



**U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy**

IMPROVING CARE FOR POPULATIONS DISPROPORTIONATELY AFFECTED BY ALZHEIMER'S DISEASE AND RELATED DEMENTIAS:

REPORT FROM THE TASK FORCE ON SPECIFIC POPULATIONS

June 2013

Office of the Assistant Secretary for Planning and Evaluation

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This report was prepared through information gathered by HHS's ASPE/DALTCP and the HHS Administration for Community Living, Administration for Intellectual and Developmental Disabilities. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/office_specific/daltcp.cfm or contact the ASPE Project Officer, Helen Lamont, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: Helen.Lamont@hhs.gov.

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Task Force on Specific Populations

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Prepared by
Office of Disability, Aging and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services or any other funding organization.

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ACRONYMS

ABA	American Bar Association
ACA	Affordable Care Act
ACL	HHS Administration for Community Living
ADHC	Adult Day Health Care
AIDD	ACL Administration for Intellectual and Developmental Disabilities
AoA	ACL Administration on Aging
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
AUCD	Association of University Centers on Disabilities
CGEP	Comprehensive Geriatric Education Program
CMS	HHS Centers for Medicare and Medicaid Services
DoE	U.S. Department of Education
FDA	HHS Food and Drug Administration
GACA	Geriatric Academic Career Award
GEC	Geriatric Education Center
GRECC	Geriatric Research, Education, and Clinical Center
GTPD	Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Providers
HCBS	home and community-based services
HHS	U.S. Department of Health and Human Services
HPC	Hospice and Palliative Care Consultation Team
HRSA	HHS Health Resources and Services Administration
IHS	HHS Indian Health Service
LEAD	Leaders Engaged on Alzheimer's Disease
LTSS	long-term services and supports
MIRECC	Mental Illness Research, Education, and Clinical Center
NACDD	National Association of Councils on Developmental Disabilities
NASDDDS	National Association of State Directors of Developmental Disability Services
NDRN	National Disability Rights Network
NDSC	National Down Syndrome Congress
NDSS	National Down Syndrome Society
NIA	NIH National Institute on Aging
NIDRR	National Institute for Disability Research and Rehabilitation
NIH	HHS National Institute on Health
NIMH	NIH National Institute of Mental Health
NREPP	National Registry of Effective Programs and Practices
NTG	National Task Group on Developmental Disabilities and Dementia Practices

OASH OMH	HHS Office of the Assistant Secretary for Health OASH Office of Minority Health
PSPC	Patient Safety and Clinical Pharmacy Services Collaborative
SAMHSA	HHS Substance Abuse and Mental Health Services Administration
TCE	Older Adult Targeted Capacity Expansion
UCEDD UCLA	University Centers for Excellence in Developmental Disabilities University of California Los Angeles
VA	U.S. Department of Veterans Affairs

The National Plan to Address Alzheimer's Disease requires the U.S. Department of Health and Human Services' (HHS') Office of the Assistant Secretary for Planning and Evaluation (ASPE) and the Administration for Intellectual and Developmental Disabilities (AIDD) within the HHS Administration for Community Living (ACL) to establish a task force to create a plan of action to address the needs of specific populations disproportionately affected by Alzheimer's disease. These populations include people with younger-onset dementia, racial and ethnic minorities, and persons with Down syndrome and other intellectual disabilities.¹ This report summarizes input and recommendations received from a wide variety of stakeholders for consideration by the members of the Federal Interagency Task Force.

¹ National Plan to Address Alzheimer's Disease (2012). Action 2.H.1 states "This Task Force shall 'better understand the unique challenges faced by these groups and create a plan of action'." Page 21. Available at <http://aspe.hhs.gov/daltcp/napa/NatPlan.shtml>.

IMPACT OF ALZHEIMER'S DISEASE AND RELATED DEMENTIAS

The National Plan identifies three specific populations that are disproportionately affected by Alzheimer's disease: people with younger-onset dementia, racial and ethnic minorities, and persons with Down syndrome and other intellectual disabilities. These are diverse groups that are differentially impacted by Alzheimer's disease and related dementias.

People with Younger-Onset Dementia

An estimated 250,000 adults have younger-onset dementia, characterized by onset of symptoms prior to age 65. In addition to the challenges faced by older people with dementia, people with younger-onset may lose their job and their health insurance coverage due to dementia symptoms. They often have difficulty obtaining a timely and accurate diagnosis, support services, and income support through disability payments.²

Racial and Ethnic Minorities

Racial and ethnic minority populations comprise approximately 37% of the United States population,³ and the proportion of older adults who belong to minority groups is rising sharply.⁴ Many older adults from minority groups have limited proficiency in English. Some racial and ethnic minorities are differentially affected by Alzheimer's disease. African-American and Hispanics are more likely than Whites to have Alzheimer's disease and other dementias; with African-Americans 2-3 times more likely to suffer from cognitive impairment, a difference that is more pronounced at younger ages.⁵ In addition, these populations suffer disproportionately from diabetes mellitus, stroke and other chronic illnesses complicating treatment. Thus understanding the role of co-morbidities is essential to early intervention, diagnosis and treatment. Rapid population increases, coupled with unmitigated health disparities' are cause for special attention, particularly because racial and ethnic minority populations are significantly underrepresented among health and behavioral health professionals and related research. This lack of attention to diversity has contributed to health care disparities in

² Alzheimer's Association (2006). "Early Onset Dementia: A National Challenge, a Future Crisis." Retrieved March 5, 2013 from https://www.alz.org/national/documents/report_earlyonset_summary.pdf.

³ U.S. Census Bureau (2012). 2012 National Population Projections. Retrieved March 8, 2013 from <https://www.census.gov/newsroom/releases/archives/population/cb12-243.html>.

⁴ Ibid.

⁵ Alzheimer's Association (2011). 2010 Alzheimer's Disease Facts and Figures. Retrieved May 11, 2012 from http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf.

the availability of, access to, and the provision of quality cultural and linguistic appropriate care.

Down Syndrome and Other Intellectual Disabilities

Adults with Down syndrome are much more likely than the general population to develop dementia: after age 60, more than half will have dementia.⁶ People with other intellectual disabilities have rates of dementia similar to the general population; however, like people with Down syndrome, they face additional challenges to getting care. The first challenge is assessing dementia when there is great variation in baseline functioning. People in this population are often cared for by their family members, who themselves are aging and perhaps facing declining health. Some stakeholders believe that it may be difficult to find supportive services to enable the person to live in the community.⁷

⁶ Alvarez, N. (2001). Alzheimer's disease in Down syndrome. Medscape Reference: Drugs, Diseases, and Procedures. Retrieved February 11, 2013 from <http://emedicine.medscape.com/article/1136117-overview#aw2aab6b4aa>.

⁷ National Task Group on Intellectual Disabilities and Dementia Practices (2012). 'My Thinker's Not Working' A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports. Retrieved January 15, 2013 from <http://www.aadmd.org/ntg/thinker>.

METHODOLOGY

The Task Force began its work in July 2012 and includes representative federal agencies engaged in dementia issues and with specific populations within HHS, the U.S. Department of Veterans Affairs (VA) and U.S. Department of Education (DoE). A list of federal Task Force agencies within these departments appears in Appendix A.

The initial Task Force meetings included a review of the inventory of federal activities prepared to inform the 2012 National Plan. After this review, the Task Force pursued four priority areas identified within the National Plan: (1) accurate and timely diagnosis; (2) access to care; (3) education on Alzheimer's disease and related dementias for practitioners who do not normally specialize in care for people with Alzheimer's disease and related dementias; and (4) special considerations for these populations. The Task Force members also identified steps to gathering additional information and volunteered to seek additional input from experts within and outside the Federal Government. Outside expertise came from "listening sessions" as well as through email and telephone consultation. The Task Force generated ideas about sources of expertise, and identified specific contacts.

The leadership of the Task Force sent guidance to each member to ensure that collection of input was consistent. That guidance included a memorandum to members describing the data collection process, a list of potential contacts, a log to record from whom input was sought and when; and a draft memorandum to external experts, which provided a basic script to ensure consistency in requesting input (see Appendix B). Task Force members solicited input from September 1 through October 8, 2012, through a variety of mechanisms including face-to-face and telephone conference listening sessions with groups and individuals, email submissions, and interviews. The Task Force reconvened in mid-October 2012 to summarize input gathered by the members and discuss possible gaps. Members also offered information based on their own training and expertise. The Task Force developed a list of broad recommendations based on the input it received. Below appears a description of the input process for each of the three specific populations identified in the National Plan, followed by a summary of the recommendations.

People Experiencing Younger-Onset Dementia

The Administration on Aging (AoA), within ACL, led collection of input regarding people experiencing younger-onset Alzheimer's disease. AoA staff emailed or telephoned major dementia-focused organizations and individuals prominent in the field of younger-onset dementia and asked them to provide input through telephone conference calls. Invited organizations included: Alzheimer's Association; Alzheimer's Foundation of America; Association for Frontotemporal Degeneration; Banner

Alzheimer's Institute; Leaders Engaged on Alzheimer's Disease (LEAD); Lewy Body Dementia Association; Indiana Alzheimer's Disease Center; the AIDS Healthcare Foundation; University of California, San Diego Shiley-Marcos Alzheimer's Disease Research Center; and the University of California Los Angeles (UCLA) David Geffen School of Medicine. Twenty-six experts participated in at least one of the two listening sessions. One of the sessions was a face-to-face meeting with an additional phone conference line, and the other was a teleconference. Additional written input was provided by some participants after the sessions.

Racial and Ethnic Minorities

The Office of Minority Health (OMH) took the lead in gathering external input regarding racial and ethnic minority populations. National and community-based organizations, universities, public health entities, providers and family members provided expert input through email and telephone conversations. A sample of the organizations participating included: City of Los Angeles Department of Aging; Latino Alzheimer's and Memory Disorders Alliance; National Hispanic Council on Aging; AoA Office for American Indian, Alaskan Native and Native Hawaiian Programs; Northern Minnesota Tribal Caregiver Coordinator; Banner's Tribal Program in Arizona; Urban Indian Health Institute, Washington; Southeast Asia Resource Action Center; Little Tokyo Service Center, Los Angeles, California; African-American Alzheimer's and Wellness Association, Columbus, Ohio; Alzheimer Disease Research Center, University of Pittsburgh Medical Center; Illinois Department of Public Health; and the Alzheimer's Association.

People with Down Syndrome and Other Intellectual Disabilities

AIDD staff gathered external input regarding people with Down syndrome and other intellectual disabilities who have Alzheimer's disease. AIDD emailed or telephoned major disability organizations and individuals prominent in the field of intellectual disabilities and Down syndrome and asked them to provide input through listening sessions. Invited organizations included: ARC of the United States; National Association of State Directors of Developmental Disability Services (NASDDDS); Association of University Centers on Disabilities (AUCD); National Association of Councils on Developmental Disabilities (NACDD); National Disability Rights Network (NDRN); National Down Syndrome Congress (NDSC); National Down Syndrome Society (NDSS); National Task Group on Developmental Disabilities and Dementia Practices (NTG); Special Olympics; and grantees of the National Institute for Disability Research and Rehabilitation (NIDRR). AIDD staff also contacted the American Bar Association (ABA). AIDD staff sought family member expertise through disability organizations and directly from known family advocates of people with intellectual disabilities because family support is widely recognized as key in the lives of people with disabilities. Several individuals, while responding in their professional capacity as scholar, researcher, practitioner, or other professional role, also identified themselves

as family members of an individual with Down syndrome. In addition, AIDD staff sought the expertise of self-advocates with intellectual disability.

Four listening sessions were held with participation ranging from one to 17 people. One of the sessions was a telephone conference, the others occurred face-to-face. The remainder of the input was received through email. The response to request for external input from these experts was robust with 77 responses representing input from across the field.

ANALYSIS OF INPUT AND SUMMARY

In late November, Task Force leadership met to review the input and draft a report for membership review by the entire Task Force prior to the December 4 meeting. The Task Force members reviewed each of the cross-cutting recommendations discussed below and identified some areas to explore for potential action.

RESULTS

This section summarizes the results of the input collected, with a particular focus on the cross-cutting recommendations made by the stakeholders in all three groups. The 21 recommendations are grouped into three categories: (1) recommendations for further exploration, (2) recommendations that are being addressed by existing work, and (3) recommendations beyond the scope of the National Plan. The specific recommendations appear in **bold** and related information about federal activity appears below them.

Recommendations for Further Exploration

The following ten recommendations were identified by the Task Force as having the potential to be addressed through federal activities, pending the availability of resources.

1. **Stakeholders assert that the National Plan needs to address and incorporate strategies that are culturally and linguistically appropriate. For example, detection tools need to be created and defined as valid (or not valid) for specific populations.**

The federal staff updating the National Plan will review the document to identify opportunities to address this recommendation. Further actions undertaken in the annual updates to the National Plan will seek to address this concern. Addressing this gap would help meet the need for information and service of an increasingly diverse population. Non-governmental groups may be effective in determining approaches to detection of Alzheimer's disease. OMH has been engaged in this effort.

2. **Stakeholders say that primary care practitioners have insufficient training to recognize symptoms of possible dementia and to refer people with such symptoms to experts for an accurate diagnosis. Furthermore, practitioners should have access to this training.**

This is an area for potential action through the Geriatric Education Centers (GECs), which provide interdisciplinary geriatric education and training to health professionals and others students. The GECs received supplemental funding in FY 2012 to provide inter-professional training on Alzheimer's disease and related dementias. In FY 2013, grantees will integrate information on specific populations into public and private provider awareness and training efforts. Both Comprehensive Geriatric Education Program (CGEP) and Geriatric Training for Physicians, Dentists, and Behavioral and Mental Health Providers (GTPD)

programs could be asked to enhance outreach to primary care providers, as many of the current grantees offer significant amounts of continuing education related to dementia.

- 3. Stakeholders assert that the Alzheimers.gov website should increase availability of culturally appropriate resources for multiple communities, in addition to the resources already available in Spanish.**

With future funding for Alzheimers.gov, there may be an opportunity for public-private partnerships to develop culturally appropriate resources to address this need. The OMH Resource Center may be engaged as consultants in developing translations and content. Reflecting the needs of our diverse society, languages beyond English and Spanish are important to the public seeking information about Alzheimer's disease. The OMH has provided expertise and sensitivity on cultural appropriateness to create and translate information on a range of health issues. In addition, it may be useful to consider public-private collaborations to address this need. Health Resources and Services Administration (HRSA) will be posting Alzheimer's disease assessment tools in multiple languages from its GEC grantees on its dementia website in FY 2013.

- 4. Stakeholders say that protection and advocacy networks nationwide do not have sufficient information regarding advanced care planning and options counseling for persons at risk of dementia and their families and that such information should be made available to these networks.**

The Task Force believes that this information should be disseminated, even more broadly than the existing protection and advocacy systems for people with disabilities. In addition, the information disseminated should be broader than advanced care planning and options counseling. Additional information needed by all of the specific populations includes: care settings and financing, protection from abuse and neglect, options counseling for services, legal decisions, spiritual and religious preferences, and end-of-life planning. More tailored efforts to address the specific needs of the populations will likely be needed and may involve partnerships with the private sector. One example of a private sector effort is the ABA's work on younger-onset legal issues and future planning.

- 5. Stakeholders say that specific populations are not aware of, nor are they enrolled in, clinical trials in sufficient numbers; stakeholders recommend that clinical trials procedures address this.**

Minority enrollment in clinical trials has historically been low, with traditional recruitment efforts not reaching these populations. Although rules to ensure broader minority enrollment in clinical trials are in place,⁸ enrollment of these populations remains low. Similarly, stakeholders, including clinicians and family

⁸ Please see http://grants.nih.gov/grants/funding/women_min/women_min.htm for more information.

members of people with Down syndrome, reported no awareness of ongoing clinical trials for this population.

The National Institute on Health (NIH) is addressing this recommendation through the National Plan, with the National Institute on Aging (NIA) and the Food and Drug Administration (FDA) taking the lead on the National Plan's Action 1.B.3.⁹ Increased public awareness of governmental efforts directed to stakeholders and health care providers nationwide may increase knowledge of clinical trials in which specific populations are enrolled or eligible. The GEC funding mentioned in Recommendation 2 requires that the continuing education programming provided by the GECs include information on clinical trials. The grantees are encouraged to educate health care providers about both local trails and national trials that are listed on the NIH website.

- 6. Stakeholders assert that persons under age 60 with dementia and their caregivers do not have access to benefits counseling, legal assistance, nutrition programs, transportation, in-home services, case management, ombudsman access, adult day care, and respite. Stakeholders recommend that these groups have access to these types of services.**

Although the Task Force does not have the authority to expand the availability of these services to younger age groups, the group sees the potential to enhance awareness about the services to which these populations already have access. For example, persons under 65 with disabilities have access to home and community-based services (HCBS) through Medicaid and state-funded programs; the National Long-Term Care Ombudsman program serves all residents of nursing homes, board and care homes and assisted living facilities; the State Health Insurance Program serves adults of all ages who have Medicare due to disability. Legal services programs are available to people under age 65.

- 7. Stakeholders are concerned about screening and detection of Alzheimer's disease among specific populations. Stakeholders also say that practitioners do not receive reimbursement for provision of regular screening for early symptoms of dementia for younger persons and those with intellectual disabilities and recommend that practitioners' reimbursement should be adjusted to address this.**

Addressing changes in reimbursement procedures for practitioners is beyond the scope of the Task Force. However, the development of assessment tools for people with intellectual disabilities is underway in the private sector. Task Force members were not aware of public or private funding for such tools.

Awareness among providers of services to persons with younger-onset dementia may be part of future provider outreach/education efforts. We do not yet know

⁹ National Plan to Address Alzheimer's Disease. Available at <http://aspe.hhs.gov/daltcp/napa/NatlPlan.shtml>.

what screening tools are effective for people who may be experiencing younger-onset dementia. Identification of tools being developed externally would be a possible next step.

8. **Stakeholders point out that another specific population that does not appear in the National Plan is people with co-morbidities involving both behavioral health conditions and dementia.**

The Task Force appreciates this recommendation and is reaching out to relevant agencies such as Substance Abuse and Mental Health Services Administration (SAMHSA) and the National Institute of Mental Health (NIMH) to determine what additional work is needed. Many of HRSA's GECs are providing education and training in the management of multiple chronic disease conditions. The two most common chronic conditions they produce trainings on are dementia and diabetes. CGEP and GTPD grantees are specifically focusing on geropsychiatry, with an emphasis on ALL of an older adult's behavioral health needs, including dementia.

9. **Stakeholders say that informal caregivers need to be integrated into planning and treatment for specific populations with dementia and that integrated, multi-disciplinary treatment should support family caregivers to the extent possible. Stakeholders also say that formal, paid caregivers need to be included in care planning for consistency in communication with health care providers and in follow through with care.**

The Task Force noted that there is a need to integrate informal caregivers in planning for the broader population with dementia, but it is not clear what additional actions could be undertaken to target these specific populations with dementia. Work is underway to examine patterns of caregiving for Alzheimer's by African-Americans and Hispanics. It might be useful to examine the inclusion of informal caregivers, as appropriate, in the patient care plan in medical home models.

10. **Stakeholders are concerned about the skill and availability of direct care workforce-caregivers.**

The Task Force recognizes the need for an expanded and stable direct care workforce to support the needs of an aging population, including the specific populations addressed in this report. Training, adequate compensation, vigorous recruitment, support, and retention are areas to pursue, with a recognition of the unique needs of specific population and the necessity of building in communication between direct care staff, family, health care provider, and individual with dementia. CGEPs are already working in this area, but much work remains to be done.

Recommendations that are Being Addressed by Existing Work

For the following recommendations, the Task Force identified work that is currently underway that will address the issue.

11. **Stakeholders say that providers of health and long-term services and supports (LTSS) need more access to dementia awareness and training activities. Stakeholders recommend that these activities be developed, promoted, and carried out.**

Through four grant programs funded by HRSA, trainings on dementia have been developed and will be carried out for providers across specific populations in 2012 and 2013. Four specific areas of this training include:

- a. The *CGEP* funds schools of nursing, health care facilities, and programs leading to certification as a nurse assistant who will serve elderly persons. Through this program, grantees develop and disseminate curricula relating to the treatment of geriatric health problems, train faculty members in geriatrics; provide continuing education to individuals who provide geriatric care, or establish traineeships for individuals who are preparing for advanced education nursing degrees in geriatrics. Many of these grantees provide inter-professional training on Alzheimer's disease including specific populations addressed in this report.
- b. The *Geriatric Academic Career Award (GACA)* supports career development of physicians, nurses, social workers, psychologists, dentists, pharmacists, and allied health professionals in academia to provide training in clinical geriatrics including the training of inter-professional teams of health professionals. Current programs support training related to Alzheimer's disease including specific populations addressed in this report.
- c. The *GECs* provide inter-professional geriatric education and training to health professionals and others students. This includes training on the latest clinical guidelines and information on how to work with people with Alzheimer's disease and their families. Health care providers learn how to manage the disease while coordinating care in the context of other health conditions, and how to link people to support services in the community. Training also addresses caregiver burden and depression. Health care providers are also trained on the tools available to detect cognitive impairment and appropriate assessment processes for diagnosis of Alzheimer's disease and related dementias. All of the GECs received supplemental funding in FY 2012 to provide inter-professional training on Alzheimer's disease and related dementias including specific populations addressed in this report.

- d. The *GTPD* supports geriatric training projects for physicians, dentists and behavioral and mental health professionals who plan to teach geriatric medicine, dentistry, or behavioral or mental health. All grantees provide training on the assessment, diagnosis, treatment, management, and evaluation of Alzheimer's disease and related dementias, including specific populations addressed in this report. All grantees also provide training on the broader issue of mental and behavioral health among older adults.

It is important that providers are aware of these and other training opportunities and that training be widely available to providers, including those who are knowledgeable about specific populations but who do not typically serve people with dementias. Opportunities to maximize current training programs may be further promoted and refined for specific populations through existing efforts or realigned efforts including those of HRSA, ACL, and the Centers for Medicare and Medicaid Services (CMS). For example, there may be opportunities to partner with the private sector through the University Centers for Excellence in Developmental Disabilities (UCEDD), a network created through AIDD and the Developmental Disabilities Assistance and Bill of Rights Act of 2000. Other private sector entities, with specialized knowledge and skill regarding specific populations, may be engaged in training and information dissemination.

12. Stakeholders recommend that there be a registry for those with Down syndrome and dementia.

NIH has an existing registry for those with Down syndrome and dementia. Stakeholders may need additional information about this registry to be disseminated to their networks.

13. Stakeholders suggested several general and specific areas for research regarding specific populations.

A meeting to develop research priorities around Alzheimer's disease and Down syndrome is scheduled for May 1-2, 2013, at NIH. Other suggestions for research have been shared with NIH.

14. Stakeholders assert that there is potential for exploitation of specific populations in clinical trials and other research approaches and safeguards against exploitation need to be woven into research procedures.

Discussions with the National Human Subjects Research Council and the NIH Office of Ethics in Research are important to address these efforts. Additional information may be found through the Alzheimer's Association which has developed an ethics statement for research participants:

http://www.alz.org/documents_custom/statements/protection_of_participants_in_research.pdf.

15. **Stakeholders point to a lack of person-centered planning and recommend that programs and policies employ person-centered planning to the extent possible by pulling culture and family into this process.**

The Task Force noted that person-centered planning is the central approach that CMS, ACL, Indian Health Service (IHS), and VA are applying to many of the programs they fund. This issue is not limited to dementia only. All federal agencies could consider whether modifications are necessary to take into account cultural issues and family caregivers and educate providers and their networks accordingly.

16. **Stakeholders say that family members of persons with dementia should be encouraged to seek certification as providers under their state Medicaid waiver program. This step would enable family caregivers to receive payment for the care they deliver as part of a Medicaid HCBS plan.**

In many state Medicaid programs, it is possible for a family member to become certified as a provider through the state Medicaid system. The Task Force sees the potential opportunity for the private sector to support the dissemination of this information where appropriate. The Task Force will forward the recommendation to the National Resource Center for Participant-Directed Services for consideration in its work with state LTSS programs.

17. **Stakeholders recommend use of the medical home model for specific populations to increase their regular and appropriate access to health care.**

The Affordable Care Act (ACA) offers opportunities to expand access to the “health home” which expands “medical home” to access a range of community supports. This issue is broader than dementia.

18. **Stakeholders emphasized that maintaining typical home and community living was important to specific populations with Alzheimer’s disease and related dementias and to their families.**

Given the history of segregation and discrimination [some] people with intellectual disabilities and their families have encountered across the lifespan, additional attention and vigilance in ensuring appropriate access to community living for this population is warranted. This attention should include alignment with the 1999 Olmstead Decision. Among all populations, family, culture and language must be factored into decisions of care within the community as well. HHS is sensitive to this concern and strives to ensure access to the least restrictive environment for all people.

19. **Stakeholders state that persons under age 65 with dementia must wait two years for Medicare once they are determined eligible for Social Security Disability Income and their families are not eligible for Medicare even after the waiting period is over. Stakeholders recommend that policies and programs address issues of access to health insurance coverage for persons under age 65 with dementia and their families.**

This need is being addressed through the ACA as people with younger-onset dementia will have access to expanded Medicaid or through the full roll out of the Affordable Insurance Exchanges. Implementation of ACA will also result in limiting exclusions for pre-existing conditions beginning January 1, 2014, addressing a concern of people experiencing younger-onset and their families.

Recommendations Beyond the Scope of the National Plan to Address Alzheimer's Disease

The Task Force noted that the following recommendations, while very important, are beyond the scope of the National Plan and/or require action by groups outside the executive branch of Federal Government.

20. **Stakeholders assert that ethnic and racial minorities, particularly those who are undocumented, need better access to health insurance coverage as the ACA is implemented and recommend that this issue be addressed.**

This recommendation is beyond the scope of the National Plan.

21. **Stakeholders say that practitioners do not have reimbursement for services they provide to caregivers and recommend that practitioners' reimbursement be adjusted to address this.**

The Task Force notes that the non-federal members of the Advisory Council on Alzheimer's Research, Care, and Services made a recommendation on this about the broader population of caregivers for people with Alzheimer's disease and related dementias. This issue is shared across all populations with Alzheimer's disease.

22. **Stakeholders assert that specific populations need better access to transportation to facilitate access to health care as well as social supports.**

Although the Task Force recognized the importance of transportation to the receipt of timely health care, challenges with transportation are beyond the scope of the National Plan.

CONCLUSION

By soliciting input from a variety of sources, the Task Force was able to get information about the challenges faced by the three specific populations of focus: people with younger-onset dementia, racial and ethnic minorities, and persons with Down syndrome and other intellectual disabilities. There were many common recommendations made across these populations. The Task Force reviewed each and determined which recommendations may be addressed in further exploration, which are being addressed by existing work, and which were beyond the scope of the National Plan. As the 2013 Update to the National Plan is written, HHS and its federal partners will explore the feasibility of implementing the most promising recommendations.

APPENDIX A: FEDERAL AGENCIES ON TASK FORCE

Department of Education

National Institute on Disability and Rehabilitation Research

Department of Health and Human Services

Office of the Assistant Secretary for Health

Office of Minority Health

Office of the Assistant Secretary for Planning and Evaluation

Office of Disability, Aging and Long-Term Care Policy

Administration on Community Living

Administration on Aging

Administration on Intellectual and Developmental Disabilities

Centers for Disease Control and Prevention

Health Resources and Services Administration

Indian Health Service

National Institutes of Health

National Institute on Aging

National Institute of Child Health and Human Development

National Institute of Neurological Disorders and Stroke

National Institute of Mental Health

Substance Abuse and Mental Health Services Administration

Department of Veterans Affairs

Social Security Administration

APPENDIX B: DATA COLLECTION DOCUMENTS

Memorandum to Task Force Members Describing Data Collection Process

August 31, 2012

Dear All,

Thanks so much for your enthusiastic participation in Tuesday's meeting of the federal Alzheimer's Disease Task Force on Specific Populations. Your interest, knowledge and commitment is great! This email summarizes our discussion about the tasks and next steps as we move forward to produce strategies and action steps related to the unique needs of persons with young onset Alzheimer's, Down Syndrome and other intellectual disabilities, as well as racial and ethnic minorities who are at increased risk of developing the disease. **Tasks and next steps are to:**

1. **Gather input from experts outside the federal government:** Task Force members volunteered to contact experts to gather input on improving care in four categories identified in the plan. Those four categories are: (1) accurate and timely diagnosis; (2) access to care; (3) education on AD for practitioners who do not normally specialize in care for people with AD; and (4) special consideration for these populations.

Attached is a list of agencies, organizations and experts identified by Task Force members and volunteer assignments. This attachment is labeled: CONTACT COMMITMENTS FOR EXTERNAL EXPERTISE.

As we discussed, we are seeking input, not feedback: We are asking you keep a record of all to whom you gave the opportunity for input, whether or not you received input from individuals or organizations contacted. Also, the category of expertise an individual represents would be important to know. You should record names, but we will not disclose names of individuals who provided information and did not represent an industry group or organization. Attached is a sample form for recording contacts with individuals from whom you "gave the opportunity for input" as well as identifying whether or not input was provided. **This attachment is labeled: INPUT Contacts External Experts.**

As you suggested, we have DRAFTED a memo for your consideration as you contact external experts. **That memo is attached and labeled: DRAFT Memo to External Experts.** Please note that the draft must be personalized by you as

to who you are contacting and how you will be following up before it is sent out to individuals or organizations. We discussed participating in listening sessions as a way of gathering input. We are not seeking feedback.

Your agency may have specific guidance and requirements as to how this step is framed and how you must proceed. We recommend that you follow that guidance.

Please send the input gathered within the four categories listed above to Helen Lamont, Mette Pedersen or Jane Tilly by October 8 so that we have enough time to put together the information you have gathered for our October 16 meeting.

2. **Completing the Inventory:** Attached please find the same inventory we worked with at the August 28 meeting. Input you gather, as well as additional information you and your agency may see is missing, should be entered into this inventory in the two columns on the far right of the inventory template. You may recall that the “Supplementary Exhibits 1, 2, and 3”, represent: (1) Alzheimer’s-specific long-term services and supports; (2) Relevant long-term services and supports (not Alzheimer’s specific); and (3) Relevant clinical care programs. ***Additions to the inventory include: special considerations and opportunities for improvement in existing federally-funded programs.***

Please send your additions to the inventory to Helen Lamont, Mette Pedersen or Jane Tilly by October 8, close of business, so that they may be included with the work of others by the October 16 meeting. **The inventory is attached to this email and is labeled: NAPA Inventory _example for Spec Pops Task Force.**

3. **Revised timeline:** We agreed to revise the timeline to include opportunities for Task Force members to gather input from external experts prior to our next meeting on October 16. **The attached timeline reflects those revisions and is labeled: SPTF Timeline and Action Steps.**
4. **Planning document:** Following is the link to the document *My Thinker’s Not Working*, with the outline of a plan addressing dementia among people with intellectual disabilities and living in their communities. This was referred to by Dr. Dawn Carlson of NIDRR during our meeting. The plan is found on page IV after the Executive Summary in the document. <http://aadmd.org/ntg/thinker>.
5. **Final Task Force product:** Task Force Members came to consensus that the final product submitted to the Federal Interagency Group on Alzheimer’s and the National Advisory Council on Alzheimer’s Research, Care, and Services will be a set of recommendations to consider for inclusion in the 2013 National Plan to Address Alzheimer’s Disease. The recommendations will be both short and long-term in scope and include suggested action steps.

6. **Interface with Federal Advisory Council on Alzheimer's Disease and next steps:** Activities of the Task Force and activities to date will be shared with the Advisory Council at its October 15 meeting. The Task Force will reconvene on Tuesday **October 16, 2012 (2-4PM)**, following the Advisory Council Meeting on the 15th, to review information gathered to date, identify additional gaps and ways to address gaps, and to edit documentation.

The Task Force will reconvene on Tuesday **December 4, 2012 (2-4PM)** to discuss suggested recommendations and timeframes.

Final recommendations will be submitted to the Federal Interagency Group on Alzheimer's and the National Advisory Council on Alzheimer's Research, Care, and Services in January 2013.

Please enter the October and December dates above into your calendars as we discussed. Not all members have access to the same scheduling system so we will each do this individually.

Dr. Helen Lamont will be returning from leave later in September and will rejoin leadership with the Task Force. Please do not hesitate to contact Helen Lamont, Mette Pedersen or Jane Tilly with questions or suggestions. Your commitment to the Task Force in identifying ways to address the care and support needs for the specific populations is very much appreciated.

Best regards,

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DRAFT Memorandum to External Experts

Dear _____,

As you may know, the National Alzheimer's Project Act has charged the federal government with creating and maintaining an ambitious national plan to overcome Alzheimer's disease. Within the plan is guidance to address the needs of "specific populations disproportionately affected by Alzheimer's Disease". These populations include racial and ethnic minorities, people with Down syndrome and other intellectual disabilities, and people experiencing younger-onset Alzheimer's disease before age 60. The Task Force on Specific Populations has been established to address the care and support needs of these specific populations.

You have unique expertise and knowledge in understanding the needs of these specific populations and how we can best plan to meet those needs.

As a member of the federal Task Force on Specific Populations within the National Alzheimer's Plan, I am asking you for your input in four areas the Task Force is focused on in order to improve care and support to the specific populations. These four areas include:

- Accurate and timely diagnosis;
- Access to care;
- Education on Alzheimer's disease for practitioners who do not normally specialize in care for people with Alzheimer's disease;
- And special considerations for these populations.

I will be **calling, writing, meeting, etc. with you** (*indicate how you will directly seek input*) to gather your thoughts and guidance as to how we can address the unique needs of these groups of people.

Sincerely,

Supplementary Exhibit 1. NAPA Inventory_example: Alzheimer’s-Specific Long-Term Services and Supports Projects and Funding by Federal Agency, FY 2010

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
ACL/AoA/ HHS	Alzheimer’s Disease Supportive Services Program	HCBS	Supports efforts to expand the availability of community-level supportive services for persons with Alzheimer’s and their caregivers and improve the responsiveness of the home and community-based care system to persons with dementia. Includes translation of evidence-based interventions into effective supportive service programs at the community level.		
ACL/AoA/ HHS	National Alzheimer’s Call Center	HCBS	National information and counseling service for persons with Alzheimer’s disease, their family members, and unpaid caregivers. Available in 56 states and territories, 24 hours a day, 7 days a week, 365 days a year, the Call Center provides expert advice, care consultation, information, and referrals nationwide, at the national and local levels.		
Department of Justice	Missing Alzheimer’s Disease Patient Alert Program	HCBS	Supports projects that aid in the protection and location of missing persons living with Alzheimer’s disease and related dementias and other missing elderly individuals.		

Supplementary Exhibit 2. Relevant Long-Term Services and Supports Projects (not specific to Alzheimer’s disease) by Federal Agency, FY 2010

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
ACL/AoA/ HHS	Home and Community-Based Supportive Services	HCBS	Provides support for community living for older adults including transportation services for critical daily activities; personal care, homemaker, and chore services to seniors unable to perform daily activities or instrumental activities of daily living; adult day care/day health services for dependent adults; and case management services to assist in assessing needs, developing care plans, and arranging services for older persons or their caregivers.		
ACL/AoA/ HHS	National Family Caregiver Support Program	HCBS	Funds a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. The program supports five services: information to caregivers about available services; assistance to caregivers in gaining access to the services; individual counseling, organization of support groups, and caregiver training; respite care; and supplemental services.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
ACL/AoA/ HHS	Lifespan Respite Care Program	HCBS	Support, expands, and streamlines the delivery of planned and emergency respite services while also providing for the recruitment and training of respite workers and caregiver training and empowerment.		
ACL/AoA/ HHS	Title IV Community Living Discretionary Grants	Planning for LTSS	<p>Funds Aging and Disability Resource Center and the Veteran-Directed HCBS programs to support older adults and persons with disabilities to live independently in their communities.</p> <p>Aging and Disability Resource Center networks serve as sources of information on the range of LTSS options for persons regardless of age, income, or disability with one-on-one help in understanding and accessing services and supports.</p> <p>See VA below for additional information on the Veterans-Directed HCBS Program.</p>		
ACL/AoA/ HHS	Model Approaches to Statewide Legal Systems/ National Legal Assistance and Support Projects	Planning for Long-Term Care	Protect older persons from direct challenges to independence, choice and financial security. These programs help older individuals understand their rights, exercise options through informed decision-making, and achieve optimal benefit from the support and opportunities promised by law.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
ACL/AoA/ HHS	Prevention of Elder Abuse, Neglect, and Exploitation Program	Quality and Safety	Strengthens elder justice strategic planning and direction for programs, activities, and research related to elder abuse awareness and prevention. Trains law enforcement officers, health care providers, and other professionals on how to recognize and respond to elder abuse; supports outreach and education campaigns to increase public awareness of elder abuse and how to prevent it; and supports the efforts of elder abuse prevention coalitions and multi-disciplinary teams.		
ACL/AoA/ HHS	Long-Term Care Ombudsman Program	Quality and Safety	Advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. Resolves problems of individual residents and advocates for changes at the local, state, and national levels that will improve residents' care and quality of life. Assists residents and their families and provides a voice for those unable to speak for themselves.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
CMS/HHS	Medicaid 1915(c) Home and Community-Based Waivers	HCBS	Waiver authority permits a state to offer a wide range of Medicaid HCBS to individuals who require a level of institutional care including nursing facility. Services include adult day care, respite, personal care, chore services, a personal emergency response system, environmental adaptations, home delivered meals, nursing care, transportation, and medical equipment.		
CMS/HHS	State Plan Personal Care Services	HCBS	States may cover personal care as a Medicaid optional service. Personal care includes help with daily activities, such as eating, bathing and dressing. For the personal care state option, beneficiaries must have a disability, but are not required to need an institutional level of care. As a regular Medicaid optional service, normal Medicaid financial eligibility rules apply; states may not limit the number of people receiving services; and there is no federal expenditure limit in terms of average expenditures		
CMS/HHS	Section 1915(I) State Plan Amendment	HCBS	This Medicaid state plan option is similar to Medicaid HCBS waivers. However, this option does not require individuals to meet an institutional level of care and provides states an opportunity to offer services and supports before individuals need institutional care.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
CMS/HHS	Money Follows the Person	HCBS; Residential Care Settings	Demonstration designed to shift Medicaid LTSS spending from institutional care to HCBS. The program transitions people living in nursing homes and other institutions to homes, apartments, or group homes. Approximately 24 states provide transitional services to individuals who have Alzheimer's disease.		
CMS/HHS	Nursing Homes	Residential Care Settings	Nursing home care is a mandatory service under Medicaid. Short-term nursing home care is covered under Medicare for people needing skilled care.		
VA	Adult Day Health Care (ADHC)	HCBS	Part of the VA Standard Benefits Package, provides health maintenance and rehabilitative services to veterans in a congregate group setting during daytime hours. Social or medical/rehabilitative services are provided depending on the individual program.		
VA	Home-based Primary Care	HCBS	Home-based Primary Care, part of the VA Standard Benefits Package, is a unique home care program that provides comprehensive, longitudinal, primary care by an interdisciplinary team of VA staff in the homes of veterans with complex, chronic, disabling disease for whom routine clinic-based care is not effective.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
VA	Homemaker/ Home Health Aide	HCBS	Part of the VA Standard Benefits Package. These services provide personal care services in the home using public and private agencies for certain patients who meet the criteria for nursing home placement. These services are provided in the community under a system of case management provided directly by VA staff.		
VA	Purchased Skilled Home Care	HCBS	Part of the VA Standard Benefits Package. Provided in the home through contract agencies to veterans who are homebound and in need of skilled services such as nursing, physical, occupational, and speech therapy, or social services.		
VA	Respite	HCBS; Residential Care Settings	Part of the VA Standard Benefits Package. Services temporarily relieve the spouse or other caregiver from the burden of caring for a chronically ill or disabled veteran at home. In-home or institutional respite care can be arranged.		
VA	Veteran Directed HCBS	HCBS	Provides veterans of all ages the opportunity to receive HCBS in a consumer-directed fashion that enables them to avoid nursing home placement. Offered in collaboration with the AoA.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
VA	Program for All-inclusive Care of the Elderly	HCBS; Residential Care Settings	The Program for All-inclusive Care of the Elderly is a managed care model of care for nursing home certifiable individuals living where the program receives a capitated payment for all acute care and LTSS. The program is heavily dependent on adult day care services.		
VA	Caregiver Supports	HCBS	VA medical centers caregiver support coordinators assist caregivers with access to VA and community support services, such as respite care, adult day health services, in-home aide services, and support groups. The supports include a Caregiver Support Line, which is a toll-free number, answered by a clinician 24 hours a day/7 days a week.		

Supplementary Exhibit 3. Relevant Clinical Care Programs (not specific to Alzheimer’s disease) by Federal Agency, FY 2010

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
CMS/HHS	Medicare Supplemental Health Insurance	Detection & Diagnosis; Treatment & Care Coordination	<p>Medicare Part B benefits cover the diagnosis, evaluation and treatment of Alzheimer’s disease, primarily by physicians. In addition, Medicare Part B covers outpatient physical, occupational, and speech therapy Medicare Part B also covers outpatient counseling concerning the management of Alzheimer’s either from a physician or from a Medicare-certified psychologist, medical social worker, or other non-physician provider. If the mental health treatment is provided by a non-physician, it must be prescribed by the patient’s doctor.</p> <p>Medicare Part B covers:</p> <ul style="list-style-type: none"> – physicians’ services – outpatient hospital services – physical, occupational, and speech therapy – diagnostic x-rays – laboratory tests – durable medical equipment – blood – home health care services (limited) – mental health services 		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
CMS/HHS	Medicare Acute Care Services	Detection & Diagnosis; Treatment & Care Coordination	<p>Medicare Part A covers acute care services such as:</p> <ul style="list-style-type: none"> – inpatient hospital care – limited skilled nursing home care – limited home health care – hospice care 		
CMS/HHS	Medicare Prescription Drug Coverage	Treatment & Care Coordination	<p>Medicare Part D covers prescription drugs and is available to all Medicare beneficiaries through private insurance plans. Each plan is different regarding the drugs it covers and the out-of-pocket costs. All Medicare drug plans cover some commonly prescribed medications to treat Alzheimer's. All plans are required to cover at least two cholinesterase inhibitors and memantine.</p>		
CMS/HHS	Hospice Benefits	Advance Care Planning	<p>Medicare beneficiaries with a terminal illness who are certified by a physician to have 6 months or less to live are eligible for the Medicare hospice benefit. Hospice enrollees must agree to receive all of their care for their terminal illness through the hospice.</p> <p>The Medicare benefit includes: nursing care provided by or under the supervision of a registered professional nurse; physical or occupational therapy, or speech-language pathology services; medical social services under the direction of a physician;</p>		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
			<p>services of a home health aide and homemaker services; medical supplies (including drugs and biologicals) and the use of medical appliances; physicians' services; short-term inpatient care (for both caregiver respite and procedures necessary for pain control and acute and chronic symptom management), but such respite care may be provided only on an intermittent, non-routine, and occasional basis and may not be provided longer than 5 consecutive days; counseling (including dietary counseling) with respect to care of the terminally ill individual and adjustment to his death; and any other item or service which is specified in the plan and for which payment may otherwise be made. Hospice is an optional benefit in Medicaid that many, but not all states cover it. Medicaid services mirror Medicare benefits, and are of importance principally to beneficiaries who are not eligible for Medicare.</p>		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
VA	Ambulatory Care	Detection & Diagnosis; Treatment & Care Coordination	Outpatient diagnostic and treatment services are part of the VA's standard benefits package. Outpatient care includes a wide range of primary and specialty care (e.g., geriatrics, neurology, psychiatry, other medical specialties). Coordination of care and interactions with family members are integral components of care. Some VA facilities have developed specialized dementia or other geriatric problem-focused specialty outpatient clinics, which may provide evaluation or ongoing care.		
VA	Home-based Primary Care	Detection & Diagnosis; Treatment & Care Coordination	Home-based Primary Care, part of the VA Standard Benefits Package, is a unique home care program that provides comprehensive, longitudinal, primary care by an interdisciplinary team of VA staff in the homes of veterans with complex, chronic, disabling disease for whom routine clinic-based care is not effective.		
VA	Home Telehealth	HCBS	Home Telehealth communication technology can play a major role in coordinating veterans' total care with the goal of maintaining independence.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
VA	Hospital Care	Detection & Diagnosis; Treatment & Care Coordination	Inpatient diagnostic and treatment services are part of the VA standard benefit package. Inpatient care includes a wide range of specialty care (e.g., geriatrics, neurology, psychiatry, surgery, and other medical specialties). Coordination of care and interactions with family members are integral components of care. Some VA facilities have developed specialized dementia inpatient units, which may provide evaluation and short-term management of complex cases.		
VA	Geriatric Evaluation and Management	Detection & Diagnosis; Treatment & Care Coordination	Geriatric Evaluation and Management is for older veterans with multiple medical, functional, and psychosocial problems and geriatric syndromes (e.g., falls) and is provided by an interdisciplinary team in either inpatient or outpatient settings. Geriatric evaluation--the assessment and care plan development--is required to be available to all veterans who may benefit from it. Geriatric evaluation is offered in geriatric evaluation and management, home-based primary care, and geriatric primary care.		
VA	Geriatric Primary Care	Treatment & Care Coordination	Geriatric primary care for frail elderly veterans targets complex patients with involved medical histories who need in-depth attention.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
VA	Geriatric Research, Education, and Clinical Centers (GRECCs)	Detection & Diagnosis; Treatment & Care Coordination	A system of 20 centers of excellence responsible for increasing basic knowledge of aging, developing improved models of clinical services, and implementing a wide variety of educational activities. Four GRECCs have a major focus on dementia.		
VA	Mental Illness Research, Education, and Clinical Centers (MIRECCs)	Detection & Diagnosis; Treatment & Care Coordination	A system of 10 Centers of Excellence whose mission is to generate new knowledge about the causes and treatments of mental disorders, apply new findings to model clinical programs, and widely disseminate new findings. Two of the Centers have a focus on dementia.		
SAMHSA/ HHS	Older Adult Targeted Capacity Expansion (TCE)	Detection & Diagnosis Treatment & Care Coordination	Designed to improve consumers' overall mental health and quality of life, Older Adult TCE helps communities provide direct services and build infrastructure to support expanded services for the behavioral health needs of clients from a variety of ethnic and cultural groups. The program provides direct clinical treatment, LTSS, and prevention services. Additionally, it provides "wraparound" and recovery support services (e.g., community integration and transportation services).		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
SAMHSA/HHS	National Registry of Effective Programs and Practices (NREPP)	Detection & Diagnosis; Treatment & Care Coordination	A searchable online registry of more than 190 evidence-based interventions supporting mental health promotion, substance abuse prevention, and mental health and substance abuse treatment. Its purpose is to connect members of the public with intervention developers to learn how to implement these interventions in their communities.		
HRSA/HHS CMS/HHS	Reducing Adverse Drug Events: Patient Safety and Clinical Pharmacy Services Collaborative (PSPC)	Detection & Diagnosis; Treatment & Care Coordination	Seeks to improve the quality of health care by integrating evidence-based clinical pharmacy services into the care and management of high-risk, high-cost, complex patients. Quality Improvement Organizations will foster reduction of adverse drug events in high-risk populations by expansion and formation of community teams focused on patients who are at high medication risk because of multiple medications, multiple providers, multiple conditions or inappropriate/inadequate medication use. The PSPC collaborative includes a joint effort targeting the Medicare population often at higher risk secondary to polypharmacy or potentially inappropriate medication prescription and use.		

Federal Agency	Program Name	Category	Program Description	Special Considerations for Early Onset, Minorities, Intellectual Disabilities	Opportunities for Improvement
VA	Home Hospice Care	Advance Care Planning	Home hospice care, part of the VA Standard Benefits Package, is provided by community hospice agencies and includes comfort-oriented and supportive services in the home for veterans in the advanced stages of Alzheimer's disease. Services are provided by an interdisciplinary team of providers and volunteers. Bereavement care is available for the family following the death of the patient.		
VA	Hospice and Palliative Care Consultation Team (HPC)	Advance Care Planning	All VA facilities are required to have interdisciplinary HPCs available to assist staff, veterans, and their families with serious illness care and end-of-life planning issues.		

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

NOTE: All requests must be in writing.

RETURN TO:

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http://aspe.hhs.gov/office_specific/daltcp.cfm

Assistant Secretary for Planning and Evaluation (ASPE) Home
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