Respite Resources from the Lifespan Respite Network in the Time of COVID-19

Update
April 29, 2020
ARCH Respite and Caregiving Resources in the Time of COVID-19

ARCH Website
New and Updated National Resources

**Medicaid**

Administration for Community Living and CMS

*Ensuring Continuity of Home and Community-Based Services (HCBS) During the COVID-19 Pandemic*, PPT Slides, April 23, 2020. Update on Respite, Caregivers and Medicaid Flexibility through waivers and Appendix K.

**National**

National Federation of Families for Children’s Mental Health

Resources for parents and caregivers include videos, toolkits, activities to use at home during the COVID-19 pandemic. [https://www.ffcmh.org/covid-19-resources-for-parents](https://www.ffcmh.org/covid-19-resources-for-parents)

Resources to assist nonprofit and family-run organizations during the COVID-19 pandemic in addressing organizational sustainability [https://www.ffcmh.org/covid-for-fros](https://www.ffcmh.org/covid-for-fros)

Public Health Institute

Supporting Family Caregivers of Older Adults through Times of Stress and Isolation
April 30 at 12pm EST

Speakers include:

• Erin E. Emery-Tiburcio, Ph.D., ABPP, Co-Director of Rush Center for Excellence in Aging, Rush University Medical Center

• Kathy Kelly, Executive Director, Family Caregiver Alliance/National Center on Caregiving

• Bryan Godfrey, LCSW; Care Management Social Worker, UNC Geriatrics Specialty Clinic

Read More and Register
https://www.resourcesforintegratedcare.com/Older_Adults/2020_Webinar/Supporting_Family_Caregivers_Stress_and_Isolation
Lifespan Respite Survey

The BREAK Exchange Director
Kim E. Whitmore, PhD, RN, CPN
Assistant Professor, School of Nursing
University of Wisconsin – Madison USA

Presenter
Susan Jankó Summers, PhD
ARCH National Respite Network and Resource Center
The BREAK Exchange
(Building Respite Evidence and Knowledge)

- International group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care
The BREAK Exchange Survey

- Disseminated Spring 2020 to collect descriptive data about current and prospective members

- Received more than 500 responses from around the globe including from Australia, Canada, Denmark, France, Germany, Ghana, Iceland, India, Ireland, Pakistan, Peru, Poland, Portugal, Senegal, Thailand, Tuvalu, UK & US
Guiding Questions for the Covid-19 Study

1. What has been the IMPACT of COVID-19 on caregiving support services?
2. How have support services been ADAPTED or what NEW services have been implemented?
3. What are the greatest NEEDS that should be prioritized/supported?
Phased Analysis

- Initial data scan to identify promising practices and key lessons
- Comprehensive inductive content analysis for written report or publication
- Breakdown data by geographical areas (regions in U.S., international approaches)
- More to come…
Data Categories & Codes

PEOPLE
- Increased Stress
- Social Isolation
- Financial Impact
- Food Insecurity
- Logistical Support
- Decreased Therapy

ORGANIZATIONS
- Changes in funding
- Changes in service
- Services refused
- Adaptations/Alternatives
- PPE and safety
- Organizational barriers
- Staff retention
Organizational Barriers

- Existing staffing patterns often don’t fit new demands
- Bureaucratic hoops may interfere with timely services

We recently have been given the option to provide services in clients’ homes but guidelines, regulations, and paperwork associated have come out slowly and we are still waiting on the official "OK" ... we then need to complete paperwork to be approved by the state before we would be able to provide those services...
Adaptations/Alternatives

- Responsive to client/family needs in real time
- Strong case management/care coordination component
- Tele-services
- Logistical support—especially with food
- Creative

We are working 24/7 providing increased supports like PPE, making face masks for our consumers and their families, providing food, medical supplies/DME, ongoing updates for mandates, information, support, fun activities, setting up tele-services, doing (contract) amendments, taking endless calls from families who are without staff/support services who need to vent, talk, cry, laugh, share etc. We are now working at least 80 hours per week.
**Client AND Staff Safety and PPE**

- PPE shortages

- Need for staff training, TA and support in safety protocols

- Move to 1:1 staff client ratio to reduce risk and prioritize highest risk families.

There are some (staff members) who have resigned due to not wanting to be a risk factor for some clients and their medical conditions.

More education on how to better handle the anxiety from our clients created by this pandemic would be helpful.

We prioritize clients based on need. Clients that have no family or other supports are receiving care over those with other support systems.
Stress and Mental Health

- Hotlines for mental health
- Regular, periodic telephone or internet check-ins with clients/families

The toil on caregivers is first of all fear, coupled with emotional disturbance of “I may be the next victim.”

As a family caregiver there was no communication to families or family members as caregivers
Compassion in Action

I paid staff 2/3 sick pay, and in process for their payroll protection program. However, I qualify for neither as I have only been in business a couple years and have not pulled a paycheck. The only thing offered is more debt.... I kept two activity directors on...We delivered Easter baskets full of crafts to all 200 assisted living homes for their clients to do. And we answer our phone to help those clients that are distraught without our services.

The pandemic is terrible for our clients. ... we call to check on them weekly. We have received a couple of different COVID-19 grants to help with food and gas costs. We know it takes more food during this time to feed our families because the children are home. We are providing gas cards to help them go pick up free lunches and breakfast at the school for children. Are families are more isolated than they ever have been and they have the stress of homeschooling the children.
Compassion in Action

We are doing support meetings over Zoom. We made sure everyone one of our families has a computer or Chrome notebook. We have several school districts that are providing the chrome notebooks for every student. Our organization has made contact with a man that is providing rebuilt computers for families in districts that do not supply computers. We are also doing face-to-face meetings with families over Skype and Zoom. We are in the process of teaching them how to set up contact with others on the computer.

We put up a large screen monitor for residents to use to communicate with family/loved ones, facilitate virtual doctors visits, and check in with resident advocates.

Advocating for caregivers to be allowed to accompany disabled patients into hospitals. Advocating for federal expansion of HCBS/LTSS legislation to be added to next COVID emergency bill. Advocating in (our state) for emergency caregiver backup funding to meet emergency needs when caregivers or clients become ill.
Compassion in Action

Note that went out to community:

Good morning, Secret Agent. Your mission, should you choose to accept it, involves bringing a smile to an isolated senior citizen, due to operation hunker down. You may select from a variety of assignments and recruit additional team members. Some suggestions are:

- Written letters
- Singing outside our headquarters
- Pictures or drawings
- Small gifts (craft, puzzle, crosswords, etc.)
- Painted rocks left outside ALH headquarters

Your target, a group of highly sophisticated civilians, capable of melting your heart and leave you believing that you made this world a better place.

Should any member of your team be caught with in 6 feet of each other, the Administration will disavow all knowledge of your actions. You have until 2:00 PM on May 1st, 2020 to accept this assignment.

Be careful Agent, we are counting on you. Headquarters address is: Report all completed missions via social media with tag Send questions to: And as always, wash your hands frequently and wear a facial covering to hide your identity.

This message will self-destruct in five seconds.
Stay Connected!

- Join our Facebook Group called “The BREAK Exchange”
- Follow on Twitter @exchange_break
- Visit our website and join the listserv at https://breakexchange.wisc.edu
- Email us at break.exchange@son.wisc.edu