



**Alzheimer's Disease
International**

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Policy News from National Plans

Intellectual and Developmental Disabilities and Dementia in National and Sub-National Dementia Plans

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Intellectual and Developmental Disabilities and Dementia in National and Sub-National Dementia Plans

A review of 79 national and sub-national dementia plans, found that 28 plans mention dementia and intellectual and developmental disabilities (IDD). Out of the 79 plans, four did not have translations into English or were unable to be accessed.

Those 28 plans that featured IDD and dementia are:

- Alaska, USA
- Arizona, USA
- Australia
- Delaware, USA
- England
- Georgia, USA
- Bavaria, Germany
- Indiana, USA
- Ireland
- Maine, USA
- Massachusetts, USA
- New Jersey, USA
- New South Wales, Australia
- New York, USA
- Northern Ireland
- North Carolina, USA
- Norway
- Pennsylvania, USA
- Rhode Island, USA
- San Francisco, USA
- Scotland
- Switzerland
- Tennessee, USA
- USA
- Vermont, USA
- Victoria, Australia
- Wales
- Washington, USA

Please note that given the emphasis on learning disabilities in England, Wales, Scotland, and Northern Ireland, a unique search on learning disabilities was conducted in these four national plans. In the plans, learning disabilities is sometimes used in direct reference to Down syndrome. For the purpose of this review, learning disabilities is included within IDD in each category below.

It should also be noted that, while the plans for England, Wales, Scotland and Northern Ireland are treated as national plans throughout this document, in the work of Alzheimer's Disease International they are generally considered to be sub-national plans.

The 28 plans address IDD and dementia in various ways. Some of them present information about IDD and dementia, and others describe actions they are taking to address the issue. The plans fall into the following categories for how they address IDD and dementia.

Risk Factors to Diagnosis

This category includes plans that explain how individuals with IDD can develop dementia earlier and/or are more at risk for dementia. Nations and sub-nations that feature this include Australia, England, Ireland, Northern Ireland, Norway, Scotland, Switzerland, Georgia, North Carolina, Vermont and Wales. Additionally, Australia, England, North Carolina and Norway include a focus on detection and diagnosis, discussing points such as how it is challenging to receive an accurate diagnosis for this population, and that specific tools should be incorporated for early detection.

Ireland's plan highlights need to review access that general practitioners and acute hospital clinicians have to specialist assessment for people with IDD, and Northern Ireland says that specialist dementia diagnostic and support services will enable full access by people with learning disabilities.

Furthermore, New South Wales in Australia stresses the need for regular assessment for dementia of people with IDD. Ireland and Georgia's plans include screening; Ireland discusses the importance of targeted screening for IDD because of high risk, and Georgia emphasizes the need to develop a plan for screening for dementia in this population.

Quality of Care

This category includes plans that discuss the care of persons with IDD and dementia. Several plans including Ireland, Australia New South Wales, Australia Victoria, Germany Bavaria, Georgia, Indiana, New York, North Carolina, Rhode Island, Vermont, mention, for example, how: resources should be available for persons with IDD and dementia; there needs to be good quality care; best practices need to be identified; and both advanced care planning and early planning should be promoted. Georgia's plan also stipulates that state contracts providing services to older adults, including those with developmental disabilities and dementia, need to include quality measures specific to dementia capable care for those who deliver IDD services. Finally, San Francisco, California discusses the need to modify dementia care for Adult Residential Facilities for Persons with Special Needs.

Awareness and Understanding

A few plans such as England, Ireland, Northern Ireland and Maine highlight the need for better awareness and understanding about dementia, and Ireland describes the need to particularly target populations at risk, such as those with IDD. England describes how a public information campaign about dementia would need to take into account that the needs of some groups, such as those with learning disabilities, may be different from the rest of the population and require tailored approaches. Northern Ireland also states that every element of their plan applies to persons with learning disabilities, including awareness raising. Finally, Georgia describes the importance of developing a marketing and media plan to help reduce the stigma associated with dementia, and target those with IDD.

Training for Services Providers

There are several plans that discuss the need to train and educate staff, service-providers, and cross-train throughout various fields. These plans include England, Ireland, Northern Ireland, Oregon, Alaska, Arizona, Delaware, Georgia, Massachusetts, New Jersey, New York, Tennessee and Washington.

Research

The New York and Pennsylvania plans place importance on the need for research into dementia and IDD. New York's focus is on promoting research on the connection

between Down syndrome and Alzheimer's in New York State research institutes. Pennsylvania calls for an increase in research to improve treatment of Alzheimer's for individuals with IDD.

Support for Caregivers

Washington state's dementia plan places importance on developing supports for family caregivers who are employed and caring for people with developmental disabilities and dementia. Washington also discusses the need to support and educate older family caregivers who provide primary care for their adult children or siblings with developmental disabilities and dementia.

National Dementia Plans

This review is based on national plans available as of 1 May 2016 in English or translations into English.

Key word search: intellectual; developmental; and learning disability. Please note that learning disability was a unique search to England, Wales, Scotland, and Northern Ireland.

Country	Reference to IDD and Dementia
Australia	<ul style="list-style-type: none"> • "People with physical and intellectual disabilities are increasingly surviving to older age and therefore are vulnerable to age-associated disorders such as dementia. It is reported that one in five people, with an intellectual disability, aged 65 and older, have dementia" (p. 6). • "There are challenges associated with achieving an accurate diagnosis in some population groups, including but not limited to people with an intellectual disability, people from CALD backgrounds, and Aboriginal and Torres Strait Islander people" (p. 11).
Costa Rica (no translation available)	
Cuba (unofficial translation)	N/A
England*	<ul style="list-style-type: none"> • "The draft strategy was very well received by the public and professionals alike, and the recommendations it set out were seen as being the right ones if dementia services are to fully meet the needs of people with dementia and their carers. Areas where changes have been made are: provision for people with learning disabilities; the need for better peer support networks; improved end of life care; housing for people with dementia; and the particular needs of people with early-onset dementia (people under 65 years of age)" (p. 11). • "The dementias all share the same devastating impact on those affected and their family carers. Dementias affect all in society irrespective of gender, ethnicity and class. They can affect adults of working age as well as older adults. People with learning disabilities are a group at particular risk. This Strategy is designed to address the needs of all people with dementia, no matter of what type, age, ethnic origin or social status" (p. 16).

Country	Reference to IDD and Dementia
England (<i>continued</i>)	<ul style="list-style-type: none"> • "In the second phase, between June and September 2008, the Department undertook a formal public consultation exercise on the draft proposals for the Strategy. Approximately 600 written responses were received from individuals, including people with dementia and their carers, and from a wide range of professional and other stakeholder groups. These responses have been analysed and have informed the development of the final strategy. In addition, 53 regional consultation events were held, organised by CSIP and the Alzheimer's Society with support from the Central Office of Information (COI). Over 4,000 individuals attended these meetings, which covered the whole of England, including rural and urban areas. As with the initial listening events, specific groups were targeted. This ensured that the views of diverse populations were taken into account in the development of the Strategy, including: younger people with dementia; people with learning disabilities; people from minority ethnic groups; people from rural and island communities; and older people in prisons" (p. 18). • "The nature and size of the issues involved means that such a public information campaign would need a phased approach, developing and continuing over time. The campaign would need to be well planned, incorporating research evidence to build effective campaign messages, and crafted carefully to ensure that it is clear and honest. It should aim to reduce anxiety and promote understanding. In the words of one person with dementia, 'It must not frighten people with dementia or their carers.' It should take account of the fact that the needs of some groups (eg those with a learning disability and dementia, younger people with dementia, those from minority ethnic groups, or those from rural, island or traveller communities) may be different from those of the majority population, and may require specifically tailored approaches" (p. 28). • "A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia for reasons that include: the belief that nothing can be done for dementia; risk avoidance; concerns about competency; and concerns about the availability of resources. This can be particularly problematic for people from specific groups, such as people with learning disabilities or younger people with dementia" (p. 36). • "Local commissioners will wish to consider the extent to which referral to such services are 'open' for the public or rely on referral through primary care or adult social care. There was a genuine divergence of opinion in those responding to the consultation on this. There will be a need to work out how services can be made to work for those from specific groups such as people with learning disabilities. Consistent feedback was received during the consultation process about how difficult it is

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Country	Reference to IDD and Dementia
England (<i>continued</i>)	<p>for this group to receive a diagnosis and appropriate help and support. People with learning disabilities are likely to be in touch already with health and social care services, so close liaison and collaboration between the different professionals involved is essential" (p. 38).</p> <ul style="list-style-type: none"> • "Services need to be able to work for the diverse groups of people who may be affected by dementia. For example, people with learning disabilities who develop dementia will generally be of a younger age group and may have needs which services designed for people 30 or 40 years older find hard to meet" (p. 48). • "Training should enable an understanding of the diversity in dementia, including younger people with dementia, those who have dementia and a learning disability, and those with particular needs from minority backgrounds" (p. 66). • "Effective commissioning for dementia involves a wide range of partners at strategic and operational levels. At all levels, commissioners need to take account of and appropriately prioritise [...] wider risk factors – targeting support for vulnerable groups who often suffer disproportionately poorer health outcomes, such as people with learning disabilities and dementia" (p. 80).
Finland	N/A
France	N/A
Greece (<i>unofficial translation</i>)	N/A
Indonesia	N/A
Ireland	<ul style="list-style-type: none"> • Available resources should be deployed on the basis of need and as effectively as possible to provide services for all people with dementia, including those with early- onset dementia and/or an intellectual disability, and should be delivered in a culturally appropriate way" (p. 13). • Better Awareness and Understanding- "target populations particularly at risk, including people with an intellectual disability" (p. 14).

Country	Reference to IDD and Dementia
Ireland (<i>continued</i>)	<ul style="list-style-type: none"> • "The Health Service Executive will review existing service arrangements so as to maximise the access that GPs and acute hospital clinicians have to specialist assessment and diagnosis of dementia, including Old Age Psychiatry, intellectual disability services, geriatric medicine, neurology services and memory clinics" (p. 14). • "A recent systematic review has found that there is no evidence that general population screening for dementia would lead to improved clinical or psychosocial outcomes. Clinical guidelines are unequivocal in this regard. There may however be merit in targeted screening for persons with an intellectual disability, including Down Syndrome given the high rate/typically early age of onset of dementia in this population. The value of establishing a reliable baseline for these groups will be examined further by the Department of Health" (p. 20). • "The Health Service Executive will examine the issues arising regarding the assessment of those with Down Syndrome and other types of intellectual disability given the early age of onset of dementia for these groups and the value of establishing a reliable baseline" (p. 23). • "The availability of service providers trained in providing care to people with dementia, (including those with younger-onset dementia, sensory disability, intellectual disability, behaviours that challenge, and early onset dementia) is very important. It is critical that equity apply to service provision, and that the importance of enablement and reablement underpin decisions on the nature of service provided" (p. 25).
Israel	N/A
Italy (<i>unofficial translation</i>)	<p><i>Please note that Italy's national plan does not mention IDD, and Italy is not included in the 28 plans that talk about IDD and dementia. However, there has been a regional response to Italy's national plan in relation to IDD and dementia. The following information is supplemental to this research and was provided from a personal communication with T. Gomiero:</i></p> <p>The Dementia plan in this region was approved in May of 2015 so many services are still to be improved and implemented in the whole territory. However, there is not a specific plan for persons with ID and dementia, and in the national plan there is not a single word indicates persons with ID. They have worked together with the Alzheimer association in Italy and have obtained and will supply appropriate general information about dementia (this information includes specific training concerning people with ID and a focus on ageing in persons with Down syndrome).</p>

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Country	Reference to IDD and Dementia
Italy (<i>continued</i>)	When a person with ID is diagnosed with dementia using specific tools for an appropriate diagnosis (for which geriatricians in evaluation units were trained), they and their family will receive the same services as the general population. The offer of support at home will be the same, but there will be professional caregivers with specific training. If they live in a group home (max. 13 people) for people with ID, the services are the same (with alternatives, where necessary). There is a special care unit and there are plans for more of these in the rest of the country. These units also have access to the same health service, including palliative care, as the general population. Only if their health conditions are incompatible with the service provided are they placed in nursing homes. For the accommodation of people with ID during advanced dementia they are slowly training the staff throughout their territory.
Japan (<i>summary of plan</i>)	N/A
Republic of Korea (<i>from a presentation</i>)	N/A
Luxembourg (<i>unofficial translation</i>)	N/A
Malta	N/A
Mexico (<i>unofficial translation</i>)	N/A
Netherlands	N/A
Northern Ireland*	<ul style="list-style-type: none"> • "Risk factors which cannot be modified are...Learning Disability - the ageing process for people with learning disability begins much earlier. People with Down's syndrome have high rates of Alzheimer's type dementia" (point 3.5). • "Many people at risk of dementia are already receiving care and treatment for other conditions such as coronary heart disease, stroke, high blood pressure, diabetes, depression or learning disability. This contact provides an opportunity for health and care staff to promote healthy lifestyles and to pick up early signs of dementia. There are existing targets for GPs in relation to management of patients with these long term conditions" (point 3.11).

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Country	Reference to IDD and Dementia
Northern Ireland <i>(continued)</i>	<ul style="list-style-type: none"> • "People with existing disease which places them at risk of dementia - Primary care professionals will be alert to the increased risk of dementia for all patients on the cardiovascular, stroke, hypertension, diabetes, obesity, depression and learning disability registers" (point 3 action). • "The prevalence of dementia in people who have learning disabilities is estimated to be 4 times higher than the general population. People who have Down's Syndrome are particularly vulnerable to developing dementia and will develop the condition at a younger age (some in their thirties) and with a much higher and increasing prevalence as they age. Some Trusts have introduced screening programmes for dementia for people with Down's Syndrome" (point 8.45). • "Every single element of this strategy will also apply to people with a learning disability, in the context of awareness raising and training, identification and early intervention, the provision of information, the availability of advocacy, a full range of medical and other interventions, and the importance of multi-disciplinary, multi-agency working. All mainstream diagnostic and support services will be expected to make the necessary reasonable adjustments to enable access by people with learning disabilities and, as part of this requirement, will need to review the skills and competencies of staff within these services" (point 8.46). • "However, recognising that people with learning disabilities will already have an established connection and a history of support from learning disability services, these services should continue to take a lead role in the planning and coordination of support" (point 8.47). • "Trusts will ensure that people with a learning disability and dementia are supported by learning disability services, with access to the full range of specialist dementia services to meet individual needs. Specialist dementia diagnostic and support services will provide the necessary reasonable adjustments to enable full access by people with learning disabilities" (point 8 action).
Norway (Dementia Plan 2020)	<ul style="list-style-type: none"> • "Life expectancy for people with developmental disabilities has risen since the mid-1900s, which has resulted in a strong growth in the number of older people with developmental disabilities (Westergaard and Larsen 2004). Research has shown that people with these disabilities have a higher risk of developing dementia (Strydom et al. 2013). This will make additional demands on municipal services. The rehabilitation service, which is part of the specialist health services, plays an important role in the evaluation and diagnosis of people with developmental disabilities who develop symptoms of dementia. Evaluation in these cases is time-consuming, complex and requires special expertise.

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Country	Reference to IDD and Dementia
Norway (<i>continued</i>)	<p>It also requires close cooperation between those who know the person, the specialist undertaking the evaluation and the municipal health and care services" (p. 22).</p> <ul style="list-style-type: none"> • "Older people with developmental disabilities in addition to dementia are particularly vulnerable; other people with special needs are individuals with a Sami or minority language background and younger people with dementia" (p. 29).
Puerto Rico (<i>English summary</i>)	N/A
Scotland*	<p>"There are five particular challenges that we want to focus on here, where a different approach or approaches may be required to ensure that people are able to achieve the same standard of outcome as others with dementia who are seen as more 'mainstream' [...] Learning disabilities: People with learning disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age. Life expectancy of people with Down's syndrome has increased significantly and the incidence and prevalence of Down's syndrome is not decreasing" (p. 20).</p>
Slovenia (<i>translation unavailable</i>)	N/A
Switzerland (<i>unofficial translation</i>)	<p>"In people with an intellectual deficiency, pathologies of dementia appear much earlier than in the general population. In people with Down syndrome, also called 'trisomy 21', the disease occurs at a particularly early stage (see Deutsche Alzheimer Gesellschaft [DAIzG], 2011)" (p. 9).</p>
Taiwan	N/A
USA	<ul style="list-style-type: none"> • "Oregon Dementia Training for Alzheimer's Disease and Related Dementias Staff. With funding from an ACL Alzheimer's Disease Supportive Services Program (ADSSP) grant, Oregon was able to provide dementia training for over 600 statewide Aging and Disability Resource Center (ADRC) Information and Assistance and Options Counseling staff. Nine online modules were developed to address ADRC staff roles in addressing issues including person-centered care for people with dementia, communication, information and referral options, decision support for people and families, care transitions, advance planning, and specific needs for people with intellectual and developmental disabilities (IDD). The training is part of Oregon's efforts to increase dementia-capability of its ADRC system and statewide LTSS" (p. 19).

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Country	Reference to IDD and Dementia
USA (<i>continued</i>)	<ul style="list-style-type: none"> • Strengthen State Aging, Public Health, and Intellectual and Developmental Disability Workforces. HHS will coordinate with states to develop workforces in aging, public health, and IDD that are AD/ ADRD-capable and culturally-competent. ACL collaborated with HRSA to provide AD/ADRD training to the Aging Network. One example is the New Jersey GEC, which provided a series of trainings to the Aging Services Network in August/September 2015. Over 2,100 health professionals and caregivers from the Area Agencies on Aging (AAAs) participated in the trainings. In addition, HRSA GWEP awardees are collaborating with 26 AAAs and 13 Quality Improvement Organizations (QIOs) to strengthen state aging, public health, and IDD workforces" (p. 20/21).
Wales*	<ul style="list-style-type: none"> • "Anyone in society can be affected with dementia, irrespective of gender, ethnicity or class. It can affect adults of working age as well as older adults, and people with learning disabilities are a group particularly at risk" (pg. 7). • "The Alzheimer's Disease Society reports that [...] Learning Disability: Studies have reported increased rates of dementia in people with Downs syndrome" (pg. 7).

*The plans for England, Wales, Scotland and Northern Ireland, while regarded as national plans in this document, are generally considered by Alzheimer's Disease International to be sub-national plans.

Sub-national Dementia Plans

This review is based on sub-national plans available as of 1 May 2016 in English or translations into English.

Key word search: intellectual; developmental

Region	Reference to ID and Dementia
Australia, New South Wales	<ul style="list-style-type: none"> • "It addresses the needs and experiences of specific population groups in accessing quality dementia care. This includes people from culturally and linguistically diverse backgrounds (CALD), Aboriginal people, people living in rural and remote communities, people with younger onset dementia (YOD), people with intellectual disability, who identify as either gay men, lesbian, bisexual, transgender or intersex (GLBTI), or in correctional centres" (p. 9). • "Regular assessments of people with intellectual disability within disability services provide an opportunity to identify any functional or behavioural decline and provide a prompt for further investigation. Ideally, diagnosis is based on a comprehensive physical, medical, neurological and cognitive assessment with measures of deterioration over time. There are a number of tools available such as the Adaptive Behaviour Dementia Questionnaire (ABDQ)" (p. 18). • "The Framework details dementia care in a service pathway from dementia awareness to palliative care. It addresses the needs of people living with dementia and their carers. It also addresses access to quality dementia care for specific population groups comprising people from CALD backgrounds, Aboriginal people, people living in rural and remote communities, people with YOD, and people with an intellectual disability, who identify as GLBTI, or are in correctional centres. It recognises that there are key enablers that span the services pathway" (p. 26).
Australia, Queensland	N/A
Australia, South Australia	N/A

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Region	Reference to ID and Dementia
Australia, Victoria	<ul style="list-style-type: none"> • "Planning for diversity: meets the expectation that department-funded programs should provide a flexible response for individual and diverse needs and preferences, including those of people of diverse backgrounds, such as Aboriginal and CALD communities; people with intellectual disabilities; people who identify as gay, lesbian, bisexual, transgender or intersex; and younger people with dementia" (p. 41). • Older people are not an homogenous group. Needs and preferences for support and services may vary among people from diverse backgrounds, for example, Aboriginal and CALD communities; people with intellectual disabilities; people who identify as gay, lesbian, bisexual, transgender or intersex (GLBTI); and younger people with dementia" (p. 41).
Germany, Bavaria (unofficial translation)	"This is where the long-term care staff, especially §§ 45a-d SGB XI [Social Security Code for people who are in need of general supervision and care in addition to basic and domestic care], have the objective to improve patient care for people with dementia, mental illness and intellectual disabilities with considerable general care requirements and so allow a longer stay in their own family life" (p. 42).
Germany, Saarland (unofficial translation)	N/A
Switzerland, Canton of Vaud (translation not available)	
USA, Alabama	N/A
USA, Alaska	"Cross-train providers who serve people with Intellectual and Developmental Disabilities, mental health disorders or Traumatic Brain Injury to prepare for these populations aging with increased risk factors for ADRD" (p. 34).
USA, Arizona	"Coordinate and conduct Alzheimer's disease and related disorders training within all of the AZ Links Regional Partnerships, focusing on the developmental disabilities support system and centers for independent living statewide" (p. 24).

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Region	Reference to ID and Dementia
USA, Arkansas	N/A
USA, California	N/A
USA, California-San Francisco	"Examples of existing residential care settings follow, each of which could be modified for dementia care: Adult Residential Facilities for Persons with Special Needs developed to address the needs of persons with developmental disabilities" (p. 67).
USA, Connecticut	N/A
USA, Colorado	N/A
USA, Delaware	"Develop strategies to train professionals who provide services to persons with mental illness and developmental disabilities to recognize and address Alzheimer's disease within their consumer populations" (p. 13).
USA, District of Columbia	N/A
USA, Florida	N/A
USA, Georgia	<ul style="list-style-type: none"> "Little is known about people with intellectual and developmental disabilities (IDD), and there has been little effort across states to develop specific policies related to people with developmental disabilities. From existing research, it appears as if most individuals with IDD experience dementia rates similar to older adults in the general population. However, some adults with intellectual disabilities are at higher risk for dementia – adults with Down syndrome are particularly susceptible. Recent studies for adults with Down syndrome show that 10-25% of individuals ages 40-49, 20-50% of individuals, ages 50-59, and 60-75% of individuals with Down syndrome older than age 60 have Alzheimer's disease (Alvarez, 2008). As people with intellectual and developmental disabilities continue to age more successfully and live longer, the numbers with Alzheimer's disease and other dementias will continue to increase. Currently, there are no state policies regarding people with intellectual and developmental disabilities and Alzheimer's disease or other dementias" (p. 16).

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Region	Reference to ID and Dementia
USA, Georgia (<i>continued</i>)	<ul style="list-style-type: none"> • "As noted in the ARGEC's most recent report, special dementia-related training topics include: Training on the unique needs of medically underserved and special populations, including racial and ethnic minorities and individuals with intellectual disabilities; and the impact of AD and cognitive impairment on mobility and driving to include dangers and public health information regarding older drivers, impact on individuals health, and effects of loss of executive function on driving among AD patients" (p. 27). • "Develop a plan for high-risk populations such as persons with mental illness and developmental disabilities to be screened for dementia and, when diagnosed, to have the diagnosis routinely recorded in medical records" (p. 41). • "Require that all State contracts providing services to older adults, including those with developmental disabilities and/or mental illness and comorbid dementia, include quality measures specific to dementia-capable care" (p. 42). • "Develop and implement an evidence-based training curriculum and implementation strategies for targeted audiences (e.g., Department of Behavioral Health and Developmental Disabilities, Office of the State Inspector General, Georgia Bureau of Investigation)" (p. 44). • "Identify best practices for the care of persons with serious mental illness (SMI) and developmental disabilities and comorbid dementia" (p. 47). • "Develop a marketing and media plan with a message that helps reduce stigma and fear related to dementia. Include the developmental disability community in the target population. Determine branding and implement the plan statewide" (p. 55). • "Promote advance care planning and advance financial planning to care partners, families, and individuals with dementia in the early stages before function declines. This population includes those with younger-onset Alzheimer's and developmental disabilities" (p. 55).
USA, Hawaii (<i>unable to access</i>)	
USA, Idaho	N/A
USA, Illinois (<i>updated</i>)	N/A

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Region	Reference to ID and Dementia
USA, Indiana	"Improve care for populations disproportionately affected by AD and facing care challenges, such as racial and ethnic minorities, people with intellectual disabilities, and people with younger-onset AD" (p. 32).
USA, Iowa	N/A
USA, Kentucky	N/A
USA, Louisiana	N/A
USA, Maine	"Outreach should also serve to increase awareness of the prevalence of those living with Alzheimer's who also have other special needs or disabilities, including those with intellectual disabilities (FMI: http://www.aaid.org/index.cfm). The U.S. Dept. of Health & Human Services intends to convene one or more groups of experts, both within and outside of the government, to take steps to address the unique challenges faced by people with younger-onset Alzheimer's disease, racial and ethnic minorities, and people with Down syndrome and other intellectual disabilities" (p. 18).
USA, Maryland	N/A
USA, Massachusetts	"Develop strategies to train professionals working with consumers with mental illness and developmental disabilities to recognize and address Alzheimer's within their consumer populations" (p. 18).
USA, Michigan	N/A
USA, Minnesota	N/A
USA, Mississippi	N/A
USA, Missouri	N/A
USA, Nebraska	N/A

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Region	Reference to ID and Dementia
USA, New Jersey	<ul style="list-style-type: none"> • "Strategy: Partner with the Alzheimer's Association; Alzheimer's NJ; NJ Department of Human Services (Divisions of Aging Services, Medical Assistance and Health Services, Disability Services, and Developmental Disabilities); NJ Department of Health; NJ Hospital Association; Home Care Association of NJ; LeadingAge; NJ Adult Day Services Association, and all other relevant entities" (p. 52). • "Strategy: Develop strategies to train professionals who provide services to persons with mental illness and developmental disabilities to recognize and address Alzheimer's disease with their consumer populations" (p. 55).
USA, New Mexico	N/A
USA, New York (<i>updated</i>)	<ul style="list-style-type: none"> • L-4.1: DOH should work with The Office of People With Development Disabilities (OPWDD) to promote research on the connection between Down syndrome and AD in NYS research institutes. • L-4.2: DOH and partners should train professionals and paraprofessionals that work with individuals with developmental disabilities to be aware of the connection between Down syndrome and AD and to identify indicators of AD. • L-4.3: DOH and partners should encourage families and caregivers of individuals with Down syndrome who suspect memory problems to communicate this concern to the individual's health care provider. • L-4.4: Families of individuals with intellectual and developmental disabilities should be encouraged to engage in early planning regarding AD (p. 29).
USA, Nevada	N/A
USA, North Carolina	<ul style="list-style-type: none"> • "Several populations are disproportionately affected by Alzheimer's disease and related dementia, including people with intellectual and/or developmental disabilities (particularly those with Down's syndrome) and a number of minority populations" (p. 16). • "Resources for underserved populations including individuals with intellectual/developmental disabilities, minority populations, homeless, and rural communities" (p. 34). • "Incorporating specific tools for early detection in all populations, including individuals with limited English proficiency and those with intellectual or developmental disabilities" (p. 37). • "Ensuring access to appropriate care settings and long-term services and supports for all populations, including individuals with intellectual/developmental disabilities and/or mental illness" (p. 53).

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Region	Reference to ID and Dementia
USA, North Dakota	N/A
USA, Oklahoma (<i>updated</i>)	N/A
USA, Oregon	N/A
USA, Pennsylvania	"Increase research to improve treatment of Alzheimer's for individuals with intellectual and developmental disorders" (p. 76).
USA, Rhode Island	"In July 2012, the University of Rhode Island was awarded a 3-year \$14 million grant by the Centers for Medicare & Medicaid Services (CMS) to provide comprehensive chronic care management and preventive care for intellectually and developmentally challenged adults and/or individuals with Alzheimer's disease / dementia – with two or more chronic conditions who receive Medicare and Medicaid benefits" (p. 115).
USA, South Carolina	N/A
USA, Tennessee	"Develop and implement evidence-based training for targeted audiences such as the Tennessee Department of Mental Health and Developmental Disabilities" (p. 27).
USA, Texas	N/A
USA, Utah	N/A
USA, Vermont	<ul style="list-style-type: none"> "Until recently, people with developmental disabilities often died at a fairly young age. Now, as a result of improved medical care and better living conditions, people with developmental disabilities are living longer and, like the general population of older adults, are at increased risk of developing dementia. The prevalence of Alzheimer's disease among adults with Down's syndrome is about 25% for those who are 40 years of age and older and about 65% for those who are 60 years of age and older. Due to their genetic makeup, people with Down's syndrome are especially vulnerable to developing Alzheimer's disease and onset of symptoms begins some 20 years earlier than in the general population.

IDD AND DEMENTIA IN NATIONAL AND SUB-NATIONAL DEMENTIA PLANS

Region	Reference to ID and Dementia
USA, Vermont (<i>continued</i>)	<p>Among people with developmental disabilities other than Down’s syndrome, the prevalence, age of onset and causes of dementia are similar to that of the general population" (p. 4).</p> <ul style="list-style-type: none"> • "A person with a developmental disability and dementia may be eligible for home and community-based services which are coordinated through Vermont’s community mental health centers. Home and community-based services are individualized and may include service coordination, home supports, respite, community supports, employment services, crisis services, clinical interventions and transportation. In particular, home supports provide supports and supervision to people in and around their residences. Minimally, this may include hourly support in the person own home or that of a family member, or 24 hour support in a shared living home (with a contracted home provider) or a staffed or group living arrangement" (p. 11/12). • "Activity: Explore models for developing the infrastructure to care for people with dementia in collaboration with specialists and primary care providers. For example, regional organizations designated as dementia care networks could include designated mental health and developmental service agencies, HHAs, AAAs, adult day centers or other regional dementia care providers" (p. 29).
USA, Virginia	N/A
USA, Washington	<ul style="list-style-type: none"> • "Develop supports for family caregivers who are employed, caring for people with developmental disabilities and dementia, and those living with younger onset dementia" (p. 4). • "Educate professionals working with families of people with younger-onset Alzheimer’s, including those in the developmental disabilities system, about the special challenges, issues and resources available for support" (p. 51). • "Provide education and supports for older family caregivers who provide primary care for their adult children or siblings with developmental disabilities and dementia (p. 51).
USA, West Virginia	N/A
USA, Wisconsin	N/A

Project Examples Concerning IDD and Dementia

The following are examples of projects related to IDD and dementia.

In Italy, when people with ID are diagnosed with dementia, they will be provided with the same services in place for the general population. The offer of support at home will also be the same for persons with ID diagnosed with dementia, however there will be professional caregivers with specific training. If they live in a group home (a maximum of 13 people) for people with ID, the type of services are the same. Additionally, there is a special care unit and there are plans to introduce more of these facilities in Italy. These units also have access at the same health service, including palliative care, as the general population. Furthermore, only if their health conditions are incompatible with the services provided are persons with ID placed in nursing homes. For the accommodation of people with ID during advanced dementia, Italy is slowly training their staff throughout their territory.¹

Rhode Island has developed their *Living Rlte* programme. Here is an excerpt from their state plan describing the programme:

“In July 2012, the University of Rhode Island was awarded a 3-year \$14 million grant by the Centers for Medicare & Medicaid Services (CMS) to provide comprehensive chronic care management and preventive care for intellectually and developmentally challenged adults and/or individuals with Alzheimer’s disease or a related disorder – with two or more chronic conditions who receive Medicare and Medicaid benefits. The project, entitled *Living Rlte- A Disruptive Solution for Management of Chronic Care Disease*, is part of CMS’s Healthcare Innovation Challenge, a highly competitive initiative that seeks to identify and support innovative opportunities to improve care delivery and achieve its three-part aim of ‘improving the individual experience of care, improving the health of populations, and reducing the per capita costs of care for populations’. The *Living Rlte* initiative’s goal is to deliver seamless and comprehensive care in an efficient manner, improving the health, well-being and employment opportunities for its target population, and at the same time lowering costs for both the Medicare and Medicaid programs. All patients are enrolled in an electronic health record system which allows all of their individual interdisciplinary team members to access and share information. Members include not only traditional health providers but also two new community health workers who are people with disabilities, a Developmental Disability peer specialist and a *Living Rite* Life Coach. The first services offered to each of the enrollees are prescription medication reconciliation and a complete physical exam with state of the art accessible equipment. Within two weeks of enrollment participants are also given assessments, which include but are not limited to, health, employment, quality of life and a test for severe impairment. Assessment results assist the client in setting realistic goals that will have a positive impact on their potential to pursue the least restrictive lifestyle possible. Furthermore,

¹ T. Gomiero, personal communication, October 11, 2016

individual care plans for participants are then developed and managed based upon assessment results. As the Centers head into the second year of the grant, they will be conducting targeted outreach to Alzheimer's disease day center clients and providing healthy lifestyle and behavior modification services to the developmentally disabled clients that will assist them in better managing their chronic conditions. Future work on the State Plan recommendations will need to incorporate the best practices and lessons learned from this ongoing project" (p. 33-34).²

To find out more about this topic, see the *IDD and Dementia* report prepared by RTI International for the United States Administration for Community Living.³

² Miller, K. *Rhode Island's state plan on Alzheimer's disease and related disorders*. Retrieved from http://act.alz.org/site/DocServer/RI_State_Plan_Sept_2013_.pdf/931185879?docID=26222

³ Gordon, K., McGinn-Shapiro, M., Gould, E., Shuman, S.B., Wiener, J.M. (2015). *IDD and dementia*. Retrieved from http://www.aoa.acl.gov/aoa_programs/hpw/alz_grants/docs/idd-and-dementia.pdf