

# A Research Agenda for Adult Day Services

ARCH Respite Research Summit  
September 29-30, 2020

William Zagorski

Chair and Research Committee Chair, National Adult Day  
Services Association






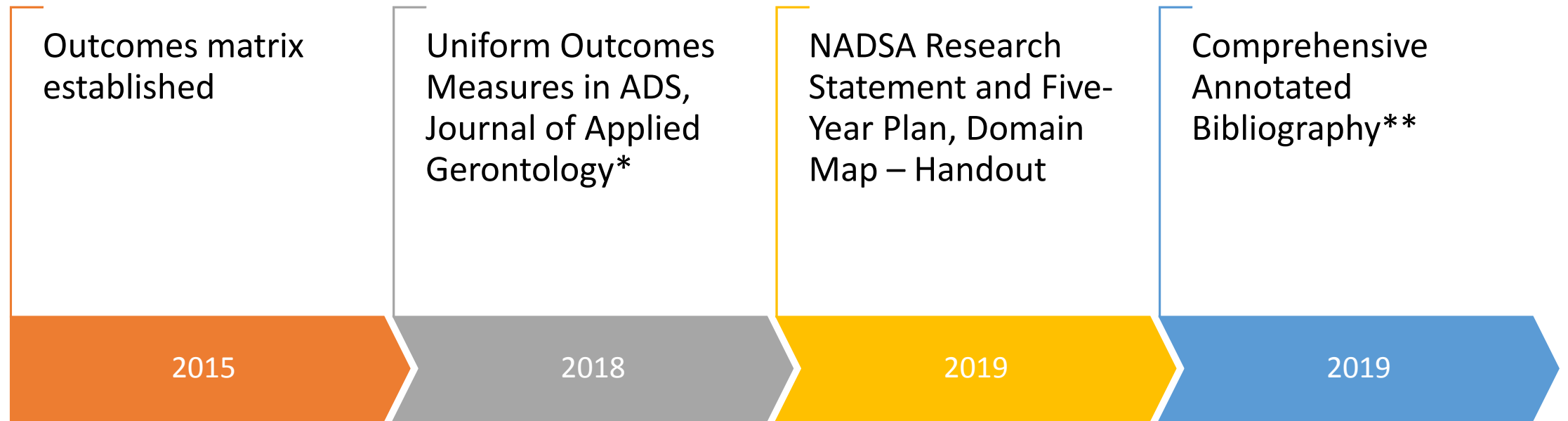
# Adult Day Services

- Adult Day Services (ADS) are a highly variable service setting providing coordinated services to adults of all ages and abilities in community-based group setting.
- ADS are designed to provide social and often health related services to adults in need of supervised or assisted care during the day, outside of their residence.
- ADS provides respite services for caregivers who otherwise provide 24/7 care for their loved ones

# National Adult Day Services Association

- NADSA is the membership association representing ADS centers across the United States
  - More than 6,000 'registered' centers, and likely another 3,000-4,000 'unregistered' centers operating throughout the nation as of early 2020.
  - NADSA created a Research Committee more than a decade ago to help align the disparate data collection and research initiatives throughout the industry.
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# NADSA Research Committee





\*<https://pubmed.ncbi.nlm.nih.gov/29900756/>

\*\* <https://www.nadsa.org/research/>

Domains reflect a cycle of planning, implementing, evaluating, and translating into practice and policy.





# Challenges and Takeaways

- Challenges
  - Standardization of ADS Models
  - Research Participation
    - Standardization of metrics, tools, and collection practices
    - Simplify, disseminate, and educate diverse providers for “grass roots” research participation
  - Data collection, analysis, and retention
    - Partnerships
- Ongoing implementation, evaluation, and updates are essential
- ADS is an effective intervention for both participants and caregivers – the data tells the story



# Respite Care/Short Breaks: Sharing an evidence review from Wales and Scotland (UK)

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# Short Breaks Research and Practice Development Group



## Short breaks research and practice development group

- To date Wales and Scotland, though Interest in the UK is broad and connections are wider
- Closer links developing with ARCH over the past two years, initially via Don Williamson

Terms of reference drafted April 2017

- The purpose...is to support a culture of research and build research capacity across the short breaks sector
- The aim is to improve understanding of the role of short breaks and respite care and to help structure future research in ways that will help support continuous improvement in policy and practice

<https://www.sharedcarescotland.org.uk/resources/research/uk-short-breaks-research-practice-development-group/>



# More about the research group

Started with an interest in developing more flexible, personalised short breaks provision

## Shared Care Scotland

- Aims to improve the quality and provision of short breaks in Scotland. Offers services including events, publications, research reports, online directory, managed by **Don Williamson**

## Research on carers outcomes in Scotland and Wales

- Research on carers outcomes in both Wales and Scotland over many years – **Diane Seddon** in Wales and **Emma Miller and others** in Scotland (*possibilities to compare/contrast with proximal/distal outcomes for caring dyads in ARCH framework*)

## Diverse carer research work at the OU

- **Joyce Cavaye** – carer journeys, life after caring
- **Roseanna Ware** - carers and disabled children

Wider collaboration between research, policy and practice is central





# Spoiler alert...

This research tells us as much about the gaps as it does about the evidence



# Scoping review

- Funded by Shared Care Scotland
- Purpose: better understand the research evidence about short breaks/respite for carers = carer outcomes
- Published literature from 2000 onwards
- Review itself conducted by Diane Seddon and Louise Prendergast (Bangor)
- SBRPDG acted as a reference group and review panel throughout

- 63 papers - carers for older people

Various types of short breaks identified:

- Includes more traditional, day-care, residential care and in-home respite (most evidence here)
- Alternative breaks, including supported holidays and access to leisure and arts

# Short break outcomes

## Carer health and well-being

The most prevalent outcome in the research

- Improvements in carer emotional well-being (sense of freedom, peace of mind and relief)
- Enhanced sense of resilience
- Opportunity to attend to self-care needs
- *Retrospective necessity*

*I initially found myself thinking, I'm the only person... the only one who can't do this, who can't get it right. But then, I began to realise that actually I was normal...they [the day center staff] helped me realise that it was normal to need a break...and after I accepted their offer...I could finally see that it works. (Phillipson and Jones 2012, 11-12).*

- Research confirms that positive health and wellbeing outcomes for carers and the individuals they support are linked to the provision of *personalised* short breaks

# Short break outcomes – flipside



## Carer health and well-being

- Some research shows that short breaks deliver *only* positive physical *but not* positive emotional outcomes (King and Parsons 2005), whilst others conclude that *any* positive benefits accruing from a break soon dissipate (McNally 2013).
- Research confirms that some carers taking short breaks report feelings of guilt, anxiety, emptiness and loneliness, particularly when the break takes the form of residential respite care, as well as sadness at being separated

*....guilt. I didn't sleep that night hardly any at all and in the morning I got up and ....cancelled. (Strang 2001, 78-79).*

- Negative effects mitigated when carers supported to accept their need for a short break as legitimate and appreciate its preventative effects

# Short break outcomes

## A life of their own

Supporting a life alongside caring is a key policy priority across the UK regions

- Opportunities for time away from the 'caring world' to pursue personal interests
- Thinking and relating to others in ways not linked to the caring role enables *temporary disconnect* from caring to focus on other roles (e.g. a grandmother, a wife) and *re-connect* with other family members/friends
- Short breaks afford opportunities to undertake routine domestic chores and mundane tasks, including shopping, but these activities may not be as beneficial as doing things that could not otherwise be done
- Use of short break time has a significant effect on carer outcomes - satisfactory use of time pursuing interests or being with family and friends is associated with positive outcomes and improved wellbeing

# Short break outcomes

## **Positive caring relationships**

- Short breaks:
  - play a key role in supporting positive caring relationships and enabling carers to continue caring
  - enable carers to positively frame their relationship with the supported person, their caring role and their achievements
- Nature and quality of the pre-existing relationship is important
- Gaps in understanding caring relationships as often reciprocal and the need to consider outcomes within dyads or other caring relationships

# Important features of short breaks

- **Quality of the break** - experience for the supported person, in particular, the opportunity for safe and meaningful engagement, critically important in determining outcomes. Short breaks have greater benefit when appraised, by the carer, as a positive experience for the supported person. Indeed, research suggests this lessens carers' sense of guilt
- **Duration** - research confirms this is linked to carer reported outcomes, with longer breaks (over 24 hours) having a greater positive effect for carers than shorter ones. Research by Dundee Carers Centre (2014) suggests that a period of less than half a day is not considered a short break. Pienaar and Reynold's (2015) work supports this.
- We need to know more about changing outcomes over time



# Scoping review – priorities for future research (and other developments)

Clustered around three key themes:

- 1. Understanding *what matters* - capture and evidence short break needs (personalisation, planning, conversation, restoration of identity, feelings of guilt etc)

*Miller and Barrie (2019) Carer Outcome Recording article in BJSW*  
<https://strathprints.strath.ac.uk/69248/>

- 2. Capturing *what matters* - outcomes from short breaks (measuring outcomes, while retaining meaning, including process outcomes)

Cost-benefits, SROI, (societal level outcomes – ARCH) Diane Seddon

Meaningful and Measurable project, Emma Miller

- 3. Commissioning, delivering and scaling up alternative short breaks provision to reflect *what matters* to carers (commissioners as facilitators, picture building, incl diversity)

ARCH hosted webinar 9<sup>th</sup> December – Diane and Maria

Forthcoming report on Get Outside projects in Scotland





# **The BREAK Exchange**

## ***ARCH Virtual Respite Research Summit***

*Presented by:*

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Assistant Professor, School of Nursing  
University of Wisconsin – Madison USA



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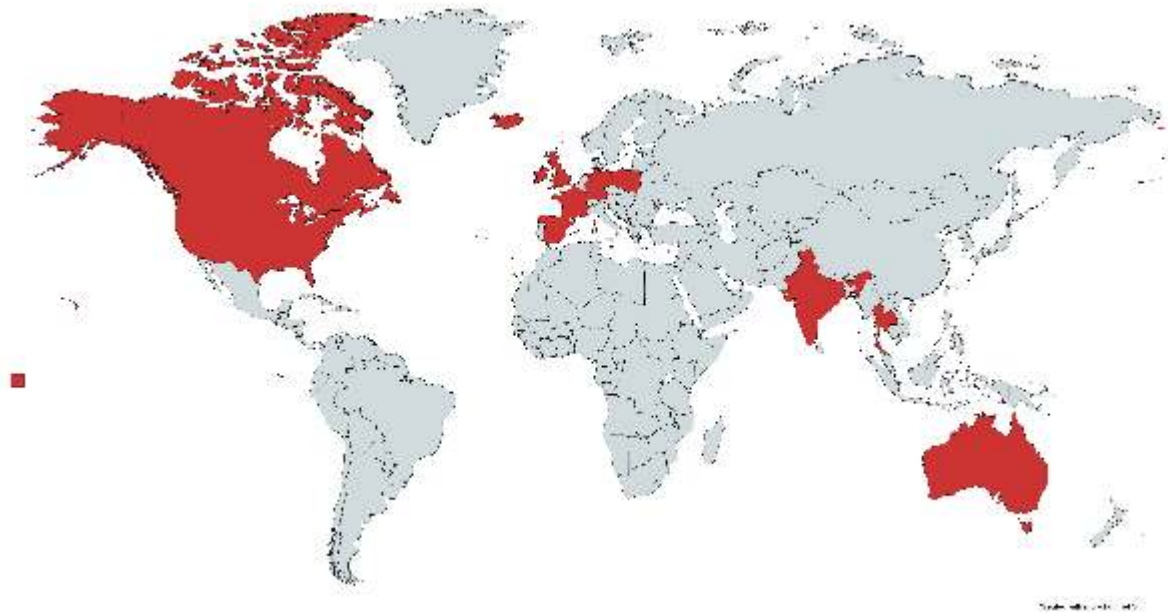
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# Overview

- ❖ What is the BREAK Exchange?
- ❖ Benefits of joining the BREAK Exchange
- ❖ Global Assessment
- ❖ Supporting Caregivers During the COVID-19 Pandemic Survey
- ❖ How to stay connected



# The BREAK (Building Respite Evidence And Knowledge) Exchange



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



# BREAK Exchange Partners



SHARED**CARE**  
scotland



School of Nursing  
UNIVERSITY OF WISCONSIN-MADISON



ISBA

International Short  
Break Association



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# ISBA Conference



JUNE 22 - 25, 2021  
**MADISON**  
WISCONSIN USA

Learn more and register at [isba.me](https://isba.me)



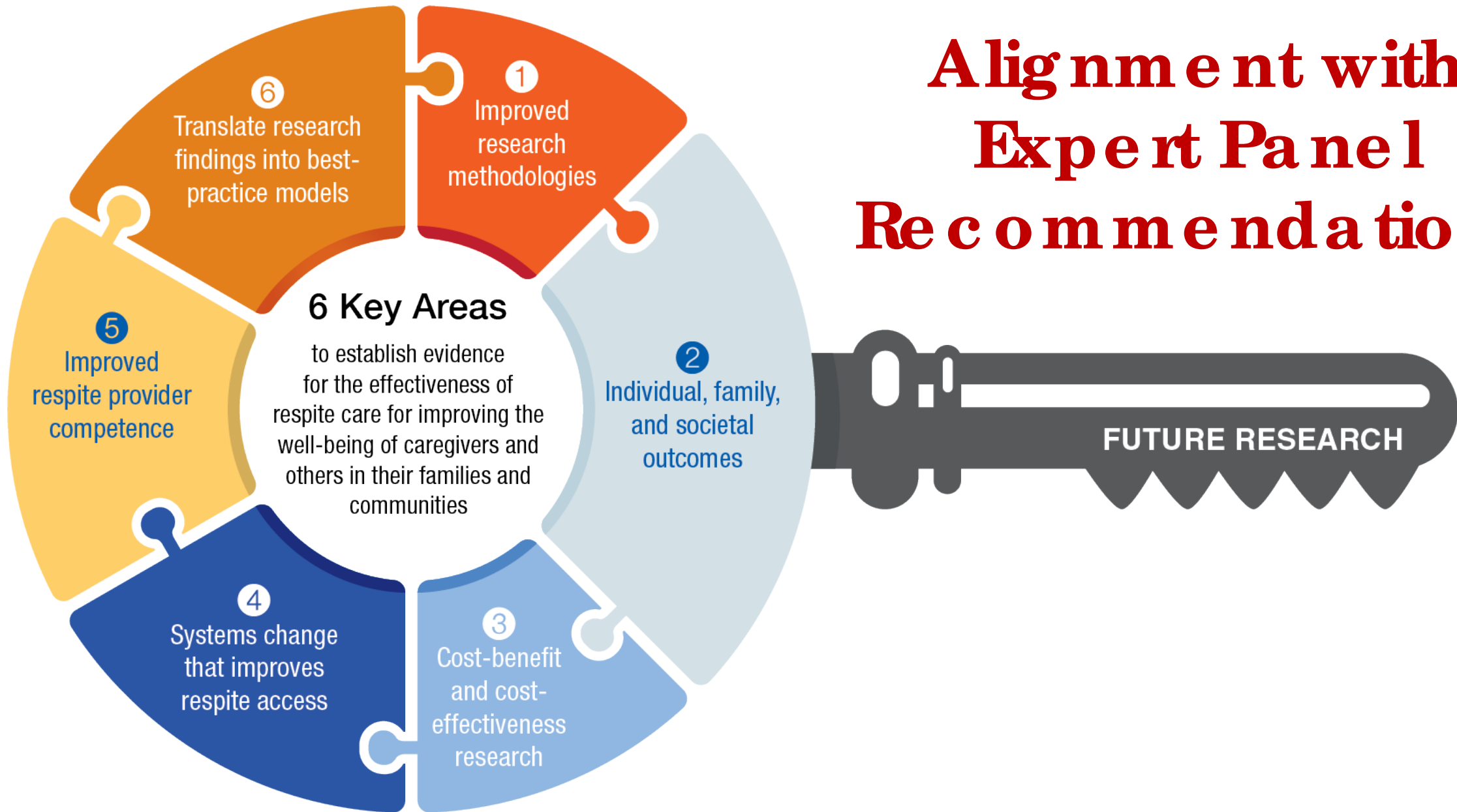
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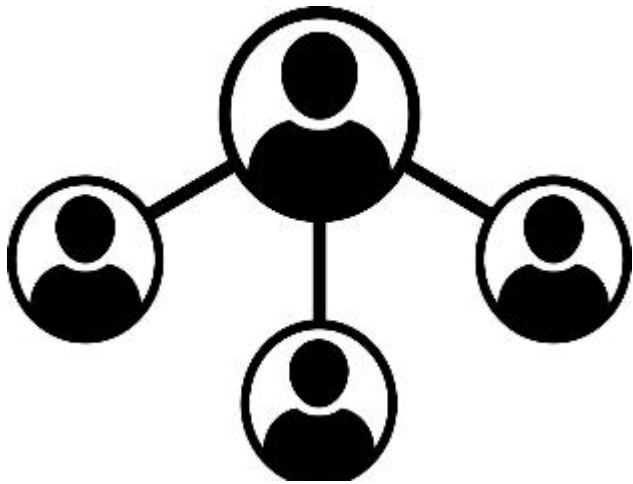
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# Alignment with Expert Panel Recommendations



# Benefits of joining the BREAK Exchange



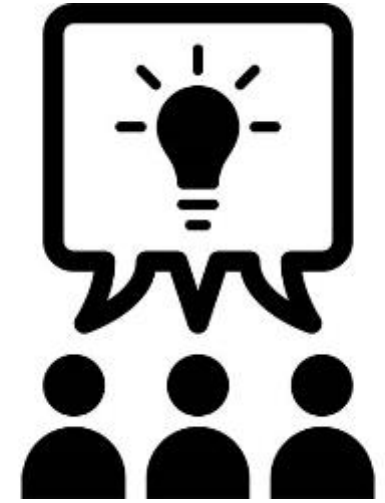
*CONNECT*



*LEARN*



*SHARE*



*COLLABORATE*



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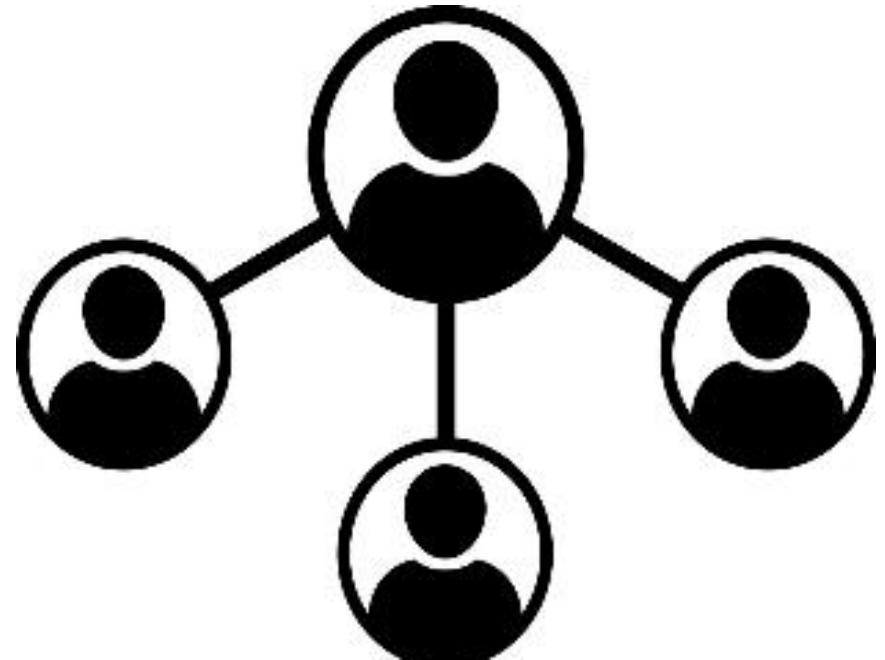
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# CONNECT

- ❖ Connect with a global network of researchers, respite providers, agencies, and individuals.
- ❖ Currently, there are more than 130 members from more than 13 countries in the Exchange!



# LEARN

- ❖ Learn about evidence-based respite care practices and research happening around the world.



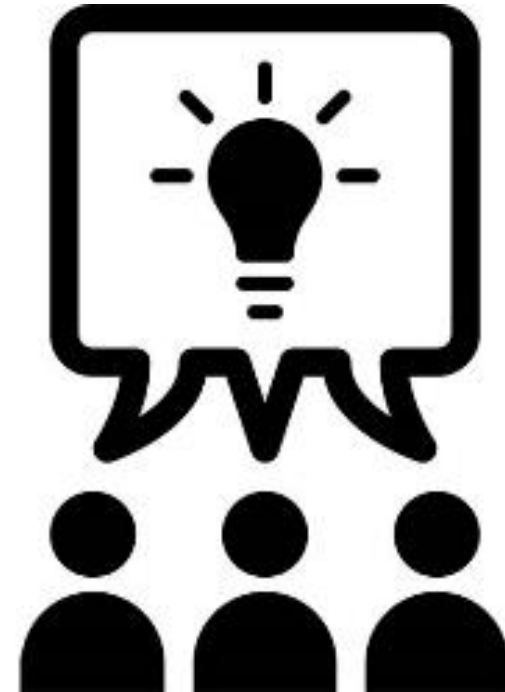
# SHARE

- ❖ Share your evidence-based practices or research with international partners.
- ❖ Feature your work in the monthly e-newsletter, on the BREAK Exchange website or social media platforms, or present a quarterly webinar.



# COLLABORATE

- ❖ Collaborate on an evaluation or research project.
- ❖ Leverage the Exchange to identify a potential partner for your next project!
- ❖ Create your Member Profile
- ❖ Search for partners in the Member Database



# Global Health Institute Grant

- ❖ Project aimed to leverage and enhance the capacity of the BREAK Exchange
- ❖ Global Assessment of the Current State of Respite Care
- ❖ Supporting Caregivers During the COVID-19 Pandemic Survey



# PRELIMINARY RESULTS

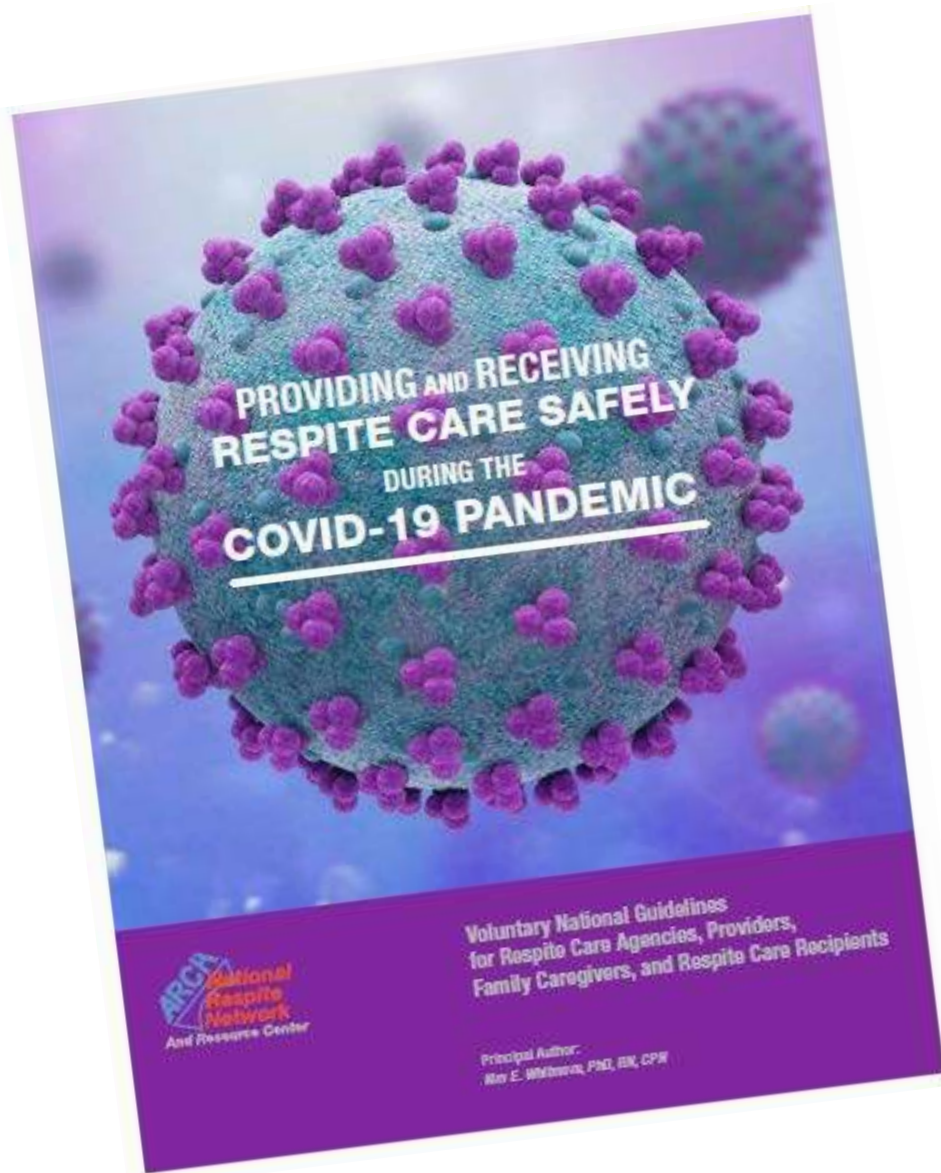
- ❖ 244 valid responses representing 15 countries
- ❖ Key lessons learned about the impact of the pandemic on respite and caregiver services, including:
  - *Key challenges*
  - *How programs have adapted*
  - *New and innovative services that have been created*
  - *Helpful resources*
- ❖ Recorded webinar of detailed results available online at <https://breakexchange.wisc.edu/webinars-preliminary-results-june-3-2020/>



# IMPLICATIONS

- ❖ Despite numerous challenges, many organizations have been able to adapt services or create new services to continue to help support caregivers
- ❖ Most organizations prioritized supporting basic needs and mental health of caregivers, families, and staff
- ❖ Organizations that were most successful were able to plan and adapt quickly and appeared to have good leadership and support





# Providing and Receiving Respite Care Safely During the COVID-19 Pandemic

Guidelines and downloadable fillable PDFs of all appendices available on the ARCH website at:

<https://archrespite.org/national-respite-guidelines-for-covid-19>



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# Stay Connected!



- ❖ Like us on Facebook **@ExchangeBREAK**
- ❖ Join our Facebook Group called **“The BREAK Exchange”**
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- ❖ Follow on Instagram **@break.exchange**
- ❖ Visit our website, join the email list, and complete your member profile at **breakexchange.wisc.edu**
- ❖ Email us at [break.exchange@son.wisc.edu](mailto:break.exchange@son.wisc.edu)





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