of caregiver-care provider communication in determining appropriate settings. She shared a personal example and described her child's communication disorder, which is often interpreted by others as a behavioral disorder.	This comment speaks not only to appropriate setting, but training to address quality. Here, a caregiver's insights are essential in care provider training.

Responses to Questions — Covid	Observations/Comments
One person commented that about half of the families her program served had interrupted services, and those families that hired family and friends fared better.	This speaks to the importance of informal supports.
One person commented about the importance of developing emergency response protocols not only for Covid, but also for any emergency families may encounter. For example, she cited the forest fires in the West and the need for an evacuation plan. Others commented that emergencies were more often less acute and more chronic and slow rolling, and that frequent check-ins and resource-referral support was important, as was anticipating emergency situations and developing back-up plans.	This speaks to the importance of anticipatory planning for emergency situations.
Kerrie (MT) talked about using robotic pets, weighted blankets and other physical props with care recipients to fee up time for caregivers. She commented that these are especially useful in rural areas where provider shortages are chronic, and said they will continue to use these adaptations post-pandemic. She also spoke about the increased need for providers and feeling a sense of urgency about this.	This speaks to the continued use of adaptations post-pandemic, and an urgent need for providers, especially in rural areas.
Cheryl Dinnell (NV) spoke about the usefulness of low-tech technology. For example, she described how helpful remote cameras could be in allowing caregivers an increased measure of freedom to take a brief neighborhood walk or work in a garden while keeping "eyes on" their loved one.	ARCH could consider compiling a list of technologies used during COVID that could be helpful long-term, from least to most technological sophisticated/costly.
Tracy (AL) shared that their Caregiver Wellness Initiative will be permanent.	This speaks to the increased recognition among leaders of respite programs of the importance of mental health supports for caregivers and families.

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Breakout Room Discussion Notes
July 14, 2021
Facilitator: Casandra Firman
Notetaker: Tracy Kahlo

Introduction: The RAISE Family Caregiving Advisory Council that Alison and Lori spoke about this morning delivered recommendations to Congress to support family caregivers across the lifespan. The next step will be to develop a national strategy to implement the recommendations.

This is the respite recommendation, under Services and Supports for Family Caregivers:

> **Recommendation 3.2**: *Increase the availability of high quality, setting appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.*

What private or public actions would you suggest to help implement respite recommendation #3:

- In NY consumer directed and access to training to respite providers they might choose; implementing respite voucher for kinship care providers, informal (aka not foster care). Offering grants and big push on volunteer respite in NY
- Awareness – using all networks (i.e. I/DD, aging, kinship, AAAs, coalitions, etc.)
- IL – bringing back respite to the state, training and respite taskforce = state local caregivers to improve and connect the wonderful services already in IL

How is your thinking about respite services changed because of COVID? Concrete supports – "hand-walking" through transportation, technology, etc.?

- WA – provided research of available respite providers to help them connect and get the support they need; increased phone support; use of Heypeers.com for a statewide support (educational) group in collaboration with our WA TBI
- IL – training of respite providers, giving caregivers opportunities to learn
- Devices given to caregivers were lifesaving
- Offering an 800#
- Connect the resources via flyers, phone, support, mapping out the resources, on bus stops (TN??), etc.

Has anyone changed the way you use funding and resources?

- Helpful if MORE FUNIDING OPTIONS – State funding = statewide respite > most coming to states for AAAs and lifespan respite without discretionary grants only for a few states
- Community based child abuse program may be an example
- Concerns re: state "funnel" of funding because of political directives, lack of support for respite, overhead/Admin higher than administrators can lead to less funding for caregivers

Adaptations and alterations during the pandemic, which ones will you be keeping?

- VA – spreading funding across months; looking at ways to
- IL – PPE as necessary and send out across the state, keeping the motivational, virtual resources, 800#, virtual training with individuals get a $50/stipend to encourage learning more and looking forward to getting back in-person and had info at gas stations

Future of Respite in a Post-pandemic Environment
Breakout Room Discussion Notes
July 14, 2021
Facilitator: Ray Kirk

This session invited attendees to offer opinions and ideas about how respite services will change, or not change, as the COVID-19 pandemic is put behind us. Participants were asked to offer their suggestions in relation to the RAISE Family Caregiver Advisory Council key guiding principles: services should be of high quality, offered in an appropriate setting, defined or directed by the caregiver, and provide a healthy, meaningful break.

Several states, notably Tennessee and Oklahoma, suggested that tangible elements of respite such as "care packages" or "caregiver care boxes" were offered as a partial substitute for the in-person services that had to be curtailed during COVID-19. Feedback from caregivers was largely positive, although the respite providers soon learned that without actual respite many of the caregivers intended to receive these packages could not travel to pick them up, and as a consequence the programs that only incurred expenses of putting the packages together but then the additional expenses of shipping or mailing the packages.

Several states, including Oklahoma, Delaware, and Arizona spoke of the necessity to rapidly adapt technology and virtual services to caregivers during COVID-19. It is noteworthy that most comments about online respite (e.g., Zoom meetings) focused on group events such as training opportunities, support groups, and conferences. Experiences of both respite providers and caregivers was mixed.

On the plus side, virtual conferences and meetings provide recorded archives that can be viewed at a later time if the schedule for the event was not convenient for some number of caregivers. With respect to conferences, these recorded archives provided the opportunity for virtual attendees to view recordings of entire conferences, rather than being forced to choose one of several simultaneous workshops or presentations.

Arizona reported its experiences with virtual events versus in-person events noting that non-emergency, in-person respite usually occurs following a negotiation between the provider and the caregiver to schedule the event at a time that works best for the caregiver and can be accommodated by the provider. However, virtual events are usually announced by the respite provider to occur at a particular time that may or may not be workable for some caregivers. In fact, they noted that even among those who registered for virtual events in advance of their occurrence, they only had about a 50% participation rate across several attempts. Similar numbers were subsequently reported by other attendees.

In describing its experiences, Delaware not only conducted virtual conferences, but also established virtual office hours for its case managers. Again, results were mixed. Delaware shared Arizona's and others' experience of participant attrition, and coined the term "Zoomed out" to describe the phenomenon of computer screen fatigue and participation in virtual events generally, which were almost certainly occurring in large numbers in other areas of caregivers' lives outside of respite.

Several states noted the existence of technological barriers which prevented providers from reaching certain populations. For example, rural and culturally/ethnically diverse regions and populations were less apt to have computer access, reliable Internet, or comfort level in making use of the available technologies. As well, training classes and support group sessions were used primarily by people who were already familiar with respite, or who have been receiving respite prior to COVID-19. They discovered that these were not suitable vehicles for identifying people who could benefit from respite but had not used it previously.

In order to improve the opportunity to participate in virtual events several states had made adjustments in their voucher programs so that voucher funds could be used to provide in-home payment to others living in the home who might give the primary caregiver a break to attend a virtual event at its scheduled time.

Feedback from caregivers, both formal and informal evaluations, following virtual events revealed that caregivers were grateful for any form of relief, but caregivers also reported missing the face-to-face contact with respite providers and even other caregivers that virtual meetings do not provide, saying it was not the same type or level of "break."

In addition to dealing with the likely modifications to respite that will remain after COVID-19, either of necessity or choice, one state noted that providers will need to re-engage with other service partners in other disciplines as the frequent contact and collaboration among service partners waned significantly as the nature of the provision of respite changed and so much of the work was done virtually.

The major takeaways from the session appear to be:

- The move to virtual mechanisms of service became immediately necessary and was very widespread with respect to respite;
- Virtual presentations of respite, training, support groups and conferences have both desirable and undesirable features:
    - increased numbers of respite options and opportunities,
    - a recorded archive of content that can be accessed later by those unable to attend or participate,
    - a decrease or absence of face-to-face contact with caregivers,
    - although virtual presentations theoretically increase the opportunity for more people to attend either at the time of presentation or thereafter by viewing the archives, certain members of society (rural communities, racially and ethnically defined communities) that may already have been difficult to reach and serve were less likely to participate, a situation difficult to remedy without face-to-face interaction.
- Different hybrids of virtual and face-to-face services may offer partial solutions to some of these issues;
- Alternative mechanisms for personal contact, such as "caregiver care packages" are much appreciated by caregivers but are not an adequate substitute for face-to-face respite;
- Different rules on the use of vouchers to accommodate the realities of respite under COVID-19 deserve serious consideration for continuation after the pandemic abates.

Future of Respite in a Post-pandemic Environment
Breakout Room Discussion Notes
July 14, 2021
Facilitator: Jill Kagan

Introduction: The RAISE Family Caregiving Advisory Council that Alison and Lori spoke about this morning delivered recommendations to Congress to support family caregivers across the lifespan. The next step will be to develop a national strategy to implement the recommendations.

This is the respite recommendation, under Services and Supports for Family Caregivers:

> **Recommendation 3.2**: *Increase the availability of high quality, setting appropriate, and caregiver-defined respite services to give caregivers a healthy and meaningful break from their responsibilities.*

What public or private actions would you suggest to help implement the respite recommendation? Focus on what your coalition or Lifespan Respite project could do.

ACL has built a network of Lifespan Respite grantees, and many have been funded for a long time. Grantees are well positioned and can play a major role in helping implement the national strategy actions to improve respite services.

South Carolina has focused on building natural supports, including services provided by the faith-community. The faith community was challenged to continue to provide services during COVID. They found that faith-based services were more readily provided if partnerships with other community-based agencies were in place, such as with teen centers or recreation commissions. Otherwise, service delivery always seemed to fall on just a few volunteers or one church and additional human capital needs to be leveraged for leadership and resources. Others raised concerns that providing respite in rural areas would be very difficult without the faith community, and that few other resources may exist.

Engaging employers could be a way to move forward with additional respite support post-covid in rural and other areas. The pandemic raised awareness among employers about their workers' caregiving responsibilities, their ability to work successfully at home, and the need for supports to make that happen.

South Carolina did not have a lot of success previously working with employers, but post COVID, they will revisit because there is greater awareness among employers. Colorado worked with employers and spent time educating their workers about caregiving resources. Many agreed that Alabama's Caregiver Wellness initiative to provide mental health counseling support might be an attractive option for employers to provide caregiver support.

One group participant raised the issue of the shortage of direct care workers. Alabama, with their new grant, will be offering at least 25 stipends to encourage people to complete online training. They are collecting data on the benefits of this approach. They are also developing core competencies for training for respite workers.

In North Carolina, they get lots of calls from caregivers who have funds to pay for respite but can't find providers. There is a moratorium in NC on new home care industries because of lobbyists opposition to expansion. We need to explore alternatives. She mentioned knowledge of an app like UBER that allows caregivers to search for PA In students to provide assistance. This might be a good way to find respite providers.

How has your thinking about respite services changed as a result of experiencing the COVID pandemic? Of the adaptations and alterations to respite services you made during the pandemic, which to you plan to keep?

In NC, they will keep voucher changes they put in place at the start of the pandemic including , relaxing requirements about who can provider respite, and increasing the maximum amount of the voucher per household. Made it easier for families to access the funds and providers. South Carolina did the same. SC also moving into way that they might identify new individuals, rather than just agencies or programs, who can provide respite and develop a list of providers who can demonstrate core competencies.

Montana used voucher funding to allow caregivers to find way to get respite without leaving the house. Allowed use voucher funding to purchase chair cushions, weighted blankets, grocery delivery, etc., to reduce caregiver burden and they will continue to offer that flexibility. Other grantees will continue reassurance calls and online support groups, as well as virtual support through providing of online activities for care recipients and caregivers.

What important lessons have you learned from the pandemic?

We can through money at the issue, but it's like a fire hose. If the state does not have the infrastructure to spend the funds, the money goes unused. The state still has waiting lists for services. Rural areas especially don't have the needed infrastructure. Not just money or workforce issues. Other barriers may still include transportation or lack of marketing. Rural areas also don't have infrastructure or and many residents don't have the know-how for internet usage. Some groups gave out tablets or provided basic internet package to help families access, but it remained a big barrier.

There is also a hesitancy among providers who don't want to sign up caregivers or bring on more clients for temporary services that may end.   NC tells providers you need to provide services even if it is temporary. In NV, providers are hesitant to bring on the manpower to provide the services if funds are just temporary.