



## HCBS Dementia Reading List

*Shared by the Community Care Network for Dementia [Data Hub](#)*

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### **Motivation**

This reading list was developed by the NIA-funded U24 [Community Care Network for Dementia](#) (CaN-D). CaN-D's goal is to accelerate *measurement of dementia home- and community-based services* and innovative research. This reading list can help get you up to speed quickly on previously published home- and community-based services research, focusing when possible, on dementia. Note that this list of articles may not be exhaustive and will be updated periodically. Please send any feedback to CaN-D's director, Dr. Regina Shih at [rashih@emory.edu](mailto:rashih@emory.edu).

### **Inclusion Criteria**

This list was generated by searching for HCBS and dementia measurement terms in Google, Google Scholar, and PubMed. The search was conducted between September-December 2023. Inclusion criteria included: articles, reports, grey literature, dashboards in English, published in the last 15 years (2008-2023), HCBS in the United States.

### **Coding**

**Blue** = peer reviewed journal articles

**Purple** = reports

**Yellow** = dashboards

### **Table of Contents**

Please note that some articles and reports sometimes fall into multiple categories. We have placed literature under its best-fitting category.

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## HCBS Quality Measures

1. Home and Community-Based Services Quality Measure Set Measure Summaries
  - 2023, Centers for Medicare & Medicaid Services (CMS)
  - 111-page report by CMS on HCBS Quality Measures
  - <https://www.medicaid.gov/sites/default/files/2023-02/hcbs-quality-measure-set-summaries.pdf>
2. Quality Measurement for Home and Community Based Services (HCBS) and Behavioral Health in Medicaid
  - 2016, Lacey Hartman & Elizabeth Lukanen, Medicaid and CHIP Payment and Access Commission (MACPAC)
  - 30-page report commissioned by MACPAC carried out by the State Health Access Data Assistance Center on Medicaid behavioral health and HCBS quality measures
  - <https://www.macpac.gov/wp-content/uploads/2017/06/Quality-Measurement-for-HCBS-and-Behavioral-Health-in-Medicaid.pdf>
3. Understanding What Works: Measuring and Monitoring Quality in Medi-Cal's Home and Community-Based Services
  - 2022, Jordan Harrison, Regina Shih, & Sangeeta Ahluwalia, California Health Care Foundation (CHCF) and the RAND Corporation
  - 20-page report by the RAND Corporation on measuring quality of HCBS in California's Medi-Cal program
  - <https://www.chcf.org/wp-content/uploads/2022/01/MeasuringMonitoringQualityMediCalsHCBS.pdf>
4. Mathematica HCBS Quality Measures
  - Debra J. Lipson, HCBS Quality Measures Issue Brief: [Assessment and Care Planning Measures](#), CMS, November 2019.
  - Debra J. Lipson, HCBS Quality Measures Issue Brief: [Measures of State Long-Term Services and Supports System Rebalancing](#), Centers for Medicare & Medicaid Services (CMS), November 2019.
  - Debra J. Lipson, HCBS Quality Measures Issue Brief: [Person-Reported Outcome Measures for Home and Community-Based Services](#), CMS, November 2019.

## HCBS Access & Utilization

1. Interventions to enhance access to and utilization of formal community care services for home dwelling persons with dementia and their informal carers: A scoping review
  - 2019, Røsvik et al., Aging & Mental Health
  - 12-page systematic review examining interventions to increase access to and utilization of community care services for people with dementia
  - <https://www.tandfonline.com/doi/full/10.1080/13607863.2018.1523876> (how to attach PDF?)
2. Barriers and Facilitators to Home- and Community-Based Services Access for Persons With Dementia and Their Caregivers
  - 2023, Waymouth et al., The Journals of Gerontology
  - Qualitative study on barriers and facilitators to HCBS access for people with dementia
  - <https://academic.oup.com/psychsocgerontology/article-abstract/78/6/1085/7075507?redirectedFrom=fulltext&login=false> (how to attach pdf?)
3. Community-Based Long-Term Services and Supports: Are the Needs of Older Adults and Their Caregivers Being Met?
  - 2021, Fabius et al., The Commonwealth Fund
  - Secondary data analysis examining adverse consequences due to unmet long-term services and supports (LTSS) needs for older adults with and without dementia
  - <https://www.commonwealthfund.org/publications/issue-briefs/2021/oct/community-based-long-term-services-and-supports-are-needs-older>
4. Home health and informal care utilization and costs over time in Alzheimer's disease
  - 2009, Zhu et al., NIH
  - 15-page secondary data analysis examining the utilization of informal (unpaid) caregiving services and formal (paid) home health services using a sample of 204 patients with Alzheimer's Disease
  - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2631654/pdf/nihms87316.pdf>
5. Influences on the access to and use of formal community care by people with dementia and their informal caregivers: a scoping review
  - 2019, Bieber et al., BMC Health Services Research
  - 20-page systematic review on the factors influencing the access to and utilization of formal community care for people with dementia
  - [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6359781/pdf/12913\\_2018\\_Article\\_3825.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6359781/pdf/12913_2018_Article_3825.pdf)
6. The Case for Conducting Pragmatic Dementia Care Trials in Medicaid Home and Community-Based Service Settings
  - 2023, Fortinsky et al., JAMDA
  - 5-page article discussing the importance of conducting pragmatic clinical trials on Medicaid HCBS for people with dementia

- <https://pubmed.ncbi.nlm.nih.gov/37918816/#:~:text=We%20found%20that%20partners%20are,relevant%20to%20persons%20living%20with>
7. Effectiveness of the Care of Persons With Dementia in Their Environments Intervention When Embedded in a Publicly Funded Home- and Community-Based Service Program
    - 2020, Fortinsky et al., Innovation in Aging
    - 11-page article presenting the results of a study in which a nonpharmacologic intervention was tested for people with dementia in a Medicaid and state revenue-funded HCBS program
    - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7745768/pdf/igaa053.pdf>
  8. Implementing the Care of Persons With Dementia in Their Environments (COPE) Intervention in Community-Based Programs: Acceptability and Perceived Benefit From Care Managers' and Interventionists' Perspectives
    - 2023, Kellett et al., The Gerontologist
    - 10-page study assessing the acceptability of the care of persons with dementia in their environments (COPE) intervention by care managers and interventionists
    - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9872768/pdf/gnac068.pdf>
  9. Literature Review of Home- and Community-Based Services (HCBS) in Diverse Communities: Utilization
    - 2023, Juliet Mayer, Long-term Quality Alliance
    - 12-page literature review prepared for the Minnesota Department of Human Services (DHS) exploring diverse communities' utilization of HCBS
    - [https://ltqa.org/documents/20231019\\_MN%20Lit%20Review%20HCBS%20Utilization%20Among%20Diverse%20Communities.pdf](https://ltqa.org/documents/20231019_MN%20Lit%20Review%20HCBS%20Utilization%20Among%20Diverse%20Communities.pdf)
  10. A Look at Waiting Lists for Medicaid Home- and Community-Based Services from 2016 to 2023
    - 2023, Alice Burns, Maiss Mohamed, & Molly O'Malley Watts, Kaiser Family Foundation
    - KFF report examining waiting lists as a measure of unmet need for Medicaid HCBS
    - [https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023/?utm\\_campaign=KFF-2023-Medicaid&utm\\_medium=email&\\_hsmt=284403982&\\_hsenc=p2ANqtz--q4Pze\\_ePdx9CkSX2NQWHUzgm4TLAXobvBVQx6IDMIARHUUOfLTlyqzNMPpsL9RkjH0VNRFuYRxngSmyFTzJNf8C2ZBQ&utm\\_content=284403982&utm\\_source=hs\\_email](https://www.kff.org/medicaid/issue-brief/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023/?utm_campaign=KFF-2023-Medicaid&utm_medium=email&_hsmt=284403982&_hsenc=p2ANqtz--q4Pze_ePdx9CkSX2NQWHUzgm4TLAXobvBVQx6IDMIARHUUOfLTlyqzNMPpsL9RkjH0VNRFuYRxngSmyFTzJNf8C2ZBQ&utm_content=284403982&utm_source=hs_email)
  11. Feasibility of Obtaining Identifiers for Self-Directing Home and Community-Based Services Users in Medicaid Claims
    - 2024, Srinivasan et al., Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services
    - 36-page report outlining a feasibility study to obtain identifiers for self-directed HCBS users in Medicaid claims data
    - <https://aspe.hhs.gov/sites/default/files/documents/d01729114aee5440103822bd16def3b3/nce-hcbs-identifiers-report.pdf>
  12. CMS Reports on Medicaid Long-term Services and Supports (LTSS) Users and Expenditures
    - 2022, Centers for Medicare & Medicaid Services

- Reports on key findings in LTSS rebalancing trends and patterns in users and expenditures for different HCBS and institutional care, nationally and across states for 2022
  - [Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022](#)
  - [Medicaid Long-Term Services and Supports Users and Expenditures by Service Category, 2022](#)
  - [Medicaid Long-Term Services and Supports Users and Expenditures Among People Ages 0 to 20, 2022](#)
  - Access the full reports on [Medicaid.gov](#)
13. **Brandeis Community Living Equity Dashboard**
- 2024, Community Living Equity Center, The Lurie Institute for Disability Policy
  - Dashboard providing national- and state-level data on estimates of who needs Long-Term Services and Supports (LTSS), who receives Medicaid LTSS (institutional services and Home and Community-Based Services), and disparities in access to Home and Community-Based Services (HCBS)
  - <https://heller.brandeis.edu/community-living-policy/clec/community-living-equity-dashboard-home.html>

## HCBS State Policies

1. **State Alzheimer's Disease Plans: Home- and Community-Based Services**
  - 2017, Alzheimer's Association
  - 11-page report by the Alzheimer's Association providing recommendations for each state to improve HCBS to decrease the need for institutionalized care
  - [https://act.alz.org/site/DocServer/HOME\\_AND\\_COMMUNITY\\_BASED\\_SERVICES.pdf?docID=4648](https://act.alz.org/site/DocServer/HOME_AND_COMMUNITY_BASED_SERVICES.pdf?docID=4648)
2. **Key State Policy Choices About Medicaid Home and Community-Based Services**
  - 2020, Musumeci et al., Kaiser Family Foundation
  - 60-page issue brief on state policies for Medicaid HCBS
  - <https://files.kff.org/attachment/Issue-Brief-Key-State-Policy-Choices-About-Medicaid-Home-and-Community-Based-Services>
3. **State-Funded Home- and Community-Based Services Programs for Older Adults**
  - 2009, Robert L. Mollica, Kristin Simms-Kastelein, & Enid Kassner, AARP Public Policy Institute
  - 88-page report on state-funded HCBS, nine of which provide services to people with Alzheimer's disease or other dementia
  - [http://www.advancingstates.org/sites/nasquad/files/hcbs/files/157/7830/State-Funded\\_HCBS\\_for\\_Older\\_Americans.pdf](http://www.advancingstates.org/sites/nasquad/files/hcbs/files/157/7830/State-Funded_HCBS_for_Older_Americans.pdf)
4. **Medicaid Eligibility and People with Alzheimer's**
  - 2023, Alzheimer's Association
  - 2-page fact sheet with information about Alzheimer's and Medicaid eligibility criteria
  - <https://portal.alzimpact.org/media/serve/id/5d23aed5e8dfa>
5. **CMS releases Medicaid LTSS expenditures report for FY 2020**
  - 2023, Health Management Associates/CMS
  - Summary of Medicaid Long-Term Services and Supports (LTSS) Annual Expenditures Report for Federal Fiscal Year 2020
  - [https://www.healthmanagement.com/blog/cms-releases-medicaid-ltss-expenditures-report-for-fy-2020/#:~:text=HCBS%20accounted%20for%2062.5%20percent,care%20\(see%20Figure%201\).&text=In%20addition%2C%20Section%201915c%20waiver,personal%20care%20at%2020.5%20percent](https://www.healthmanagement.com/blog/cms-releases-medicaid-ltss-expenditures-report-for-fy-2020/#:~:text=HCBS%20accounted%20for%2062.5%20percent,care%20(see%20Figure%201).&text=In%20addition%2C%20Section%201915c%20waiver,personal%20care%20at%2020.5%20percent)
6. **Innovation and Opportunity: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers**
  - 2023, Reinhard et al., AARP
  - Fifth edition of a report and online database that provides state-level measures of HCBS access, structure, and cost such as Medicaid HCBS Presumptive Eligibility, Assisted Living Supply, Support for Family Caregivers, and HCBS Quality Benchmarking (NCQA, NCI-AD, HCBS CAHPS, Respite Care Through Medicaid Waivers, Home Care Cost)
  - <https://ltsschoices.aarp.org/scorecard-report/innovation-and-opportunity>
7. **Advancing Equity for Older Adults without Family Caregivers: Trends in Medicaid Waivers**

- 2024, Jane Lowers & Stephanie Herr, ADvancing States
- 18-page report analyzing waiver language related to family caregivers and older adults without family caregivers
- <https://www.advancingstates.org/sites/nasoad/files/u34188/Caregiving%20Report%20FINAL%2011.13.24.pdf>

## Interventions for & Perspectives of Dementia Family Caregivers/Home Care Workers

1. **The Need for Stability in Paid Dementia Care: Family Caregiver Perspectives**
  - 2023, Reckrey et al., Department of Health & Human Services
  - 18-page qualitative study in which researchers interviewed 15 family caregivers of people with advanced dementia to determine important characteristics of paid caregivers
  - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9636070/pdf/nihms-1798353.pdf>
2. **Barriers and enablers in the use of respite interventions by caregivers of people with dementia: an integrative review**
  - 2018, Leocadie et al., Archives of Public Health
  - 10-page systematic review examining use and effectiveness of respite interventions for caregivers of people with dementia
  - [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6249779/pdf/13690\\_2018\\_Article\\_316.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6249779/pdf/13690_2018_Article_316.pdf)
3. **Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review**
  - 2008, Parker et al., JBI Library
  - Systematic review examining the effectiveness of different interventions for caregivers of people with dementia living in the community
  - <https://pubmed.ncbi.nlm.nih.gov/27820474/>