The Role of Technology in the Care & Monitoring of Persons with Dementia Living Alone

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Today's presenters

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Today's agenda

- **Profile of persons with dementia living alone**
  - Prevalence and demographic characteristics
  - Factors contributing to vulnerability
  - Caregiver roles for persons with dementia
  - Unmet needs, safety concerns & challenges with providing care
- **ADI-SSS/ADSSP grantees**
  - Service gap areas
- **The role of technology in reaching persons with dementia living alone**
  - Existing technologies for persons with dementia and family caregivers
  - ACL grantees using technology
  - <u>Grantee example</u>: Delaware Department of Health & Social Services
- **Insights from the Delaware ADI-SSS pilot program**
  - Important considerations when deploying technology in the home
  - Lessons learned from employing tech-enabled services for persons with dementia and family caregivers
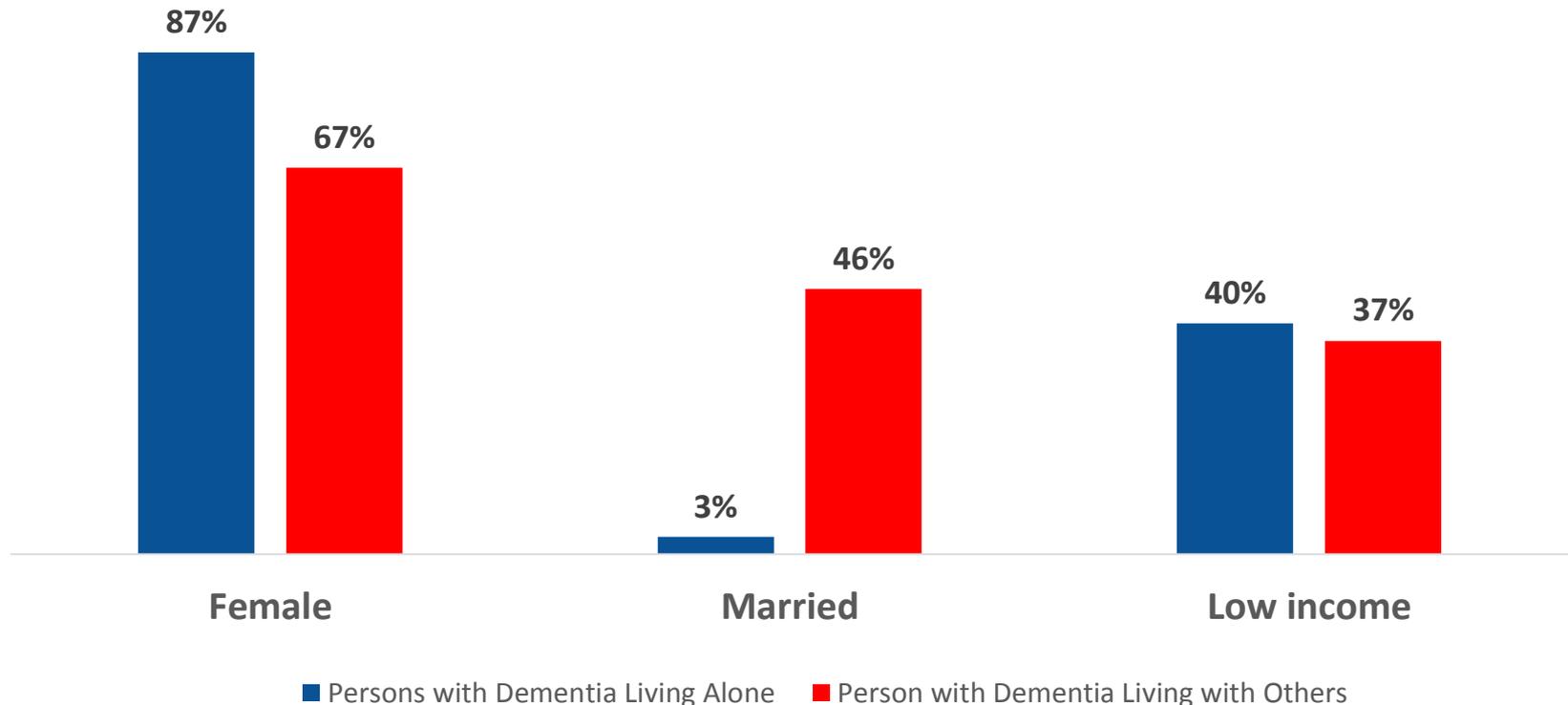
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# Prevalence and characteristics of people with dementia living alone

More than 30% of people with dementia lived alone in 2011[1]

Demographics of Persons with Dementia

Chart: Demographics of Persons with Dementia

- **Female** — Persons with Dementia Living Alone: 87%; Person with Dementia Living with Others: 67%
- **Married** — Persons with Dementia Living Alone: 3%; Person with Dementia Living with Others: 46%
- **Low income** — Persons with Dementia Living Alone: 40%; Person with Dementia Living with Others: 37%

Legend: ■ Persons with Dementia Living Alone   ■ Person with Dementia Living with Others

Sources: Edwards, D. F., & Morris, J. C., (2007). Alone and confused: Community-residing older African Americans with dementia. *Dementia, 6*(4), 489–506.; [1]Amjad, H., Roth, D. L., Samus, Q. M., Yasar, S., and Wolff, J. L. (2016). "Potentially Unsafe Activities and Living Conditions of Older Adults With Dementia." *Journal of the American Geriatrics Society 64*(6): 1223–32.

Prevalence and characteristics of people with dementia living alone

Persons with dementia living alone exhibit fewer cognitive & functional impairments
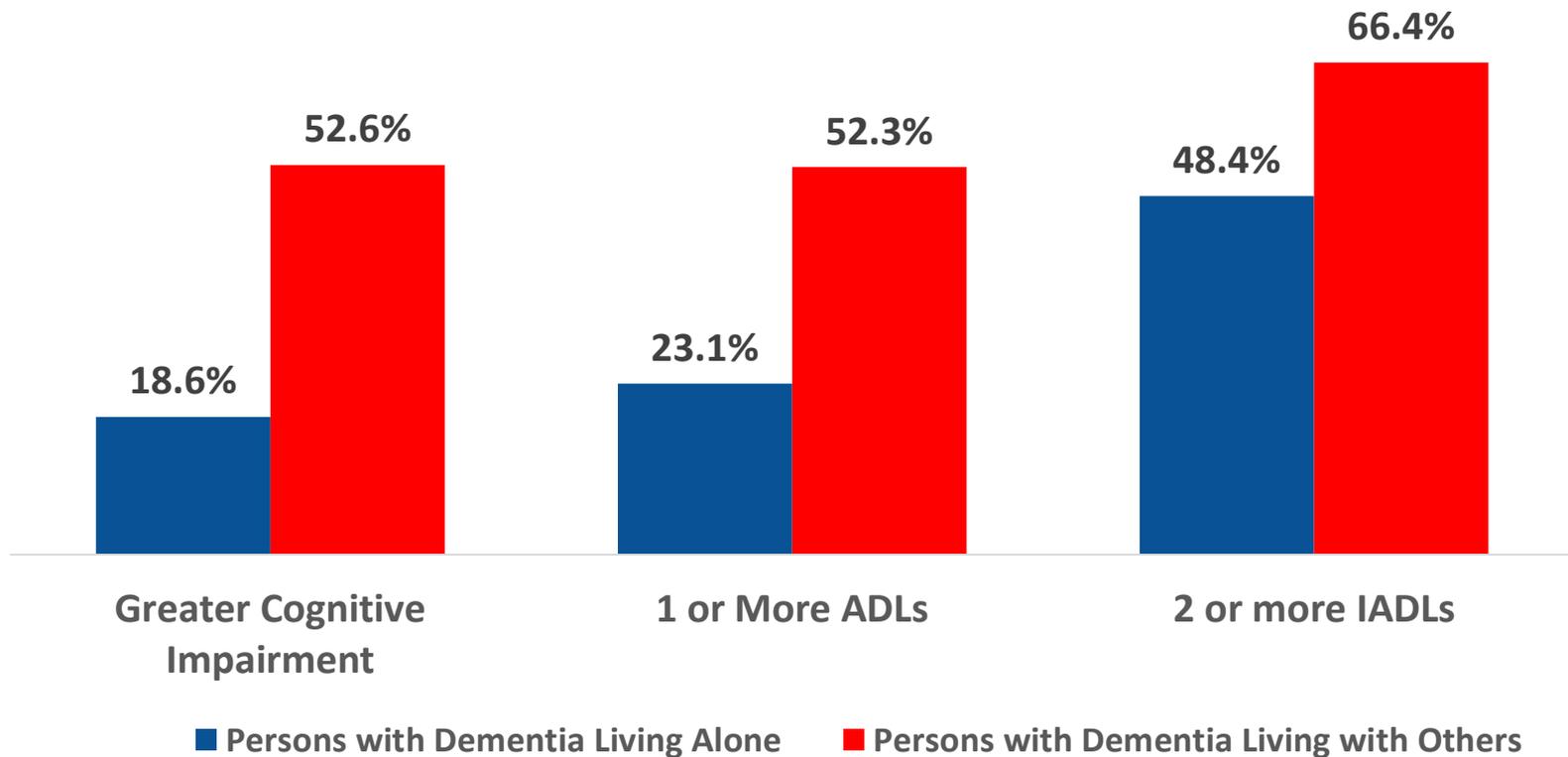
Factors contributing to vulnerability among persons with dementia

- **Vulnerability factors**
  - Lack of awareness of cognitive impairment
  - Impairments in vision, gait, and ability to speak coherently and understand spoken and written language compound
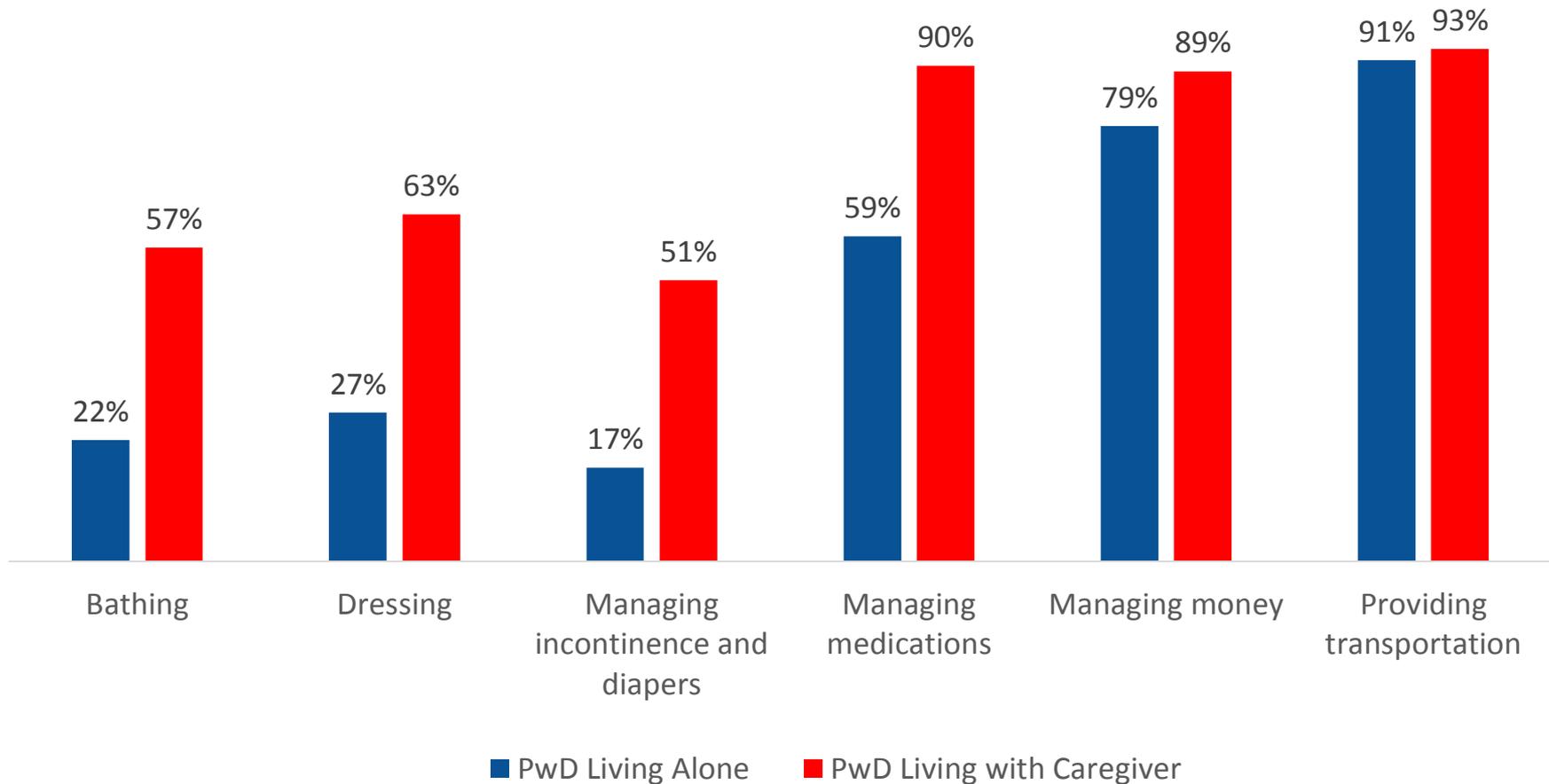
- **Needs change over time**
  - Progression through several stages that coincide with reverse developmental levels (American Occupational Therapy Association, 2017)
  - Increased difficulties in the ability to plan, organize, and follow through with daily activities and personal care needs.

"If no one else lives in the home who can observe changes, the progressive decline associated with dementia may go unnoticed until an emergency occurs." (Soniat, 2004)

Caregiver roles for people with dementia living alone

Proportion of Caregivers Who Reported Helping the Person with Specific Activities, 2009

Bar chart showing:

Activity	PwD Living Alone	PwD Living with Caregiver
Bathing	22%	57%
Dressing	27%	63%
Managing incontinence and diapers	17%	51%
Managing medications	59%	90%
Managing money	79%	89%
Providing transportation	91%	93%

■ PwD Living Alone   ■ PwD Living with Caregiver

Unmet needs and safety concerns

- **Unmet needs**
  - Ability to manage personal care needs and daily activities
  - Ability to manage health conditions and medications
  - Falls risk
  - Nutrition and hydration
  - Social isolation and loneliness

- **Safety Concerns**
  - Home safety
  - Unattended wandering
  - Ability to respond in an emergency
  - Financial exploitation

Sources: Miranda-Castillo et al., 2010; Edwards and Morris, 2007; Bourgeois et al., 2009; National Center on Elder Abuse, 1998

Challenges in providing care to persons with dementia living alone

Several challenges associated with providing essential services for people with dementia who live alone:

- Identifying individuals with dementia who live alone

- Building trust

- Supporting safety and autonomy

- Involving family and friends

- Coordinating paid providers and formal support services

- Assisting with transition to a new setting

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Alzheimer's Disease Initiative-Specialized Supportive Services (ADI-SSS)

Target gaps developed on advice of NAPA Council:

- Provision of effective supportive services to **persons living alone with ADRD** in the community + **persons living with moderate to severe impairment from ADRD and their caregiver**

- **Improvement of the quality and effectiveness of programs and services** dedicated to individuals aging with intellectual and developmental disabilities with ADRD or those at high risk of developing ADRD

- **Delivery of behavioral symptom management training and expert consultation** for family caregivers

→ Evidence-based/evidence informed intervention, direct service and match requirements

# Alzheimer's Disease Supportive Services Program (ADSSP)

Mission is to support state efforts to expand the availability of community-level supportive services for persons with ADRD and their caregivers

- Program focuses on **serving hard-to-reach and underserved communities**

- Evolved over the years, **moving from innovative practices and evidence-based interventions to current focus on building dementia capability within state systems**

- Evidence-based/evidence informed intervention, direct service and match requirements
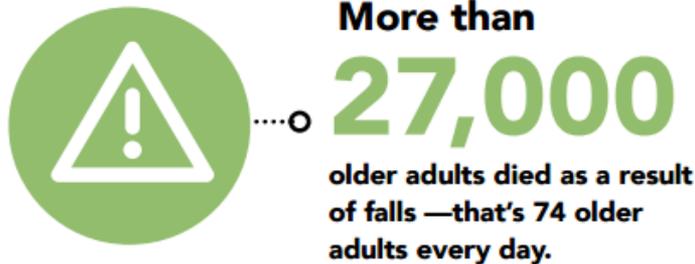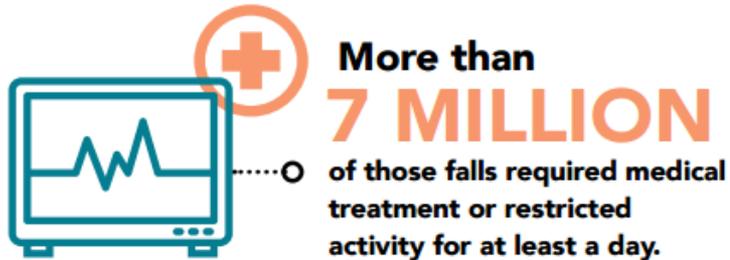
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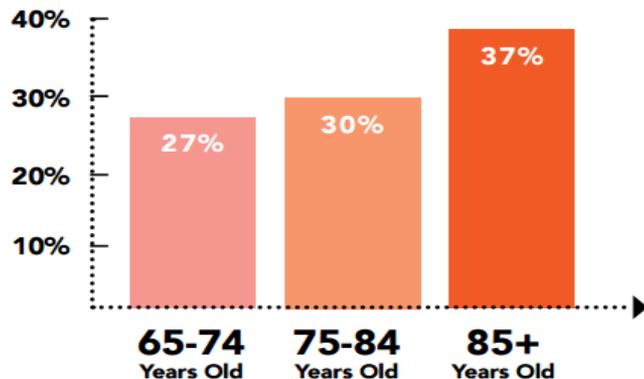# Trends in older adult use of internet, social media, and electronic devices
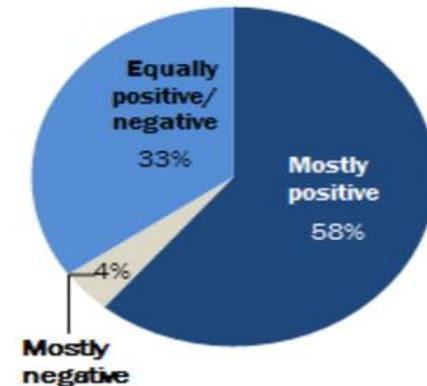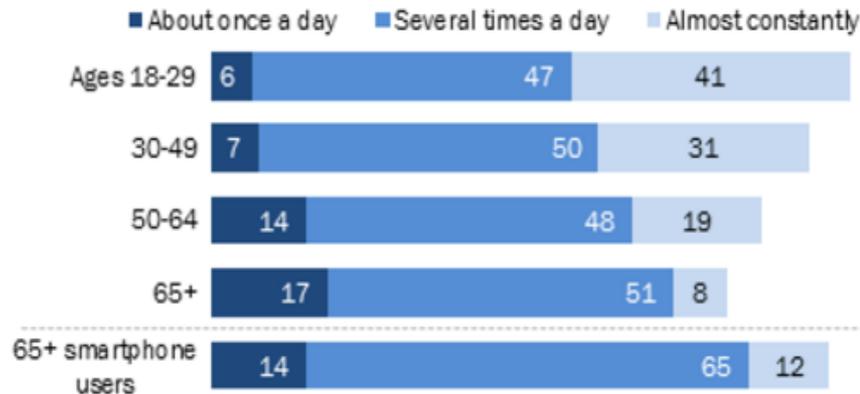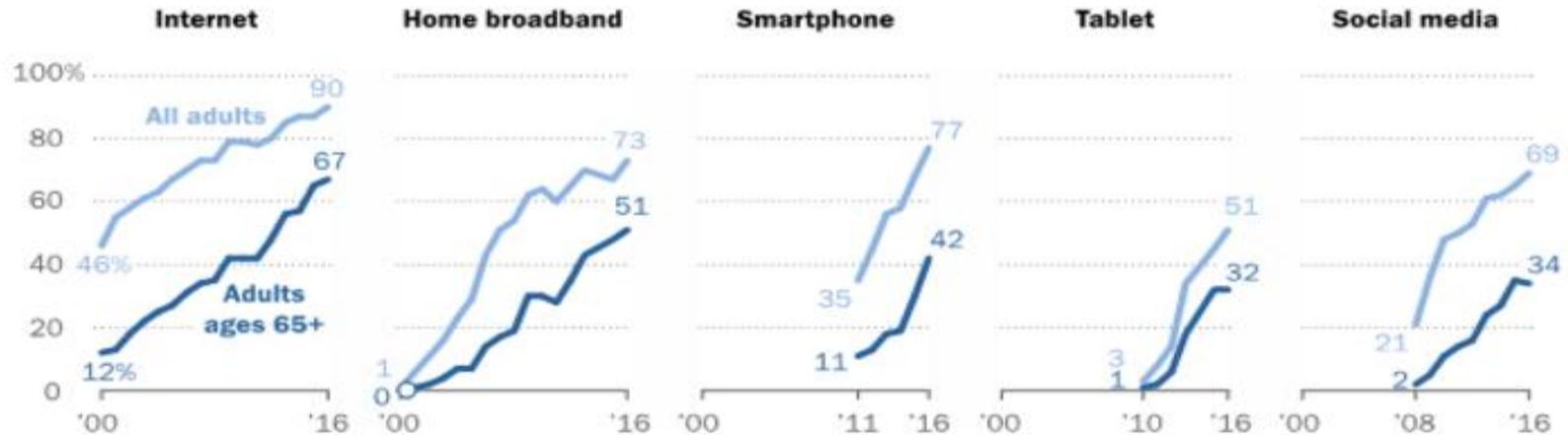
Older adults are increasingly using internet and electronic devices, using their mobile devices multiple times a day, and have a positive perception with regard to the use and benefits from technology

Example technologies for <u>falls prevention</u> & wandering

More than
7 MILLION
of those falls required medical treatment or restricted activity for at least a day.

More than
27,000
older adults died as a result of falls —that's 74 older adults every day.

Falls Increase with Age:*

40%	
30%	37%
20%	27% 30%
10%	

65-74 Years Old   75-84 Years Old   85+ Years Old

* Percent of older adults who reported a fall

<u>Falls-prevention technologies:</u>
- **"Lo-tech"**
  - In-home modifications including:
    - Grab bars, handrails, adjustable shower heads/outlets

- **"Hi-tech"**
  - Sensor-based technologies
    - Wearable sensors (e.g., sensors embedded in shoes/socks)

    - Nonwearable sensors (sensors placed in key living spaces of home)

Example technologies for falls prevention & <u>wandering</u>

Wandering is highly prevalent among persons with dementia:
- <u>**6 in 10 with dementia thought to wander**</u>[1] (e.g., disorientation, reduced awareness of familiar environments)

- Can lead to <u>**falls and exposure to high-trafficked areas**</u>

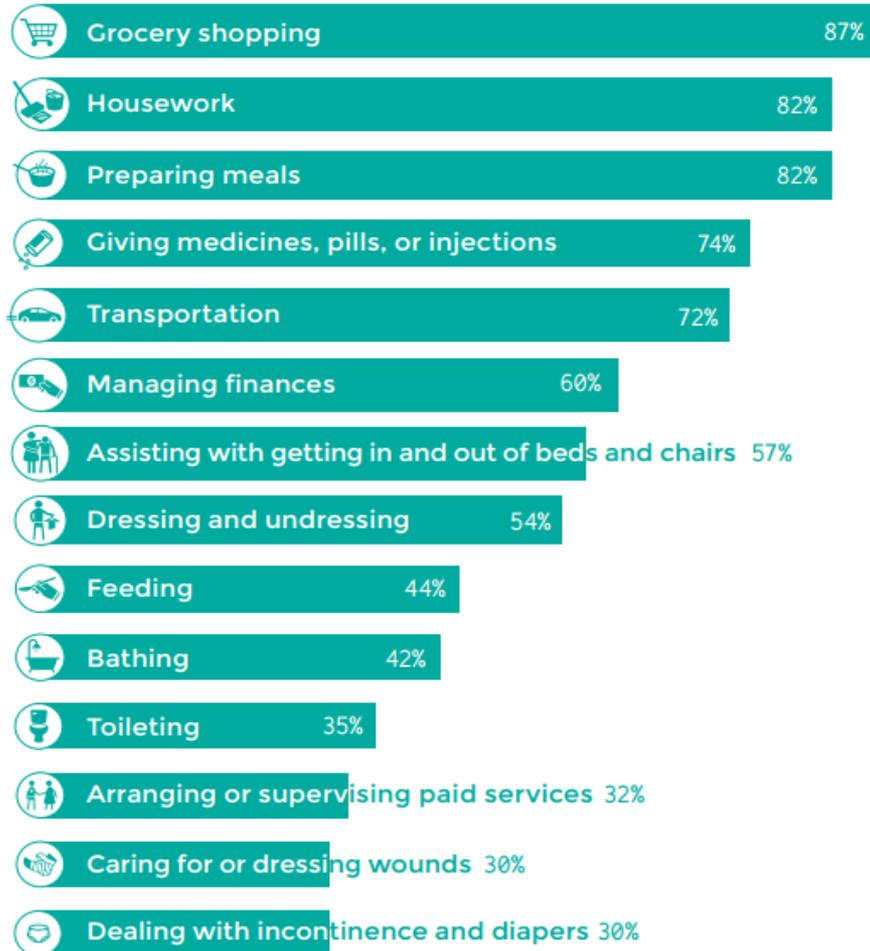**"Lo-tech" solutions to wandering:**
- Use alarms and locks to keep track of care recipients whenever they are moving[2]

- Have a system in place whenever a door, window, or other forms of entry/exit is used[1]

"Hi-tech" solutions to wandering:
- Tracking via means of wearable devices (via shoes, wrist, etc.) with GPS/location capability

Sources: [1]http://www.alz.org/care/alzheimers-dementia-wandering.asp; [2]http://www.mayoclinic.org/healthy-lifestyle/caregivers/in-depth/alzheimers/art-20046222?pg=2

Complementing caregiver roles and responsibilities: A role for technology?

Caregivers have diverse demands…

Task	%
Grocery shopping	87%
Housework	82%
Preparing meals	82%
Giving medicines, pills, or injections	74%
Transportation	72%
Managing finances	60%
Assisting with getting in and out of beds and chairs	57%
Dressing and undressing	54%
Feeding	44%
Bathing	42%
Toileting	35%
Arranging or supervising paid services	32%
Caring for or dressing wounds	30%
Dealing with incontinence and diapers	30%

& have a big interest in technology

Task	%
Rx refill + pickup	79%
Making and supervising medical appointments	78%
Assessing health needs and conditions	78%
Ensuring home safety	78%
Monitoring Rx adherence	77%
Checking in on care recipient	76%
Managing stress and emotional challenges (of caregiver)	74%
Grocery and other shopping	72%
Transportation, providing and arranging	71%
Managing finances	70%
Housework	67%
Making medical or care decisions	67%
Providing meals	67%
Budgeting	67%
Arranging or supervising paid services	67%
Giving medicines, pills or injections	65%
Making legal decisions	63%

Caregivers interested in technology to boost social engagement and knowledge

	Already Use	Likely to Use	Neutral	Unlikely to Use
Connect socially with other caregivers to share and learn from personal experiences	5%	**63%**	14%	18%
Contribute to or view inspirational stories about providing care to a loved one	5%	**52%**	15%	31%
Gain emotional or mental health support from professionals to help you manage the challenges of providing care to a loved one	5%	**59%**	14%	22%
Social media or social networking related to caregiving	8%	**62%**	13%	19%
Information and resources on how to access services for emotional, mental health, or social support to help you manage the challenges of providing care to a loved one	5%	**52%**	15%	31%

Family caregivers express high rates of potential take-up of tech-enabled services that provide ways to engage with other family caregivers

If you recall...Alzheimer's Disease Supportive Services Program (ADSSP)

Mission is to support state efforts to expand the availability of community-level supportive services for persons with ADRD and their caregivers

- Program focuses on **serving hard-to-reach and underserved communities**

- Evolved over the years, **moving from innovative practices and evidence-based interventions to current focus on building dementia capability within state systems**

- Evidence-based/evidence informed intervention, direct service and match requirements

ACL Grantees Using Technology: Closed Grants
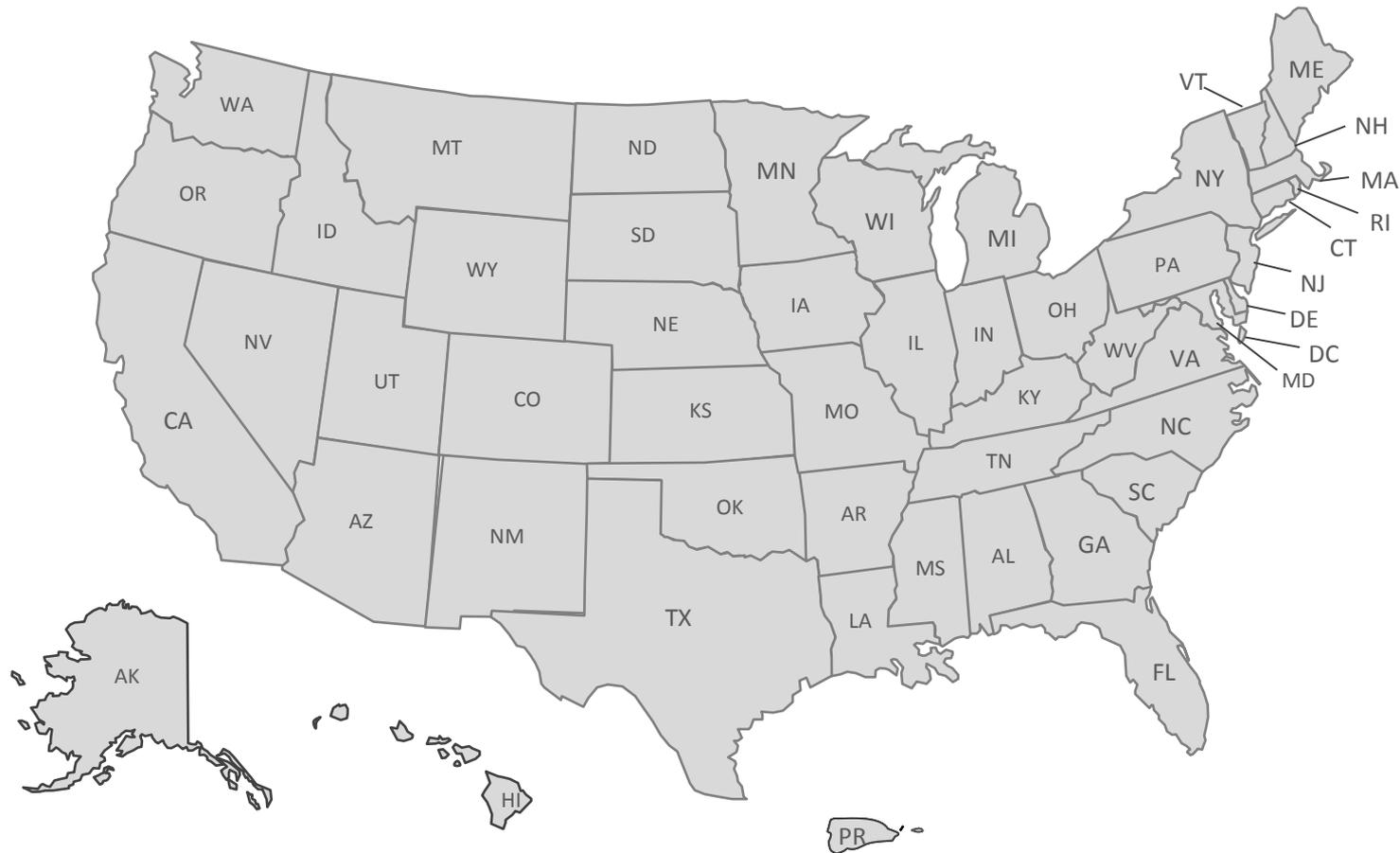
- 77 closed ADSSP grants initially funded between 2007 and 2010

- Across 35 states, District of Columbia, and Puerto Rico

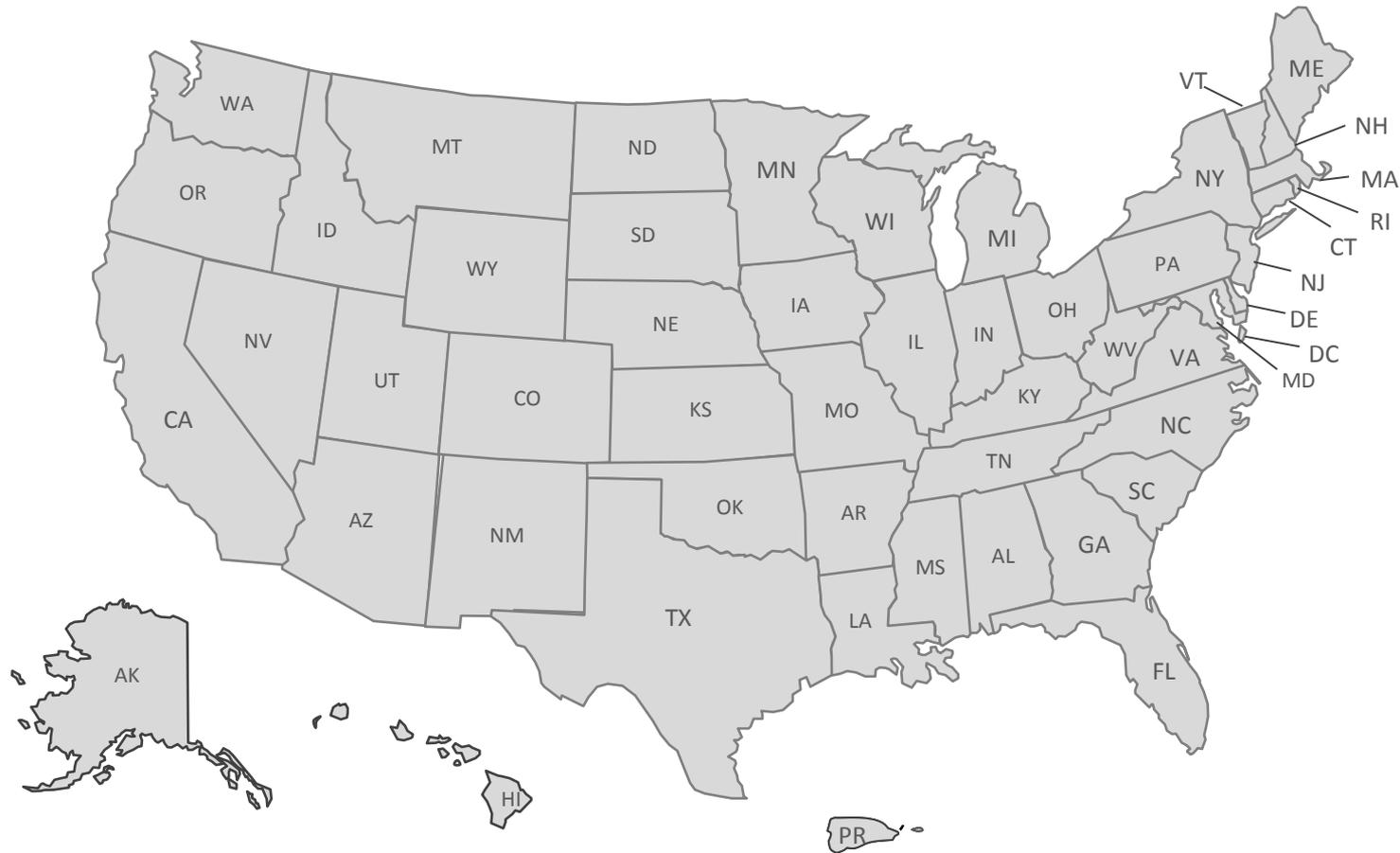# ACL Grantees Using Technology: Closed Grants
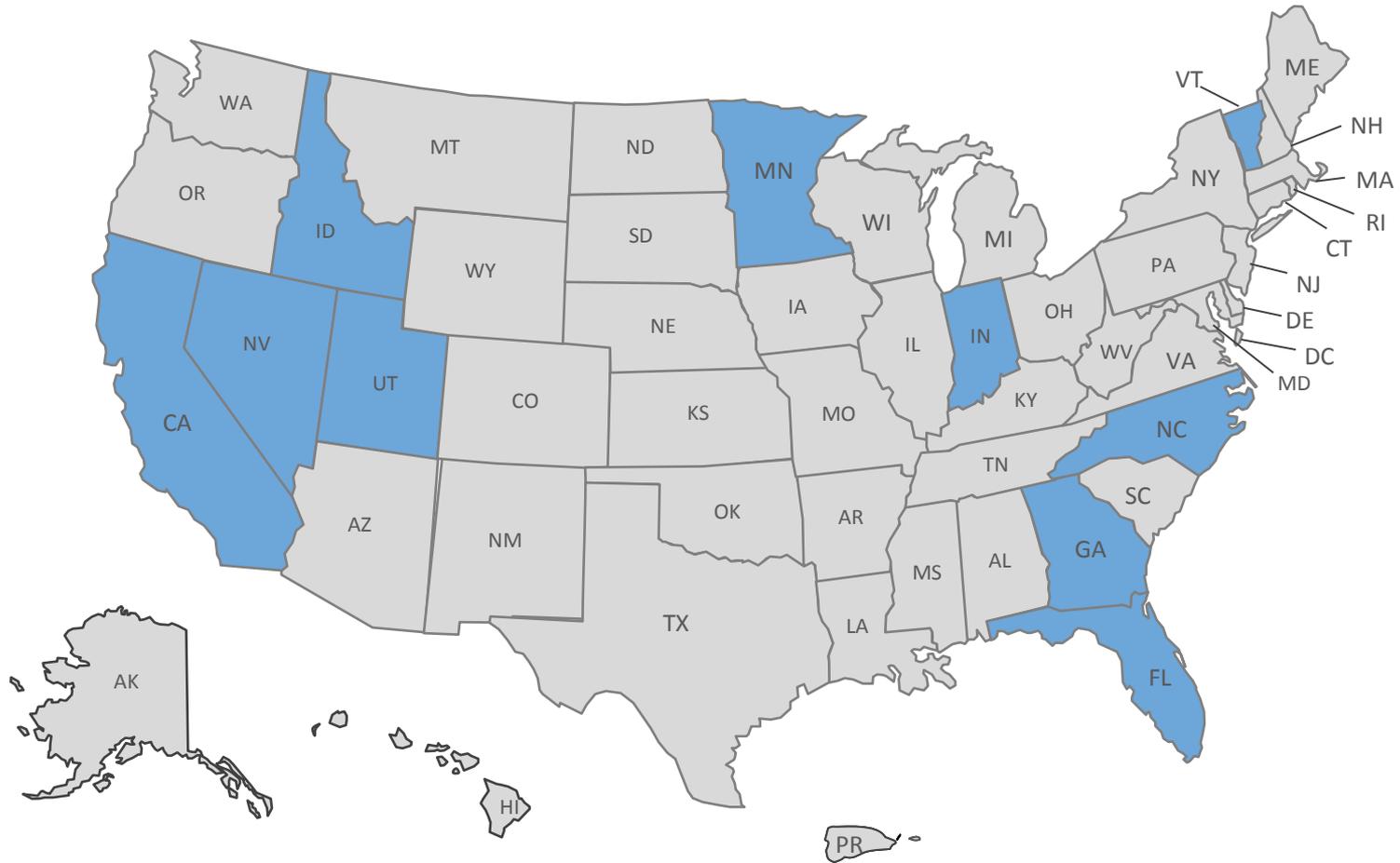
- 12 ADSSP grants across 10 states
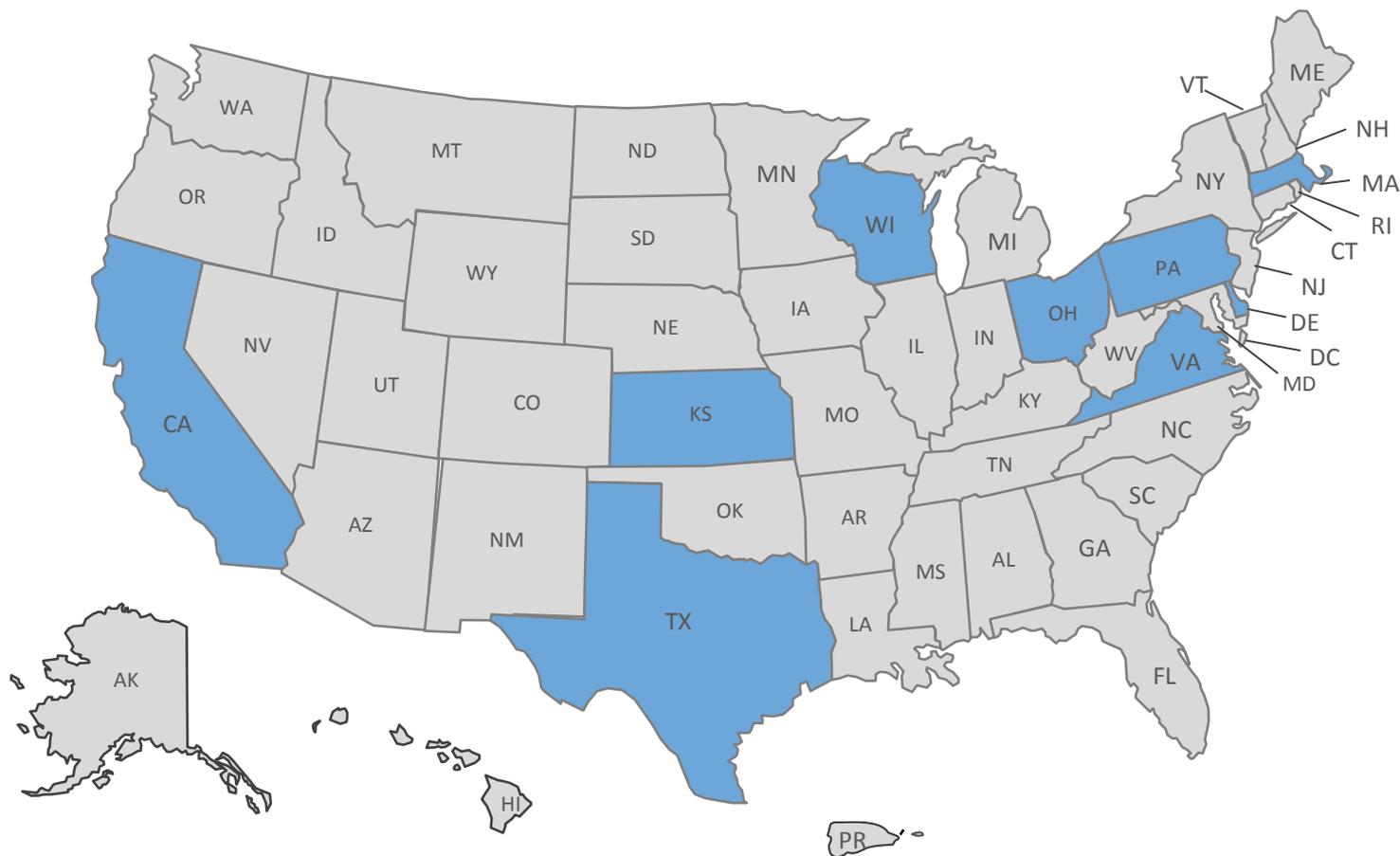
ACL grantees using technology: Closed grants

Grantee	Intervention	Type of Technology	Outcome?
Florida	REACH II	Telephone	⬆
Georgia	REACH II	Telephone	⬆
Georgia	REACH II	Telephone	⬆
North Carolina	REACH OUT	Skype	⬆
Vermont	REACH OUT	FaceTime	MIXED
Minnesota	NYUCI Family Sessions	Telephone	⬆
California	NYUCI Family Sessions	Skype	UNCLEAR
Utah	NYUCI Family Sessions	Telephone	MIXED
Georgia	Telephone Reassurance Program	Telephone	⬆
Idaho	Building Better Caregivers Program	Online Portal	⬆
Indiana	Assist. technological equip. for caregivers	Video monitoring, medication dispensers, blood pressure units & weight monitoring, safety monitoring	⬆
Nevada	Workshops & behav. counseling	Telephone & interactive videos	⬆

ACL Grantees Using Technology: Current Grants

- 52 grants across 30 states with 2014-2019 funding period

- 32 ADI-SSS grants and 20 ADSSP grants

ACL Grantees Using Technology: Current Grants

- 5 ADSSP and 6 ADI-SSS grants across 9 states

ACL grantees using technology: Current grants

Grantee	Intervention	Type of Technology
California	Music & Memory	iPods
Delaware	Sensory Technology Pilot Program	Sensory technologies
Kansas	Mobile Reducing Disability in Dementia	Video conference software and tablet computers
Massachusetts	Guide and access to assistive technology	Telephone, tablets, iPods, tracking devices, room monitors, and alarms
Ohio	Music & Memory	iPods
Pennsylvania	Caregiver messaging providers directly via online patient portal	EPIC Patient Portal
Texas 90AL0004	Benjamin Rose Institute Caregiver Consultation	Telephone
Texas 90DS2023	Benjamin Rose Institute Caregiver Consultation	Telephone
Virginia	FAMILIES adaption of NYUCI	Web-based audio-visual communication technology (WebEx), telehealth equipment
Wisconsin 90AL0006	Music & Memory	iPods
Wisconsin 90DS2020	Music & Memory	iPods

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DELAWARE ALZHEIMER'S DISEASE INITIATIVE SENSORY TECHNOLOGY PILOT PROGRAM

DELAWARE HEALTH AND SOCIAL SERVICES

Division of Services for Aging and Adults with Physical Disabilities

Delaware's Alzheimer's Disease Initiative

- **<u>Fill the gaps in Delaware's dementia-capable system of long-term services</u>** and supports to better meet the needs of persons with Alzheimer's disease and related disorders and their caregivers

- Activities of the initiative include:
  - **Pilot sensory technology program**
  - Caregiver training and consultation
  - Respite vouchers
  - Community integration services
  - Partner dementia competency training
  - Expanded legal services

Delaware's Alzheimer's Disease Initiative

- **Provide support** to individuals with Alzheimer's disease and related dementias (ADRD) and their caregivers **by monitoring home activity through technology systems**

- Offers the caregiver a way to **remotely monitor their loved one**, using the technology to be alerted if there is a safety concern

- **Eligible participants have:**
  - early- to moderate-stage ADRD
  - a caregiver who either lives with the individual or lives close and has a smartphone or computer access to wireless internet in the home

Factors in choosing a pilot program

- **Streamlined Services**: Delaware is a Single Unit on Aging

- **Size**: Delaware **consists of only three counties,** and one can travel from the northernmost point to the southernmost point in less than 3 hours

- **Buy-In**: Leadership was looking at innovative ways to use technology and **wanted to learn if other sources of funding can support this in the future** (emergency response systems)

- **Expense:** Currently, the technology is expensive and a full roll-out supported by grant funding would not be possible

How do you choose the right technology and vendor?

- Delaware developed an RFI and RFP process to ensure that the right technology was chosen for this pilot program

- There were two proposals for bids and ultimately Element Blue, a subsidiary of IBM, was chosen

- The pilot has **10 participants** use the technology for a 1-year period, starting in July 2017

How do you choose the right technology and vendor?

- The pilot has **<u>10 participants</u>** use the technology for a 1-year period, starting in July 2017
  - 5 male/5 female

  - 6 rural/4 urban

  - Ages range from 64-91

  - 3 live alone/7 have caregivers they live with

How do you choose the right technology and vendor?

- ☐ Delaware developed an RFI and RFP process to ensure that the right technology was chosen for this pilot program

- ☐ There were two proposals for bids and ultimately Element Blue, a subsidiary of IBM, was chosen

- ☐ The pilot has **10 participants** use the technology for a 1-year period, starting in July 2017

- ☐ The total cost of the program is $149,000, which includes the technology, setup, technical assistance, and breakdown

- ☐ Element Blue works directly with DSAAPD nurses to make sure the technology is working appropriately

In-home sensing technology and associated benefits

Service Area	Sensor Type		Benefits
1 Kitchen Area Monitor	Temperature		• Detect movement, monitor presence and use of lights • Check for use of faucet and duration of use • Monitor living conditions such as temperature and humidity • Watch for leaks and running water
	Humidity		
	Water Flow – Faucet under sink		
	Presence		
	Luminosity		
	Water Leakage – Baseboard under sink		
1 Bathroom Monitor	Temperature		• Detect movement, monitor presence and use of lights • Check for use of faucet and duration of use • Monitor living conditions such as temperature and humidity • Watch for leaks and running water
	Humidity		
	Water Flow – Faucet under sink		
	Presence		
	Luminosity		
	Water Leakage – Baseboard under sink		

In-home sensing technology and associated benefits

Service Area	Sensor Type		Benefits
1 Bedroom or sleeping area Monitor	Temperature		• Detect movement, monitor presence and use of lights • Monitor living conditions such as temperature and humidity • Watch for changing sleeping and rest periods.
	Humidity		
	Presence		
	Luminosity		
1 Living Area Monitor	Temperature		• Detect movement, monitor presence and use of lights • Monitor living conditions such as temperature and humidity • Monitor door opening and closing for security.
	Humidity		
	Presence		
	Luminosity		
	Hall effect – Door sensor		
Voice Interface	Amazon Echo		Amazon echo is an internet enabled interface that will be set up for participants and caregivers to be able to query via voice commands for alerts, events, or current conditions.
Interaction	Web based Interface		The SensorInsight web and mobile application is a secure way to access information and set/monitor alerts or changes in activity.
	Mobile Application		

Intake survey for family caregiver/person with dementia: Obtaining a baseline assessment

- **Thoughts on the installation**, training, and accessibility of the sensory technology, and **concerns about safety** for the person with dementia

- **How often specific situations** occurred with the person with dementia prior to the installation of sensory technology (e.g., **appliances left on when not in use, falls in the home, house too hot or cold**)

- **Considered assisted living or skilled nursing settings** for person with dementia and how likely to seek out alternative housing options in the next year

- **Whether emergency responders (e.g., police, fire department, ambulance) had come** to the home prior to the installation of the sensory technology

Potential benefits from pilot program

- Complement existing state programs and services
  - State of Delaware currently has a 'Personal Emergency Response System'

- Share lessons learned from pilot with existing programs and services
  - Identify which sensing technologies placed in home are most beneficial and target efforts to share these with larger community

  - Findings from pilot will allow an assistive technology center operated by Caregiver Resource Center to promote specific sensing technologies

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Important considerations for technology use in home

- Require user digital literacy among caregivers or person with dementia and the staff/interventionists going into the home

- Ensure that assistive technology product matches the person's abilities and preferences

- Conduct ongoing assessment to identify any cognitive changes that may negatively impact the person's ability to continue to use the technology

- **System/Infrastructure requirements**
  - Need technology infrastructure and wireless connectivity
  - Integration with other health information and electronic health records
  - Access and approval of appropriate devices
  - Security considerations
  - Financial resources

Factors to consider if interested in tech-enabled services for individuals with dementia

- **Involve people with dementia** and their family caregivers in identification and development of assistive technology

- **Determine who can benefit** from a specific technology and the optimal setting and time for introducing it

- **Include persons with dementia living alone** as research participants in studies examining the benefits of technology

- **Examine factors that affect the adoption and continued use** of assistive technology in older adults and ADRD communities

Thank You!...Contact Us

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Available resources

- Guide for Professionals on Practical Strategies for Persons with Dementia Living Alone https://nadrc.acl.gov/node/98

- Identifying and Meeting the Needs of Individuals with Dementia Who Live Alone (issue brief) https://nadrc.acl.gov/node/79

- Identifying and Supporting People With Dementia Who Live Alone (webinar) https://nadrc.acl.gov/node/54

- Mobile Applications for the Community and Law Enforcement to Assist Vulnerable Adults (webinar) https://nadrc.acl.gov/node/68

- American Society on Aging *Generations* Fall 2017 Special Issue (forthcoming September 2017):
  - Reducing Dementia Caregivers' Burden: Is There a Role for Assistive Technology?
  - Individuals with Dementia Who Live Alone: When to Intervene

- NADRC Quarterly Article Resource Lists of published articles on topics that include persons with dementia living alone and technology-based interventions https://nadrc.acl.gov/

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