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TRANSFORMING DEMENTIA CARE

Strategies to Implement ePCTs in Home and Community-Based Settings – Issues and Successes in Assisted Living and Adult Day Centers

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Housekeeping

- All participants will be muted
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions and ask them at the end
- Want to continue the discussion? Associated podcast released about 2 weeks after Grand Rounds
- Visit impactcollaboratory.org
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@IMPACTcollab1

https://www.linkedin.com/company/65346172

Learning Objectives

Upon completion of this presentation, you should:

- Understand the national scope of assisted living and adult day centers (i.e., home and community-based settings)
- Recognize common challenges conducting ePCTs in home and community-based settings
- Be familiar with strategies to address challenges conducting ePCTs in home and community-based settings

Home and Community-Based Settings

Home and community-based long-term care settings -- most notably, assisted living and adult day centers -- differ from nursing homes in ways that are consequential for embedded pragmatic clinical trials (ePCTs)

- Psychosocial mission
- More variability (setting, residents, regulations)
- Fewer resources
  - professional staff
  - record-keeping / technology

Assisted Living

Care setting regulated by states to provide room and board to four or more residents, at least two meals a day, around-the-clock supervision, and help with personal care to a predominantly adult population

- 31,400 communities nationwide
- 55% of long-term care residents; primary provider of dementia care

Mission: Core Principles (select)

Create a residential environment that actively promotes quality of life, privacy, choice, dignity, and independence;
offers quality, individualized supportive services;
fosters a social climate to develop and maintain relationships

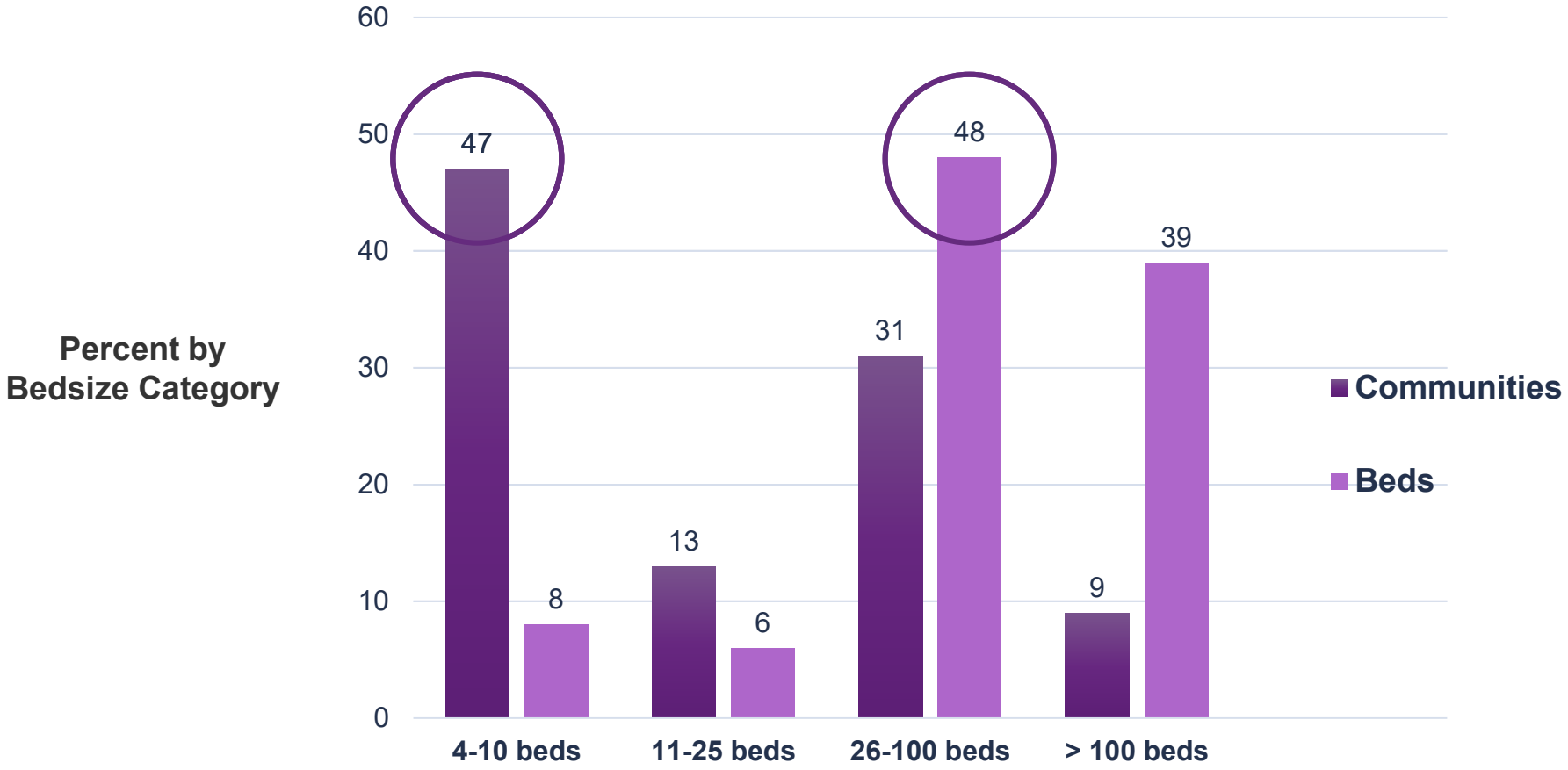
State Regulated: Variable; No National Uniform Data

Community Variability

Range from 4 to 418 beds (average 38 beds)

Size

Most communities are small, but most beds are in larger communities



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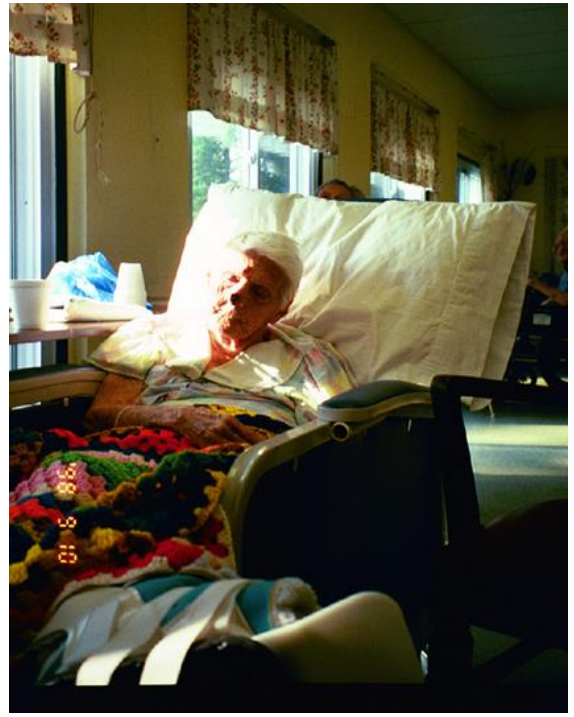
Sengupta et al. Post-acute and long-term care providers and services users in the United States, 2017-2018. Vital Health Stat 3(47), 2022.

Resident Variability

"Like nursing home residents in past"



Resident Variability and Size

Residents in smaller communities require more assistance

	Percent Requiring Assistance, by Bed Size			
	Total	4-25 beds	26-50 beds	> 50 beds
Bathing	64	79	69	60
Walking/locomotion	50	60	46	48
Dressing	49	62	47	46
Toileting	43	57	40	40
Transferring	34	46	27	32
Eating	22	38	21	17

Caffrey et al., NCHS Data Brief Number 454; December 2022.

Regulatory Variability

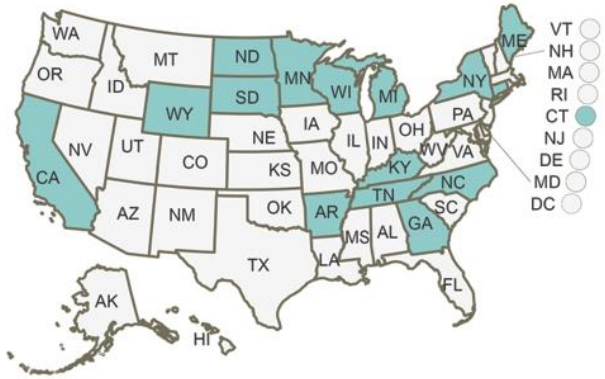
Six types based on health service regulatory specificity

- Housing: minimal allowance for (silent on) health services
- Holistic: require on-site health care; do not allow third-party care
- Hybrid: require nurse staffing; allow third-party care
- Hospitality: few nurse staffing requirements; high allowance for third-party
- Healthcare: specific nurse staffing requirements; high allowance for third-party
- Health support: require some licensed nursing; allow skilled nursing

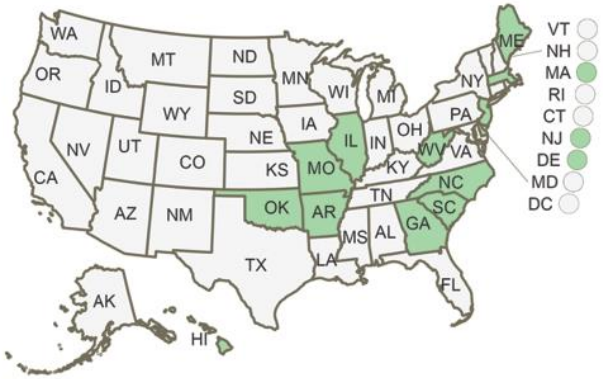
Smith et al. A national typology of health service regulation in assisted living. Gerontologist 2023; in press.

Regulatory Variability

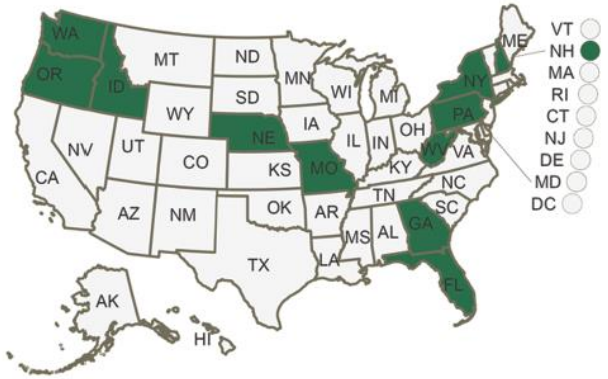
Housing



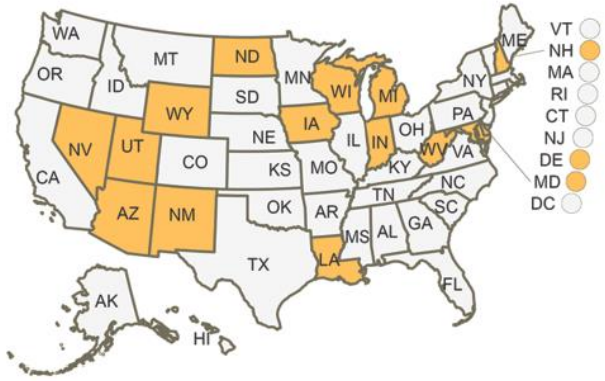
Holistic



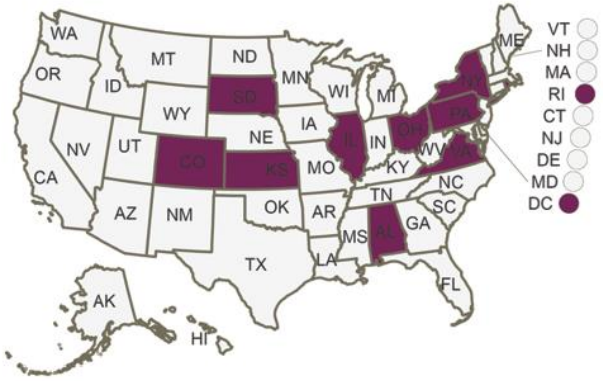
Hybrid



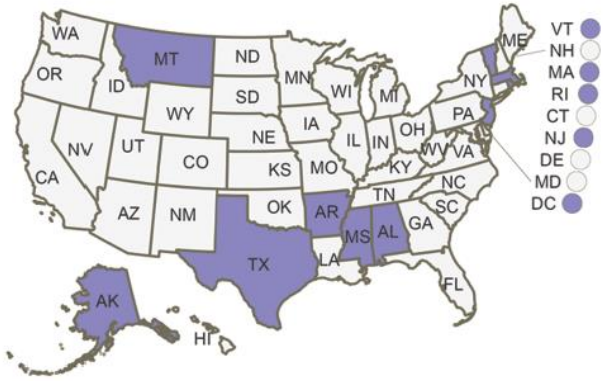
Hospitality



Healthcare



Health Support



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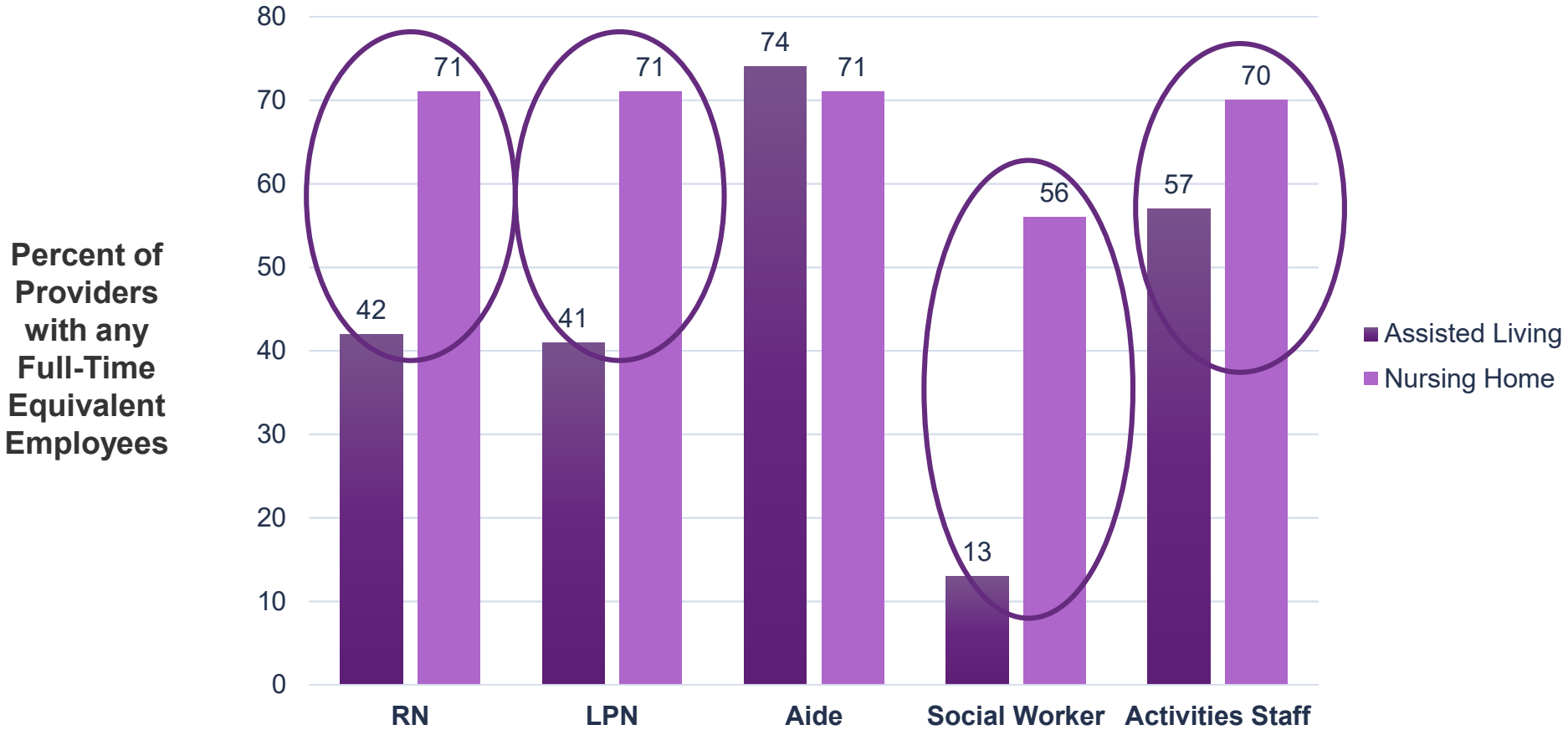
Smith et al. A national typology of health service regulation in assisted living. Gerontologist 2023; in press.

Resources: Staffing

Fewer communities have professional staff than in nursing homes



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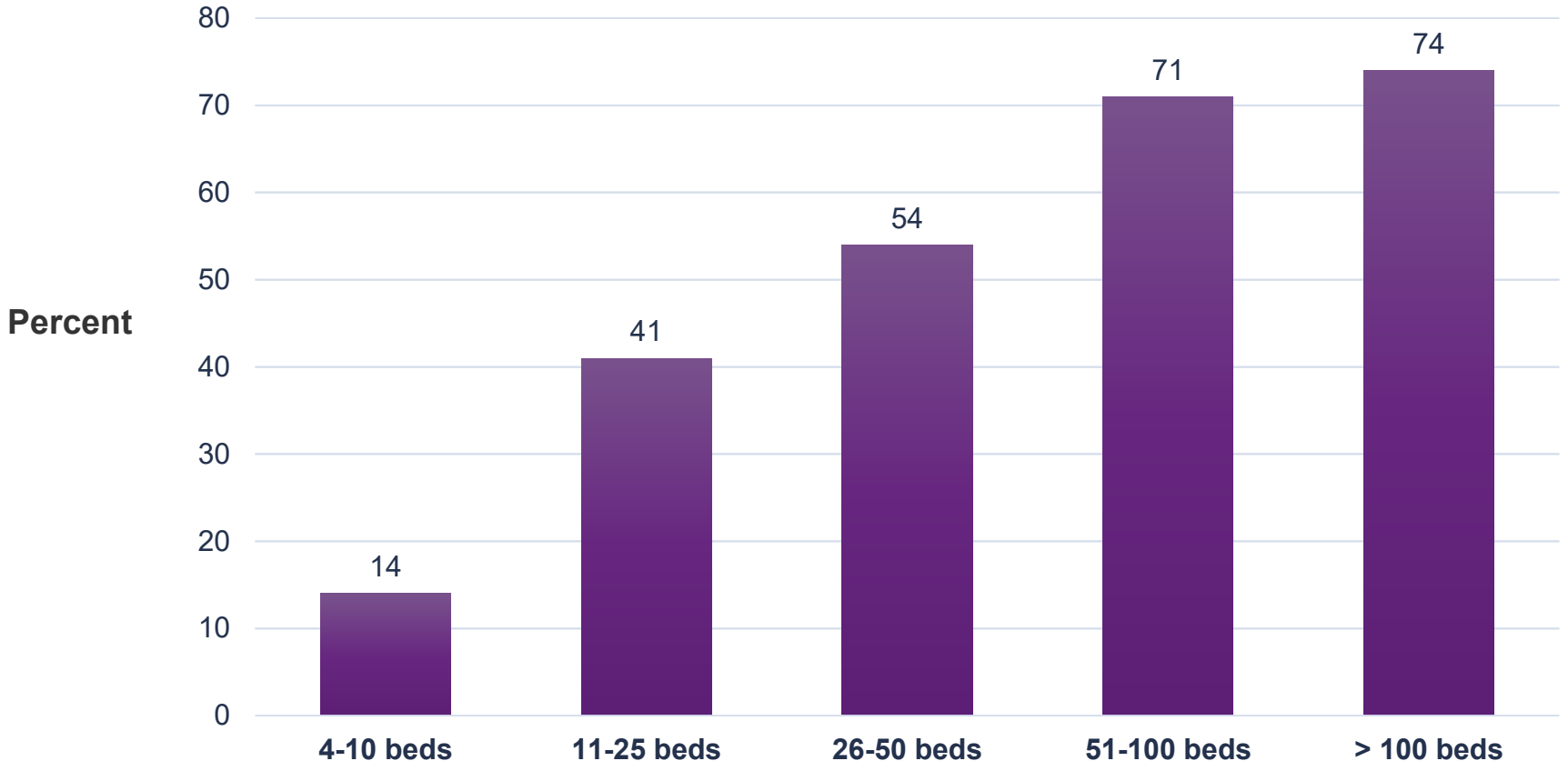
Sengupta et al. Post-acute and long-term care providers and services users in the United States, 2017-2018. Vital Health Stat 3(47), 2022.

Resources: Electronic Health Records

Two-fifths of communities (41%) use electronic health records



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Data from the National Post-acute and Long-Term Care Study.

Assessing Pragmatism: The PRECIS-2

Dimension	Assessment of Pragmatism
Recruitment of investigators and participants	
Eligibility	To what extent are the participants in the trial similar to patients who would receive this intervention if it was part of usual care?
Recruitment	How much extra effort is made to recruit participants over and above what would be used in the usual care setting to engage with patients?
Setting	How different are the settings of the trial from the usual care setting?
The intervention and its delivery within the trial	
Organization	How different are the resources, provider expertise, and organization of care delivery in the intervention group of the trial from those available in usual care?
Flexibility in delivery	How different is the flexibility in how the intervention is delivered from the flexibility anticipated in usual care?
Flexibility in adherence	How different is the flexibility in how participants are monitored and encouraged to adhere to the intervention from the flexibility anticipated in usual care?
The nature of follow-up	
Follow-up	How different is the intensity of measurement and the follow-up of participants in the trial from the typical follow-up in usual care?
The nature, determination, and analysis of outcomes	
Primary outcome	To what extent is the primary outcome of the trial directly relevant to participants?
Primary analysis	To what extent are all data included in the analysis of the primary outcome?

Challenged by variability and staffing

Challenged by record keeping

Challenged by mission

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Ford, Norrie. Pragmatic trials. N Engl J Med 2016;375:454-463.

Assisted Living: ePCT Challenges

- **Mission prioritizes psychosocial outcomes**
  - More challenging to measure than health care events and rates
  - Less likely to be captured in records
  - Less likely to be captured similarly across communities

- **Variability raises issues related to representation**
  - There is no “usual care;” selection must be informed and purposeful
  - Generalizability based on inclusion criteria must be recognized

Assisted Living: ePCT Challenges

- **Fewer professional staff affects capacity**
  - Adoption is less likely
  - Oversight and adherence/fidelity are less likely
  - Ability to participate in data collection is restricted

- **Less record-keeping/electronic health records affects data**
  - Ease of data capture is limited
  - Consistency across communities is less likely

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Assisted Living: ePCT Strategy

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Assistant Professor,

Brown University School of Public Health

ePCT Barrier:
Lack of common data across assisted living communities

- Nursing homes have Minimum Data Set and a few dominant EMR vendors
  - Allows for pragmatic identification of participants and evaluation of outcomes
- Many assisted living communities do not have EMRs
- No federally-mandated assessments

Partial Solution: Leveraging large physician group data

Bluestone Physician Services and Bluestone Accountable Care Organization (Bluestone) serve over 4,000 high-risk patients with on-site medical care in approximately 500 assisted living communities across Florida, Minnesota, Wisconsin

Mission Driven
Bluestone developed their care model of collaboration with assisted living staff, patients, and their families to accomplish their mission to bring the highest-quality health care directly to residents in assisted living communities, memory care, and group home communities.

Leading edge development
Bluestone is a market leader in the delivery of timely, complex care management services, which aim to improve quality of life by personalizing care to patient values and beliefs.

Electronic Medical Record
Bluestone maintains a comprehensive EMR for all their patients, two-thirds of whom have dementia.

Partnership Highlights: moving from reactive to proactive management & value-aligned care delivery

Decrease costs for ongoing care episodes	Intervene earlier to prevent unnecessary care episodes	Proactively monitor areas for improvement
Bluestone's *ED Early Response* program **Goal**: avoid unnecessary hospitalizations by providing timely clinical information and outpatient supports to ED team **Collaboratory Role**: systematic evaluation of process and clinical outcomes	**Bluestone's palliative care program** **Goal**: use high-risk algorithm to prioritize patients who are likely to benefit from comprehensive case management focused on providing preference-aligned palliative care services **Collaboratory Role**: develop and test high-risk algorithm, provide clinical expertise for intervention design, evaluate effectiveness of intervention on patient-centered outcomes	**Ongoing monitoring** **Goal:** identification of areas for potential quality improvement and cost savings **Collaboratory Role**: data analytics for Bluestone prioritized metrics, matching researchers with expertise in prioritized areas for rigorous implementation and evaluation of Bluestone's best-practice programs

Considerations for Researchers

- **Partner with physician group, not directly with assisted living community**
  - Opportunities to engage assisted living corporations with high Bluestone penetration
- **Claims data**
  - Bluestone EMR data linked to Medicare claims through NIA-supported LINKAGE
  - Claims in LINKAGE 9-12 months delayed, closer to two years for MA
  - For most IMPACT pilots and demonstrations, need to obtain outcomes from EMR
- **Works when partner chooses the project**
  - may or may not be aligned with Collaboratory investigator interests
- **When it works, it's a lot of fun!**

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ePCTs in Adult Day Centers: Scope, Challenges & Strategies

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CareMobi

2023 FINALIST NIA START-UP CHALLENGE

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The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

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Adult Day Services (ADS)

aka "~~Adult Day Care~~"

What ADS is

- *Non-residential congregate settings*
- *Professionally staffed (RN, LCSW)*
- *Serving those with physical or cognitive disabilities requiring supervision*
- *Support health, nutritional, social, & daily living needs*
- *Provide Caregiver Respite, person-centered care*
- *Opportunities to socialize and alleviate loneliness*

What ADS is not

- *"Dancing and dominoes"*
- *A "senior center"*
- *Full of healthy, able-bodied seniors*
- *Day care*
- *"A free lunch"*

About ADS

- **Roughly 4,130 ADS sites nationally (per CDC)**
  - Questionable and not inclusive of “shadow” market
- **Most diverse sector of long-term care**
  - 60% are racial/ethnic minorities
- **No standardized/national reporting requirements**
  - Regulated at state levels
  - Not covered by Medicare (Medicaid, VA, Long-Term Care Insurance)
- **Highly variable in services and programs provided**
  - Health, Social, Dementia-only models, PACE programs
- **Significant closures post-covid due to “non-essential” designation**

Research Challenges in ADS

Dearth of Electronic Data

- Lack of electronic record capture systems
- Lack of regulatory data to draw on
- Reliance on clinical judgment, not validated measures

Resource Constraints

- ”Surviving not Thriving” post-Covid
- Staffing shortages and turnover
- Preference for research that will yield $ benefits
- Lack of technological resources

Variability

- Variety of program types
- Varying regulation across states
- Varied ethnicities and languages
- Varying workflows

Approaches to Research in ADS

Example 1

Using Data from Billing Software

Research | Open access | Published: 22 June 2022

Multimorbidity patterns in adult day health center clients with dementia: a latent class analysis

Tina Sadarangani, Carla Perissinotto, Jonelle Boafo, Jie Zhong & Gary Yu

BMC Geriatrics **22**, Article number: 514 (2022) | Cite this article

Sample
• n = 3,053
Data Source
• ADS Billing Software • California Individualized Plan of Care
Results

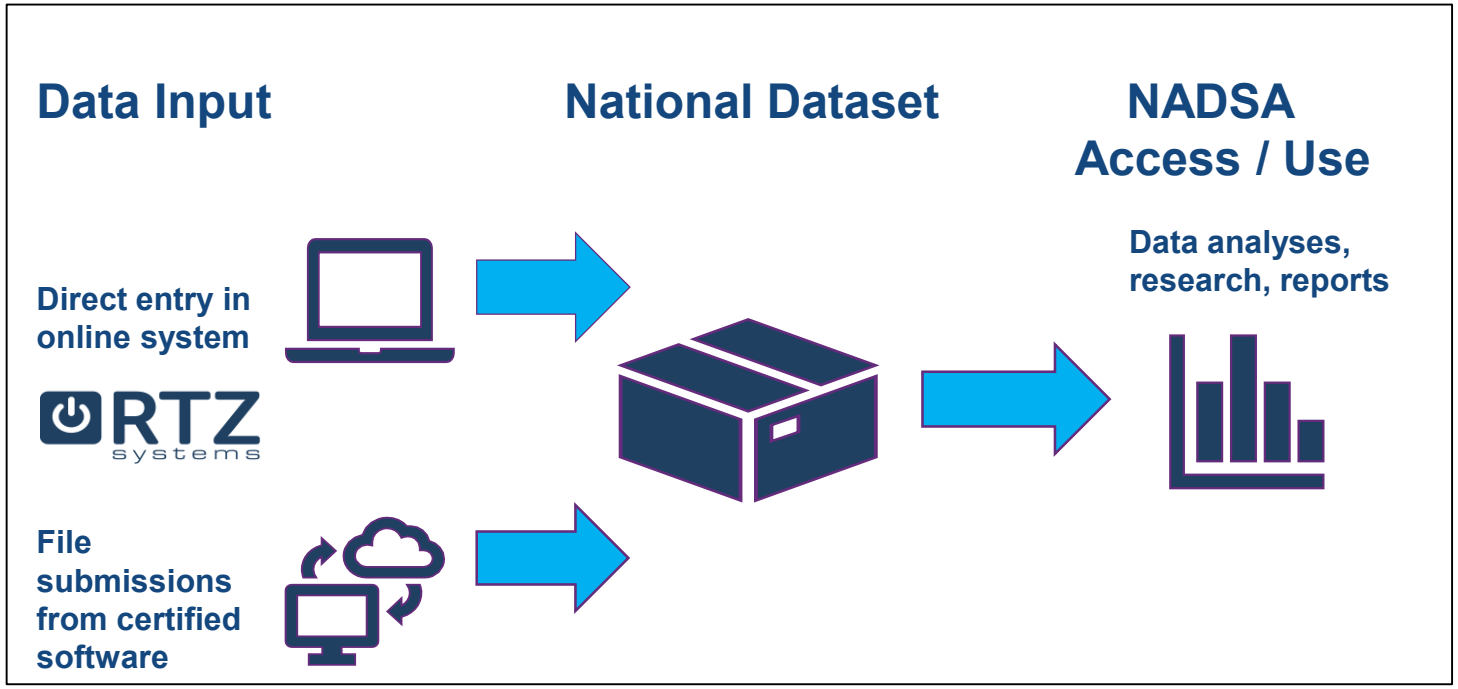
• High medical complexity group had
  • 5+ chronic conditions + ADRD
  • 12.7 medications
  • 49% had LEP, ~19% lived alone

Challenges
• No standardized measures • Significant missing data (race) • Equity implications

Approaches to Research in ADS

Example 2

Community Partner-Led Data Collection nadsa National Adult Day Services Association



About

- Data points and Outcomes Identified in Prior Publication (Anderson et al.)
- Longitudinal Design
- Actively recruiting and enrolling centers via NADSA membership outreach

Examples of Early Data	
% Female	53%
% Non-White	30% (23% missing)
% with ADRD Dx	41%
GDS-15	2.59 (> 5 = Depression)
SLUMS Score	13.19 (< 20 = Dementia)
UCLA Loneliness	21.12 (lower = lonely)

Approaches to Research in ADS

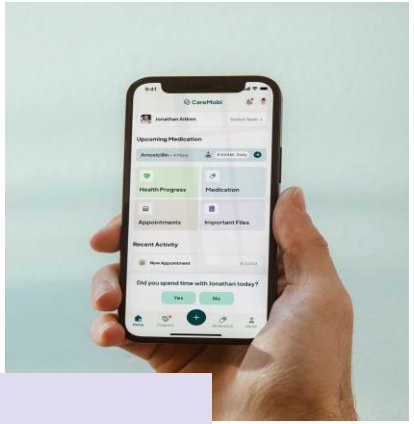
Example 3

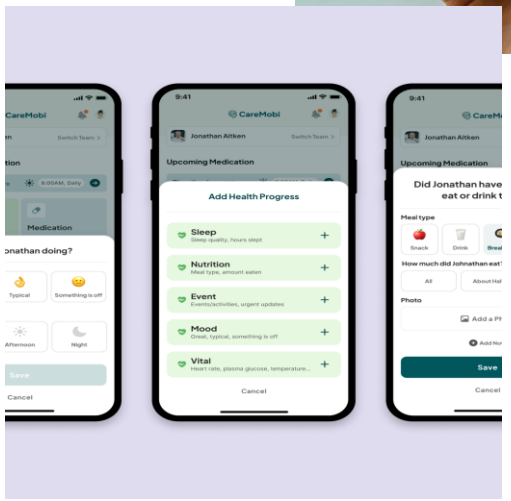
Care Coordination

CareMobi

Available on the App Store

GET IT ON Google Play





Portable Low-Cost Technology

- Light-weight, low-cost, smartphone application
- Centralized hub for family caregivers to track and exchange information about their loved one's day-to-day health with their adult day center
- Supports integrated care
- Pilot testing in 5 sites (MO, CA, TN)
- Assessing Feasibility, Usability
- Trying to Overcome "Technophobia," Workflow challenges, "Double Documentation," Language Barriers

Strategies for Research Success in ADS

- Research priorities should be aligned or, preferably, guided by ADS
- Work with ADS to design details of intervention delivery
- Provide meaningful incentives and financial resources to the ADS site
- Explain how research will help them leverage additional funding
- Don’t rely on ADS staff to collect your data
- Be patient and flexible

Interested in ADS Research?

- Stay in Touch

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NIH National Institute on Aging

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2023 FINALIST NIA START-UP CHALLENGE

Summary

- Need to better understand HCBS priorities, capacity, workflow, variability
- Identify priorities and collaboratively design trials accordingly
- Because HCBS are typically less involved in research/trials, they may need more guidance (including re: adherence to protocols)
- They will also require additional resources – plan accordingly

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Questions?