



**CaN-D**  
Community Care  
Network for Dementia

# Data Collection Efforts Within Adult Day, Respite Care, and Home Care Services

CaN-D Quarterly Meeting  
March 19, 2024



# Welcome to our second Quarterly Meeting!

If you have not already, please consider joining the network. Scan the QR code to fill out the member survey to receive network communications on upcoming events and activities.



# There's still time to join a Working Group(s):

- 1) State policies
- 2) Access/Unmet needs
- 3) Interventions

Scan the QR code to complete the interest survey and be added to a Working Group email list.





# Meet the panelists





**Bill Zagorski**  
**CEO, American Senior Care Center, Inc.**  
**Board Chair and Research Committee Chair, National**  
**Adult Day Services Association**



**Kim Whitmore, PhD, RN, CPN**  
**Assistant Professor, Marquette University College**  
**of Nursing**



**Kerri Pendley**  
**Chief Growth Officer, FirstLight Home Care**

# Standardization of Adult Day Services Outcomes and Data Collection – The Path Forward

- ▶ **Bill Zagorski, CEO, American Senior Care Centers, Inc., Chair, NADSA Board of Directors, and Chair, NADSA Research Committee**



# nadsa

## National Adult Day Services Association

- ▶ The National Adult Day Services Association (NADSA) is a professional membership association and is the leading voice of the rapidly growing Adult Day Services (ADS) industry as well as the national focal point for ADS providers.
- ▶ Our mission is to advance the national development, recognition and use of Adult Day Services.
- ▶ Our members include Adult Day Services providers, state and regional provider associations, corporations, strategic, academic and institutional partners, educators, students, retirees and others interested in working to build better lives for adults in Adult Day Services programs every day. We positively impact the lives of participants, families, communities and our nation.
- ▶ **2020: Adult Day Services is a system of professionally delivered, integrated, home and community-based, therapeutic, social and health-related services provided to individuals to sustain living within the community.**

# Modern Healthcare is Data Driven

- ▶ Adult Day Services can no longer operate in a vacuum
- ▶ ADS must compete and collaborate with other service delivery models (e.g. PACE, ACOs, etc.)
- ▶ To compete, ADS needs **DATA**



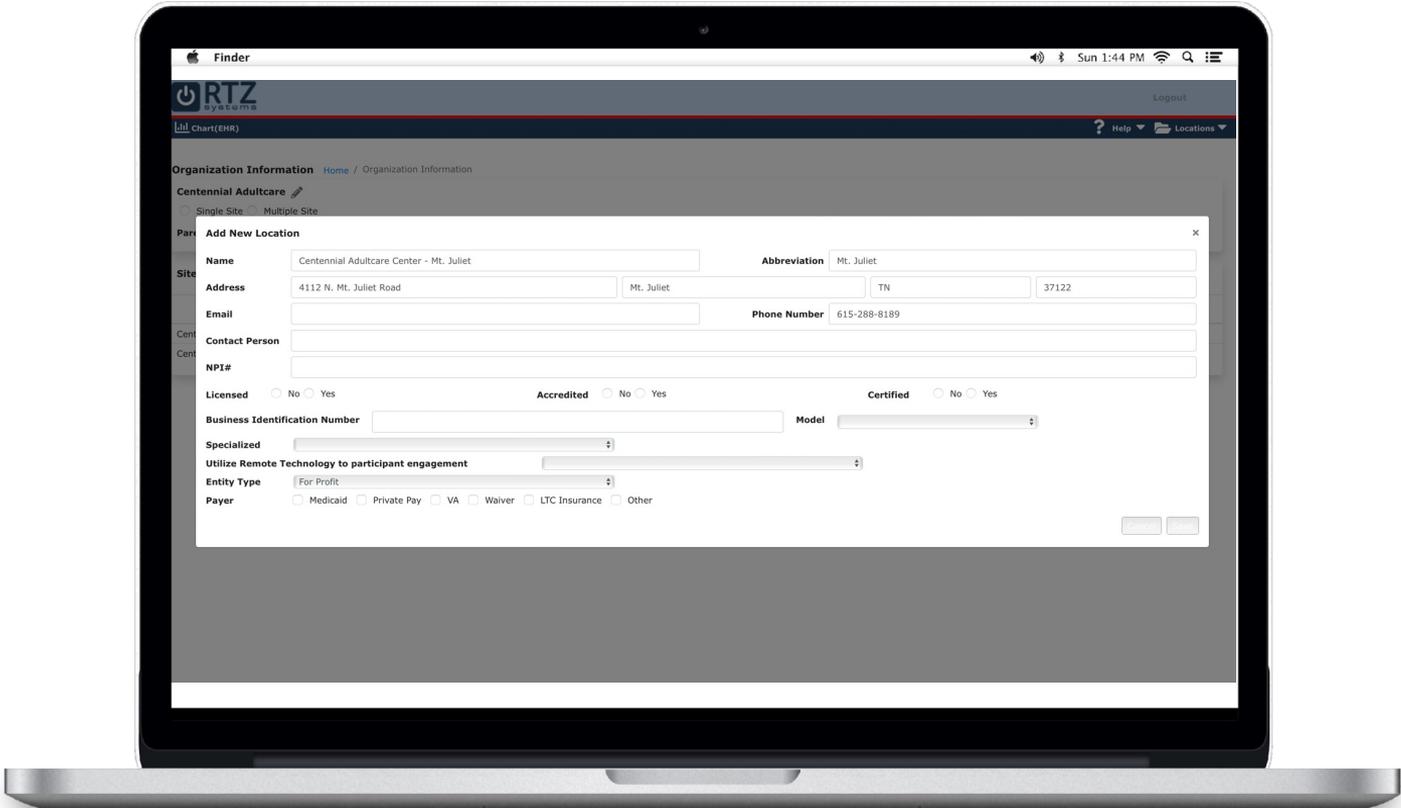
# Demonstrate Value by Documenting Services, Interventions, Outcomes

- ▶ Identify services that lead to positive impacts on
  - ▶ Participant (Health Outcomes)
  - ▶ Caregiver (Burden Reduction)
  - ▶ Community and Payor (Cost Avoidance/Savings)
- ▶ But how and what?
  - ▶ 2018 Journal of Applied Gerontology, Anderson et al, Developing a Set of Uniform Outcomes Measures for Adult Day Services
    - ▶ Detailed Participant Demographics
    - ▶ Individual Outcomes (Standard Tools)
    - ▶ Health Occurrences
    - ▶ Caregiver and Community-Based Outcomes

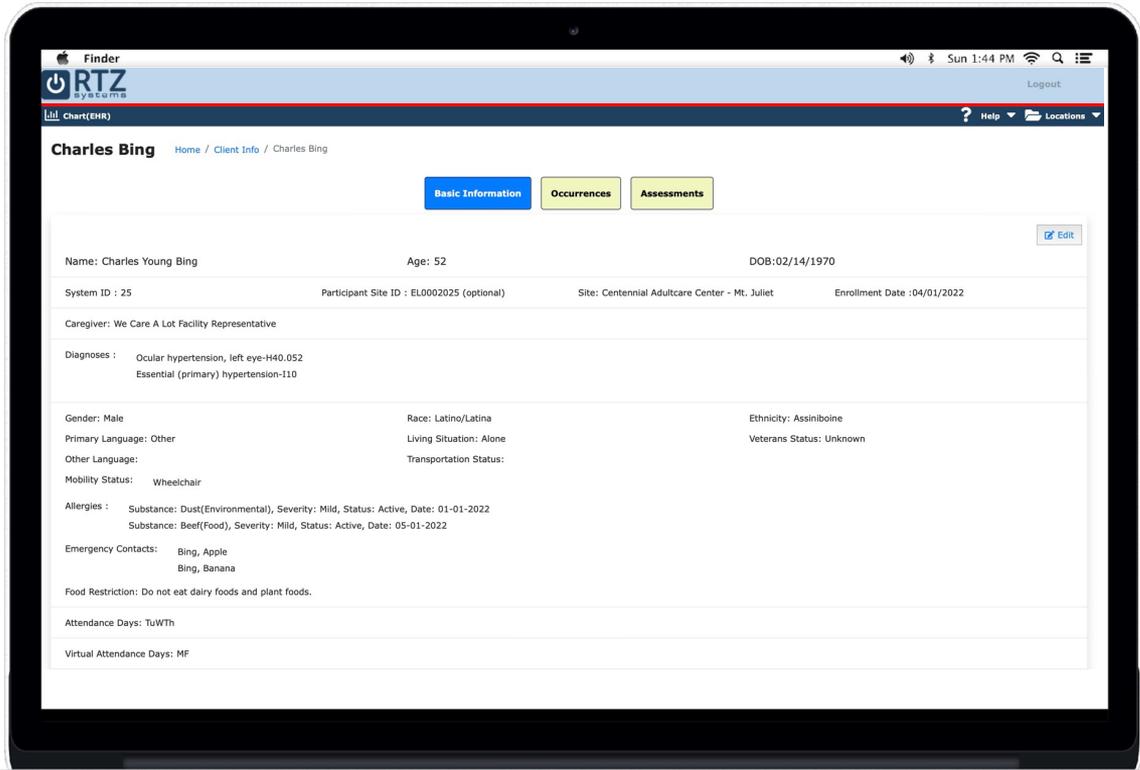
# Process: Overview



# Organizational Data



# Participant Data - Demographics



# Participant Data - High-Cost Health Care Utilization

Outcome	Tool/Scale	Frequency
ER Visit	Numeric with Date	Occurrence Based
Hospital Admission	Yes/No - With Admitting Diagnosis	Occurrence Based
Length of Hospital Stay	Numeric with Admission Date	Occurrence Based
Hospital Readmission	Yes/No - With Admitting Diagnosis and original admission date	Occurrence Based
Injury Inducing Fall	Date and resulting ER or Hosp. Admission	Occurrence Based
Medication	Numeric - number of prescribed medication	At enrollment and annually thereafter
Hospice/Palliative care use	Yes/No - With Admitting Date	Occurrence Based
ALF/SNF Placement	Yes/No - With Admitting Date	Occurrence Based
Date of Death	Date	Occurrence Based

# Participant Data - Outcomes

Outcome	Tool/Scale	Frequency
Functional Health - ADL	<b>Katz Index</b>	At Enrollment and at least annually thereafter
Functional Health - iADL	<b>Lawton Scale</b>	At Enrollment and at least annually thereafter
Fall Risk	<b>Hendrich II</b>	At Enrollment and at least annually thereafter
Depression	<b>GDS-15</b>	At Enrollment and at least annually thereafter
Loneliness	<b>UCLA-8</b>	At Enrollment and at least annually thereafter
Nutrition Assessment	<b>DETERMINE</b>	At Enrollment and at least annually thereafter
Cognitive Function	<b>SLUMS</b>	At Enrollment and at least annually thereafter
Pain Assessment - Optional	One-Time NRS Pain Scale	At Enrollment and at least annually thereafter
Physical Health – Optional	One-time Self-perceived Physical Health Scale	At Enrollment and at least annually thereafter

# Participant Data - SDOH (Phase 2)

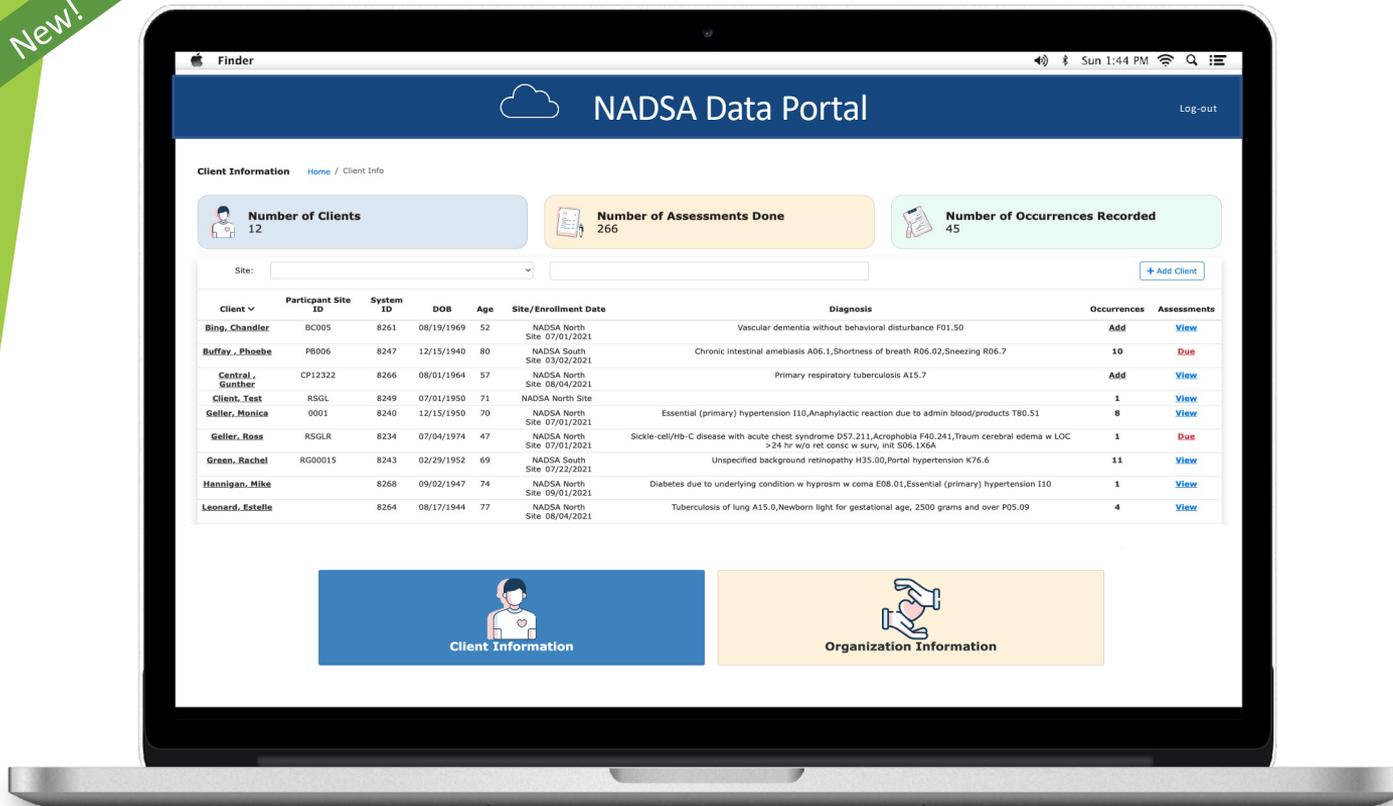
Outcome	Tool/Scale	Frequency
Housing Security	Modified AHC-HRSN	At enrollment and annually thereafter
Nutrition - Meal/Food Access at home	Modified AHC-HRSN	At enrollment and annually thereafter
Transportation Access	Modified AHC-HRSN	At enrollment and annually thereafter
Medication Access	Modified AHC-HRSN	At enrollment and annually thereafter
Personal Care Access @ home	Modified AHC-HRSN	At enrollment and annually thereafter
Healthcare Power of Attorney	Modified AHC-HRSN	At enrollment and annually thereafter
Healthcare appointments where possible	Numeric, based on PCP, Specialty, Dentist, etc.	Occurrence based

# Caregiver Outcomes (Phase 2)

Outcome	Tool/Scale	Frequency
Physical Health	One-time Self-perceived Physical Health Scale	At enrollment and annually thereafter
Emotional Health	Modified Caregiver Strain Index	At enrollment and annually thereafter

New!

Illustration of pre-production system shown.



Client Information Home / Client Info



Number of Clients  
12



Number of Assessments Done  
266



Number of Occurrences Recorded  
45

Site:

[+ Add Client](#)

Client	Participant Site ID	System ID	DOB	Age	Site/Enrollment Date	Diagnosis	Occurrences	Assessments
Bling, Chandler	BC005	8261	08/19/1969	52	NADSA North Site 07/01/2021	Vascular dementia without behavioral disturbance F01.50	<a href="#">Add</a>	<a href="#">View</a>
Buffav, Phoebe	PB006	8247	12/15/1940	80	NADSA South Site 03/02/2021	Chronic intestinal amebiasis A06.1,Shortness of breath R06.02,Sneezing R06.7	10	<a href="#">Due</a>
Central, Gunther	CP12322	8266	08/01/1964	57	NADSA North Site 09/04/2021	Primary respiratory tuberculosis A15.7	<a href="#">Add</a>	<a href="#">View</a>
Client, Test	RSGL	8249	07/01/1950	71	NADSA North Site		1	<a href="#">View</a>
Geller, Monica	0001	8240	12/15/1950	70	NADSA North Site 07/01/2021	Essential (primary) hypertension I10,Anaphylactic reaction due to admin blood/products T80.51	8	<a href="#">View</a>
Geller, Ross	RSGLR	8234	07/04/1974	47	NADSA North Site 07/01/2021	Sickle-cell/Hb-C disease with acute chest syndrome D57.211,Acrophobia F40.241,Traum cerebral edema w LOC >24 hr w/o ret consc w surry, inf S06.1X6A	1	<a href="#">Due</a>
Green, Rachel	RG00015	8243	02/29/1952	69	NADSA South Site 07/22/2021	Unspecified background retinopathy H35.00,Portal hypertension K76.6	11	<a href="#">View</a>
Hannigan, Mike		8268	09/02/1947	74	NADSA North Site 09/01/2021	Diabetes due to underlying condition w hyposm w coma E08.01,Essential (primary) hypertension I10	1	<a href="#">View</a>
Leonard, Estelle		8264	08/17/1944	77	NADSA North Site 08/04/2021	Tuberculosis of lung A15.0,Newborn light for gestational age, 2500 grams and over P05.09	4	<a href="#">View</a>

  
Client Information

  
Organization Information

# Preliminary Data 2023

As of July 31, 2023. All data are preliminary. Statistical significance will increase as sample size grows. Based on **500+ total participants** (22 sites)

## Demographics



### Race

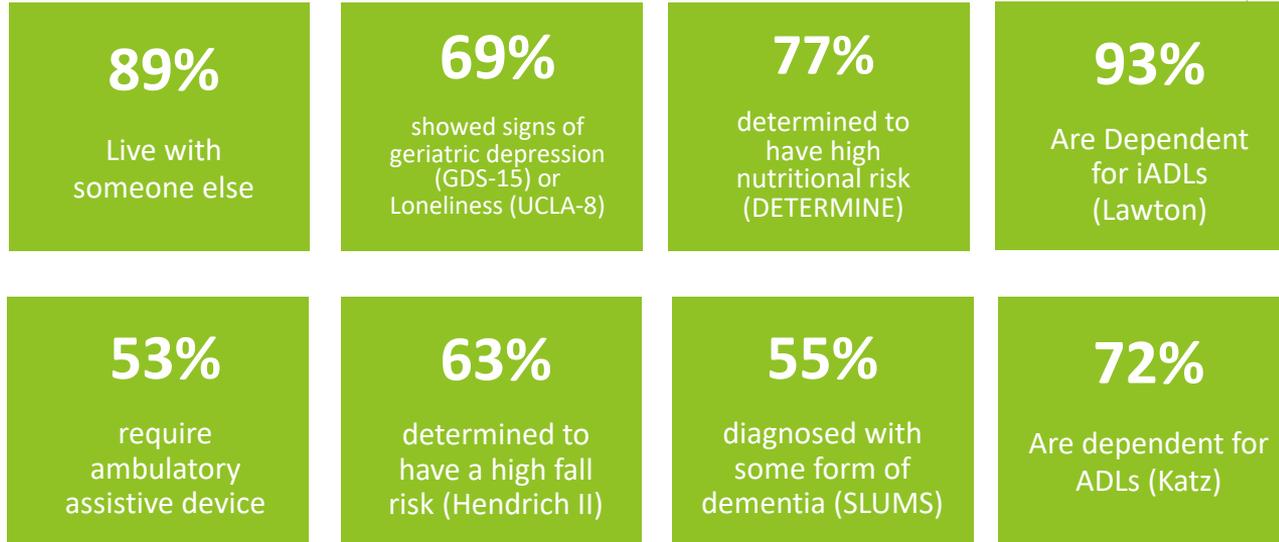
White	40%
Black	20%
Other Minority	13%
Missing Data	17%

### Primary Language

English	81%
Spanish	13%
Other	2%
Missing Data	4%

# Preliminary Data 2023

As of July 31, 2023. All data are preliminary. Statistical significance will increase as sample size grows. Based on **500+ total participants** (22 sites)



**Preliminary data demonstrate the high acuity and need of individuals served in ADS across the US. Additional data will highlight the longitudinal benefits to participants, caregivers, and community as well as the cost savings to all pay sources.**

# For more information and involvement

- ▶ NADSA National Conference: September 18-20, Atlanta Marriott Buckhead
  - ▶ <https://www.nadsa.org/education-events/2024-conference-information/>
- ▶ NADSA Research Committee - Research Office Hours, April 29, June 19: 12pm ET
  - ▶ <https://us06web.zoom.us/j/81612810731?pwd=kUsazvsGnwQP8RfuumMtUq8HS2Wlqb.1>  
Meeting ID: 816 1281 0731 Passcode: 230242
- ▶ NADSA Institutional and Academic Partner Membership
  - ▶ <https://www.nadsa.org/institutional-academic-partner-memberships/>

[William.Zagorski@centennialadultcare.com](mailto:William.Zagorski@centennialadultcare.com)

615-298-3399

# Home Care Association of America

## Mission, Vision & Purpose

As the industry's leading trade organization representing home care agencies and their suppliers across the country, the Home Care Association of America (HCAOA) strives to provide member agencies with practical resources to enhance operations, margins, and improve training and quality within our industry. Our association advocates to help ensure caregivers have safe and secure environments in which to work and the industry continues to innovate care in our communities. Finally, our association brings together innovators and suppliers to help sustain families as they age, helping build independence and choice.

**Membership:** Over 4,200 members providing companionship, personal care, skilled care (non-medicare certified)

**Website:** <https://www.hcaoa.org/>

info@hcaoa.org

**Email:**



**STATE OF HOME CARE**  
**Industry at a Crossroads**



**HOME CARE ASSOCIATION OF AMERICA'S NEW POLICY PRIORITIES**

- **ESTABLISH NATIONAL STANDARDS OF CARE**
- **COLLECT, EVALUATE, AND UTILIZE DATA TO VALIDATE THE VALUE OF HOME CARE**
- **EMBED HOME CARE IN THE HEALTHCARE ECOSYSTEM**
- **SUPPORT CAREGIVERS: RECRUITMENT, TRAINING, CAREER PATHING**
- **FINANCE CARE IN AN ERA OF RISING LONGEVITY**
- **ADDRESS IMMIGRATION TO ENSURE WE HAVE THE CAREGIVERS WE NEED**

# 2024 HCAOA Policy Pillars

## **Provider and Agency Supports:**

- State licensure assistance
- National quality metrics / data collection
- Reducing regulatory burden
- Workforce tax incentives

## **Workforce Supports:**

- Immigration
- Educational incentives
- Efficient scope of practice (expanding scope bc of shortages), incorporating technology
- Reducing barriers to entry for caregivers (training, licensure, background checks)

## **Client and Family Supports:**

- Veterans
- Client access to home care services
- Family caregivers (paid)
- Additional supports for families of home care clients (unpaid, i.e. respite care)

# HCAOA White Paper Topics for 2024

1. Immigration
2. Quality metrics
3. Family caregivers
4. Licensure

# Key Performance Indicators

## Most Common KPIs Being Tracked:

- Revenue, Hours served / billed
- Average length of service / stay
  - *Median 9 months*
- Caregiver turnover
  - *Median 77.1%*
- Customer turnover
  - *Median 50.2% - lowest in 5 years*
- Client satisfaction
- Payor mix
  - *65.3% private pay revenue reported by survey participants*
- Top 5 Payors
  - *Private pay, LTCL, VA, Medicaid & Medicaid Waiver*

\*Homecare Pulse Benchmark Report 2023

# Key Performance Indicators Cont....

## Important KPIs Not Being Tracked:

- Hospitalization tracking & Readmission tracking  
*Only 25% of survey participants reported they are tracking*
- Changes in Condition and reporting
- Missed visit percentages
- Length of time to start services
- Authorization utilization

# FirstLight: Our Story

Founded in  
**2009**  
and headquartered in  
**Cincinnati, OH**



We at FirstLight Home Care exist to **help people have their best day, every day.** Our mission is to provide compassionate home care so that the families we serve have peace of mind knowing their loved ones are receiving the support they need to enjoy the quality of life they deserve.



FirstLight Home Care **provides companion care, personal care and skilled nursing services** to seniors, adults with disabilities, those with dementia and others in need of assistance.

**100+**  
franchises operating in  
**200+**  
locations



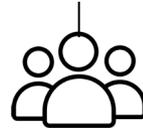
**37**  
states



**69**  
single-unit  
owners



**42**  
multi-unit  
owners



**580,000**  
hours billed monthly

# FirstLight Home Care's Compassionate Memory Care Program

FirstLight Home Care's Compassionate Memory Care Program is designed to join the journey of those living with dementia by adapting the overall approach to care. FirstLight's care professionals modify communications, tasks, and the environment to ensure those in their care have their best day, whatever that means for them.

The Compassionate Memory Care Program is based on five core principles:

1. Create an environment that encourages the best ability to function
2. Find the person in the client
3. Encourage engagement and participation in meaningful activity
4. Believe all people can communicate beyond words
5. Focus on a person's current abilities

FirstLight caregivers receive comprehensive training to help them understand the changes caused by dementia, as well as the abilities a client may have in each stage. Caregivers focus on person-centric activities that bring clients joy and help improve their overall quality of life.

# Data Collection & Challenges

- Two client management systems
- Created a data lake / centralized repository
- Care coordination module implementation
- Memory care program

# Contacts:

Home Care Association of America: [info@hcaoa.org](mailto:info@hcaoa.org)

Kerri Pendley: [kpendley@FirstLightHomecare.com](mailto:kpendley@FirstLightHomecare.com)

# Data Collection Efforts Within Adult Day, Respite Care, and Home Care Services

*Presented by Kim Whitmore, PhD, RN  
Assistant Professor, Marquette University  
Research Consultant, ARCH*



**ARCH**  
National Respite Network  
AND RESOURCE CENTER

# Overview

- Overview of ARCH's Respite Research Initiative
- Committee for Advancement of Respite Research (CARR)
- Current Data Collection Efforts
- Alignment with the 2022 National Strategy to Support Family Caregivers

## An Inclusive Definition of Respite\*

“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some *measurable improvement* in the well-being of the caregiver, care recipient, and/or family system”

*(Kirk & Kagan, 2015)*

*\*Pre-pandemic*

# The ARCH National Respite Network and Resource Center

**Training and Technical Assistance Division** provides support to State Respite Coalitions, service providers and families through consultation, training, evaluation, and research ([archrespite.org](http://archrespite.org));

**National Respite Locator Service (NRLS)** helps family caregivers and professionals locate respite services and funding sources in their communities ([archrespite.org/respitelocator](http://archrespite.org/respitelocator));

**National Respite Coalition** is the policy and advocacy division of ARCH ([archrespite.org/national-respite-coalition](http://archrespite.org/national-respite-coalition)); and

**Lifespan Respite Technical Assistance and Resource Center**, funded by the U.S. Administration for Community Living, supports State Lifespan Respite grantees and their partners in developing state respite systems serving caregivers of persons of all ages and conditions ([archrespite.org/ta-center-for-respite](http://archrespite.org/ta-center-for-respite)).



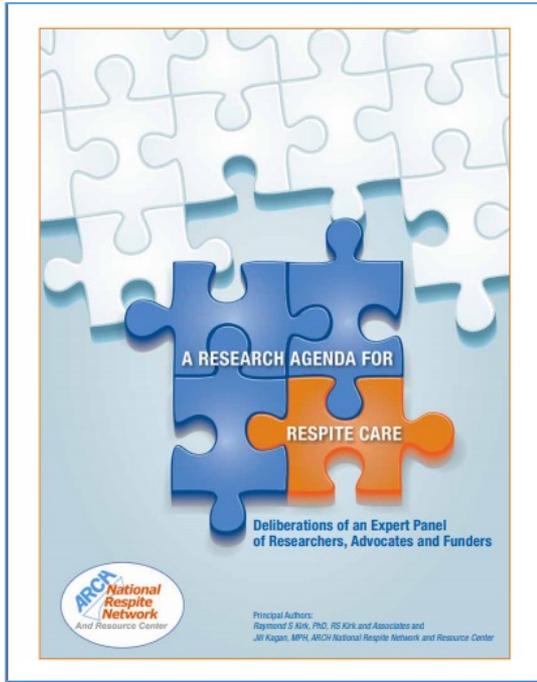
**ARCH**  
National Respite Network  
AND RESOURCE CENTER

# ARCH Goals for Advancing Respite Research

- Improve access to and quality of respite services
- Identify aspects of respite services and models that make them exemplary
- Evaluate and replicate promising respite services
- Translate research findings into practice and policy
- Identify additional possibilities (e.g., funding opportunities for research)



# ARCH Expert Panel on Respite Research



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Explore in-depth the current status of respite research

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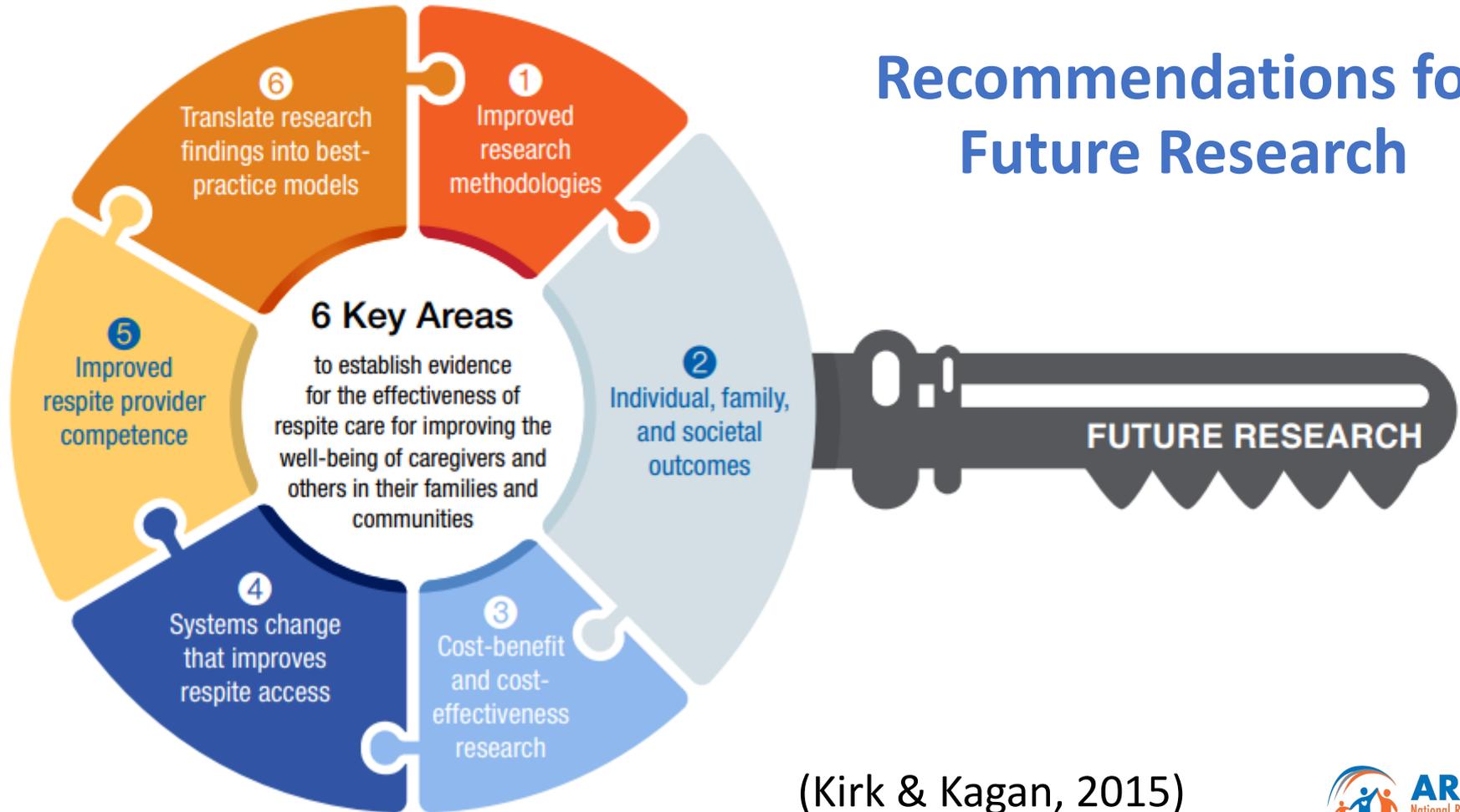
Propose strategies to overcome barriers to research

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Develop a plan to encourage rigorous research in key areas that will translate to meaningful strategies and approaches to care.

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# Recommendations for Future Research



(Kirk & Kagan, 2015)





**Annotated Bibliography  
of Respite and Crisis Care  
Studies, 6th Edition**

**2022**

**ARCH National Respite Network  
and Resource Center**

**Annotated  
Bibliography of  
Respite and Crisis  
Care Studies  
*6th Edition***

# 2020 Respite Research Summit Research Considerations

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Model definition: Describing the respite model under investigation

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Research funding

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Measures and measurement

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Culturally appropriate research with hard-to-reach populations

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Rethinking cost-effectiveness and cost/benefit studies

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Workforce development and access to respite

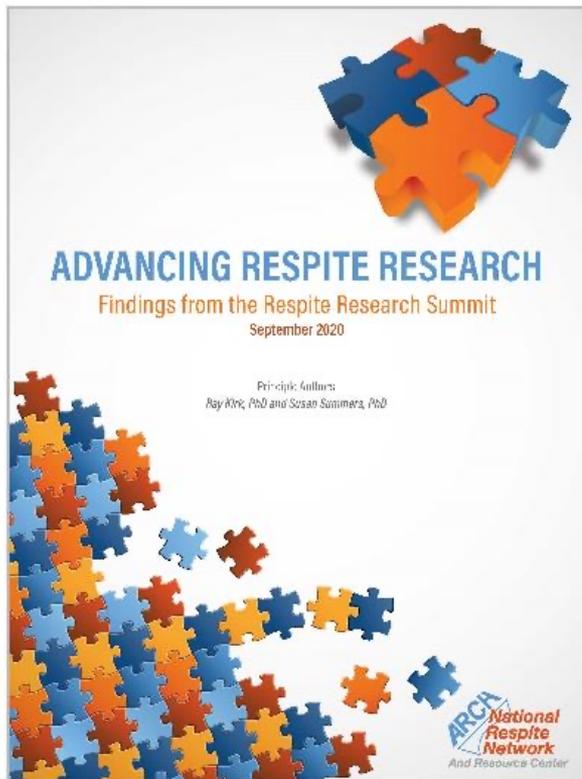
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Utilizing research findings to inform and improve policy and practice

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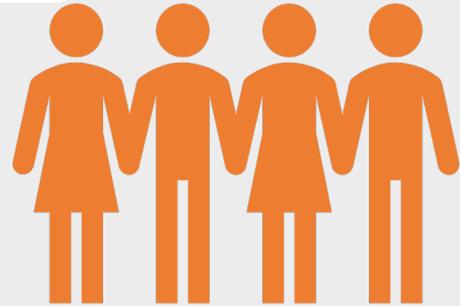
Impact of COVID-19 on respite and post-pandemic respite

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# Committee for Advancement of Respite Research (CARR)

- Advises ARCH on the execution of its respite research initiative
- Comprised of former members of the Expert Panel on Respite Research, research scholars and evaluators, and foundation representatives



# CARR Work Groups



Define and measure the **VALUE** (cost-effectiveness) of respite



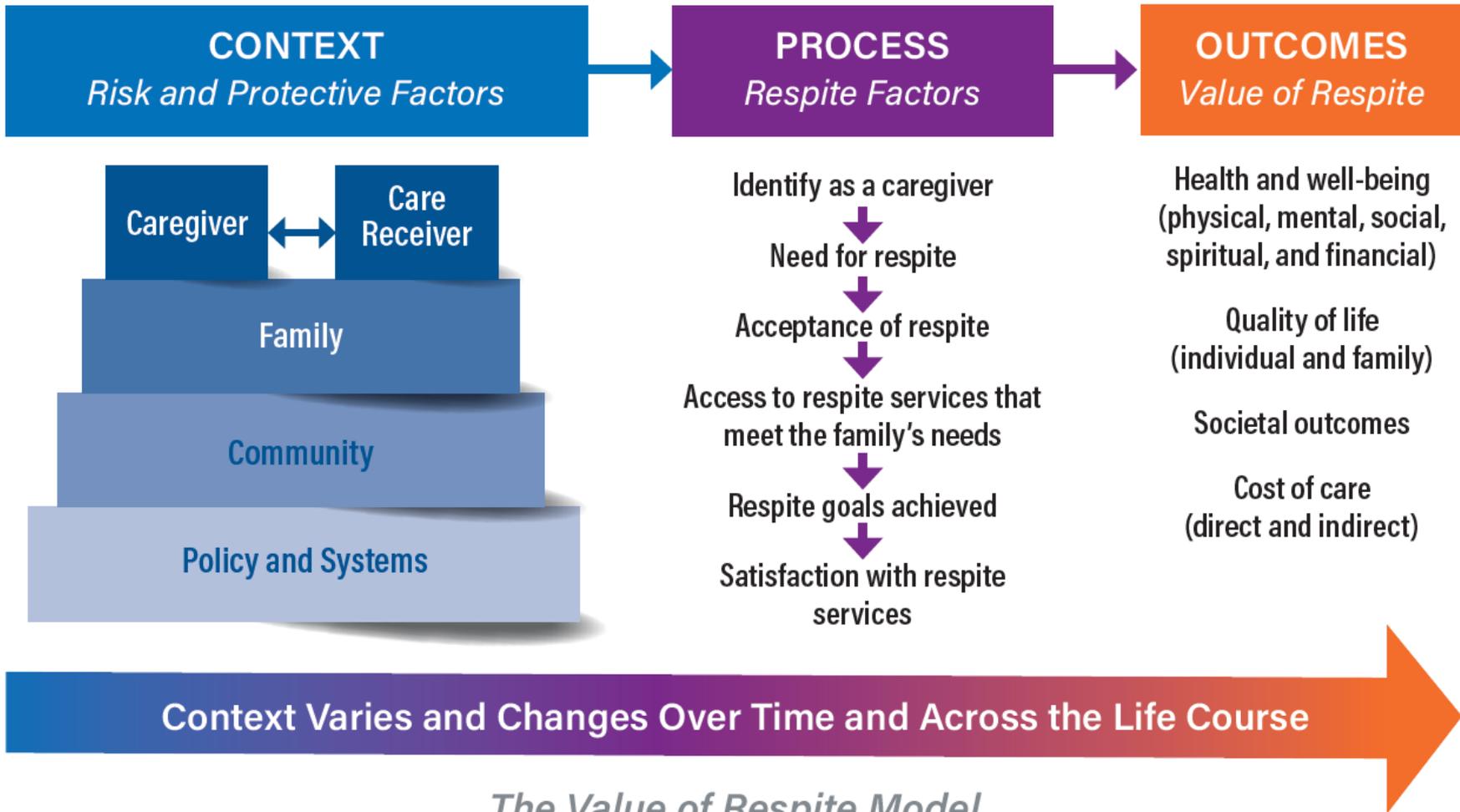
Recommend common data elements (**CDE**) for respite-related research



Expand **CULTURALLY** appropriate research with historically underrepresented populations

# Products

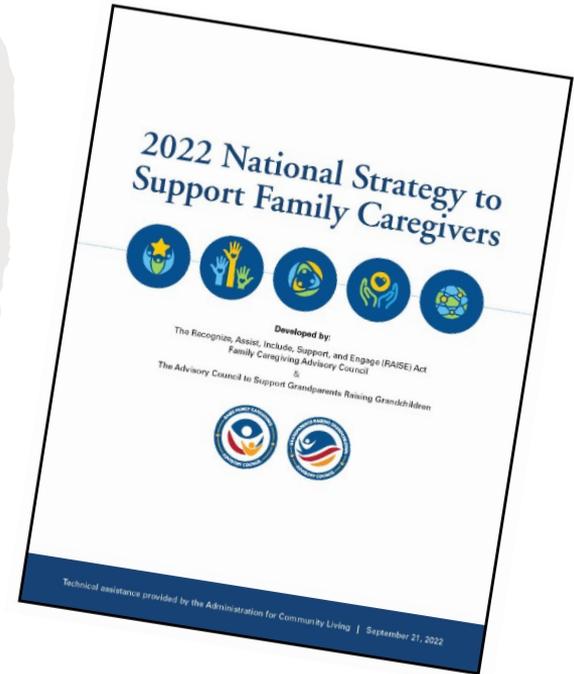
- Measuring the Value of Respite
- Recommended Common Data Elements (CDEs) for Respite-related Research
- Resources for Culturally and Linguistically Competent Respite Research
- Ensuring Cultural and Linguistic Competence: A Guide for Respite Researchers
- Learn more at [archrespite.org/research](https://archrespite.org/research)



*The Value of Respite Model*

# Alignment with the 2022 National Strategy to Support Family Caregiving

- Goal 5: Expand data, research, and evidence-based practices to support family caregivers
- CARR Work Groups Crosswalk
- National Alliance for Caregiving CARE Agenda



# 2024 National Lifespan Respite Conference

MAY 21-23 . ALBANY, NY



RAISE the Bar for

**Respite**

*Strategies to strengthen family caregivers*

2024 National Lifespan Respite Conference ✦ May 21-23, 2024 • Albany, NY

# Respite Research Consortium

- **CONNECTS** interested researchers and funders to engage in respite research that will strengthen the evidence base for respite services
- Get **UPDATES** on new research studies, current literature reviews, data sources, funding opportunities, upcoming events and new report releases
- **SHARE** information about your respite research study on the ARCH website in order to recruit family caregivers, respite providers or other study participants
- **SUBSCRIBE** at [archrespite.org/research/respite-research-consortium/#Subscribe](https://archrespite.org/research/respite-research-consortium/#Subscribe)

# Join the BREAK Exchange



- International group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care
- Currently, there are more than 292 members from 18 countries in the Exchange!
- Follow the BREAK Exchange on Social Media
- Visit our website, join the email list, and complete your member profile at **breakexchange.org**
- Email us at [info@BREAKexchange.org](mailto:info@BREAKexchange.org)





# CONTACT INFORMATION

## [archrespite.org/respite-research](https://archrespite.org/respite-research)

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### Lifespan Respite Technical Assistance Center

This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.



# Q&A

**Please raise your hand or drop your question in the Q&A box**

- **If your question is specific to one panelist, please state their name**



# Panelist Questions

**What are some unique challenges for dementia consumers within your setting/types of care?**

**What would be some potential harmonized measures across your settings/types of care?**



**What would it take to develop harmonized measures across these three settings/types of care?**

# Have you registered for our upcoming Learning & Development Session: “Equitable Partnerships in Research” on May 2?

Scan the QR code to register and receive the Zoom meeting link.  
[Register here](#)





**Thank you for joining us!**

