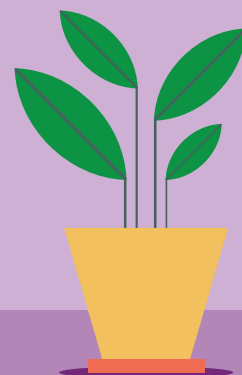


International Short Break Conference

Moving Respite Forward



JUNE 22 - 25, 2021
VIRTUAL



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on Twitter **@ISBA_ShortBreak**.



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International Short Break Conference

Moving Respite Forward



2021 Conference Schedule At-A-Glance

Time displayed in CDT

Tuesday, June 22, 2021

9:45 am - 11:15 am	Opening Ceremony
11:20 am - 12:00 pm	Opening Keynote Speaker: <i>Stephanie Summerville, USA</i>
12:00 pm - 1:00 pm	Lunch Break
1:00 pm - 1:25 pm	Breakout Session A
1:30 pm - 1:55 pm	Breakout Session B
2:00 pm - 2:25 pm	Breakout Session C
2:25 pm - 3:30 pm	Exhibitor Time Networking

Wednesday, June 23, 2021

9:00 am - 9:45 am	Exhibitor Time Networking
9:45 am - 9:55 am	Welcome and Conference Overview
9:55 am - 10:55 am	Opening Keynote Speaker: <i>Sister Edna Lonergan, USA</i>
10:55 am - 11:10 am	Break
11:10 am - 12:40 pm	International Respite Policy Panel
12:40 pm - 1:30 pm	Lunch Break
1:30 pm - 1:55 pm	Breakout Session D
2:00 pm - 2:25 pm	Breakout Session E
2:30 pm - 2:55 pm	Breakout Session F
2:55 pm - 3:30 pm	Exhibitor Time Networking
4:00 pm - 5:30 pm	Virtual Happy Hour

Thursday, June 24, 2021

9:00 am - 9:45 am	Exhibitor Time Networking
9:45 am - 9:55 am	Welcome and Conference Overview
9:55 am - 10:55 am	Opening Keynote Speaker: <i>Dr. Vibha Krishnamurthy, India</i>
11:00 am - 11:25 am	Breakout Session G
11:30 am - 11:55 am	Breakout Session H
12:00 pm - 12:25 pm	Breakout Session I
12:25 pm - 1:30 pm	Lunch Break
1:30 pm - 1:55 pm	Breakout Session J
2:00 pm - 2:25 pm	Breakout Session K
2:30 pm - 3:00 pm	Breakout Session L
2:45 pm - 3:30 pm	Exhibitor Time Networking

Friday, June 25, 2021

9:15 am - 9:25 am	Welcome and Conference Overview
9:25 am - 9:45 am	The Wisconsin Alzheimer's Institute "Amazing Grace" Chorus®
9:45 am - 10:00 am	Break
10:00 am - 11:00 am	Global Response to Respite and Caregiving in a Post-Pandemic World
11:00 am - 11:45 am	COVID-19 and Respite Round Table Discussions
11:45 am - 12:00 pm	Round Table Discussions Report-Out
12:00 pm - 12:15 pm	Closing Remarks and Announcement of Location for ISBA 2023

Short break is the more common term for "a break from caregiving" in Europe and many other countries, while in the USA and Australia, respite is the more commonly used term.

Virtual Platform Tips

About the Virtual Platform

The conference will be hosted in the OnAir Virtual Platform. Login details will be sent on Tuesday, June 15.

How Do I Get My Login Details for the OnAir Platform?

Your log in details will be sent on Tuesday, June 15. If you do not receive this email please check your Spam folder or contact isba2021@union.wisc.edu.

Keep your login details handy. They will remain the same throughout the conference.

Using Live Q&A

Each session will be running a Live Q&A at the end of the presentation. Throughout the presentation please write your questions in the Q&A tab on the right-hand side of the session page. You can also "up-vote" questions others have asked by giving them a thumbs up.

Using the Meeting Hub

The Meeting Hub allows you to connect and communicate with other attendees. Once you have located an attendee you want to connect with, click the Connect button. Once the other attendee accepts your request, you can choose to interact with your connection by starting a live chat or live video call. You can also schedule to meet at a future time, send messages and take notes. Contact information for all attendees you have connected with will be included when you export your contacts (see the Exporting your Notes and Contacts for additional information).

You cannot see yourself in the Meeting Hub so do not be alarmed if you are not visible.

How Long will the Platform be Open?

The platform will be available to login from Tuesday, June 15, 2021 and will remain open until Friday, July 23, 2021.

Display the Agenda in My Time Zone

The OnAIR timeline will display in your browsers time zone. To edit your time zone, click "My Settings" located at the top right-hand side of the OnAIR Platform.

Exporting My Notes and Contacts

You can take notes and connect with attendees, exhibitors, sponsors, and speakers throughout the conference. Notes and contacts can be exported during the conference, although we recommend exporting at the end. You can also download session handouts and materials.

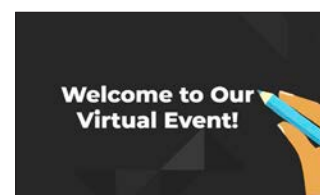
Optimizing Your Platform Experience

The following tips are recommended to optimize your OnAir Platform experience.

- Keep your login in handy. You will need it to access the conference.
- Log in before the conference and familiarize yourself with the platform.
- Check your profile, add a photo, and update your time zone.
- Access to a stable internet connection, preferably a wired connection.
- We recommend using Google Chrome.
- Close other applications or streaming sites.
- Use Headphones
- Use the "Back to Timeline" button inside OnAir to navigate in the platform, rather than the internet browser back button.

Video on How the Virtual Platform Works

Watch a short, 4-minute [video](#) to make the most of your OnAir Virtual Platform experience.



Commitment to Diversity, Equity, and Inclusion

The ISBA Conference is intended to foster the exchange of diverse ideas and perspectives, providing participants with an opportunity to present their lived experiences, best practices, and research findings, establish/renew collaborations, and learn, teach, and network with an international community of individuals interested in short breaks/respite care. ISBA is committed to creating a safe, equitable, and inclusive environment to all participants, including staff and vendors. Discrimination on the basis of gender or gender identity, sexual orientation, age, disability, physical appearance, race, religion, national origin, or ethnicity will not be tolerated. Participants are expected to adhere to these principles and respect the rights of others. Participants should report any behavior inconsistent with the principles outlined here to isba.shortbreak@gmail.com.



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#ISBA2021 on Facebook, Instagram, Snapchat, and
on Twitter **@ISBA_ShortBreak**.



Welcome to ISBA 2021!

The conference theme, ***Moving Respite Forward***, has a special relevance in light of the COVID-19 pandemic. In many ways, the pandemic cast a harsh light on the lack of support for caregivers, but in doing so, helped elevate their long unmet needs to a new level of awareness that is leading to a reimagining of respite and to real change. Sometimes, we may feel as though we have taken a step backward during these difficult times, but we are optimistic that because of all we have learned the past year about supporting caregivers in creative new ways, a positive path forward is inevitable in 2021 and beyond!

Even though we are not meeting in person, this conference will provide a meaningful virtual space to advance knowledge and understanding of respite by learning from and with international leaders in the field of respite. The conference will also challenge us to utilize evidence-based practices and discover innovative strategies to improve and perhaps even redefine respite to meet the challenges ahead. Together, we are ***Moving Respite Forward!***

The more than 60 breakout sessions with presenters from more than 15 countries will share a wealth of information on new approaches to short breaks and respite for children and adults, evolving research that builds an evidence-base for respite, exciting ways to engage family caregivers using technology, pathways to growing the respite provider workforce, lessons on engaging faith and volunteer communities, and so much more. Policy and program experts from many countries will educate us about the barriers to respite in their respective countries, but they will also enlighten us with emerging and far-reaching policy changes and public health approaches that might not have been possible pre-pandemic.

Amazing and exciting keynote speakers will engage and motivate us to tell our stories, will demonstrate how to reach across generations to provide nurturing care, and show us how, even in countries ravaged by the pandemic, there is real hope for supporting families. We'll experience joy in music from a chorus of individuals with dementia and their caregivers, and, in the true ISBA tradition, wave our countries' flags in the spirit of global friendship.

The conference will aptly reflect these successes and joys, but more importantly it will challenge us to fully participate in international, national, local, and even community responses that are ***Moving Respite Forward!***

Take advantage of everything the conference has to offer and let's energize the future of respite together!

Your 2021 International Short Break Conference Hosts:

Kim E. Whitmore, PhD, RN, CPN
ISBA President and Conference Chair
Assistant Professor, Marquette University

Lisa Schneider
Executive Director
Respite Care Association of Wisconsin

Jill Kagan
Director
ARCH National Respite
Network and Resource Center



Senator Tammy Baldwin

Spirit of a Leader Award

On behalf of Respite Care Association of Wisconsin and the ARCH National Respite Network and Resource Center, we recognize Senator Tammy Baldwin of Wisconsin with a Spirit of a Leader award for championing the passage of the Lifespan Respite Care Program Reauthorization Act.

The Lifespan Respite Care Program was authorized by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are statewide coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Such programs reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels.

Senator Tammy Baldwin was born in Madison, Wisconsin. Her grandfather was a scientist at the University of Wisconsin and her grandmother was a seamstress at the university theater company. Tammy was raised by her grandparents in the Badger State, and later served as her grandmother's primary caregiver as she grew older.

Tammy graduated from Madison West High School and went on to double-major in political science and mathematics at Smith College. In 1989, she received her law degree from UW-Madison. She served on the Madison Common Council; was elected to four terms on the Dane County Board of Supervisors; and in 1992, she was elected to the Wisconsin State Assembly, serving three terms.

In 1998, Wisconsin's 2nd Congressional District elected Tammy to Congress. After serving 14 years in the House of Representatives, Tammy was elected to the Senate in 2012 and she was reelected in 2018.

Senator Baldwin serves on the Senate Appropriations Committee and is the Chair of the Senate Appropriations Subcommittee on Agriculture, Rural Development, and Food and Drug Administration. In addition, Senator Baldwin is a member of the Senate Committee on Health, Education, Labor and Pensions (HELP), and the Senate Committee on Commerce, Science, and Transportation.

In the Senate, Senator Baldwin has long worked to provide much-needed support for family caregivers and help ensure that older adults and loved ones with disabilities receive the highest quality care. Senator Baldwin worked across the aisle to introduce the bipartisan Lifespan Respite Care Reauthorization Act, which was recently signed into law. Tammy will continue working to ensure our family caregivers can access the support and relief they need.



Wisconsin Governor Proclaims Respite Care Awareness Week

The Honorable Tony Evers,
Governor of the State of
Wisconsin, issued a Proclamation
designating June 22–25 as Respite
Care Awareness Week to coincide
with the 12th International Short
Break Conference.





The International Short Break* Association (ISBA) is a worldwide initiative made up of agencies and organizations providing health care and respite services for families concerned with disabilities. Their work is inclusive and responsive to their client's needs.

ISBA exists to provide the opportunity to acquire knowledge and experience of Short Break Care, across national and cultural boundaries. We want to create professional and physical tools with the aim of securing the home life of families and ensuring the integrity of the family unit.



History of ISBA

The first International Short Break Conference was held in the Canadian city of Thunder Bay, Ontario in 1995. This initiative was taken in an effort to create an international network for the exchange of knowledge and working practices, focused on Short Break Care for people with disabilities and their families. The central theme of the Conference was "Best practices in caring".

<i>Number</i>	<i>Year</i>	<i>City/Country</i>	<i>Theme</i>
1st	1995	Thunder Bay, Canada	Rendezvous on Respite
2nd	1999	Canterbury, England	Short Breaks in the 21st Century
3rd	2001	Sydney, Australia	Global Issues, Local Solutions
4th	2003	Orlando, Florida, USA	A Universal Break: Respite for Caregivers
5th	2006	Evry, France	Take Care of the Caregivers
6th	2008	Copenhagen, Denmark	Unconditional Client Focus
7th	2010	Galway, Ireland	Short Breaks: A Path to Inclusion – Whose Needs? Whose Rights? What Choices?
8th	2012	Toronto, Canada	Respite is Key
9th	2014	Wolfenbüttel, Germany	Inclusion Worldwide – Supporting People with Disabilities and Their Families
10th	2016	Edinburgh, Scotland	Unlocking the Potential of Short Breaks
11th	2018	Reykjavik, Iceland	Opportunities and Co-Creation
12th	2021	Virtual, hosted by USA	Moving Respite Forward

Learn more about ISBA online at [ISBA.me!](https://www.isba.me)



The **MISSION** of the [ARCH National Respite Network and Resource Center](#) is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums.

The ARCH National Respite Network includes the [National Respite Locator](#), a service to help caregivers and professionals locate respite services in their community; the [National Respite Coalition](#), the policy division of ARCH that advocates for preserving and promoting respite in policy and programs at the federal, state, and local levels; and the [Lifespan Respite Technical Assistance and Resource Center](#), which is funded by the Administration for Community Living in the U.S. Department of Health and Human Services to help state agencies, state respite coalitions, and the respite network improve and expand respite services, access, and affordability for all family caregivers.

ARCH was established with funding from the U.S. Children's Bureau in 1990. The first national respite conference was sponsored by the Children's Bureau with ARCH's assistance in the fall of 1991 in Washington, DC. In 1998, ARCH took on a lifespan perspective and became the main sponsor of the annual national respite conference with state respite coalition collaboration and has hosted a national U.S. event nearly every year since then. ARCH has also been a leader in the international respite network. In 2003, ARCH hosted the International Short Break Conference in Orlando, Florida. In 2006, at the international conference in France, ARCH, as a founding member, helped launch the official establishment of the International Short Break Association.

ARCH, which stands for *Access to Respite Care and Help*, is a program of Families and Communities Rising in Durham, NC.

archrespite.org



Respite Care Association of Wisconsin, Inc. (RCAW) is a 501(c)(3) non-profit charitable organization established in 1987. In 1999, Wisconsin adopted the Lifespan Respite Care legislation and contracts with RCAW to administer the program. We are funded by state General Purpose Revenue (GPR) through the Wisconsin Department of Health Services (DHS).

Our **MISSION** is to promote, support, and expand quality, statewide respite care across the lifespan. We are an organization that achieves the greatest success and sustainability by working collaboratively with existing service delivery systems to:

- **Promote** by initiating, sponsoring, and promoting educational programs, collaborating with other subject matter experts to increase outreach and opportunities for respite providers and primary caregivers.
- **Support** through the utilization of our Respite Care Certification Program & Wisconsin Respite Care Registry, Caregiver Respite Grant Program, Group Respite Grant program, and our CORE Grant Program.
- **Expand** the pool of quality, trained respite care providers, and connect them to primary caregivers, in need of respite via the Wisconsin Respite Care Registry.
- Serving 72 counties **Statewide**
- **Across the Lifespan** – regardless of age, ranging from birth to end of life.

RCAW offers free programming in 5 key areas:

- **Training**
- **Grants**
- **Registry**
- **Resources**
- **Outreach & Information**

To find out more about RCAW, visit respitecarewi.org

*ISBA sincerely thanks our co-hosts and sponsors
for supporting our mission and making the International Conference possible!*

2021 Conference Co-Hosts



2021 Conference Sponsors

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FRIENDS OF RESPITE



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2021 Conference Tracks



INNOVATIVE SERVICES

In this dynamic track, presenters will describe respite services on the cutting edge that provide new and innovative approaches to short breaks, especially as a result of changes in service delivery imposed by the pandemic. Sessions will focus on engaging volunteers and the faith community to provide respite. Some will explore how they successfully reach families across the age and disability spectrum in meaningful ways; how they reach and serve invisible and unserved groups who are often ineligible for public funding streams or who are geographically or culturally isolated from mainstream services. The special needs of working caregivers will also be addressed.



RESEARCH & EVALUATION

As service providers and caregivers make a case for respite availability and funding, we need to demonstrate a solid evidence-base for respite. Research also provides an understanding of the health and well-being of family caregivers and the overall effect of respite on societal outcomes, including cost-benefits. This track presents findings from evaluations of respite activities, respite models, technologies, policies, and interventions to assist care recipients and their family caregivers.



FAMILY CAREGIVER PERSPECTIVE

This track is primarily geared to family caregivers and those who work with family caregivers who want to learn more about successful caregiving strategies, respite for specific populations, technologies and resources that support caregivers, and impactful stories related to the benefits of respite and caregiver wellness programs.



2021 Conference Tracks (cont.)



CAPACITY & SUSTAINABILITY

Increasingly, we have come to understand that our efforts to sustain the vital work we do in caregiving and respite is inextricably linked to our changing economic, social, and political environment, as well as to the most recent challenges imposed by the worldwide pandemic. This track will feature presentations that address the value of fostering new partnerships; utilizing business practices to ensure sustainability; partnerships with health systems or employers to promote respite; outreach and financing strategies for sustainability; embedding respite activities into larger state or country-wide health or social services systems; and addressing the worldwide shortage of direct service workers.



ADVOCACY & NETWORKING

Policies, politics, the media, and changing community demographics influence how we will reach and serve families. We must be advocates and collaborators as well as service providers. These sessions will explore exciting new public awareness campaigns, legislative advocacy, emerging national and international policies that impact caregivers and respite, and other explosive but illuminating contexts for providing and promoting respite and moving respite forward.



LIFESPAN RESPITE

These sessions may be of particular interest to Lifespan Respite grantees and their partners. Through the federal Lifespan Respite Program, the U.S. Administration for Community Living awards competitive grants to state agencies in partnership with state respite coalitions and others to develop statewide coordinated systems of community-based respite services for family caregivers caring for children and adults; provide planned and emergency respite for unserved family caregivers; increase respite capacity and options through innovation of community-based, volunteer and faith-based services that are person and family-centered; address the workforce shortage by recruiting and training respite workers and volunteers, and linking family caregivers to respite services and resources. This track will shine a spotlight on best practices in current Lifespan Respite grant activities and systems.



Keynote Speakers



Tuesday, June 22, 2021

The Respite Care Story: How Telling It Moves You Forward

Stephanie Summerville, Musical Theater Performer and Storyteller, New York, NY, USA

Stephanie Summerville is a New York-based actress, speaker, and storyteller, most known for work with the Moth, a live storytelling events organization, and The Moth Radio Hour on National Public Radio. Her stories have been published in major publications across five continents in four languages. Most recently, her stories have been featured in The Huffington Post UK edition, and on the BBC Radio Program Outlook.

When not circling the globe on cruise ships as a speaker and performer, she lives as a nomad, declaring home to be "wherever I hang my hat."



Wednesday, June 23, 2021

Intergenerational Care for All Ages and Abilities: A New Social Model of Community-Based Care

Sister Edna Lonergan, 2019-2020 AARP Purpose Prize Winner, Founder and President, St. Ann Center for Intergenerational Care, Milwaukee, WI, USA

As a nurse, occupational and massage therapist and gerontologist, Sr. Edna Lonergan is a leading advocate promoting the benefits of intergenerational programs. Through her vision and guidance, St. Ann Center became the first dementia-specific day care in Milwaukee and one of the first fully integrated intergenerational day cares in the United States – serving children, frail elders and adults of all ages with disabilities and their caregivers in one home-like setting. Since opening St. Ann Center's Stein Campus on Milwaukee's south side in 1999, she replicated the center at the Bucyrus Campus, opened in 2015, on the city's near north side – one of the most economically challenged and underserved areas of Milwaukee.

St. Ann Center for Intergenerational Care, sponsored by the Sisters of St. Francis of Assisi, reflects Franciscan values in meeting the spiritual, physical, psychological, and social needs of all who participate, regardless of faith, culture, or ability to pay. Sr. Edna's credo for those in her care: "It doesn't matter what age they are...everyone needs a sense of purpose."



Thursday, June 24, 2021

The Big Little Things – What We Learnt from Children and Caregivers During the Pandemic

Dr. Vibha Krishnamurthy, Founder and Executive Director, Ummeed Child Development Center, Mumbai, India

Vibha Krishnamurthy is a Developmental Pediatrician with 21 years of experience in working with children with disabilities and their families in India. She trained in Developmental Pediatrics at Children's Hospital, Boston, and founded Ummeed Child Development Center in 2001 where she is currently the Executive Director. Ummeed is one of India's leading not for profits that works with children with disabilities and their families. She has led the team at Ummeed in its delivery of services, training, advocacy, and research in the field of child development and disability. She serves as an expert on Early Childhood Development and Disability for the Government of India, WHO and UNICEF. She is the past President and Board member of the International Developmental Pediatrics Association.

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on Twitter **@ISBA_ShortBreak**.



International Respite Policy Panel

Wednesday, June 23, 2021 • 11:10 am – 12:40 pm



Jon Bartholomew, AARP, USA

Jon is a Senior Legislative Representative for AARP's Government Affairs Team. In this role, he assists AARP state offices with health care policy. Prior to this position, he was the Government Relations Director for AARP Oregon for five years. His experience also includes serving as the Public Policy Director at the Alzheimer's Association Oregon Chapter, where he coordinated the creation of the State Plan for Alzheimer's disease in Oregon. He has worked in public policy for 24 years, working on issues such as after-school program funding and media reform. Originally from Pennsylvania, he earned his Master's in Public Administration at the University of Washington.



Joseph Caldwell, PhD, Brandeis University, USA

Dr. Caldwell has over 25 years of experience in the fields of aging, disability and family caregiving as a researcher, policy expert, and family member. His research has focused on supports for aging caregivers of adults with developmental disabilities, outcomes of person and family-directed supports, and promising practices in family support across the lifespan and disability populations. Prior to his current position at the Community Living Center, Lurie Institute for Disability Policy, Brandeis University, he worked to advance federal long-term services and supports policy at the National Council on Aging, Association of University Centers on Disabilities, and as a Joseph P. Kennedy, Jr. Fellow on the Senate Health, Education, Labor, and Pensions (HELP) Committee. Joe has served on the boards of the National Alliance for Caregiving and Consortium for Citizens with Disabilities. He currently is an appointed member of the RAISE Family Caregiving Advisory Council.



Jo Chopra-McGowan, Latika Roy Memorial Foundation, India

Jo is an American who has lived in India for the past 42 years. She and her husband Ravi have three children, the youngest of whom – Moy Moy – was disabled. Jo is the founder and director of the Latika Roy Foundation, a leading non-profit in Dehradun, India which is dedicated to providing services to disabled children and adults. Moy Moy died in 2018 but her memory lives on in the Foundation. Jo is a writer who has authored five books and hundreds of essays and articles in major US and international publications.

International Respite Policy Panel (cont.)



Piotr Kuzniak, *Imago Foundation, Poland*

Over the last 13 years, Piotr developed skills as a social project manager (an author of 11 transnational and 22 national projects dedicated to persons with disabilities and their families). Since 2009, he's been running his own foundation – an expert organization in cross-sector initiatives. Especially interested in transnational cooperation and short break development projects, Mr. Kuzniak is responsible for coordinating international and national work groups, organizing workshops and seminars in the field of short breaks, and networking and creating links between local administration and NGOs. He has authored numerous reports, research studies and articles, and has participated in multiple ISBA conferences in Wolfenbuttel, Edinburgh, and Reykjavik.



Janet Leach, *Contact, United Kingdom*

Janet is currently a Trustee and Director of Contact, a national charity for families with disabled children. Janet has worked in the field of disability for over 40 years, qualifying as a social worker in 1984. Janet recently completed an MSc in Voluntary Sector Management researching into the impact of poverty on disability. Janet has extensive board and leadership experience and has championed parent partnerships throughout her career. Janet enjoys being on the ISBA committee, sharing ideas - and much laughter - whilst learning from colleagues around the world.



Emma Miller, *University of Strathclyde, Scotland*

Emma has been a senior research associate at Strathclyde since 2012 and was previously attached on an honorary basis from 2009. Emma has a background in social work practice, and interagency working. Since completing her PhD in 2004 she has worked between research, policy and practice on the theme of personal outcomes. Based on knowledge exchange and action research, this has focused on embedding an outcomes approach to practice and has involved partnership between a wide range of national bodies and local organisations to re-orient culture, systems and practice accordingly. The primary purpose of this work is to support outcomes focused and person centred engagement at the frontline, with a secondary purpose to measure outcomes and use this information for service planning and improvements. In the past few years, the work has drawn increasing interest from wider UK and international universities and agencies.



Catharine Shanahan, *Family Respite Services Windsor-Essex, Canada*

Catharine is the Executive Director of Family Respite Services in Windsor Ontario, Canada. Family Respite Services supports over 1200 children with disabilities, providing a wide spectrum of in-home, out-of-home and community-based respite supports. Catharine has been a member of the ISBA committee since 2010. Ms. Shanahan chairs the Provincial Respite Network in Ontario and is a member of the Leadership group for supportyourway-respiteservices.com.

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on Twitter **@ISBA_ShortBreak**.



Global Response to Respite and Caregiving in a Post-Pandemic World Panel

Friday, June 25, 2021 • 10:00 am – 11:00am



Amanda Batten, *Contact, United Kingdom*

Amanda is Chief Executive of Contact, the charity for families with disabled children. She joined the charity as Chief Executive in May 2014. Amanda founded and Chairs the Disabled Children's Partnership, a coalition of over ninety organisations campaigning for improved health and social care for disabled children, young people and their families. Amanda has worked in the disability sector for 15 years, and contributes to a range of advisory boards and national partnerships. She is a Fellow of the Royal Society of Arts.



Amy Coupal, *The Ontario Caregiver Organization, Canada*

Amy is the CEO of the Ontario Caregiver Organization (OCO) in Ontario Canada. OCO is a non-profit that was formed in 2018 to support Ontario's 3.3 million caregivers. A visionary leader with 15 years of experience in the not-for-profit sector, Amy has extensive experience building organizations from the ground up and is excited to be leading the Ontario Caregiver Organization through its early days of growth. She has held a number of CEO roles, including CEO of Learnography and My Class Needs Foundation, and has expertise in the latest innovations and technologies related to learning and education. Amy is passionate about mobilizing change through knowledge sharing and building collaborative initiatives that positively impact the lives of individuals and communities.

Amy has a Masters of Education from the University of Calgary and is an Adler-trained coach. Her insights have been shared through speaking and media engagements, both internationally and here in Canada.

Amy has a deep understanding of the benefits and challenges associated with caregiving. As a caregiver for most of her life, Amy helped to support her brother who had Cerebral Palsy. She was also a caregiver to her mother throughout her cancer journey and now supports her elderly father.

Global Response to Respite and Caregiving in a Post-Pandemic World Panel (cont.)



Jaia Peterson Lent, *National Center on Grandfamilies, Generations United, USA*

Jaia is the Deputy Executive Director at Generations United, a national advocacy organization based in Washington, DC, where she has worked since 2000. Generations United's mission is to improve the lives of children, youth and older people through intergenerational collaboration, public policies and programs. Jaia is a co-director of the National Center on Grandfamilies, a leading voice for families headed by grandparents or other relatives. She is a trusted voice on Capitol Hill on issues related to grandfamilies and intergenerational cohesion. She has testified before the U.S. Senate Special Committee on Aging and serves as cochair of the federal Advisory Council to Support Grandparents Raising Grandchildren. She is a sought-after speaker, nationally-recognized columnist and blogger and respected media resource. She has been named one of the Top 50 Influencers in Aging by Next Avenue. Under her leadership, legislation has passed to support grandfamilies in areas ranging from housing to family caregiving to child welfare. Lent holds an MSW from Syracuse University and is a licensed social worker.



C. Grace Whiting, J.D., *National Alliance for Caregiving, USA*

As NAC's current President and CEO, Grace followed in the footsteps of the National Alliance for Caregiving Founder Gail Gibson Hunt to helm one of the nation's leading public policy and advocacy organizations for friend and family caregivers. With previous experience as COO and the Director of Strategic Partnerships, Grace doubled the organization's budget in her tenure to date and created the Hunt Research Program.

Grace led the nation's first national policy study of 1,400+ rare disease caregivers with Global Genes. She has led other original NAC research including Sandwich Generation in the U.S. with Caring Across Generations; A National Study of Caregivers of Individuals with Crohn's Disease or Ulcerative Colitis with the Crohn's and Colitis Foundation and ImproveCareNow; Cancer Caregiving in the U.S. with the National Cancer Institute and Cancer Support Community; and Dementia Caregiving in the U.S. with the Alzheimer's Association, among others.

Grace has spoken on caregiving at several national and international conferences and also served as a resource to major media on the topic of caregiving and aging, including C-SPAN, The Wall Street Journal, Time Magazine, Oprah Magazine, Women's Health Magazine, and Kiplinger's Retirement Report.



Don Williamson, *Shared Care Scotland, Scotland*

Don has been Chief Executive of Shared Care Scotland since January 2006. Prior to this he was the Programme Director in Edinburgh for Common Purpose, an international leadership development charity, and before this was eight years with The Duke of Edinburgh's Award, latterly as Deputy Director for Scotland. Don has also worked in the outdoor education and natural heritage sectors. Between 2014-16 he served as President of the International Short Breaks Association, as part of Shared Care Scotland's hosting of the 10th International Short Breaks conference in Edinburgh in 2016. In a voluntary capacity, he serves on the Board of the Green Team, an Edinburgh-based environmental youth work project.

International Short Break Conference

Moving Respite Forward



Conference Schedule

Tuesday, June 22, 2021

Time displayed in CDT

9:45 am - 11:15 am **OPENING CEREMONY**

The opening ceremony will feature welcome remarks from the conference co-hosts, celebratory music, inspirational caregiving stories, and an international flag ceremony representing all countries of those attending the conference. The Spirit of a Leader Award will be presented to Senator Tammy Baldwin (D-WI) for her championing of the Lifespan Respite Care Reauthorization Act.

11:20 am - 12:00 pm **OPENING KEYNOTE: *The Respite Care Story: How Telling It Moves You Forward***

Moderated by Casandra Firman, ARCH National Respite Network and Resource Center and ISBA Committee Member, USA



Stephanie Summerville, Musical Theater Performer and Storyteller, New York, NY, USA

Stephanie shares with us her story of how, in her twenties, her college pursuits were disrupted, and she ended up with a job caring for an unlikely and challenging patient. She will explain how the power of personal storytelling can provide momentum to overcome obstacles and help you to achieve your goals.

12:00 pm - 1:00 pm **Lunch Break**

BREAKOUT SESSION A

The Lifespan Respite presentation in this session has a different end time.

1:00 pm - 1:25 pm

A1: Tips and Tricks for Recruiting, Hiring and Keeping Quality Caregivers



Erica Andres, Self-Advocate, WI, USA

Everyone in Wisconsin and around the country is very well aware of the Caregiver Crisis we are facing right now. This session will focus on real-life examples and stories from a person living with Muscular Dystrophy who has done hiring both on the professional and personal side. Learn some unique places to find workers, questions to ask when interviewing and some tips for keeping good workers once you find them.

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1:00 pm - 1:25 pm

A2: Intersection of Respite and Self-Directed Long-Term Services and Supports: State Policies and Practices



Molly Morris, *Applied Self-Direction, USA*

In the Spring and Summer of 2019, AARP combined forces with Applied Self-Direction (ASD) to carry out a National Inventory of Self-Direction Programs. This was the fourth such Inventory since 2011 and it identified all self-direction programs currently operating in the 50 states and the District of Columbia. The 2019 Inventory looked specifically at the intersection of respite and self-directed services. This presentation will address the results of this study and the prevalence of respite services within a self-direction context. It will also explore the impact of the COVID-19 pandemic on self-direction and the role of family caregivers.

1:00 pm - 1:25 pm

A3: How do Parent Carers and Professionals Work Together in a Spirit of Co-production to Achieve Lasting Change and Improved Short Break Services



Janet Leach, *Contact, UK*

Gail Walshe, *Contact, UK*

The presentation will look at how England has developed co-production, which is when parents play an integral and equal part in the decision-making process and are fully engaged in shaping, developing, implementing, and evaluating services and systems. Presenters will discuss how co-production concepts were used to address the findings from Parliamentary Hearings on Services for Disabled Children (2006) that children's limited access to respite care, now termed short breaks, including access to play activities, to be the greatest source of unhappiness among parents.

Evidence shows that partnerships often make the best use of people's time and money, whilst also improving outcomes for disabled children. Presenters will consider how local areas have developed these partnerships and established parent carer forums with strong connections across all agencies promoting trust, understanding and constructive challenge and how this collaborative approach is changing and influencing the delivery of services and short breaks. The session will also briefly explore the national picture and the work and influence of the National Network of Parent Carer Forums (NNPCF) which aims to create a culture of co-production and participation for all families living with special educational needs and disabilities.

1:00 pm - 1:25 pm

A4: Summer Respite Camp Immersion for Undergraduate Nursing Students



Kim Whitmore, *Marquette University, WI, USA*

Jennifer Fiegel-Newlon, *University of Wisconsin-Madison, WI, USA*

Gail Krummen-Lee, *University of Wisconsin-Madison, WI, USA*

Nursing students often have little exposure to individuals with disabilities as a part of formal nursing education. The Summer Respite Camp Immersion was developed as a six-week summer course that meets the requirements of a second-year undergraduate nursing course where they spend three weeks at a summer respite camp providing direct care to both children and adults with disabilities. Students participating in this new course will gain confidence and skill through hands-on experience providing nursing care to children and adults with disabilities and gain an appreciation of the demands of family caregiving and the importance of respite care for families. Session participants will learn more about this program and how it might be adapted to other nursing programs around the world as an innovative way to provide undergraduate nursing students with experience working with individuals with disabilities.

1:00 pm - 1:25 pm

A5: As Safe As Possible – Empowering People with Disabilities to Say “No” to Exploitation and Human Trafficking – An Overview for Caregivers



Brandon Chase, *Community Living Essex County, Canada*

Empowering people with disabilities to say “no” to exploitation and human trafficking is what Community Living Essex County’s As Safe As Possible (ASAP) Project is all about. ASAP is a dynamic partnership with the Ontario Provincial Police, Windsor-Essex Children’s Aid Society, Legal Assistance of Windsor, and people with an intellectual disability to create an informed, comprehensive, community-based response. ASAP is a two-pronged message of empowerment for people with intellectual disabilities and awareness for justice personnel to improve the safety and well-being of people with disabilities.

The 25-minute presentation will introduce the audience to the ASAP project and discuss 5 main reasons why people with an intellectual disability are at risk. This presentation will also showcase the two multi-faceted in-person and online training curriculums for people with disabilities and justice professionals; and encourage and provide tools for replication of this valuable work in other communities.

1:00 pm - 2:10 pm

A6: Moving Respite Forward in New York State



Deana Prest, *New York Office for the Aging, Division of Policy, Planning, Program and Outcomes, NY, USA*

Abbey Lavazzo, *New York Office for the Aging, Division of Policy, Planning, Program and Outcomes, NY, USA*

Doris Green, *New York State Caregiving and Respite Coalition, NY, USA*

Through presentation materials and interactive activities, participants will learn about core components used for Lifespan Respite in New York State to build capacity, engage partners, and undertake ongoing sustainability planning and implementation. Presenters will share information about our history, structure, and growth as a Lifespan Respite state grantee from 2010 to the present. Presenters will discuss use of the ARCH Sustainability Toolkit for Lifespan Respite action planning and implementation to help move respite forward, focusing on two of the New York State Caregiving and Respite Coalition (NYSCRC) services important to its sustainability: (1) The NYSCRC Caregiver Simulation, and (2) NYSCRC in its role as the national point of contact for Respite Education and Support Tools (REST) Master Training. As part of its Lifespan Respite model, presenters will share information about how the New York State Office for the Aging (NYSOFA) is implementing the NY Connects No Wrong Door system for access to long-term services and supports across the state, including access to its public NY Connects Resource Directory and its respite listings. New York also is expanding efforts to focus on caregivers in the workplace and will provide information on the tools being developed for caregivers and employers, including use of the Employed Caregiver Survey developed by the University of Wisconsin-Madison Division of Extension.

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BREAKOUT SESSION B

1:30 pm - 1:55 pm



B1: A Comprehensive Model of Supporting People with Disabilities and Their Families from Birth to a Dignified Death on the Example of the Milicz Association of Friends of Children and Disabled People (MSPDiON)

Malgorzata Biernacka, *Milicz Association of Friends of Children and People with Disabilities, Poland*

This session will focus on the mission of the Milicz Association to provide comprehensive support of a person with a disability and their family from birth to a dignified death. Respite care is provided at various stages of life. The presenter will describe the range of services provided, including diagnosis and early intervention, preschool, school age services at the Daily Rehabilitation and Education Center and afterschool programs, the Environmental Self-Help House for individuals with the greatest need, and Occupational Therapy Workshops for adults with disabilities. Throughout the lifespan, continuous family and caregiver support is provided. Supports to families include support groups, therapeutic trips that include child therapy as well as workshops for parents. Children are followed through school and families supported through respite. Finally, the presenter will describe the training flat and "respite room" as an alternative for adults with various disabilities, that permit learning self-reliance, and give parents a respite from 24-hour care.

1:30 pm - 1:55 pm



B2: Demand and Usage of Disability Respite Services in Ireland – Information for Policy from National Disability Databases

Patsy Carr, *Department of Health, Ireland*

Sarah Fanagan, *Health Research Board Dublin, Ireland*

Eithne Fitzgerald, *Department of Health, Ireland*

Internationally, there is little research that maps national systems of respite care/short breaks delivery, and measures this against the characteristics of the population who receive or require short breaks. The Department of Health, Ireland's social care authority, has carried out a detailed national analysis of provision of and access to short break services for people with disabilities, to underpin development of a national policy on respite. In this session, presenters will describe their research that examines trends over time in provision of respite breaks against trends in the number of people with disabilities at different ages living in the parental home; documents the dominant forms of such respite breaks; looks at age-related patterns of use; regional variations; use by level of disability; occupancy rates of respite facilities, and intensive (few individuals, many breaks) versus extensive (many individuals, fewer breaks) provision of services. The presented paper sets out policy considerations and signposts to future direction of national respite policy in Ireland.

1:30 pm - 1:55 pm

B3: A Parental Perspective on Short Break Design in the Southern Health and Social Care Trust, Northern Ireland



Sophie Castell, *National Autistic Society, United Kingdom*

The presentation will start by exploring what the concept of “short breaks” means to parents and young people. The needs that short breaks fulfill will be dimensionalised through considering a range of first-person, lived experiences of both parents/carers and young people. The presentation will also reflect on how the needs of parents, young people and, collectively, families, change as young people transition through childhood, adolescence and into adulthood. Some of the barriers and enablers that parents experience in meeting these needs will be considered as well as some of the strategies that parents develop to address them. The focus will be on practical, day-to-day lived experience and bringing to life the fears and hopes of families. The presentation will then explore practical ways in which mutual benefit can be achieved through genuine partnership working and shifting from a model of consultation to a model of co-production and will conclude with reflections on how both parents and professionals can work synergistically for the benefit of young people with special needs and disabilities.

1:30 pm - 1:55 pm

B4: Telling Your RESPITE Story: The Art of Nonprofit Communication



Ken Smythe-Leistico, *Carlow University, PA, USA*

Regardless of what field we work in, we are often thrust into communication roles. Within the nonprofit sector, the tasks of practitioner and communicator often overlap. Yet, few have ever had any formal training in communication strategies. This workshop will cover the basics of articulating your organization’s mission, key functions, and successes through: Communications 101: building care, hope, and collective action; Communications Pitfalls: common mistakes; and developing your message for various target audiences. This engaging workshop will be tailored to your work in the RESPITE field. Numerous activities will allow attendees to examine their own organization’s website, flyers, and marketing strategies. Key skills gained will include creating an elevator pitch, prioritizing target audiences, best practices in messaging, and developing a rubric for content review.

1:30 pm - 1:55 pm

B5: Growing Along with ISBA



Piotr Kuźniak, *Imago Foundation, Poland*

Magda Stempska, *Imago Foundation, Poland*

Repeated protests by parents of people with disabilities in Poland, including the most recent demonstrations in May 2018, confirmed that policies supporting caregivers and ensuring social services and a right to short break and respite services were needed. The presenter will describe how the political movement of caregivers forced the government to enact legislation on the Solidarity Support Fund for Persons with Disabilities, which launched the first national short break program. Poland has looked to the International Short Break Association for assistance with service development. The presenter will share the work of the Imago Foundation, which has been developing tools, standards and good practices; educating NGOs and public administration about short breaks; co-creating with local and national administration careers’ support policy; and creating a national network of service providers.

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BREAKOUT SESSION C

The Lifespan Respite presentations in this session have different start and end times.

2:00 pm - 2:25 pm

C1: Give Me a Break – Easing the Responsibilities of Caregiving



Anil Patil, *Carers Worldwide, United Kingdom*

The presenter, who is the founder and Executive Director of Carers Worldwide, that reaches carers in 17 projects in India, Nepal and Bangladesh, will share findings from their most recent survey that showed that 90% of caregivers are concerned about not being able to take a break. He will describe a pilot project, an innovative, community-led alternative known as “community caring centres.” Led jointly by caregivers and community members, with the support of local NGOs, these centres provide a haven for both caregiver and cared-for. For a small daily fee, caregivers can leave the child or adult secure in the knowledge that their loved one will be kept safe, well-fed, and stimulated. Participants will be given the opportunity to provide suggestions to improve the initiative, especially in low and middle income (LAMI) countries.

2:00 pm - 2:25 pm

C2: Time for Living and Caring (TLC): A Virtual Coach to Maximize the Benefit of Respite Time Use



Rebecca Utz, *University of Utah, UT, USA*

Prior research demonstrated that caregivers who used respite to do what they had most desired, needed, or had planned to do had the highest satisfaction with their time-use and reported the most positive wellbeing over time. Presenters from the University of Utah will describe the development of an intervention, Time for Living and Caring (TLC), designed to maximize the benefit of caregivers’ respite time. TLC, as originally conceptualized, relied on trained facilitators delivering as many as 15-20 visits or phone calls to ensure fidelity. To overcome challenges for sustainability and implementation, the TLC intervention has now been translated into a self-administered, web-based platform to make it more scalable for real world application. In this session, attendees will learn about the new TLC intervention that will be evaluated with a clinical trial supported by the National Institute on Aging.

2:00 pm - 2:25 pm

C3: The Family Support Group: Parents as Partners in the Care of Children with Developmental Disabilities



Jill Sanghvi, *Ummeed Child Development Center, India*

Aditi Jha, *Ummeed Child Development Center, India*

India has over 50 million children with disabilities under the age of 15. For Mumbai alone, the estimate is around 650,000 children. However, there is not a single formal respite center for families with children with developmental disabilities in Mumbai, where opportunities for leisure are limited. Presenters will discuss the family support group model that provides a low cost, unique, inclusive, and participatory approach to respite for families in middle income countries. They will share experiences of the groups; lessons learned and plans for the future. The audience will have an opportunity to witness the importance of respite for families in India and the workings of the model in a different cultural context. The presentation will include video recordings from the group where parents speak about their own experiences and what this space means to them. It will also include photos as well as video recordings of groups in action.

2:00 pm - 2:25 pm

C4: Better Not Bigger – Creating Sustainable, High Quality Supports in an Individualised Funding Environment


 **CAPACITY & SUSTAINABILITY**

Jake Pearson, Interchange Illawarra, Australia
Susan Wallis, Interchange Illawarra, Australia

The introduction of Australia's National Disability Insurance Scheme (NDIS), a person-centered, individualised model of funding for over 400,000 Australians living with disability has had a profound effect on government, service providers and people with disabilities and their carers. For the first time, people with a disability now have individualised funding budgets and hence the opportunity to choose their providers. This commercial and transaction-focused landscape has challenged the survival of traditional, mostly not-for-profit organisations to rethink strategy, structures, and service delivery offerings in order to survive. Presenters will share how their organization, Interchange Illawarra, a very small not-for-profit, boutique disability service, has decided to buck the trend and adopt the "Better not Bigger" mantra. This presentation will explore Interchange Illawarra's strategic intention to remain small and boutique, the strategies employed to survive and thrive in a competitive, low margin environment, and how this translates to quality outcomes for people with disabilities and their carers.

2:00 pm - 2:25 pm

C5: Together for Change


 **ADVOCACY & NETWORKING**

Tamara Kralj, Center for Rehabilitation Zagreb, Croatia
Martina Pavic, Center for Rehabilitation Zagreb, Croatia

Presenters will describe a new program of supported living in the local community in Zagreb which today provides services for 96 adults with intellectual disabilities. Inspired by ISBA 2016, they applied for funds from the European Union to start a project aimed at empowering families that take care of a family member with intellectual disability by introducing the short break program. The project has been approved for the period of two years and it started in June 2020. During this session, we will present the project which brings novelty in the social care department for families that take care of adults with intellectual disabilities. We will also share challenges we have encountered during the implementation of the new service and our first accomplishments.

2:15 pm - 2:50 pm

C6: Partnerships for Caregivers in a No Wrong Door/ADRC Environment During a Pandemic

 **LIFESPAN RESPITE**

Alicia Hess Blater, North Carolina Division of Aging and Adult Services, NC, USA
Jessalyn Bridges, North Carolina Division of Aging and Adult Services, NC, USA

We often hear, "I wish I had known about your service earlier" or "Why didn't anyone tell me about you?" How can you equip staff outside your organization to share information about your services, and maybe even sign them up to receive those services? Come to this presentation to hear about how North Carolina partnered with their United Way 2-1-1 Call Center Staff and other organizations who interact with family caregivers seeking services to increase referrals to local respite services and the state's Lifespan Respite Voucher Program. We'll also discuss methods for finding and building local referral partnerships that could be great at sharing your message if only they knew who you were and what you did.

2:55 pm - 3:30 pm

C7: Lifespan Respite in Adult Day Health Centers – Successes and Challenges



Jutta Ulrich, Arizona Caregiver Coalition, AZ, USA

Brandon Baxter, Nacog Area Agency on Aging, AZ, USA

The Arizona Caregiver Coalition works with the Arizona Department of Economic Security to administer the Lifespan Respite grant. Arizona chose to apply funds to respite provided in adult day health centers (ADHC) and added a voucher program for in-home respite in the third year of the grant. This presentation will review the challenges in working with the adult day health centers as well as the positive outcomes for family caregivers. The limitations of the day centers helped highlight some of the shortcomings of the respite network: lack of overnight respite, centers for younger people, respite for families caring for a person with behavioral health issues, and evening or weekend respite for caregivers who are working. The presenter will also share how the analysis of demographic data indicated that additional care must be taken to serve individuals other than caregivers of older adults and to serve sub-populations such as Hispanic and Native American families.

2:25 pm - 3:30 pm **Exhibitor Time | Networking**



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Wednesday, June 23, 2021

Time displayed in CDT

9:00 am - 9:45 am Exhibitor Time | Networking

9:45 am - 9:55 am WELCOME AND CONFERENCE OVERVIEW

9:55 am - 10:55 am **OPENING KEYNOTE: *Intergenerational Care for All Ages and Abilities: A New Social Model of Community-Based Care***

Moderated by Lisa Schneider, Respite Care Association of Wisconsin, WI, USA

Sister Edna Lonergan, 2019-2020 AARP Purpose Prize Winner, Founder and President, St. Ann Center for Intergenerational Care, Milwaukee, WI, USA



More than 30 years ago, Sr. Edna Lonergan saw the need for a day care center that is intergenerational, where kids, adults with disabilities, seniors and even people with dementia interact in the same fun and compassionate space. St. Ann Center for Intergenerational Care has served tens of thousands of adults and children in two locations in Milwaukee, and is recognized as a model, inspiring other centers around the globe. Sr. Edna will share: the stories behind the creation of an intergenerational day care that challenges age segregation; the impact and unique benefits of bringing the generations together for both children and adults; how to provide seamless adult day care and overnight respite in one full-service center; and designing a respite center that feels like home and reflects your clients' culture.

10:55 am - 11:10 am Break

11:10 am - 12:40 pm **INTERNATIONAL RESPITE POLICY PANEL**

Moderated by Kim Whitmore, Marquette University, USA

Jon Bartholomew, AARP, USA

Joseph Caldwell, PhD, Brandeis University, USA

Jo Chopra-McGowan, Latika Roy Memorial Foundation, India

Piotr Kuzniak, Imago Foundation, Poland

Janet Leach, Contact, United Kingdom

Emma Miller, University of Strathclyde, Scotland

Catharine Shanahan, Family Respite Services Windsor-Essex, Canada

The International Respite Policy Panel will focus on respite care/short break and family caregiver policies, including the impact of worldwide changing demographics, family caregivers in the workplace, and the global shortage of direct care workers. Panelists will offer insights on successful current respite and caregiving policies in their countries, examine the challenges that impede policy development and implementation, and describe progress being made to overcome those challenges.

12:40 pm - 1:30 pm Lunch Break

BREAKOUT SESSION D

Several presentations in this session have slightly different start and end times.

1:30 pm - 1:55 pm

D1: Children, the Forgotten Caregivers



Judy Wroda, *Southwestern Independent Living Center, NY, USA*

In my presentation, I will explore the need for a better understanding of a family's cultural background, as well as the need for a more informed and educated social system, to better assist children who are designated/identified as caregivers to another member in the family. We will delve into the lives of two children who face circumstances that are demanding and heart wrenching, as well as the outcomes of each case.

1:30 pm - 1:55 pm

D2: Advancing Respite Research – Findings from the 2020 Respite Research Summit



Ray Kirk, *ARCH National Respite Network and Resource Center, USA*

On September 29-30, 2020, ARCH convened the virtual Respite Research Summit attended by more than 130 national and international participants. The Summit was part of an ongoing initiative by ARCH to advance a respite research agenda developed by an Expert Panel previously convened by ARCH. The Summit provided an opportunity to assess progress made in advancing the Expert Panel's respite research agenda and a forum for participants to recommend next steps. The results of the Summit will inform the Committee on Advancement of Respite Research (CARR), a committee of experts newly convened by ARCH to assist with the ongoing agenda to build an evidence base for respite. Session attendees will become knowledgeable about the status of respite research, ARCH's continuing efforts and activities to strengthen the evidence-base for respite, and findings from the Summit that will inform the work of ARCH and the CARR moving forward to advance and strengthen respite services.

1:30 pm - 1:55 pm

D3: Bringing Respite to Your Community



Val Madsen, *Respite Care Association of Wisconsin, WI, USA*

In Wisconsin, there is funding available to pay for respite care. But in most communities throughout the state, there are very few, if any, respite care providers. This session will provide a high-level overview of a new, innovative, replicable training series called Bringing Respite to Your Community that helps participants walk through their interest in starting a respite care program in their community. This comprehensive training series provides participants with the information and building blocks needed to create a respite program in their community. The goal of the Bringing Respite to Your Community workshop series is for participants to have a start on a business plan or program design for a respite program. Each week, participants are given pertinent information to build their plan. At the end of the training series, participants have completed a plan that allows them to make an informed decision on whether to move forward or not with their plan without having to incur unnecessary costs or risks.

1:30 pm - 1:55 pm



D4: Collaboration at a National Level to Research, Develop, Test, and Measure a National Respite Provider Training Core Curriculum Pilot

Lisa Schneider, *Respite Care Association of Wisconsin, WI, USA*

Kim Whitmore, *Marquette University, WI, USA*

In this session, you will learn how and why collaboration at the State and National level is important to develop, test, and scale a respite workforce recruitment, training, and retention program to better meet the respite needs of families, particularly in light of the impact of the COVID-19 pandemic on the workforce. The project is managed by the ARCH National Respite Network and Resource Center in collaboration with the National Academy for State Health Policy under a Lifespan Respite special project grant. The Respite Care Association of Wisconsin (RCAW), in collaboration with an evaluation consultant at Marquette University, will build upon RCAW's Respite Care Certificate Program (RCCP). RCAW's respite provider training curriculum will be enhanced to meet respite-specific core competencies developed by an Expert Work Group and then field-tested, along with a recruitment campaign, in up to 10 states. Presenters will then announce the application process and criteria for selecting States interested in piloting this project for one year.

1:30 pm - 2:45 pm



D5: Models of Innovative and Exemplary Practices in Respite Care/Short Break Programs in the U.S.

Cassandra Firman, *ARCH National Respite Network and Resource Center, USA*

Susan Summers, *ARCH National Respite Network and Resource Center, USA*

Barb Williams, *ChildServe Respite – Johnston, IA, USA*

ARCH National Respite Network and Resource Center solicits applications for respite/short break programs and services across the United States to identify models of Innovative and Exemplary respite practices. The presenters will describe the 7 qualities and characteristics of programs and services that make them Innovative or Exemplary; highlight how one program designated by ARCH as Innovative and Exemplary applies these criteria in their day-to-day practice; and provide real-life examples and commonly used strategies for bringing excellence to respite/short break programs and services no matter the program size, location or funding level.

1:30 pm - 2:45 pm



D6: Innovative Strategies for Working Across State Programs Providing Respite Services in Massachusetts

Leanne Winchester, *Massachusetts Lifespan Respite Program and University of Massachusetts Medical School Commonwealth Medicine, MA, USA*

Amy Nazaire, *Massachusetts Lifespan Respite Coalition and Massachusetts Department of Developmental Services, MA, USA*

Family caregivers provide critical supports to care recipients across the lifespan. Respite can benefit caregivers who are burdened by the challenges they face in this role. However, long-term services and supports provided by state agencies primarily focus on the needs of care recipients. This presentation will describe how the Massachusetts Lifespan Respite Program, through an Advanced Lifespan Respite Grant, leveraged the experience and expertise across state agencies and community partners in a strategic way to increase the capacity to serve individuals eligible for state agency services and the wider constituency of caregivers who would benefit from respite. Presenters will engage attendees in discussion of collaboration theory and the rubric used to measure collaboration, as well as the process collaborators used to define a common vision.

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BREAKOUT SESSION E

2:00 pm - 2:25pm

E1: Assistive Technology: The Next Step for Working Smarter, Not Harder



Laura Plummer, Wisconsin Department of Health Services, WI, USA

Assistive technology programs and services are often an untapped resource for providing respite and caregiving services. Technology is evolving at a rapid pace and it's time to harness the capabilities as we move forward. Learning about new devices and the opportunities they present for respite and caregiving can often seem overwhelming. This session will provide an overview of the solutions and programs available to meet the needs when resources are stretched thin. Participants will learn about the Assistive Technology Act and how it can serve as an ideal model for getting assistive technology into the hands of people with disabilities, their caregivers, and other service providers. Participants will have a hands-on opportunity to learn about and use various types of assistive technology. Case examples and discussion will enhance the lecture and demonstration formats of this session.

2:00 pm - 2:25pm

E2: Giving Respite During a Natural Disaster



Dennis Pieper, Voices of Care, IL, USA

Sarah Gaffney, Voices of Care, IL, USA

Over the last decade, natural disasters have been on the increase, affecting millions of people every year. However, almost nothing is reported about the effects of these disasters on people with disabilities and their caregivers. These families often live with daily stress of providing a safe and nurturing atmosphere for a person with disabilities. However, during a natural disaster, providing care can be even more overwhelming when no support system is in place. This session will explore the use of respite during a disaster, including using trained respite volunteers to set up temporary respite drop off events or provide one-on-one care to families in need. The presentation will include an overview of the REST (respite education and support tools) training program and how it is used in providing care during a Disaster Response Respite Event.

2:00 pm - 2:25pm

E3: Share the Care™: An Evidence-Informed Approach to Ease the Stress and Isolation of Family Caregiving



Sheila Warnock, Sharethecaregiving Inc. Aka Share the Care, NY, USA

Share The Care™(STC) is an evidence-informed model to create a team of friends, family, colleagues, faith community and neighbors to unite together in support of a family caregiver no matter the circumstance. This workshop will take participants on the journey of how the STC model evolved out of real-life experience, how it works, and introduce STC groups and their inspiring accomplishments, including how the model has been used to transition someone who requires 24/7 care into assisted living, a nursing home or hospice while continuing their efforts even through end-of-life. The presenter will share supportive evidence confirming STC as a best-practice caregiving model that can be easily replicated, is low cost, adaptable, sustainable, and reduces the risk of caregiver burden and social isolation. Examples of how STC is used in other countries will be presented.

2:00 pm - 2:25pm

E4: Innovative Respite Care for Military Families with Children Having Special Needs



Andrew Coates, *Child Care Aware of America, USA*

Child Care Aware® of America (CCAoA) has been improving respite care implementation for military families for over twelve years. The program evolved from initial concepts to full development by understanding and addressing families' needs and adapting respite care to meet those needs, focusing on the enhanced referrals of quality caregivers. The presenter will convey innovative practices in respite care delivery to families having children with special needs and describe the evolution of the CCAoA program based on observations, empirical measures, parent feedback, continuous development, and forward movement of the program over time. Information about the program's enhanced referral process, provider training, and provider-agency agreements will be offered. With the events of 2020 in mind, particular interest will be paid to practices that promote program confidence and success.

BREAKOUT SESSION F

The Lifespan Respite presentation in this session has a different start and end time.

2:30 pm - 2:55 pm

F1: A Musical Journey



Mandy Hansen, *Tennessee Respite Coalition, TN, USA*

Learn how the Music and Memory concept can be used in respite provision and how it helps caregivers and care recipients. In January 2017, the Tennessee Respite Coalition began the process to integrate Music and Memory with the Senior Companions Program. The partnership is one of the first to use the Music and Memory model to enhance the in-home respite experience. We will share our experiences for many respite purposes, and discuss preliminary outcomes for caregivers, care recipients and volunteers, and ideas of how other programs could implement Music and Memory.

2:30 pm - 2:55 pm

F2: Building a Full Life: Today, Tomorrow and Beyond 18. Expanding the Impact of Respite Supports



Susan McKee, *Family Respite Services, Windsor-Essex, Canada*

Cindy McPhedran, *Family Respite Services, Windsor-Essex, Canada*

Presenters will describe how they developed and implemented a series of family gatherings and learning opportunities for families that explore how the role of respite or short breaks could be broadened to have the greatest impact for their sons or daughters. Topics for the learning opportunities included identifying strengths of their sons and daughters; building friendships; exploring community; community asset mapping; valued roles; and using a life trajectory tool to allow families to consider if the current path will lead to the desired outcome. Session participants will be provided with an overview of the family workshops with a focus on how the series helps to further strengthen families. It will also address how respite supports and direct support providers/respite providers may act as a bridge for community inclusion and the development of friendships, contributing to building a full life for people with a disability.

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2:30 pm - 2:55 pm

F3: Family Caregiver Wellbeing: How Care, Compassion and Understanding Cost so Little and Mean so Much



Joanna Griffin, Affinity Hub, United Kingdom

The presenter is a Parent Caregiver of a 14-year-old with cerebral palsy, a learning disability and autism. She is also a Chartered Counselling Psychologist engaged in Doctoral Research into 'Emotional Wellbeing in Parents of Disabled Children' at Middlesex University/Metanoia Institute in London, UK. She has authored a book, *Day by Day: Emotional Wellbeing in Parents of Disabled Children*, informed by her personal and professional experience. In this presentation, she will refer to her own family experiences and those of caregivers she interviewed to outline the simple things that have made a difference to their lives. By sharing these experiences, Short Breaks providers will learn about small adjustments they can make to their services that will make a meaningful difference to those families they support.

2:30 pm - 2:55 pm

F4: Providing and Receiving Respite Care Safely During the COVID-19 Pandemic



Kim Whitmore, Marquette University, WI, USA

Providing Respite Care Safely During the COVID-19 Pandemic: Voluntary National Guidelines for Respite Care Agencies, Providers, Family Caregivers, and Respite Care Recipients was developed with guidance and expertise from a US national workgroup convened by ARCH National Respite Network and Resource Center. As more communities across the country begin to re-open in the midst of the ongoing pandemic, many respite care agencies and other respite providers are also planning to resume services. The guidelines provided in this document are designed to assist providers as well as family caregivers with careful and thoughtful planning and implementation strategies to provide and receive respite care as safely as possible during the COVID-19 pandemic.

2:55 pm - 3:30 pm

F6: Creating Respite Where It Doesn't Exist: A "Gap-Filling" Person-Centered Approach to Respite



Jamie Ahumada, Nevada Aging and Disability Services Division, NV, USA

Cheryl Dinnell, Nevada Lifespan Respite Care Coalition, NV, USA

Through a pilot program funded by the Administration for Community Living's Lifespan Respite Care Program, we will share what it takes to provide respite to unserved and underserved populations across the lifespan of caregivers. Nevada's Lifespan Respite Rx pilot program is a "self-directed" service model that incorporated a person-centered approach, using the MyLifeCourse Respite portfolio, specifically for caregivers who do not meet eligibility criteria of other programs. Caregivers determined the design and delivery of the respite service. The program not only funds respite but helps a caregiver "create respite where it doesn't exist" by providing support not typically found in other respite programs. The goal was for caregivers to use respite regularly for one full year. Respite Rx was the prescription; 2-4 hours per week was the recommended dosage. Respite Rx provides valuable insight at the program level to the supportive direct services that caregivers prefer. Attendees will get to see how the MyLifeCourse Respite Portfolio tool and other supports helped tailor respite to the caregiver's and care recipient's needs.

2:55 pm - 3:30 pm **Exhibitor Time | Networking**

4:00 pm - 5:30 pm **VIRTUAL HAPPY HOUR**

Participants will have the opportunity to "mix and mingle" in various breakout rooms for a fun and casual networking event hosted by members of the ISBA International Committee.

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Thursday, June 24, 2021

Time displayed in CDT

9:00 am - 9:45 am Exhibitor Time | Networking

9:45 am - 9:55 am **WELCOME AND CONFERENCE OVERVIEW**

9:55 am - 10:55 am **OPENING KEYNOTE: *The Big Little Things – What We Learnt from Children and Caregivers During the Pandemic***

Moderated by Jo Chopra, Latika Roy Memorial Foundation, India



Dr. Vibha Krishnamurthy, Founder and Executive Director, Ummeed Child Development Center, Mumbai, India

The pandemic presented challenges, but also some opportunities, for children with disabilities and their families. We heard from children in India and their families about their 'jugaad' – the word means problem solving using innovative approaches when your resources are limited. The session will feature stories from Ummeed of these life hacks which we have now incorporated into the way we work with families.

BREAKOUT SESSION G

Several presentations in this session have slightly different end times.

11:00 am - 11:25 am

G1: Caregiver Respite – Thinking Outside the Box



Jane Mahoney, Greater Wisconsin Agency on Aging Resources, WI, USA

The Oxford dictionary defines respite as “a short period of rest or relief from something difficult.” With a job as taxing and all-encompassing as caring for another person, the importance of having periods of rest cannot be emphasized enough. However, there are many reasons that traditional respite – when another person takes over the responsibility of caregiving for a short time – will not be part of the picture. During a global pandemic and with a shortage of paid care providers, many families do not have access to home care workers or adult day care programs. Without a substitute care provider to take over their role, creative thinking, planning and partnerships must take place to provide the caregiver with ways to find a sense of reprieve and to recharge their energy to continue to provide care for their loved one.

In this session, participants will learn why traditional respite may not be the best support for some caregivers; explore unique alternatives to traditional respite that can still offer a “period of rest” for caregivers; and hear about the partnership between Wisconsin’s state and federal caregiver support programs and lifespan respite program to provide additional support for caregivers.

11:00 am - 11:25 am

G2: The Building Respite Evidence and Knowledge (BREAK) Exchange



Tyler Engel, *Barrier Busters Designs, WI, USA*
Kim Whitmore, *Marquette University, WI, USA*

The BREAK Exchange is an international collaboration of researchers, respite providers, agencies and individuals who are committed to building a culture of evidence-based respite care. The BREAK Exchange's network promotes a 2-way communication between the stakeholders in order to develop and evaluate new respite programs, develop best practices, facilitate research collaboration, and assess the current state of respite care. The BREAK Exchange currently has 180 members from 15 countries. These members are caregivers, care recipients, respite providers, and researchers. In this session, presenters will provide the history of the BREAK Exchange, and describe BREAK Exchange activities to assess the current state of respite care services and research around the globe. During the presentation, we will engage the audience to build collaborations in research and practice to move respite forward.

11:00 am - 11:25 am

G4: Effective Practices when Working with Families of Latino Heritage



Hector Portillo, *PADRES E HIJOS EN ACCIÓN, WI, USA*

Positive relationships with families in need of respite start with a safe, trusting, culturally responsive environment in which all are empowered to have open conversation, share personal information, and create authentic connections. This session will provide participants with information and strategies to engage with families of Latino Heritage using positive, culturally responsive practices. Participants will be provided with opportunities to increase their understanding of culture through research, videos, and personal stories. Family Engagement strategies will be provided to help participants learn ways to effectively welcome, honor and connect families with children with special needs. Special attention will also be given to the Latino/Hispanic culture, values, and religion and gender roles to help participants understand how this can impact family engagement strategies. The information provided will be helpful for professionals as they interact with children and families across various settings and disciplines.

11:00 am - 12:15 pm

G5: Advocacy to Action – Advancing State Respite Funding Across the U.S.



Jon Bartholomew, *AARP, USA*
Helen Marks-Dicks, *AARP, USA*

Presenters will share how advocates in some states are coming together to find funding for respite for more caregivers who are low to middle income through a new concept developed by AARP, RELIEF for Caregivers. This workshop will provide participants with a greater understanding of how to run a successful respite funding campaign, based on successful efforts in Hawaii and Oregon. Participants will brainstorm potential coalition partners in their state/nation and discuss strategic targets for their advocacy. Participants will also gain an understanding of how the RELIEF concept works, and how this model has begun to roll out in Washington State. Participants will also learn about how Hawaii has managed to secure funding for respite from the legislature without the use of a Medicaid waiver, and how it has improved caregivers' lives through the Kupuna Caregivers program.

11:00 am - 12:15 pm



G6: Lessons Lifespan Respite Washington Learned from Collaborating with Diverse Groups of Caregivers Prior to and Mid-Pandemic

Dana Allard-Webb, Aging and Long-Term Support Administration, Washington State Department of Social and Health Services, WA, USA

Geene Delaplane, Aging and Long-Term Support Administration, Washington State Department of Social and Health Services, WA, USA

Tracy Kahlo, PAVE and Lifespan Respite Washington, WA, USA

Rosalyn Alber, Aging and Long-Term Support Administration, Washington State Department of Social and Health Services, WA, USA

This presentation will walk through a history of trial, error, and evolution in working with distinct communities who share a reluctance in using respite services. Washington has been challenged to provide culturally relevant outreach and services to Native American Tribes. Lifespan Respite Washington also experienced resistance in another unique population - caregivers of people who have a traumatic brain injury. We will share our journey of reinvention and collaboration, prior to and mid-pandemic. We will take advantage of group knowledge among participants during our presentation. Attendees will be asked to share in the conversation, ask questions and explore best practices and ideas to move respite services forward for underserved populations and expansion to other populations that are challenged in using mainstream programming.

BREAKOUT SESSION H

The presentations in this session have slightly different start and end times.

11:30 am - 11:55 am



H1: How ISBA Connects the World – A Danish-German Sailing-Weekend

Andreas Karger, VBS Bethel, Respite Care Haus Brücke, Germany

At the ISBA conference in 2018 in Reykjavik, delegates from a German respite program (Haus Brücke) learned about the experiences of a Danish respite program (Lunden) that takes their respite guests sailing in the Baltic Sea. The Danish and German delegates agreed to organize a sailing-weekend with guests (the care recipients) and staff of Haus Brücke and Lunden. The intent of the sailing trip was to meet and learn about other countries and cultures, and to have fun together. This weekend of sailing and respite occurred in August 2019, when we spent 5 days on a small island in the Baltic Sea with 4 guests of each organization and care-provider staff. The two groups had some lovely days of sailing, bathing, talking, discovering the island, and having fun together.

In this presentation, you will learn about the sailing weekend and get an idea of the spirit of this weekend. Hopefully, others will be encouraged to think about similar cross culture/cross country projects. Danny, a guest of Haus Brücke, who took part in the sailing weekend, may be able to report about his experiences with Haus Brücke.

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11:30 am - 11:55 am

H2: A PhD in Caregiving: Designing a Family University



Jo Chopra-McGowan, *Latika Roy Memorial Foundation, India*

Almost universally, the birth of a disabled child finds families unprepared, confused and in need of information. In India, where there is low awareness, a dearth of reliable resources, no organized system of developmental monitoring and no social welfare programs to support caregivers, families are literally on their own. For most, this means late diagnosis, no early intervention, difficulty accessing basic rights and services, limited social opportunities and non-existent formal caregiver support.

The presentation will focus on the work of the Latika Roy Foundation, which works at multiple entry points in the community: helping disabled children and adults develop independence and social skills; educating doctors, nurses and health care workers on early identification and referral; training teachers about inclusive education and sensitizing the community about disabled people's needs and rights.

The presenter will describe a new pilot program called The Family University. Using a traditional university structure as the framework, parents and other family members will have the chance to enroll in the university at the time of getting a diagnosis. The presentation will be followed by a brainstorming exercise to help the Foundation take thinking and planning to the next stage. Using a selection of college brochures and catalogs, participants will reimagine the university experience to design a curriculum and a "campus life" adding up to a PhD in caregiving.

11:30 am - 11:55 am

H3: Multigenerational Respite: Moving Forward through Kinship Caregiving



Carrie Savage, *Catholic Charities Denver, CO, USA*

In the United States today, approximately 2.6 million children are being raised by a grandparent or other relative. The number of people stepping into these roles, often referred to as Kinship caregivers, continues to rise across the country. As many Kinship caregivers are older adults, challenges they face are significantly different than traditional parents. As a family with multiple generations, respite is critical to the family's long-term success. Through this presentation participants will gain a better understanding, from the Kinship caregivers' perspective, of the importance of respite services, who represents this population of caregivers, what needs they have, and how the Kinship Caregiver Program at Catholic Charities of Denver is helping to support these families as they navigate through their caregiving journey.

Participants will engage in activities that emulate the role of a caregiver as they strive to move forward while providing stability, care and love to the children in their home. Have you met a grandparent raising a grandchild and wondered how they stepped into this role and what their needs are? By attending this presentation, you will learn more about the Kinship caregiver role, what works and what does not work while providing respite care and creative ways to serve multigenerational families.

11:30 am - 12:45 pm

H4: The Cost of Moving Forward: Calculating the Cost of Short Break/Respite Services



Cassandra Firman, ARCH National Respite Network and Resource Center, USA

MaryJo Alimena Caruso, FRIENDS National Resource Center for Community-Based Child Abuse Prevention, USA

Catharine Shanahan, Family Respite Services, Canada

We know that short breaks and respite are beneficial to families caring for a loved one with special needs, but do we know how much it really costs in dollars and cents (or pounds and pence, euros and cents, or the currency of your choice)? Respite programs may be a sound investment in the health and well-being of individuals with special needs, their families, and the larger community, but the actual cost to deliver services is not always clear. For greater accountability to funders, staff, policy makers, and the families we serve, simple but credible methods of cost analysis are needed.

This presentation will highlight a cost-analysis resource from the FRIENDS National Center for Community-Based Child Abuse Prevention (FRIENDS) that has been adapted for use by respite programs. In this workshop, we will explore why and how to conduct cost analysis of your short break or respite programs. The presenters will help attendees identify the data needed for producing accurate estimates of the cost to deliver services and for estimating cost avoidance and return on investment.

BREAKOUT SESSION I

12:00 pm - 12:25 pm

I1: Using Respite to Reach Therapeutic Goals



Sarah Stonier, Children's Hospital of Eastern Ontario (CHEO), Canada

The primary goal of short break/respite services will always be to provide families with a much-needed break in caring for their loved ones with medical needs. However, to keep respite sustainable and relatable, additional goals can, and should be set for those in our care. Short break/respite cannot exist in a vacuum. Respite providers need to be included as part of an interdisciplinary team along with parents; a family doctor; occupational, speech language, seating, and mobility therapists; and nurses. The presenter will demonstrate that modifications to respite services to meet therapy goals are frequently minimal and low or no cost to implement. While examples of how this can be done with children ages 6 months-7 years will be used, it will be shown that the basic principles of using respite to reach therapeutic goals can be universally applied across the lifespan. Viewing respite as a tool to reach therapeutic goals is essential for supporting clients, now and in the future.

12:00 pm - 12:25 pm

I2: Supportyourway.ca – A Central, Multipurpose Website and Database for Respite and Direct Support Services



Carolyn Harris, Empower Simcoe, Canada

[Supportyourway.ca](https://supportyourway.ca) is an innovative online tool that was developed as a service collaborative for the planning and coordination of adult and children's respite services. Currently accessible across multiple provinces, it connects families, caregivers, individuals and professionals to respite information, services and supports. A core service connects families to screened one-to-one support workers. The site is fully flexible for host members to customize the information and service delivery to meet their own individual community needs while offering consistent branding through a broad-based tool to navigate caregivers to the services they require. Presenters will describe the services offered and how it has benefitted caregivers.

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12:00 pm - 12:25 pm

I3: **Claude Moore Precious Time – A Mutually Transformative Respite Care Program**



Melissa Leisen, James Madison University, VA, USA

Eric Schmucker, James Madison University, VA, USA

In this session, the Claude Moore Precious Time Model (CMPT) at James Madison University in Virginia will be described. Presenters will share the history behind the program, its development, and how it's continuing to move respite forward through expanding education, awareness, services, consultation, and research. Acknowledging that careful preparation and support for respite care providers is vital to the success of a respite care program, they will present on how nursing students are prepared to provide pediatric home-based respite care. Information on a research study into the experiences of nursing students providing care to children with special health care needs (CSHCN) in the context of home-based pediatric respite care may help nursing faculty gain further insight into how best to prepare future nurses on the unique care needs of CSHCN and their families. Lastly, the presenters will lead the participants in exercises designed to explore how they may apply the CMPT respite care model to help empower their communities. This model was recognized by ARCH as an Innovative and Exemplary Respite Service.

12:25 pm - 1:30 pm **Lunch Break**

BREAKOUT SESSION J

Several presentations in this session have slightly different start and end times.

1:30 pm - 1:55 pm

J1: **Asking for Respite is a Sign of Strength as Families Raise Their Young Children**



Amy Kendal, Maryville Crisis Nursery, IL, USA

Joanne Deuter, Maryville Crisis Nursery, IL, USA

The Crisis Nursery Coalition of Illinois is comprised of seven crisis nurseries in Illinois. The intent of this workshop is to demonstrate crisis nurseries as a preventative model of care that provides emergency support, respite and childcare for children ages birth to six, 24/7, 365 days a week. The model is designed to keep children safe as families face challenges that can impact child safety and family stability. Presenters will engage in exercises with the participants about how stress affects families with young children and how they should consider the ways that they view the family's ability to cope. Thoughtful discussion will be encouraged about the day-to-day life of parents with young children with little to no support. Interventions will be discussed and the importance of how sensitive listening, observation and resources can be important to strengthen a family.

1:30 pm - 2:45 pm

J2: **Cultural Competency and Diversity Planning: A Pathway Moving Respite Forward**



Jed Johnson, CARF International, Washington, DC, USA

Kesha Carter, Coordinator Care Services, Inc., NY, USA

In our increasingly diverse world, embracing inclusion and celebrating differences are not only hallmarks of true person-centered service delivery, but are essential components leading to organizational success and sustainability. For respite care providers, diversity is a core theme that is woven throughout U.S. National Respite Guidelines in areas such as family involvement, provider recruitment and training, and individualized services. The goal of this interactive session is to enhance an organization's efforts to demonstrate an awareness of, respect for, and attention to the diversity of all stakeholder groups including persons served, families, staff, and volunteers.

1:30 pm - 2:45 pm



J3: Siblings Journey Forward: Addressing the Needs of Caregiver Siblings of People with Disabilities from Childhood through Adulthood

Harriet Redman, *WisconSibs, Inc., WI, USA*

Growing up with a sibling with disabilities is filled with both positive and negative experiences but one thing is clear. Siblings greatly benefit from support in their caregiver role as they move forward through their unique life-long journey. While often not recognized as caregivers (either by themselves, their families, or funders/legislation/professionals), siblings perform critical caregiver tasks. Even the youngest siblings may assist parents with medications, therapy, supervision, companionship, physical and emotional support. This workshop presentation will offer video, slides, and stories to provide information on needs of siblings and how to support siblings through evidence-based programs; include guided interaction activities between audience members to utilize their collective experiences to broaden the conversation beyond Wisconsin USA; and interview a panel of teen and adult caregiver siblings.

1:30 pm - 2:15 pm



J4: Storytelling in the Workplace: A Tool for Transformation

Stephanie Summerville, *USA*

In this session, you will learn how compelling storytelling can be used to influence audiences to take action. You can tell stories to potential donors or legislators and convince them your project really makes a difference. And you can tell stories to motivate your target audiences to use their voice by answering your call for action. Storytelling is an interactive art of using words and actions to reveal the elements and images of a story while engaging the listener. The interactive nature of storytelling partially accounts for its immediacy and impact. At its best, storytelling can directly and tightly connect the teller and audience. Listen as Stephanie Summerville shares her story of storytelling. Attendees will learn the power of a story, how it is structured, and what key ingredients are used in a simple storytelling format so you can develop your own story to tell.

1:30 pm - 2:45 pm



J5: Engaging the Broader Community on Innovative Ways in "Moving Respite Forward"

Jeff Keilson, *Advocates, Inc, MA, USA*

Pam McKillop, *Autism Alliance of Metrowest, MA, USA*

During this interactive workshop, participants will learn about what Advocates, in partnership with families and community resources, is doing to "move respite forward". Advocates is a human services agency supporting 30,000 individuals and families in central and eastern Massachusetts, USA. Advocates works with a wide variety of populations of all ages including people with mental health, brain injuries, Autism, Intellectual/Developmental Disabilities, and people in addiction recovery. Presenters will discuss ways respite services are provided and how the broader community is engaged to help reduce the stress on family caregivers, including a description of how business and the educational community can create a corps of trained respite workers for families to access and how a caregiver can recruit respite providers. Strategies to support families to accept non-family members to provide respite will also be discussed. Finally, funding sources for respite will be explored.

1:15 pm - 1:50 pm

J6: Virginia Lifespan Respite Voucher Program: Successes, Challenges and Lessons Learned



Nick Slentz, Virginia Department of Aging and Rehabilitative Services (DARS), VA, USA

Liza White, Virginia Department of Aging and Rehabilitative Services (DARS), VA, USA

The Virginia Lifespan Respite Voucher Program (VLRVP), supported by grants from the Administration for Community Living, has worked in partnership with the Virginia Caregiver Coalition (VCC) to provide desperately needed respite opportunities to Virginians since 2009. This session will provide a detailed overview of how the Virginia Lifespan Respite Voucher Program is designed, how it is implemented, the successes of the program design, and overcoming the challenges associated with it. Presenters will also discuss best practices and knowledge gained from the effective implementation over the last decade. Demographic data about individuals served by the program will be highlighted.

BREAKOUT SESSION K

The presentations in this session have slightly different start and end times.

2:00 pm - 2:25 pm

K1: How Rewarding Work Uses its Web-Based Matching Service, Unique Approach to Recruitment and Model of Collaboration to Deliver Respite Opportunities



Dafna Krouk-Gordon, Toward Independent Living and Learning, MA, USA

Jeff Keilson, Toward Independent Living and Learning, MA, USA

Rewarding Work (RW), a nonprofit founded in 2004, is using its extensive experience operating web-based matching service directories to move respite forward. This presentation focuses on a self-directed model and unique approach to recruiting respite staff and direct care workers that gives families access to respite. Recruiting strategies that work and outreach needed to encourage families to take advantage of respite services will be discussed.

1:55 pm - 2:30 pm

K6: Advancing the Breakroom in South Carolina's Faith Communities



Joe Ward, South Carolina Respite Coalition, SC, USA

Kathy Mayfield-Smith, South Carolina Respite Coalition, SC, USA

Nicholas Julian, South Carolina Respite Coalition, SC, USA

In the South Carolina Respite Coalition's initiative to engage with faith communities, we have expanded our work over the last year to include piloting respite Breakrooms in several churches across the state. Presenters will provide program specifics, lessons learned in implementation, status, and adjustments through Covid19, and the building of the Breakroom as a model for other communities. Because of the diversity in the types of congregations we have worked with, we will address the unique challenges faced in this project, as well as successes and possibilities for wider replication. Session participants will learn about commonalities, challenges, and the desire among congregations to serve and mobilize to meet the community need for respite programming and expanded service.

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BREAKOUT SESSION L

The presentations in this session have slightly different start and end times.

2:30 pm - 3:00 pm

L1: Co-Design: Accelerating Transformation of Respite and Short Breaks by Putting People and Families in the Driver's Seat



Janeen Halliwell, People Minded Business, Canada

Jennifer Warnell, Community Living Toronto, Canada

Pina Bresciani, Community Living Toronto, Canada

Adrineh Bennett, Community Living Toronto, Canada

In 2018, ISBA encouraged service providers to embrace co-creation as a way to move respite and short break supports forward. Community Living Toronto (CLTO) took-up the challenge and put the pedal to the metal. A commitment was made to evolve the organization's existing models of respite using 'co-design' - the deliberate engagement of people, families, service providers and other experts in actively exploring and designing future supports together. Collectively, they became the co-creators of new and innovative approaches to respite and short breaks. In this eye and mind-opening session, attendees will receive a guided tour of the co-design process the children and adults with developmental disabilities, their families, and service providers engaged in at CLTO. Attendees will be introduced to the variety of tools and techniques CLTO used - many from the creativity and design thinking disciplines - ones that garnered authentic engagement in generating ideas and solutions for the purpose of bettering respite and short break experiences. There will be time for attendees to use some of these 'power tools' that are putting people and families in the driver's seat of change, hands on the wheel, foot on the gas, moving forward in a direction that serves them.

2:35 pm - 3:10 pm

L6: Innovative Insight: Understanding Your Needs by Identifying Yourself as a Caregiver



Megan Schwalm, Tennessee Respite Coalition, TN, USA

To address barriers to respite, the Tennessee Respite Coalition and Tennessee Technical University have partnered to create an innovative website with the goal of helping people identify as caregivers and to provide online trainings to assist them in more effectively caring for their loved ones. The presentation will introduce participants to an immersive, 360-degree experience that allows users to virtually visit a house that has been altered to accommodate a family member in need, accompanied by four voices reflecting on their daily lives taking care of their loved one. Additional modules and assessment tools will be described.

2:45 pm - 3:30 pm Exhibitor Time | Networking

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Friday, June 25, 2021

Time displayed in CDT

9:15 am - 9:25 am WELCOME AND CONFERENCE OVERVIEW

9:25 am - 9:45 am THE WISCONSIN ALZHEIMER'S INSTITUTE "AMAZING GRACE" CHORUS®

The Wisconsin Alzheimer's Institute "Amazing Grace" Chorus® is a Milwaukee-based diverse Chorus made up of people living with dementia and their Caregivers. The Chorus serves to improve the "quality of life" of its participants through socialization and music, and provides education and assistance to connect families to Alzheimer's supportive care resources, and respite opportunities. The Chorus premiered in 2014. To learn more visit: wai.wisc.edu/chorus



9:45 am - 10:00 am Break

10:00 am - 11:00 am GLOBAL RESPONSE TO RESPITE AND CAREGIVING IN A POST-PANDEMIC WORLD PANEL

Moderated by Kim Whitmore, Marquette University, USA

Amanda Batten, Contact, United Kingdom

Amy Coupal, The Ontario Caregiver Organization, Canada

Jaia Peterson Lent, National Center on Grandfamilies, Generations United, USA

C. Grace Whiting, J.D., National Alliance for Caregiving, USA

Don Williamson, Shared Care Scotland, Scotland

An international panel will discuss the impact of the COVID-19 pandemic on caregiving and respite care/short break services. Panelists will offer insights on best practices and lessons learned and discuss potential ways responses to the pandemic have helped move respite forward in their countries.

11:00 am -11:45 am COVID-19 and Respite Round Table Discussions

Conference attendees will have the opportunity to engage in round table discussions with panelists to discuss how lessons learned from the COVID-19 pandemic will help move respite forward.

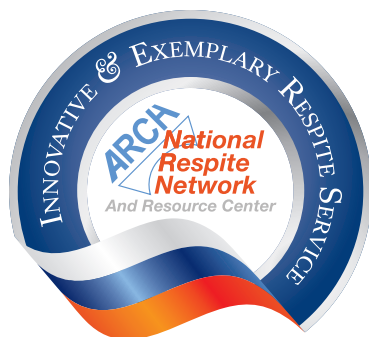
11:45 am - 12:00 pm Round Table Discussions Report-Out

Panelists will share key insights from the round table discussions.

12:00 pm - 12:15 pm CLOSING REMARKS AND ANNOUNCEMENT OF LOCATION FOR ISBA 2023

We will be giving away 3 FREE registrations to the 2023 ISBA Conference during the closing remarks (must be present to win).

Innovative and Exemplary Respite Services



The ARCH National Respite Network and Resource Center is proud to recognize Innovative and Exemplary Respite Services for 2021.

The ARCH National Respite Network and Resource Center recognizes four Innovative and Exemplary respite services from across the U.S. Each respite service met a stringent set of selection criteria and all have outstanding programs that address the needs of family caregivers of children, adults or older adult family members. By recognizing exceptional respite services, ARCH hopes to encourage the expansion and replication of quality respite to meet the growing need. To read more about the application and selection process, and details about each program, visit the [ARCH website](#).



ALS Association Saint Louis Regional Chapter's Caregiver Relief Program

The ALS Association Saint Louis Regional Chapter initiated their **Caregiver Relief Program** 11 years ago. Operating in three locations and using case managers from multiple disciplines – including social work, counseling, occupational therapy and nutrition – to support patient and caregiver choice, the Caregiver Relief Program links families with screened and trained Gold Star respite programs. Visit their [website](#).



Crisis Nursery

The **Crisis Nursery** in Urbana, Illinois has provided emergency crisis respite care to children birth to six-years- of-age for 37 years. Based on best practice research and observed need, the Crisis Nursery began offering planned respite to further support family caregivers. The Crisis Nursery works to reduce caregiver stress and risk of child maltreatment, and to improve parenting skills directly related to parent-directed goals. Visit their [website](#).

Home Away from Home Respite Center



The **Home Away from Home Respite Center** at SUNY Geneseo was created five years ago to serve older adults with Alzheimer's and other dementias. After a comprehensive intake process and interview that includes caregiver-selected goals and guidance in selecting person-centered activities, care recipients attend two, 4-hour sessions each week at a local interfaith center while their caregivers receive eight hours of respite each week. Respite is provided by trained college student interns and volunteers, providing social contacts that are intergenerational and ethnically, socially, and culturally diverse. View the [website](#).



Lutheran Services in Iowa Respite Care

Lutheran Services in Iowa Respite Care

has offered respite to caregivers of children with disabilities and mental and emotional conditions for 19 years. Based on both research and caregiver preferences, one respite care service the program offers is a 48-hour weekend, providing caregivers with extended time for self-care. The program also offers individualized respite options in one of three settings – the primary caregiver's home, the respite provider's home, or the community. Using a consumer- directed, family-centered process of matching caregivers, the Respite program emphasizes use of family-selected care providers who offer informal supports, such as neighbors, grandparents and other kinship caregivers, especially in rural parts of the state where provider availability is scarce. Visit the [website](#).

Rising Star



The **Tennessee Respite Coalition** was recognized as a Rising Star in 2021 because of the adaptations they made to continue providing services and supports to caregivers and their families during the COVID-19 pandemic through mini grants for caregiver-identified needs. The Tennessee Respite Voucher Program also provided respite in innovative ways that allowed for safe social distancing, but maintained caregiver-provider contact in ways that kept caregivers socially connected during times of increased stress and isolation.



JUNE 22 - 25, 2021

VIRTUAL

Virtual Exhibitor Hours and Tips

The Virtual Exhibit Booths will be available for you to visit throughout the conference. There are scheduled times during the conference that exhibitors will be open/live and available to interact with you. Please see the scheduled times below. When visiting the booths you are able to view the uploaded materials and meet with the exhibitors. When requesting a meeting with an exhibitor your camera and microphone will be enabled.

You can use the Meeting Hub to connect with Exhibitors and Sponsors during off hours. Click the Connect button and choose to interact with them by live chat or video call. You can also schedule to meet at a future time, send messages and take notes.

You cannot see yourself in the Meeting Hub so do not be alarmed if you are not visible.

Scheduled Exhibit Hours

TUESDAY, JUNE 22: 2:25 pm – 3:30 pm CDT

WEDNESDAY, JUNE 23: 9:00 am – 9:45 am and 2:55 pm – 3:30 pm CDT

THURSDAY, JUNE 24: 9:00 am – 9:45 am and 2:45 pm – 3:30 pm CDT



ISBA International Committee

The international committee of ISBA organizes the biennial ISBA Conference and provides professional exchange. Click [HERE](#) to learn more about ISBA.

Australia

Jake Pearson
[Interchange Illawarra](#)

France

Loïc Guilcher
[Grath](#)

Poland

Piotr Kuzniak
[Imago Foundation](#)

Canada

Catharine Shanahan
[Family Respite Services](#)

Leslie Atkinson
[Safeguards Training for Children and Adult Services](#)

Daniel McGoey
[Wesway](#)

Dana MacMillan
[Wesway](#)

Germany

Thomas Stoch
[DRK Wolfenbüttel – Integrations- und Therapiezentrum \(ITZ\)](#)

Iceland

Margrét Lía Steingrimsdóttir
[Skammtimavistun Álfalandi](#)

India

Jo Chopra-McGowan
[Latika Roy Foundation](#)

Scotland

Don Williamson
[Shared Care Scotland](#)

USA

Kim Whitmore (ISBA President)
[Marquette University](#)

Cassandra Firman
[ARCH National Respite Network and Resource Center](#)
and [FRIENDS National Resource Center](#)

Denmark

Thor Simony
[Granbohus](#)

Ireland

Colette Daly
[Ability West](#)

England

Janet Leach
[Enfield's Joint Service for Disabled Children](#)

Emeritus Members

Candida Smith
England

Sheelagh McInerney
Ireland



National Planning Committee for the ISBA International Respite Conference

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Maryland Department of Human Services
Baltimore, MD*

Dana Allard-Webb

*Aging and Long-Term Support Administration
Washington State Department of Social and Health Services
Olympia, WA*

MaryJo Caruso

*FRIENDS National Resource Center
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Rochester, NY*

Mandy Hansen

*Tennessee Respite Coalition
Mt. Juliet, TN*

Sharon Johnson Groh

*Formerly with the Nebraska Lifespan Respite Network
Nebraska Department of Health and Human Services
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Vegas Valley
Las Vegas, NV*

Kathy Mayfield-Smith

*South Carolina Respite Coalition and Division of Medicaid
Policy Research
Institute for Families in Society
University of South Carolina
Columbia, SC*

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Hathorne, MA*

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*Division of Provider Services and Quality Assurance
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Little Rock, AR*

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Local Planning Committee

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Barrier Buster Designs

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Hannah Scott, CMP
Conference Coordinator

Kristy Carlson, CMP
Conference Coordinator



Thank you for participating in ISBA 2021.



We look forward to seeing you at ISBA 2023!