



## Research and Evaluation Track

As service providers and caregivers make a case for respite availability and funding, a solid evidence-base for respite is essential. Research provides an understanding of the health and well-being of family caregivers and the overall effect of respite on societal outcomes, including cost-benefits. Good data collection is important for continuous quality improvement in the respite we provide. This track is intended to present findings from evaluations of lifespan respite activities, respite models, alternative respite and support interventions, strategies for meaningful performance measurement, and practices to assure diversity, equity, inclusion, and accessibility in all research and evaluation efforts.



*Aligns with National Strategy to Support Family Caregivers Goal 5.*

**Wednesday, May 22 | BREAKOUT SESSION A | 11:00 AM -12:00 PM**

### **Exhale – The Family Caregiver Initiative: Overview, Multisite Evaluation and a Case Study of Innovative Respite Programming**

#### Description

Exhale, The Family Caregiver Initiative, supports innovation and expansion of respite services for caregivers of older adults. Exhale provides project development and implementation funding; a learning community; and assistance in creative problem solving, evaluation, communications, and sustainability. Exhale includes 16 projects in western New York and southeast Michigan. Project models are diverse as re-imagined respite can take many forms; examples include technology supports (home cameras, tablets), wellness activities, and musical programming for caregivers and carees.

#### Speakers

**John Tyler** • Senior Philanthropic Advisor, The Philanthropic Initiative (TPI), Boston, MA

**Linda Weiss** • Senior Researcher, Center for Evaluation and Applied Research, The New York Academy of Medicine, New York, NY

**Ann Battaglia** • Chief Executive Officer, Healthy Community Alliance, Gowanda, NY

**Ashley Conti** • Director of Programs, Healthy Community Alliance, Gowanda, NY

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**Wednesday, May 22 | BREAKOUT SESSION B | 2:15 – 3:15 PM**

## **Stress Reduction Through a Group Respite Intervention for Parents of Children with Special Needs**

### Description

The challenges and stress of providing care at home can impact both the child's and family's environment and quality of life. A 12-week group respite program during the spring of 2023 was provided on a 1:1 ratio by nursing and PT student volunteers. Using a mixed method approach, this study examined the impact of a specific intervention, a group respite program, on caregiver stress among family caregivers (parents) of children with special needs.

### Speaker

**Christine McGrane, PhD, RN, CNE** • Clinical Assistant Professor, College of Nursing, University of Rhode Island, Providence, RI

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## **Respite Experiences of Latinx Families of Children with Special Healthcare Needs**

### Description

This presentation will highlight a study of the respite experience of Latinx families of children with special healthcare needs. The Latinx Respite Survey involved Latinx parents of children with special healthcare needs (CSHCN) completing an anonymous survey that included questions about the CSHCN, their experience with respite care, as well as the Family APGAR, Perceived Stress Scale (PSS-10), and the Global Family Quality of Life Scale. Participants were also invited to schedule an interview to share more about their experience.

### Speaker

**Kim Whitmore, PhD, RN, CPN** • College of Nursing, Marquette University, Milwaukee, WI

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**Wednesday, May 22 | BREAKOUT SESSION C | 3:45 – 4:45 PM**

## **Priority Needs of Texas Family Caregivers: Findings from a 2023 Mixed-Method Study**

### Description

This presentation from the Public Policy Research Institute at Texas A&M highlights key barriers to respite service use by family caregivers, respite providers, and other respite stakeholders in Texas. Funded by Texas Health and Human Services Commission (HHSC), the 2023 multi-stage needs assessment study findings reflect on critical perspectives of barriers and hindrances from Texas family caregivers of all ages and backgrounds. Lessons inform existing initiatives to motivate utilization of respite services by Texas family caregivers.

### Speaker

**Nandita Chaudhuri, PhD** • Research Scientist, Public Policy Research Institute, Texas A&M, University, College Station, TX

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## **Wisconsin Provider Needs Assessment**

### Description

The Wisconsin Respite Survey was the first statewide survey to assess the current state of respite, current use, and barriers to receiving and providing respite in Wisconsin. Over 700 primary caregivers, respite providers, care recipients, and agencies completed this survey. Learn more about the survey, conducted as part of the WI Lifespan Respite Care grant, and the results.

### Speaker

**Kim Whitmore, PhD, RN, CPN** • College of Nursing, Marquette University, Milwaukee, WI  
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**Thursday, May 23 | BREAKOUT SESSION D | 10:15 AM – 11:15 AM**

## **Piloting Virtual Reality at In-home and Drop-in Respite Programs**

### [Description](#)

Innovative digital technologies, specifically virtual reality (VR), are emerging as a solution to improve social support for community-dwelling persons living with memory loss and their care partners. This presentation describes a community-based participatory research project examining the implementation of VR into Lifespan of Greater Rochester's Partners In Caring (PIC) respite program. Identified barriers and facilitators to implementing the VR intervention will be shared. Findings, tips and lessons learned will be discussed for successful VR implementation.

### [Speakers](#)

**Kelly Allen** • Partners In Caring Respite Program Manager, Lifespan of Greater Rochester, Inc., Rochester, NY

**Katy Allen** • Division Leader Caregiver Services, Lifespan of Greater Rochester, Inc., Rochester, NY

**Cassidy Macdonald** • Education Coordinator, Lifespan of Greater Rochester, Inc., Rochester, NY

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## **College Students' Experiences Providing In-Home Respite: Implications for Training and Support**

### [Description](#)

The present study explored the perspectives of college students (n = 189) on their past experiences providing respite care to families of children/adults with intellectual and developmental disabilities. The goal of this study was to identify perceived challenges, successes, and training needs in order to design evidence-based initiatives to recruit and train college students as respite care providers. In this session, we will summarize our findings and lead an interactive discussion around curriculum development.

### [Speakers](#)

**Ashley Woodman** • Director, Developmental Disabilities and Human Services, University of Massachusetts Amherst, Amherst, MA

• **Elodie Carel** • Clinical Research Assistant, Center for Autism at Children's National, Hospital, Rockville, MD

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**Thursday, May 23 | BREAKOUT SESSION E | 11:30 AM – 12:30 PM**

## **Respite Care Among Parents of Autistic Children/Adults: Findings from a National Survey**

### Description

In this session, we will summarize and discuss our findings from a national survey of 539 parents of autistic children and adults. This study aimed to understand to what extent parents of autistic children/adults use respite care services as well as their level of satisfaction with finding and keeping a quality provider. Among those who had never used respite care services, barriers to access were examined.

### Speakers

**Ashley Woodman** • Director, Developmental Disabilities and Human Services, University of Massachusetts Amherst, Amherst, MA

**Tihitina Bekele** • Doctoral Student, Developmental Science, University of Massachusetts, Amherst, Amherst, MA

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*Prepared by the [ARCH National Respite Network and Resource Center](#), May 2024*