Identifying Services to Address Dementia in Aging Adults

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Alzheimer’s vs. dementia

Alzheimer’s disease is the name of a neuropathology – or brain disease – that leads to general dysfunction.

Dementia is the behavioral expression of the brain disease – usually via memory loss and behavioral dysfunction.

Causes of dementia among aging adults:
- Alzheimer’s disease
- Stroke and related vascular accidents
- Neurological diseases (Parkinson’s)
- Idiopathic changes in the brain (Lewy, FTD)
The ‘NAPA’

- **National Alzheimer’s Project Act** *(became law in early 2011)*
  - Requires DHHS to submit an annual Alzheimer’s plan to Congress – from 2012 to 2025

- Administered by federal **Department on Health Human Services** (DHHS)

- **Advisory Council on Alzheimer's Research, Care, and Services**
  - Council composed of Presidential appointees and federal agency staff
  - Creates the National Plan to Address Alzheimer’s Disease with annual updates

**National Plan called for** -- among other things:
- ✓ Issuance of practice guidelines for care and supports and expanded public education
- ✓ Promotion of assessment tool for detection of cognitive impairment as part of the annual wellness visit
- ✓ Enhanced supports for caregivers
- ✓ Expanded research
- ✓ Special population focus - I/DD

First released on May 15, 2012
Continues to be updated annually until 2025!
What does NAPA mean to the States?

• Tie-in to State Alzheimer’s Plan’s objectives

• GWEPs* – enhancing the capacity of the workforce (working in dementia-related areas
  • http://bhw.hrsa.gov/grants/geriatricsalliedhealth/index.html

• Potential implications of CMS’ Setting Rule – Alzheimer’s
  • https://www.medicaid.gov/medicaid/hcbs/index.html

• Healthy Brain Initiative
  • http://www.cdc.gov/aging/healthybrain/index.htm

• Alzheimer’s Disease Initiative—Specialized Supportive Services (ADI-SSS) Projects
  • http://www.aoa.acl.gov/AoA_Programs/HPW/Alz_Grants/
  • ID oriented grants in RI, HI, WI, CA

*Geriatrics Workforce Enhancement Program
The National Task Group is a collective composed of over 300 agency personnel, academics, government officials, family members, and persons affiliated with various associations and organizations.

The NTG is associated with several organizations (American Academy of Developmental Medicine and Dentistry and the University of Illinois at Chicago’s RRTC on Aging and Developmental Disabilities and Health), as well as numerous university centers and national organizations.

'The Thinker's Not Working'

- To define best practices that can be used by agencies in delivering supports and services to adults with intellectual disabilities affected the various dementias
- To identify a workable national a ‘first-instance’ early detection / screening instrument
- To produce educational materials of use to families, people with ID, and providers of services
- To further public policy with respect to dementia as it affects adults with intellectual disabilities

www.aadmd.org/ntg
NTG Activities

Early detection-screening instrument (NTG-EDSD)
Various language versions available
Access at www.aadmd.org/ntg

Practice guidelines
Community supports guidelines issued
Health advocacy & Assessment guidelines issued
Community care setting program standards pending

Training and education activities
National education curriculum on dementia & ID
Training workshops & webinars
Meetings with professional groups
Family information promotion & support group

Linkages
Administration on Community Living, NIH Summit, HRSA
NASDDDS, N4A, NACDD & state activities
CARF & national program standards
NDSS, Dementia Connect, Biomarkers Research Consortium
The Arc, Alzheimer’s Association
### Factors: ID and dementia

| Rate of occurrence\(^{1,3,5,8,14}\) | - Age-cohort percent for adults with intellectual disability (ID) is same as in general population (~5-6% over 60)
- Much higher prevalence (60% >age 60) and neuropathology indicative of AD in most adults with Down syndrome (DS) |
| Dementia type\(^{2,9}\) | - Generally dementia of the Alzheimer’s type is prevalent in DS
- Similar range of dementias found in other ID as in other people |
| Risk\(^{15}\) | - DS and head trauma are significant risk factors in ID |
| Onset and duration\(^{1,2,3,10}\) | - Average onset age in early 50s for DS – late 60s for others
- Most DAT diagnosed within 3 years of “onset” in adults with DS |
| Behavioral changes\(^{2,3,6,11,12,13}\) | - In DS - early change in personality more evident
- In other ID - initial memory loss more evident
- Notable changes in behavior - apathy, sleep disturbance, agitation, incontinence, uncooperativeness, irritability, aggressiveness |
| Neurological signs\(^{1,2,4,7,16,17,18,19}\) | - Late onset seizures in 24%-53% of adults w/DS
- Late onset seizures in DS indicator of life expectancy of less than 2 years
- Seizures more common it end-stage (84%) versus at mid-stage (39%) Alzheimer’s disease |
| Prognosis\(^{2,17}\) | - Aggressive AD can lead to death <2 years of onset in DS
- 2-7+ years mean duration in DS; probable death within 3-5 years of onset
- Same duration expected among other ID as in other people with dementia |

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\(^3\) Evenhuis, H. (1997). The natural history of dementia in ageing people with intellectual disabilities. JIDR, 41(1), 97
\(^10\) Lana et al., (2007). Fifteen year follow-up of 92 hospitalized adults with DS. JIDR, 51, 463
\(^17\) Treppner, P., & Watson, P.C. Personality and behavior changes mark the early stages of Alzheimer’s disease in adults with Down’s syndrome. Clinic Proceedings, 88(8), 831
Clinical/research/tx aspects of dementia and intellectual disability: Impact on Services

Onset

*When change is first noticed*
- For DS: $\bar{x} = 52$
- For ID: $\bar{x} =$ late 60s - early 70s
- Prevalence (DS $\uparrow$ 66%+; ID $\downarrow$ 5 - 6%)

Progression

*Patterns of change and decline*
- For DS: Some quick losses, other more normative (changes in personality before memory)
- For ID: Varied trajectories; leading to progressive decline

Duration

*Length of time persons are affected*
- For DS: Compressed duration
- For ID: Similar to general pop
Why is ‘onset’ of importance?

• Knowing expected onset gives a head’s-up for surveillance
  • Look for changes
  • Introduce periodic screening
  • Alert staff to be watchful
  • Provides for an ‘index of suspicion’

• Helps us to begin to reformulate services and care practices
  • Creating safer environments
  • Introducing cues for movement and way-finding
  • Engaging in planning ahead for eventualities
  • Setting goals for terms of service – adapting personal program plans
Critical factors

- Degree of retention of function
- Expected trajectory of progressive dysfunction
- Duration (remaining life years)
- Type of dementia
- Health status
- Environmental accommodations

Varying trajectories have implications for continual assessment and adaptations to care management.

Source: Figure 1 from Wilkosz et al., (2009). Trajectories of cognitive decline in Alzheimer’s disease. International Psychogeriatrics, 28,1-10
Implications of trajectories and duration

• Knowing something about variations in trajectories
  • Anchors around potential duration of ‘stay’ at same level of functioning
  • Ideas about potential changes and their nature
  • Creates a schedule for timing changes in service orientation – planning care, evaluating patterns of care, and organizing staffing and environmental modification
  • Provides an empirical basis for expectations of co-morbidities
  • Gives staff information about anticipating changes
  • Helps with introducing ameliorative interventions or aids for day-to-day functioning
  • Long-term planning for care financing (budgeting for shifts in staff and housing)
Features concerning dementia

• Older adults with Down syndrome are at high risk of Alzheimer’s disease
• Not every adult will show signs of dementia as he or she ages
• Age-associate decline may be due to aging and not dementia
• Institute baseline for (‘personal best’) functioning at age ~40 for Down and at ~60 for other ID
• Useful to know the signs of MCI* and dementia and keep track of capabilities after age 40
• Early detection screening useful to identify possible progression into MCI or dementia
• Early referral for assessment or diagnosis if signs present is advised (to rule out alternatives)

*mild cognitive impairment
What are the needs for agency planning and services development...

- Orientation of staff who work with middle-age and aging adults to pick up cues of dementia onset
- Train staff to gain capacity to provide ‘dementia-capable’ supports
- Review of expense and payment screens to permit adjustments as health and function declines affect variations in costs
- Housing that incorporates measures for dementia supports / care
- Review of support / care settings to examine how they adjust to stage-based progression – particularly as adults move to advanced dementia
- Establish clinical supports for consultation to staff working with adults with dementia
- Secure diagnostic resources for early screening, assessment, and diagnostic tracking
Prevalent dementia care options

**Institutional care**
[long term care facilities, nursing homes, old age homes, dementia special care units]

**Family care**
[living with family, other relatives, or other family members of carers]

**Neighborhood group homes**
[generic group homes, specialized group homes]
- Group homes for persons with ID who age in the homes
- Group homes for specialized dementia care

**Sheltered dementia care**
[assisted living, dementia care homes]

**Carer support**

**Small personalized care settings**
Prevalent models of group home-based dementia care

**AGING-IN-PLACE**
- single care home and stable stay

**IN-PLACE-PROGRESSION**
- multiple care homes & movement with progression

**Linear adaptations and care**

**Sequential adaptations and care**

Mid = mid-level

Source: JANICKI (2010)
Screening-Assessment-Diagnosis Process

Screening

Done by carers or staff
- Picks up key problem areas — some associated with MCI or dementia — confirms suspicions
- Signals areas for further surveillance by carers or staff
  ‘The starting point’

Assessment

Form used by carers or staff to begin discussion about concerns with clinician
- Clinician uses noted items for more in-depth assessment and tracking
- Suspicions can be confirmed or revisited periodically

Diagnosis

Clinic or clinicians ascertain whether dementia dx is viable
- Eventual review of symptoms and application of range of general dementia ascertainment measures
- Designation of possible or probable dementia and potentially clinical etiology
‘NTG-Early Detection Screen for Dementia’ (NTG-EDSD)

Usable by support staff and caregivers to note presence of key behaviors associated with dementia

✓ Picks up on health status, ADLs, behavior and function, memory, self-reported problems

✓ Available in several languages

Pages ①②: Basic information

Pages ③④: Information about function and indicators of problem areas associated with dementia

Page ⑤: Coincident conditions

Page ⑥: Medications & Comments

www.aadmd.org/ntg/screening
Guidelines for Dementia-related Health Advocacy for Adults with Intellectual Disabilities and Dementia of the National Task Group on Intellectual Disabilities and Dementia Practices

www.aadmd.org/ntg/guidelines
Dementia is a condition that lessens an individual’s ability to be left alone – thus, *living without supervision is not an option*.

- **What are needed supports?**
  - Help for caregivers and the person
  - Advanced planning for alternative care
  - Diagnostic and intervention assistance
  - Support groups for caregivers (family or staff)
  - Dementia capable community housing (group homes)
  - Respite for caregivers
  - Health care and social supports

- **State Planning & Operations**
  - Determining the extent of service population at-risk or diagnosed with dementia
  - Designating supports for dementia-related impairments
    - housing
    - clinical support teams
    - training of staff
    - assessment & diagnostics
  - Resourcing help for families
    - aiding care at home
    - alternative care planning
    - supports for caregivers
Need information?

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www.aadmd.org/ntg
Alzheimer’s and other Dementia and ‘At-risk’ in the NCI Adult Consumer Survey

NASDDDS Meeting
November 11, 2016

Alix Bonardi
abonardi@hsri.org
Adult Consumer Survey

- Standardized, face-to-face interview with a sample of individuals receiving services

  - Background Information - includes health information
    - Section I (no proxies allowed)
    - Section II (proxies allowed)
  - No pre-screening procedures

- Conducted with adults only (18 and over) receiving at least one service in addition to case management
NCI Goals

• Establish (and maintain) a **nationally recognized set of performance and outcome indicators** for DD service systems

• Ensure **valid** and **reliable** data collection methods & tools

• Report state comparisons and national benchmarks of **system-level** performance
As of 2016-17: 46 states, the District of Columbia and 22 sub-state regions
People identified in the NCI population with dementia and at-risk.
National Core Indicators

NCI Adult Consumer Survey (ACS) data, 2014-15 survey cycle

- 32 States & Washington DC
- 25,820 individual surveys

Analyses are based on available, valid responses. e.g. age, diagnoses required – only include surveys with valid responses)
The population reported to have with Alzheimer’s disease/dementia.

609 of 22,904 valid responses = 2.6% across all ages
## Diagnosed with Alzheimer’s/Other Dementia

<table>
<thead>
<tr>
<th></th>
<th>Alzheimer’s/Other Dementia (n=609)</th>
<th>Entire NCI Sample (including those with Alz./Dementia diagnosis)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average Age</strong></td>
<td>57.8</td>
<td>41.8</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><em>American Indian or Alaska native</em></td>
<td>0.7%</td>
<td>0.9%</td>
</tr>
<tr>
<td><em>Asian</em></td>
<td>2.3%</td>
<td>3.9%</td>
</tr>
<tr>
<td><em>Black or African American</em></td>
<td>7.8%</td>
<td>16.7%</td>
</tr>
<tr>
<td><em>Pacific Islander</em></td>
<td>0.5%</td>
<td>0.4%</td>
</tr>
<tr>
<td><em>White</em></td>
<td>83.5%</td>
<td>65.5%</td>
</tr>
<tr>
<td><em>Other race</em></td>
<td>4.3%</td>
<td>11.5%</td>
</tr>
<tr>
<td><strong>Ethnicity: Hispanic</strong></td>
<td>7.6%</td>
<td>13.9%</td>
</tr>
<tr>
<td><strong>Male</strong></td>
<td>52.5%</td>
<td>57.7%</td>
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</tbody>
</table>
Age Patterns of Dementia Diagnosis (n= 609)

Diagnosis with Alzheimers or other Dementia

National Core Indicators (NCI)
Diagnosis of Alzheimer's/other dementia by age (N=22,347)
Alzheimer’s / Dementia and Down Syndrome

In people 45 and older:

Without Down Syndrome: 4% have diagnosis of Alz. Disease or other dementia.

With Down Syndrome 20% have diagnosis of Alz. Disease or other Dementia

(N=9351)
Portion of ‘Age over 55’ ranges 16% to 35%

NCI State Average: 25%
People over 55 more likely to live in Institutional and Community Group settings

- Institutional Setting/ICF: 7% <55, 16% >=55
- Group home / Community: 26% <55, 44% >=55
- Independent home/apt: 13% <55, 16% >=55
- Parents/relatives home: 48% <55
- Foster care/host home: 5% <55, 7% >=55
- Other: 1% <55, 4% >=55

National Core Indicators (NCI)
Outcomes by Age and Dementia diagnosis

- Shopping: <55 = 89%, >=55 = 75.0%, >=55 with Alzheimer's diagnosis = 80.0%
- Errands: <55 = 81%, >=55 = 80.0%, >=55 with Alzheimer's diagnosis = 81%
- Entertainment: <55 = 71%, >=55 = 61%, >=55 with Alzheimer's diagnosis = 84%
- Eat out: <55 = 84%, >=55 = 74%
- Religion: <55 = 43%, >=55 = 38%, >=55 with Alzheimer's diagnosis = 50%
- Sports: <55 = 50%, >=55 = 33%, >=55 with Alzheimer's diagnosis = 46%
- Vacation in past year: <55 = 29%
Relationships / Friendships

Has friends who are not staff or family (all - by age)

Has friends who are not staff or family (over age 55)
Medications and Behavior Plans

At least one medication to treat mood, anxiety, psychotic and/or behavior disorders?

- Alzheimer's disease or other dementia: 67%
- No Alzheimer's disease or other dementia: 53%

Behavior plan?

- Alzheimer's disease or other dementia: 36%
- No Alzheimer's disease or other dementia: 31%
Alzheimer’s Disease and Mortality

MASSACHUSETTS DDS Mortality Report*

Alzheimer’s disease is the underlying cause in 12-15% of deaths in the population as reported in MA.

Compares to 3-3.5% in the general population

- Co-occurring diagnoses place this population at greater risk (e.g. DS), however important to examine and ensure specialized screening, diagnosis, and supports.

* Massachusetts Mortality Report
Moving Forward....

Opportunities to learn about the experience of people receiving IDD services who are at-risk and diagnosed with dementia and their families.

- Direct stakeholder input
- NCI ACS results –[Background Information]
  - note states may add questions
- NCI Family Surveys FGS and AFS (*looking ahead)
- Admin records and other surveys to individuals and families.

**Data Briefs** - support identification and monitoring of QA/QI in supports to people with IDD.
www.nationalcoreindicators.org

For Additional info:

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Findings on Alzheimer's and Dementia in NCI-AD
What is NCI-AD?

- Quality of life survey focused on older adults and adults with physical disabilities
- Assess outcomes of state LTSS systems
  - Skilled nursing facilities
  - Medicaid waivers
  - Medicaid state plans
  - PACE programs
  - MLTSS populations
  - State-funded programs, and
  - Older Americans Act programs
- Data crosswalks to National Core Indicators (NCI)
- Adult consumer survey with option for proxy respondents
- Launched nationally June 1, 2015
NCI-AD Adult Consumer Survey

- **Pre-survey Form**
  - Used to setup interviews, for use by the interviewers only

- **Background Information** (21 questions)
  - Demographics and personal characteristics: gathers data about the consumer from agency records and/or the individual

- **Consumer Survey** (90 (51 proxy) questions)
  - Includes subjective satisfaction-related questions that can only be answered by the consumer, and objective questions that can be answered by the consumer or, if needed, their proxy

- **Interviewer Feedback Sheet**
  - Asks interviewer to evaluate the survey experience and flag concerns
# National Report Categories for State Samples

<table>
<thead>
<tr>
<th>State</th>
<th>Combined Medicaid program</th>
<th>Aging Medicaid program</th>
<th>PD Medicaid program</th>
<th>BI Medicaid program</th>
<th>OAA</th>
<th>SNF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colorado</td>
<td>EBD Waiver (N=312)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>OAA (N=88)</td>
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<tr>
<td>Georgia</td>
<td>CCSP Waiver (N=331)</td>
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<td>N/A</td>
<td>N/A</td>
<td>HCBS (N=470)</td>
<td>N/A</td>
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<tr>
<td>Maine**</td>
<td>Consumer Directed PC Services; Elder and Adults with Disabilities Waiver; Private Duty Nursing; MaineCare Day Health (N = 261)</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>OAA (N=90)</td>
<td>N/A</td>
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<tr>
<td>Mississippi</td>
<td>Assisted Living Waiver; Elderly and Disabled Waiver (N=529)</td>
<td>N/A</td>
<td>IL Waiver (N=293)</td>
<td>TBI/SCI Waiver (N=113)</td>
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<tr>
<td>North Carolina</td>
<td>MFP (N=56)</td>
<td>PACE (N=57)</td>
<td>CAP/DA (N=224)</td>
<td>N/A</td>
<td>HCCBG (N=296)</td>
<td>SNF (N=331)</td>
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<tr>
<td>New Jersey</td>
<td>NJ Family Care (4 MCOs) (N=415)</td>
<td>PACE (N=101)</td>
<td>N/A</td>
<td>N/A</td>
<td>OAA (N=104)</td>
<td>SNF (N=104)</td>
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<td><strong>Total N</strong></td>
<td>1904</td>
<td>158</td>
<td>517</td>
<td>113</td>
<td>1048</td>
<td>435</td>
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</table>
Population Overview

- Average age – 69
- 12% aged 90+
- 65% report having some kind of physical disability
- 17% report a diagnosis of Alzheimer’s or other dementia
- 69% female

Race and Ethnicity
- 60% White
- 29% African American
- 2% Hispanic or Latino

- 67% living in own or family home; 13% SNF
Proportion of people who forget things more often in past 12 months

Forgets Things More Often Than Before (In the Past Year)

- Combined Medicaid Program: 46%
- Aging Medicaid Program (PACE): 47%
- PD Medicaid Program: 51%
- BI Medicaid Program: 32%
- OAA: 49%
- SNF: 42%

NCI-AD Average: 49%
Proportion of people who have discussed forgetting things with a doctor or a nurse

Discussed Forgetting Things With Doctor or Nurse

<table>
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<tr>
<th>Program</th>
<th>Proportion</th>
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<tbody>
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<td>Combined Medicaid Program</td>
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<tr>
<td>Aging Medicaid Program (PACE)</td>
<td>72%</td>
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<tr>
<td>PD Medicaid Program</td>
<td>55%</td>
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<tr>
<td>BI Medicaid Program</td>
<td>41%</td>
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<tr>
<td>OAA</td>
<td>51%</td>
</tr>
<tr>
<td>SNF</td>
<td>60%</td>
</tr>
</tbody>
</table>

NCI-AD Average (57%)
Houses:

- Project overview
- Reports
- Webinars
- Presentations
- Staff contacts
- State-specific project information
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