Integrating Public Health Approaches to Dementia Caregiving into Your State Plan

Facilitated by Heidi Holt
Healthy Aging Branch, DPH/NCCDPHP/CDC
www.cdc.gov/aging
What Is a Public Health Approach To Dementia Caregiving?

✔ Not duplication
✔ Population-based
✔ Enhancing Sustainability
✔ Systems, Environments and Policies
What is sustainability?

Continuation of program and its activities and resources after the conclusion of the project period
When should sustainability be considered?

Sustainability starts at the beginning of project/program and should **not** be the final phase of the project.
How is sustainability achieved in Public Health?

1. Partners
2. Policies (P and p)
3. Systems
4. Environments
How does it work?

<table>
<thead>
<tr>
<th>Characteristics of Event or Program</th>
<th>Characteristics of PSE Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>One time</td>
<td>Ongoing</td>
</tr>
<tr>
<td>Additive: often results in only short-term behavior</td>
<td>Foundational: often produces behavior change over time</td>
</tr>
<tr>
<td>Individual level</td>
<td>Community/Population level</td>
</tr>
<tr>
<td>Not part of ongoing plan</td>
<td>Part of an ongoing plan</td>
</tr>
<tr>
<td>Short term</td>
<td>Long term</td>
</tr>
<tr>
<td>Non-sustaining</td>
<td>Sustaining</td>
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</tbody>
</table>

Source: [Food Trust](#)
Partners

❖ Diversity
❖ Different paradigms
❖ Additional organizational connections
❖ Enhanced opportunity for systems changes
What is Policy Change?

- Policies at the legislative or organizational level.
- Institutionalizing new rules or procedures.
- Passing laws, ordinances, resolutions, mandates, regulations.
- Organizational policies.
What is Systems Change?

✔ Change made to the rules within an organization.
✔ Systems change and policy change often work hand-in-hand.
✔ Changing infrastructure within a school, park, worksite, or health setting or instituting processes or procedures at the system level that ensure a healthier workplace.

Other Examples:
• Increase geriatric education within accredited medical schools
• Developing a connected system of clinical community linkages
What is Environmental Change?

- Change made to the physical environment.
- Social and economic determinants of health.
- Stigma and acceptance.
- Reflect a population-focused effort.

System, Environment and Policy changes can be very similar and overlap. Sometimes together referred to as “structural change.”
### Examples

**Example Goals**
*(Corresponding HBI Road Map Series Actions)*

<table>
<thead>
<tr>
<th>Policies</th>
<th>Level of Prevention &amp; Example activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase adoption and create incentives for system-wide risk reduction interventions.</td>
<td><strong>Primary Prevention</strong> <em>(i.e., risk reduction)</em>&lt;br&gt;Promote the system-wide coordination of high-quality care for those with dementia.</td>
</tr>
<tr>
<td>Promote the value of brain healthy behaviors at young ages in elementary, middle and high schools.</td>
<td></td>
</tr>
<tr>
<td>Integrate brain health and stigma reduction curriculum in education settings. <em>(W-1, W-3, W-5, IC-7)</em></td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>Systems</th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Partner to promote healthy behaviors, including physical activity, smoking cessation, access to nutrient-dense food. <em>(E-2, E-7, IC-1, IC-2, IC3)</em></td>
<td>Promote the value of brain healthy behaviors at young ages in elementary, middle and high schools.</td>
<td>Modify <em>medical school curriculum</em> to include the value of early detection and diagnosis of dementia.</td>
<td>Encourage improved training to coordinate referrals and services for improved clinical and community linkages.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Environments</th>
<th></th>
<th></th>
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<tbody>
<tr>
<td>Increase adoption and create incentives for system-wide risk reduction interventions.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(P-1, E-7, W-4, M-3, IC-2)</td>
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*bit.ly/hbistateplan*
Bridging the GAP
How can we incorporate PSE into our state plans?
Please welcome our next speakers.

Kristy Russell
ADRD State Plan Specialist
Utah Department of Health & Human Services

Raven Albertson
Program Manager
Alzheimer’s Association, Utah Chapter
**Kristy Russell**

- Alzheimer’s Disease and Related Dementias State Plan Specialist for the Utah Department of Health and Human Services
- Certified Health Education Specialist
- Coordinates the ADRD State Plan
  - Coordinating Council
  - Leads the state’s collaborative efforts on addressing dementia
  - Provides statewide education
- Assists individuals in accessing resources available to those with dementia, their caregivers and loved ones
- Has experience as a professional and family caregiver

**Raven Albertson**

- Program Director for the Utah Chapter of the Alzheimer’s Association
- Certified Health Education Specialist
- Partner and stakeholder for the Utah ADRD State Plan and Coordinating Council
- Oversees efforts to educate and support Dementia caregivers
  - Persons living with dementia
  - Health care providers
  - The general public
- Has experience as a family caregiver

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The Public Health Opportunities and Challenges of Dementia
Caregiving National Conference June 14-15 2022
2012
• ADRD State Plan unanimously adopted by state legislature

2014
• Bill passed assigning the state plan to the Department of Health.
• Appropriation for a State Plan Specialist.

2016
• A statewide ADRD Coordinating Council was formed to oversee the state plan activities

2018
• ADRD State Plan funding increased by the legislature.
• Funding appropriation changed from one time to ongoing for the ADRD state plan, council and implementation of goals.

2019

2022
• Utah Department of Health and Utah Department of Human Services merged.
• ADRD moved to Aging and Adult Services offering increased collaboration with the Area Agencies on Aging.

The Public Health Opportunities and Challenges of Dementia Caregiving
National Conference June 14-15 2022
ADRD Coordinating Council

❖ Currently 145 members statewide
❖ Quarterly meetings
❖ Provides a monthly newsletter
❖ Focus on reducing duplication of efforts and expanding impact through collaboration
ADRD Coordinating Council

- Caregivers & Volunteers: 12.0%
- University Representatives: 21.1%
- State Legislators: 2.3%
- DHHS Employees: 14.3%
- Non-Profit Organizations: 20.3%
- Local Businesses: 5.3%
- Hospital Systems: 3.8%
- Home Health & Hospice Agencies: 3.8%
- Long Term Care Services: 4.5%
- Adult Day Services: 0.8%
- Elder Law Attorneys: 0.8%
- Area Agencies on Aging: 11.3%
A DRD State Plan

Current goals
1. Dementia Aware Utah
2. Support and Empower Family and Other Informal Caregivers
3. Dementia-Competent Workforce
4. Expanded Research in Utah

New goal
➤ Living Well with Dementia
1. Dementia Aware Utah

• Raise broad public awareness of ADRD through culturally appropriate education.
• Ensure that reliable, up-to-date disease and care information is disseminated.
• Provide Utah citizens with the best evidence on how to reduce their own risk for cognitive decline.
• Improve access to a timely diagnosis, differential treatment and supportive services.
• Website Under Construction: UtahAging.org
2. Support and Empower Family and Other Informal Caregivers

• Advocate for and promote education on the vital role of informal caregivers with guidance on quality care and the best utilization of resources throughout the process of the disease.
• Increase the utilization of existing caregiver education programs and support systems.
• Address the needs of working caregivers.
3. Dementia-Competent Workforce

- Develop a dementia-capable and culturally competent professional healthcare workforce who cares for older adults and people with dementia through the continuum of care.
- Improve dementia care capacity, competency and proficiencies of healthcare providers.
- Train professionals in non-healthcare fields who interface increasingly with people who have dementia.
- Coordinate efforts and improve communication between healthcare professionals, healthcare providers and professionals in non-healthcare fields that interact with individuals with dementia.
4. Expanded Research in Utah

- Engage in a public health approach to address the significant projected growth in ADRD in Utah.
- Advocate for research funding.
- Promote participation in research and clinical trials.
Contact Information

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Arkansas

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Section Chief, Nutrition, Physical Activity and Obesity
Arkansas Department of Health

David Cook
Senior Policy Manager
Alzheimer’s Association
Arkansas Chapter
The Impact of Alzheimer’s on Arkansas Families

Prevalence
NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER’S

<table>
<thead>
<tr>
<th>Year</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020</td>
<td>58,000</td>
</tr>
<tr>
<td>2025</td>
<td>67,000</td>
</tr>
</tbody>
</table>

ESTIMATED % CHANGE 15.5%

Health Care
HOSPICE (2017)
3,133
# of people in hospice with a primary diagnosis of dementia
18%
% in hospice with a primary diagnosis of dementia

HOSPITALS (2018)
1,530
# of emergency department visits per 1,000 people with dementia
21.5%
Dementia patient hospital readmission rate

MEDICAID
$396M
Medicaid costs of caring for people with Alzheimer’s (2020)
14.6%
Projected change in costs from 2020 to 2025

MEDICARE
$23,982 per capita Medicare spending on people with dementia (in 2021 dollars)

Caregiving (2021)

<table>
<thead>
<tr>
<th>Category</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Caregivers</td>
<td>93,000</td>
</tr>
<tr>
<td>Total Value of Unpaid Care</td>
<td>$2,160,000,000</td>
</tr>
<tr>
<td>Total Hours of Unpaid Care</td>
<td>139,000,000</td>
</tr>
</tbody>
</table>

23.4% % of caregivers with depression
73.4% % of caregivers with chronic health conditions
11.4% % of caregivers in poor physical health
Arkansas’ Historical Response to Dementia

2009: State Appoints Task Force to begin State Plan Work

2011: State releases its first state plan

2014: Creation of Alzheimer’s Advisory Council 
(Sunset 2016)

2018: Stakeholder group was convened to begin the process of updating the state plan.
Independent Stakeholder Group

- AARP
- Alzheimer’s Association - Arkansas Chapter
- Alzheimer’s Arkansas
- Arkansas HealthCare Association
- Arkansas Hospital Association
- Broyles Foundation
- Homecare Association of Arkansas
- Hospice and Palliative Care Association of Arkansas
- The University of Arkansas for Medical Sciences Centers on Aging
- State Agency Partners
- AR Department of Health
- AR Minority Health Commission
- AR. Dept. of Human Services
Arkansas’ Historical Response to Dementia

2020: State plan update adopted and released

2021: Act 391 established a permanent Alzheimer’s and Dementia Advisory Council
State Plan Priorities

1. Public Awareness and Education (Educate and Empower)
   • Establish a Permanent Alzheimer’s and Dementia Advisory Council (2021) (P-3)

2. Dementia Training and Workforce Development (Educate and Empower)
   • Increase collaboration between the non-profit sector and the medical community to ensure they are aware of the resources available to them and to caregivers. (W-1)

3. Building support for family caregivers

4. Access and Quality of care for persons with dementia
Thank You

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1. What similar processes or goals for systems change in dementia caregiving are in your plans?

1. How do you see these goals that address changes to systems, environment and policies as different than other, more individual programmatic goals?
Thank you

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Healthy Brain Initiative

BOLD

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
Division of Population Health
The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

The Public Health Opportunities and Challenges of Dementia Caregiving National Conference June 14-15 2022