



# The NDWS Survey Questionnaires

---

Joanne Spetz, PhD  
*University of California, San Francisco*

# Purpose of NDWS



- Overarching goal: to answer critical questions about the workforce and its impact on care and outcomes for persons living with dementia
- Conducting the first large, annual surveys of the dementia care workforce in the United States
- Survey data will be linked with other data sources to create an unprecedented resource for researchers
- Sponsored by the NIH National Institute on Aging

# Where do PLWD receive care?



- Clinicians' offices
  - Physicians, nurse practitioners (NPs), physician assistants (PAs)
  - Other staff include medical assistants, registered nurses (RNs), social workers, care coordinators...
- Nursing homes
  - 93.5% of nursing homes have between 31-80% of residents with dementia<sup>1</sup>
- Assisted living communities
  - 18% have a dementia care unit, 42% of residents have dementia<sup>2</sup>
- In the home: home health and home care agencies

<sup>1</sup>Mukamel et al., Health Affairs, 2023, <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2022.01263>

<sup>2</sup><https://www.ahcancal.org/Assisted-Living/Facts-and-Figures/Pages/default.aspx>

# Who provides care to PLWD?



- Clinicians' offices
  - Most of the care: Family medicine, general internal medicine, geriatrics, neurology, psychiatry, NPs, PAs
- Assisted living communities
  - Home health and personal care aides: 27%
  - Nursing assistants: 16%
  - LPNs: 4.7%
  - RNs: 3.4%
  - Other personal care and service workers: 3.3%
  - Recreation and fitness workers: 2.6%
- Nursing homes
  - Nursing assistants: 33.3%
  - Licensed practical/vocational nurses (LPNs): 12.7%
  - RNs: 9.3%
  - Home health and personal care aides: 3.6%
- Home health and home care
  - Home health and personal care aides: 57.2%
  - RNs: 11.3%
  - LPNs: 5.4%
  - Nursing assistants: 5.3%
  - Therapists: 2.7%

# The surveys



A family of 4:

- Community Clinicians (Physicians, Nurse Practitioners, Physician Assistants)
  - Nursing Home Staff
  - Assisted Living Staff
  - Home Health/Care Staff
- } - licensed nurses (RN & LPN)  
- direct care workers (aides & assistants)

Plus, surveys of administrators of nursing homes, assisted living communities, and home health/home care agencies

# Survey design team

- Alissa Bernstein Sideman, PhD, MPH, MA
- Susan Chapman, PhD, RN, FAAN
- Winston Chiong, MD, PhD
- Esther M. Friedman, PhD
- Lauren Gerlach, DO, MS
- Krista Lyn Harrison, PhD
- Johanna v.T.S. Hickey, MSW
- Lauren Hunt, PhD, RN, FNP
- Soo-Jeong Lee, PhD, RN, FAAN, FAAOHN
- Ulrike Muench, PhD, MSN, RN, FAAN
- Katherine Possin, PhD
- Joanie Rothstein, MPH, MPP
- Sofia Sandoval, BA
- Joanne Spetz, PhD
- Laura M. Wagner, PhD, RN, GNP, FAAN
- Elizabeth White, PhD, APRN
- Jarmin Yeh, PhD, MPH, MSSW
- Sheryl Zimmerman, PhD

Special thanks to Amber Rose, BA, who was part of the survey team last year and now is a Direct-Entry Master's in Nursing student at the University of Nevada Las Vegas!

# How we developed the questionnaires

- Literature review, including questionnaires from other studies
  - >120 articles and questionnaires
  - National recommendations such as NCHWA's "minimum data set"
- "Call for survey content" to seek input and ideas
  - Received 38 responses
- Survey design team meetings and reviews across sub-teams
- Reviews by 6 consultants & our Scientific Officer
- Cognitive testing of all questionnaires
- Translation of staff questionnaires to Spanish

# Key survey content domains

- Education, training, experience
- Employment status
- Dementia care knowledge, attitudes, and practices
- Working conditions and organization practices
- Worker outcomes
- Demographics

In future years, surveys will include a longitudinal follow-up component to help us understand workforce exit



# Education/training questions: Staff

- Current & past state licenses, certification, or registration
- Current enrollment
- Highest level of education
- Formal and informal training in understanding dementia, responding to resident behaviors, end-of-life care, protecting against injury, cultural competence, etc.
- Whether training prepared for what it is like to actually work in this job

# Employment questions: Staff

- Experience in LTC in general, tenure with current employer
- Number of jobs held and types of other jobs
- Hours per week, weeks per year, shift type, stability of work schedule
- Wage, health insurance, paid time off, other benefits (offer & enrollment)
- Mode of commuting, reliability of transportation
- For home health/care: how many clients, living with client, travel time between clients, how travel between clients is paid, mandated overtime, ease of contacting agency for help

# Practice, attitudes, & work conditions: Staff

- Whether they specialize in memory/dementia care
- Stability of assignments to residents/clients
- Medication administration
- Dementia Attitudes Scale (short version: DAS-6)
- Sense of Competence in Dementia Care Staff (SCIDS) scale
- Support to grieve residents/clients who are dying or have died
- Availability of PPE, equipment & staff assistance for transferring/lifting
- Perception of whether management prioritizes safety
- Whether job demands interfere with personal life

# Worker outcomes: Staff

- Job satisfaction (17 items)
- Burnout (validated one-question scale)
- Intention to quit
- Having enough time to give residents individual attention, fulfill duties
- Being informed when doing a good job
- Feeling part of a care team
- Communication problems
- Disrespectful behaviors of residents, family members
- Perceived discrimination
- Work-related injuries
- Whether they'd recommend the facility/agency

# Education/training questions: Clinicians

- Licensure, education, fellowship training, national certification
- Years of practice
- Degree to which formal training prepared for providing care for people with dementia

# Employment questions: Clinicians

- Number of clinical positions, number & types of non-clinical positions
- Type of practice, practice setting
- Types of clinicians and other staff in practice
- Whether practice sites are in underserved community
- Years with current employer
- Hours per week, days of on-call
- Allocation of time: direct care, indirect care, admin, teaching, research
- Patient volume at practice
- Use of electronic health record
- Mode of medical interpretation service available

# Practice & dementia care questions: Clinicians

- Patient panel size, number of patients per day, typical visit length
- Characteristics of patient panel: percent with dementia, SMI, SUD, living in nursing home, homeless, LBGTQ+, limited English proficiency...
- Provision of cognitive assessments in annual Medicare wellness visit
- Confidence in diagnosing types of dementia
- Types of tests ordered & referrals for suspected cognitive impairment & dementia
- Prioritization & frequency of provision of non-medical assessments & referrals
- Prioritization & frequency of provision of prescribing specific medications, biomarker testing
- Views on appropriateness of specific medications to address dementia-related behaviors
- Familiarity with community resources
- Factors that interfere with providing high-quality care

# Worker outcomes: Clinicians

- Job satisfaction (9 items)
- Burnout (validated one-question scale)
- Intention to quit



# Demographic questions (at the end!)

- Birth year
- Race & ethnicity with subgroups
- US vs. overseas birth, when immigrated, citizenship
- “Do you ever worry that you or a family member could be detained or deported?”
- Sexual & gender orientation
- Veteran/service status
- Other languages spoken
- Identification as person with a disability
- Number of adults, children, older adults at home
- Responsibility for care for an adult family member with disability

# Administrator surveys

Completed by each organization participating in Nursing Home, Assisted Living, and Home Care Staff surveys:

- Facility/agency setting and characteristics
- Benefits offered to staff
- Union representation
- Dementia-specific care as part of:
  - hiring
  - training
  - ongoing education



Thank you!

[www.ndws.org](http://www.ndws.org) • [info@ndws.org](mailto:info@ndws.org)