International Summit on Intellectual Disability and Dementia

Glasgow, Scotland – October 13-14, 2016

Report of the Summit Working Group on Nomenclature and Dementia & Intellectual Disability

Matthew P. Janicki, Philip McCallion, Michael Splaine, Flavia H. dos Santos, Seth Keller, & Karen Watchman

**Question:** How might we harmonize and standardize the terminology used in research papers, practice guidance and policy documents when referring to dementia and people with intellectual disability/Down syndrome?

**Premise**

We propose that two critical issues be addressed: Agreement on a common terminology related to cognitive impairment related to dementia among persons with intellectual disability and recommendations for standardization of terminology within studies and reports on dementia and intellectual disability

**Area #1 Rationale for Common Terminology**

As noted in sourced definitions, nomenclature is a system of names or terms, or the rules for forming these terms in a particular field of arts or sciences. It is recognized that the principles of naming vary from the relatively informal conventions of everyday speech to the internationally agreed

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1 This report was developed as an output from the 2016 International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland, 13-14 October 2016, and hosted by the University of Stirling and University of the West of Scotland, funded by the RS MacDonald Trust, the Scottish Government, and Alzheimer Scotland. Collaborating sponsors included the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States and the University of Illinois at Chicago. The Summit was composed of individuals and representatives of many international and national organizations with a stake in issues related to adults with intellectual disability affected by dementia. The contents of this report were partially developed under a grant from the United States Department of Health and Human Services, Administration for Community Living (ACL), National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant # 90RT5020-03-00. However, those contents do not necessarily represent the policy of the US Department of Health and Human Services, nor the endorsement by the US federal government. The opinions expressed represent those of the Summit participants and of the NTG.
principles, rules, and recommendations that govern the formation and use of the specialist terms used in scientific and other disciplines. The use of names connects nomenclature to theoretical linguistics, while the way humans mentally structure the world in relation to word meanings and experience relates to the philosophy of language. Together they encourage consistency in applications and this equally applies to expressions of neuropathologies such as dementia, particularly consistency in terms with respect to clinical treatment and diagnostics. Such consistency in taxonomy, by defining and adopting precise and equivalent criteria, also facilitates scientific replication, raises the need for cross-cultural studies, and is the basis for refining prevalence studies. The selection and definition of terms should also be designed to avoid stigma and misunderstanding when speaking about or with persons affected by dementia, whether ‘patients’ or family members.

Reviews of publications (whether journal articles, book chapters, or reports and plans) involving intellectual disability show mixed uses of terms that generally relate to dementia or the diseases associated with it (see Appendix C). Terms in use (including dementia, Alzheimer’s, and other like descriptors) lack precision or consistency when applied inappropriately. Some of this may be attributed to a lack of understanding of the distinction in the terms, the nuances involved with neuropathologies, or inconsistent use of language as well as absence of or inconsistency in an agreed upon core group of methods used in diagnosis. However, in the intellectual disability field this lack of precision in language in and of itself affects the understanding of the condition under discussion and confusion is further increased by a lack of agreement on common terminology.

This lack of precision is not solely found in the intellectual disability field, as witnessed by recent efforts in the mainstream Alzheimer’s and dementia field to address the same issue. The concern over coherency and lack of agreement on terminology was recently discussed in a presentation on nomenclature at the Alzheimer’s Disease-Related Dementias 2016 Summit, held under the auspice of the National Institutes of Health in the United States.

Taylor in a presentation at the Summit noted a range of terms that are used within the field:

Age-associated memory loss, mild cognitive impairment, minor neurocognitive impairment, dementia, memory disorder, major neurocognitive impairment (DSM-5), Alzheimer’s disease, dementia due to Alzheimer’s disease, Dementia with Lewy bodies, Lewy body dementias, Lewy body disease, Lewy body disorders, frontotemporal dementia, degeneration, behavioral variant FTD, Pick’s disease, primary progressive aphasia, progressive supranuclear palsy, corticobasal syndrome, FTD/MND, FTD/ALS, vascular dementia, vascular contributions to cognitive, impairment and dementia, mixed dementia, mixed etiology dementia.

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Taylor’s presentation stimulated a dialogue on dementia-related nomenclature addressing: (1) dementia in general, regardless of the etiology, (2) specific clinical syndromes, and (3) underlying etiologies. The identified problems with inconsistency in terminology included: (1) Alzheimer’s disease is synonymous with dementia, (2) low public awareness of other forms of dementia, and (3) lack of recognition that ‘Alzheimer’s disease’ services are also for those affected by non-Alzheimer’s dementias. The presentation noted that diagnosing, treating, and educating persons affected by dementia is often based on judgements of cognitive status (i.e. normal, MCI, dementia), clinical syndrome, and suspected underlying pathology (with or without biomarkers) – factors whose need for precision is affected by how the condition diagnosed is explained, understood, treated, and followed. The presentation at the Summit called for greater sensitivity in differentiation between etiology and clinical syndrome and differentiation between disease stages (i.e., preclinical, prodromal, and symptomatic).

Nomenclature has also been discussed at meetings of the U.S. National Advisory Council on Alzheimer’s Research, Care and Services, which under federal legislation (the National Alzheimer’s Project Act; NAPA)⁶ is responsible for the National Plan to Address Alzheimer’s Disease in the United States. In a presentation by Dr. Ron Petersen, the chair of the Council, it was noted that additional ‘confusion’ was introduced by the new DSM-5 characterizations of ‘mild neurocognitive disorder’ (MCI) and ‘major neurocognitive disorder’ (dementia).⁷,⁸ While this dichotomy has organized the syndrome into a symptom-based manner, it has also introduced controversy as it has caused a loss of ‘condition recognition’ in the eyes of the public and among practitioners – i.e., when a commonly recognizable general term has been replaced by a diagnostic and clinical one. Another concern raised is the possibility that when an adult is diagnosed with “minor neurocognitive disorder due to Alzheimer’s disease”, he or she may assume it is a minor situation, not of concern, and the diagnosis will not raise recognition of the seriousness of the diagnosis in terms of disease progression and will not support compliance with treatment, taking prescribed medications to slow progression, beginning involvement with constructing a will and assigning a power of attorney, and obtaining an advance directive.⁹

Given the concerns raised, recommendation #4 by the public members of the National Advisory Council on Alzheimer’s Research, Care and Services, in the 2016 US National Plan Update¹⁰, states that “Emphasis should be given to the standardization of terminology in dealing with cognitive and dementing disorders.” Further, the Update recommends that “an integrated conference should be convened to develop consistent language for cognitive disorders among scientists, care providers and the public... [and there is a need to] engage all of the stakeholders around these issues to reach a

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consensus for the benefit of persons with dementia, their family members and caregivers, and the scientific and service communities.\textsuperscript{11}

Language can and does shape and form our perceptions of a condition or situation. As noted by Alzheimer’s Europe, “Some words and metaphors are used liberally and paint a very biased picture of dementia, whilst others are avoided and considered demeaning, depersonalizing, and insulting. Even standard medical terms are sometimes used with great caution due to an awareness of the possible impact on people’s lives and wellbeing. Words clearly matter. They describe, communicate and reinforce our current perceptions of dementia.”\textsuperscript{12} Language usage and terminology is germane to how people affected by dementia are viewed and to what extent the terms used minimize stigma.\textsuperscript{13} Clearly, ‘people-first’ language [i.e., adults with dementia] creates positive imagery and can go far to minimize negative perceptions.

Another aspect is the ease with which the general population grasps the concept behind the disease or neuropathology – so avoiding ‘high science language’ in documents directed toward general readership audiences can facilitate understanding. Using terms and definitions that are in common usage can help to ensure the communication of messages. Conversely, creating definitions that minimize the course and eventuality of brain changes leading to dementia can leave conditions untreated.

Communicating the definition and process of dementia to people with intellectual disability creates a further conundrum. To enable understanding, language and phrasing needs to be at a word-level that persons communicating with self-advocates or adults affected by dementia can effectively convey concepts associated with dementia.\textsuperscript{14,15} Further, the concepts need to be communicated in a manner so as to convey the seriousness of the condition, while not creating confusion or undue anxiety. To examine the degree of concept conveyance through the level of language used, Appendix A also reports both the reading ease and grade level of definitions conveyed by different organizations. Of the 16 definitions extracted from organization websites and documents, the reading ease level ranged from


\textsuperscript{14} See ‘What is dementia’ [Edinburgh, Scotland: Down’s syndrome Scotland; n.d.], a booklet designed to explain dementia to persons with intellectual disability, where dementia is defined as “an illness of the brain; it affects many things, but mostly the way people remember and do things.”

\textsuperscript{15} Even among Down syndrome advocacy organizations, the definitions and explanations of dementia (or Alzheimer’s disease) used tend toward complexity – see Appendix D. However, when materials are developed for people with intellectual disability, more simple concepts are used. An example of a simple language definition is found in the Down’s syndrome Scotland publication, What is dementia? A booklet about dementia for adults who have a learning disability. It reads “Dementia is an illness in the brain. It affects many things, but mostly the way people remember and do things.” [See: http://aadmd.org/sites/default/files/whatisdementiabooklet.pdf].
60.70 to 0.0 (X = 26.68) and the grade level ranged from 7.8 to 18.6 (X = 13.84). In general, the higher the reading ease score, the more generally understandable wording is. With respect to the grade level, lower scores correspond with low grade level reading abilities. It appears that most of the definitions in Appendix A encompass complex concepts, even when directed at the general public. Those definitions directed toward professionals are clearly in the realm of technical language.

However, the purpose of this report is not to quibble with perspectives on wording usage in the general dementia field, or to be overly influenced by U.S. or general dementia population deliberations. The focus of this report is to further highlight the need to examine how terms related to dementia are used in the intellectual disability field and propose how we may introduce more clarity and precision.

While it was not the function of the topic working group to standardize a definition of ‘dementia’, we recognized that its primary features are characterized by the progressive loss of brain function that occurs with certain neuropathological diseases or trauma, often associated with aging. The expression of the resultant behavioral changes includes marked memory disorders, personality and behavioral changes, and impaired reasoning. In addition, we recognized that dementia-like behavioral dysfunctions also can be associated with adverse drug reactions, depression, psychological trauma, and a range of other causes with their defining feature a clearing/reduction of symptoms upon treatment. Subordinate terms in the field tend to offer further uncertainty.

The intent of this report is not to rectify inconsistencies in dementia-association language usage across the general field of dementia, but to promote the understanding of the distinctions among the terms in prevalent usage, and advance the application of precise usage and agreement on dementia related terms that are commonly used in association with intellectual disability. Such a result would advance clearer differentiation and appropriate usage among clinical terms such as: dementia, Alzheimer’s disease, cognitive impairment, Alzheimer’s disease spectrum, pre-clinical Alzheimer’s disease, dementia due to Alzheimer’s disease, mild cognitive impairment due to Alzheimer’s disease, early versus late onset disease, and mild, moderate and advanced dementia (Alzheimer’s disease), and others. We are not proposing a standard definition of dementia or the acceptance of range of associated terms to apply to work in intellectual disability – no such consensus on terms exists in the general dementia literature or documents (save for those that appear in the DSM-5 or ICD-10 for diagnostic purposes) – but are suggesting that writers do provide an operational definition of their choosing so as to offer readers a clear understanding of the variable and notions related to the population being described.

A number of English-language international and national organization’s resources contain attempts at defining dementia – See Appendix A. It is evident that these definitions vary in their conceptualization, as these sources variously describe dementia as a collective name, condition, disease, general term, illness, symptoms, and syndrome. These definitions are ones that are readily accessible to

\[\text{\textsuperscript{16}}\] The Flesch Reading Ease scores and the Flesch-Kincaid Grade Level scores, analytic instruments that are embedded within Microsoft Word, were used to determine both the reading ease score and grade level score for each definition cited in Appendix A.

the general public and workers in the field. It is clear that core themes of dysfunction run through these, even if different means are used to describe them. General descriptors are prevalent among websites that appeal to social care workers and caregivers. Much of the focus in the general descriptions note behavioral changes mostly associated with Alzheimer’s disease; some of the sites do offer nuanced information referring to other forms of dementia. More precise descriptors are prevalent in sources that address assessment and diagnostics, and sources devoted to specific neuropathologies resulting in dementia (such as frontotemporal, vascular, Lewy body, Parkinsonian) offer more precision with diagnosing the dementia covered.

Appendix B contains a listing of variations of the common dementia-related terms drawn from the literature with relevance to intellectual disability, and provides a sampling of definitions (albeit not definitive – as the general dementia field has itself not arrived at a consensus on common definitions). This taxonomy is intended to illustrate the variations used to describe similar phenomenon and to help differentiate the meanings of the terms and aid writers with appropriate usage with the construction of organic, functional, and operational definitions. It also addresses the range of dementia-related social care terminology prevalent in the field and used in varying degrees in the intellectual disability literature.

Thus, as part of this Summit report we recommend reviewing the taxonomy provided in Appendix B of terms typically found in dementia reports and documents, and suggest that it be used as a resource for researchers, agency personal, carers, and others who need to understand and use more precise terminology.

#2 Standardization in Reporting

Usage of terms can affect clarity in understanding which subject population is being referenced and what conditions are being discussed. In an unscientific sampling of articles and reports related to intellectual disability and dementia found in the literature, term usage was found to be variable and at times less than clear (see Appendix C). Authors in general used ‘dementia’ as a common term defining the nature of the condition being discussed in their article or report. However, there was often mixed reference to Alzheimer’s disease, dementia of the Alzheimer’s type, and generic ‘dementia’ without linkage to standard definitions (such as those in the ICD-10 and DSM-5). While the usage served the intended purpose — of defining the general concern of the article — it left open interpretations of how the condition was identified in the subjects, to what degree it was progressing, and what may have been the underlying neuropathology. While in general most of these data may not always be readily available in social care research, it should be in medical research and in articles advancing or relying upon standardized assessment.

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18 Operational definitions define concepts and labels by the way they are measured and offer precision in explaining a concept.
Noted was the high preponderance of articles in the intellectual disability and dementia literature that focused predominantly on Down syndrome. Given the high risk for Alzheimer’s disease among adults with Down syndrome this is not unexpected. However, it is important that

- Authors are clear in reporting results and generalizing effects that the information provided relates to dementia in adults with Down syndrome.
- In other articles and reports the number or percentage of subjects with Down syndrome be identified within their study populations of adults with intellectual disability.
- As most studies involving adults with Down syndrome relate to dementia of the Alzheimer’s type, this should be noted in the subject descriptions, and/or any variations in forms of dementia should also be noted.
- Subject recruitment documents contain concise definitions of dementia.

As seen in Appendix C most articles related to intellectual disability and dementia reporting clinical or medical research are more apt to provide a definition of dementia or related terms, while social care articles tend to only use the term, but not define it or provide substantiation of study subject diagnoses. It would be helpful if social care articles also provided definitions and the basis for ascribing dementia to the persons in the studies offering more precision and permitting cross-article comparisons and contrasts.

A further concern is that often many of the articles examined failed to define the subject population with respect to age, sex, level of intellectual disability, etiology, and other demographic variables. When definition of subject populations in articles on dementia and intellectual disability is absent or loose, this impedes adding substance to the literature.

We are not proposing wording for a standard definition of dementia or the adherence to the range of associated terms that apply to work in intellectual disability – no such consensus terms exist in the general dementia literature or documents (with the exception of the DSM-5 or ICD-10 diagnostic definitions – as noted in Appendix A) – but are suggesting that writers provide an operational definition of their choosing of the condition being considered, and ancillary demographic and clinical data so as to offer readers a clear understanding of the population being described and encourage replication and permit comparisons across studies on common factors. We also suggest that reports stemming from studies undertaken by the authors contain information about how diagnoses were obtained as well as the protocols employed. This should include reporting the instruments used and the criteria for the diagnosis of dementia.

We recommend movement toward the standardization of language and terms involved in work related to dementia and intellectual disability. Such standardization would require a guidance document on how to accurately define and present information about the individuals or group being referenced. The document should include both formal diagnostic criteria and general definitions of the various dementias. We recommend that such a guidance document be developed, be supported by a consortium of associated intellectual disability and gerontology groups, and appear in a relevant publication (for archival purposes).
Therefore, it is also our recommendation that such an archived guidance document be created and adopted and that from then forward reports addressing neuropathologies or cognitive decline or impairment utilize the recommended definitions and at a minimum include the subjects’ ages, sex, level of intellectual disability, residential situation, basis for dementia diagnosis, presence of Down syndrome, years from diagnosis, and if available, scores on an objective measure of changing function that is a recognized and validated dementia scale.

Suggested citation:

Report filed - 2016

Note: This report is in the public domain. Use is encouraged, but with attribution. A companion Summit Statement on Nomenclature and Dementia and Intellectual Disability is available at http://www.learningdisabilityanddementia.org/id-dementia-summit.html and www.aadmd.org/ntg/summit.
### Appendix A: Sampling of definitions of ‘dementia’ by international and national organizations

<table>
<thead>
<tr>
<th>Organization</th>
<th>Source</th>
<th>FRE/F-KGL</th>
<th>Definition of Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Associations (USA)</td>
<td><a href="http://www.alz.org/dementia/types-of-dementia.asp">http://www.alz.org/dementia/types-of-dementia.asp</a></td>
<td>52.0/9.5</td>
<td>Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain.</td>
</tr>
<tr>
<td>Alzheimer’s Disease International (INT)</td>
<td><a href="https://www.alz.co.uk/about-dementia">https://www.alz.co.uk/about-dementia</a></td>
<td>29.1/14.1</td>
<td>Dementia is a collective name for progressive degenerative brain syndromes which affect memory, thinking, behaviour and emotion. Symptoms may include: loss of memory, difficulty in finding the right words or understanding what people are saying, difficulty in performing previously routine tasks, and personality and mood changes. Dementia knows no social, economic, ethnic or geographical boundaries. Although each person will experience dementia in their own way, eventually those affected are unable to care for themselves and need help with all aspects of daily life. There is currently no cure for most types of dementia, but treatments, advice, and support are available.</td>
</tr>
<tr>
<td>Alzheimer’s Europe (INT)</td>
<td><a href="http://www.alzheimereurope.org/Glossary/dementia">http://www.alzheimereurope.org/Glossary/dementia</a></td>
<td>29.1/16.8</td>
<td>“Dementia” is a syndrome (i.e. a pattern of symptoms) and typically involves loss of memory, mood changes and problems with thinking, orientation, comprehension, calculation, learning capacity, language and judgement. It is the umbrella term used to describe the symptoms that occur when the brain is damaged as a result of one or more diseases or conditions, resulting in memory and intellectual impairments which are sufficiently severe as to interfere with daily life. There are over 100 different diseases or conditions which can lead to dementia, the most common being Alzheimer’s disease and a series of strokes. The underlying cause is often referred to when describing the form of dementia; although a person may actually be affected by more than one type of dementia.</td>
</tr>
<tr>
<td>Alzheimer’s Foundation of America (USA)</td>
<td><a href="http://www.alzfdn.org/AboutDementia/definition.html">http://www.alzfdn.org/AboutDementia/definition.html</a></td>
<td>32.0/17.9</td>
<td>Dementia is a general term that describes a group of symptoms—such as loss of memory, judgment, language, complex motor skills, and other intellectual function—caused by the permanent damage or death of the brain’s nerve cells, or neurons.</td>
</tr>
<tr>
<td>Alzheimer Scotland (SCT)</td>
<td><a href="http://www.alzscot.org/information_and_resources/about_dementia">http://www.alzscot.org/information_and_resources/about_dementia</a></td>
<td>40.5/14.0</td>
<td>Dementia is an illness that affects the brain, making it harder to remember things or think as clearly as before. Dementia can affect every area of human thinking, feeling and behavior, but each person with dementia is different—how the illness affects someone depends on which area of their brain is damaged.</td>
</tr>
<tr>
<td>Alzheimer’s Society (CAN)</td>
<td><a href="http://www.alzheimer.ca/en/About-dementia/What-is-dementia">http://www.alzheimer.ca/en/About-dementia/What-is-dementia</a></td>
<td>28.5/13.3</td>
<td>Dementia is an overall term for a set of symptoms that are caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person’s ability to perform everyday activities. A person with dementia may also experience changes in mood or behaviour. Dementia is progressive, which means the symptoms will gradually get worse as more brain cells become damaged and eventually die. Dementia is not a specific disease. Many diseases can cause dementia, including Alzheimer’s disease, vascular dementia (due to strokes), Lewy Body disease, head trauma, fronto-temporal dementia, Creutzfeldt-Jakob disease, Parkinson’s disease, and Huntington’s disease. These conditions can have similar and overlapping symptoms.</td>
</tr>
<tr>
<td>Alzheimer’s Society (UK)</td>
<td><a href="https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120">https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200120</a></td>
<td>52.8/10.0</td>
<td>The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s disease or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse.</td>
</tr>
</tbody>
</table>
| American Psychiatric Association (USA)    | Diagnostic and Statistical Manual of Mental Disorders-5 (DSM-5).       | 8.1/18.2    | The DSM-5 manual replaces the term “dementia” with major neurocognitive disorder and mild neurocognitive disorder. In DSM-5, a minor neurocognitive disorder is defined by the following:  
  • There is evidence of modest cognitive decline from a previous level of performance in one or more of the domains outlined above based on the concerns of the individual, a knowledgeable informant, or the clinician; and a decline in neurocognitive performance, typically involving test performance in the range of one and two |

**REPORT OF THE SUMMIT WORKING GROUP ON NOMENCLATURE AND DEMENTIA & INTELLECTUAL DISABILITY**
Dementia is a syndrome due to disease of the brain that occurs with certain neuropathological diseases or trauma and is often associated with aging. It is marked by memory disorders, personality and behavioral changes, and impaired reasoning. Dementia is not a disease itself, but rather a group of symptoms that are caused by various degenerative brain diseases or conditions, such as Alzheimer's disease, stroke, or other brain trauma. Alzheimer’s disease is the most prevalent cause, associated with some two-thirds of the instances of dementia. There are different types of dementias, among them Alzheimer’s dementia, vascular dementia, fronto-temporal dementia, Lewy body dementia are the most prevalent. Dementia related to a brain disease, such as Alzheimer’s, generally has a progressive nature so that over time the individual affected continually loses more cognitive and functional skills and eventually is totally unable to function independently.

In DSM-5, a major neurocognitive disorder is defined by the following:

- The cognitive deficits are not primarily attributable to another mental disorder (e.g., major depressive disorder, schizophrenia).
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits are sufficient to interfere with independence (i.e., requiring minimal assistance with instrumental activities of daily living).
- The cognitive deficits are sufficient to interfere with independence (i.e., requiring minimal assistance with instrumental activities of daily living).
- The cognitive deficits are insufficient to interfere with independence (e.g., instrumental activities of daily living, like more complex tasks such as paying bills or managing medications, are preserved), but greater effort, compensatory strategies, or accommodation may be required to maintain independence.
- The cognitive deficits do not occur exclusively in the context of a delirium.
- The cognitive deficits are not primarily attributable to another mental disorder (e.g., major depressive disorder, schizophrenia).

### Australian Institute of Health and Welfare (AUS)

Dementia is not a single specific disease. It is an umbrella term describing a syndrome associated with more than 100 different diseases that are characterized by the impairment of brain functions, including language, memory, perception, personality and cognitive skills. Although the type and severity of symptoms and their pattern of development varies with the type of dementia, it is usually of gradual onset, progressive in nature and irreversible.

### National Task Group on Intellectual Disabilities and Dementia Practices (USA)

Dementia is a term that characterizes the progressive loss of brain function that occurs with certain neurobiological disorders or trauma and is often associated with aging. It is marked by memory disorders, personality and behavioral changes, and impaired reasoning. Dementia is not a disease itself, but rather a group of symptoms that are caused by various degenerative brain diseases or conditions, such as Alzheimer’s disease, stroke, or other brain trauma. Alzheimer’s disease is the most prevalent cause, associated with some two-thirds of the instances of dementia. There are different types of dementias, among them Alzheimer’s dementia, vascular dementia, fronto-temporal dementia, Lewy body dementia are the most prevalent. Dementia related to a brain disease, such as Alzheimer’s, generally has a progressive nature so that over time the individual affected continually loses more cognitive and functional skills and eventually is totally unable to function independently.

### National Institute on Aging (USA)

Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—and behavioral abilities to such an extent that it interferes with a person’s daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect a person’s functioning, to the most severe stage, when the person must depend completely on others for basic activities of daily living.

### New Zealand Ministry of Health (NZ)

Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, that results in cognitive function including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. Impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behavior, or motivation. Dementia occurs in Alzheimer’s disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain.

### National Health Service (UK)

Dementia is a common condition. Your risk of developing dementia increases as you get older, and the condition usually occurs in people over the age of 65. Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. This includes problems with: memory loss, thinking speed,
mental agility, language, understanding, and judgement. People with dementia can become apathetic or uninterested in their usual activities, and have problems controlling their emotions. They may also find social situations challenging, lose interest in socialising, and aspects of their personality may change. A person with dementia may lose empathy (understanding and compassion), they may see or hear things that other people do not (hallucinations), or they may make false claims or statements. As dementia affects a person’s mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with dementia will therefore usually need help from friends or relatives, including help with decision making.

Dementia is a syndrome in which there is deterioration in memory, thinking, behavior and the ability to perform everyday activities.

Dementia (F00-F03) is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation. This syndrome occurs in Alzheimer’s disease, in cerebrovascular disease, and in other conditions primarily or secondarily affecting the brain.

Dementia is the name for a group of symptoms caused by disorders that affect the brain. It is not a specific disease. People with dementia may not be able to think well enough to do normal activities, such as getting dressed or eating. They may lose their ability to solve problems or control their emotions. Their personalities may change. They may become agitated or see things that are not there. Memory loss is a common symptom of dementia. However, memory loss by itself does not mean you have dementia. People with dementia have serious problems with two or more brain functions, such as memory and language. Although dementia is common in very elderly people, it is not part of normal aging. Many different diseases can cause dementia, including Alzheimer’s disease and stroke. Drugs are available to treat some of these diseases. While these drugs cannot cure dementia or repair brain damage, they may improve symptoms or slow down the disease.

Note: FRES: Flesch Reading Ease score\(^\text{19}\); F-KGL: Flesch-Kincaid Grade Level score [Rates text on a U.S. grade-school level. For example, a score of 8.0 means that an eighth grader can understand the document.]

\(^\text{19}\) https://en.wikipedia.org/wiki/Flesch%20%E2%80%93Kincaid_readability_tests

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<thead>
<tr>
<th>Grade Range</th>
<th>Grade Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>90.0–100.0</td>
<td>5th grade</td>
<td>Very easy to read. Easily understood by an average 11-year-old student.</td>
</tr>
<tr>
<td>80.0–90.0</td>
<td>6th grade</td>
<td>Easy to read. Conversational English for consumers.</td>
</tr>
<tr>
<td>70.0–80.0</td>
<td>7th grade</td>
<td>Fairly easy to read.</td>
</tr>
<tr>
<td>60.0–70.0</td>
<td>8th &amp; 9th grade</td>
<td>Plain English. Easily understood by 13- to 15-year-old students.</td>
</tr>
<tr>
<td>50.0–60.0</td>
<td>10th to 12th grade</td>
<td>Fairly difficult to read.</td>
</tr>
<tr>
<td>30.0–50.0</td>
<td>college</td>
<td>Difficult to read.</td>
</tr>
<tr>
<td>0.0–30.0</td>
<td>college graduate</td>
<td>Very difficult to read. Best understood by university graduates.</td>
</tr>
</tbody>
</table>
### Appendix B: Taxonomy of terms related to dementia and intellectual disability

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
<th>Usage/applications</th>
<th>Source</th>
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<tbody>
<tr>
<td><strong>Diagnostic and condition-specific terms</strong></td>
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</tbody>
</table>
| Alzheimer’s disease   | [1] Alzheimer’s disease (AD) is an age-related, non-reversible brain disorder that develops over a period of years. Initially, people experience memory loss and confusion, which may be mistaken for the kinds of memory changes that are sometimes associated with normal aging. However, the symptoms of AD gradually lead to behavior and personality changes, a decline in cognitive abilities such as decision-making and language skills, and problems recognizing family and friends. AD ultimately leads to a severe loss of mental function. These losses are related to the worsening breakdown of the connections between certain neurons in the brain and their eventual death.  
[2] Alzheimer’s disease is a progressive, degenerative disorder that attacks the brain’s nerve cells, or neurons, resulting in loss of memory, thinking and language skills, and behavioral changes. These neurons, which produce the brain chemical, or neurotransmitter, acetylcholine, break connections with other nerve cells and ultimately die. For example, short-term memory fails when Alzheimer’s disease first destroys nerve cells in the hippocampus, and language skills and judgment decline when neurons die in the cerebral cortex. Two types of abnormal lesions clog the brains of individuals with Alzheimer’s disease: Beta-amyloid plaques—sticky clumps of protein fragments and cellular material that form outside and around neurons; and neurofibrillary tangles—insoluble twisted fibers composed largely of the protein tau that build up inside nerve cells. Although these structures are hallmarks of the disease, scientists are unclear whether they cause it or a byproduct of it. Alzheimer’s disease is the most common cause of dementia. | General diagnostic descriptor  
### Alzheimer’s disease spectrum

Term identifying the entire spectrum of Alzheimer’s disease (AD) including preclinical AD, mild cognitive impairment due to AD, and dementia due to AD; a major feature to distinguish between the clinical characteristics of the disorder and the pathological features. The criteria include the use of imaging and other biomarkers to aid in diagnosis.

Theoretical medical descriptor


### Behavioral and psychological symptoms of dementia (BPSD)

Behavioral and psychological symptoms of dementia (BPSD), also known as neuropsychiatric symptoms, represent a heterogeneous group of non-cognitive symptoms and behaviors occurring in subjects with dementia. BPSD constitute a major component of the dementia syndrome irrespective of its subtype. They are as clinically relevant as cognitive symptoms as they strongly correlate with the degree of functional and cognitive impairment. BPSD include agitation, aberrant motor behavior, anxiety, elation, irritability, depression, apathy, disinhibition, delusions, hallucinations, and sleep or appetite changes. It is estimated that BPSD affect up to 90% of all dementia subjects over the course of their illness, and is independently associated with poor outcomes, including distress among patients and caregivers, long-term hospitalization, misuse of medication, and increased health care costs. Although these symptoms can be present individually it is more common that various psychopathological features co-occur simultaneously in the same patient. Thus, categorization of BPSD in clusters taking into account their natural course, prognosis, and treatment response may be useful in the clinical practice. The pathogenesis of BPSD has not been clearly delineated but it is probably the result of a complex interplay of psychological, social, and biological factors.

General descriptor


### Cognitive disability

1. The term cognitive disabilities encompasses various intellectual or cognitive deficits, including intellectual disability, developmental delay, developmental disability, learning disabilities, and conditions causing cognitive impairment such as acquired brain injuries or neurodegenerative diseases like dementia.

2. A cognitive disability causes a person to have greater difficulty with one or more types of mental tasks than the average person; cognitive disabilities can be characterized as functional disability or by clinical disability. Clinical diagnoses of cognitive disabilities include autism, Down syndrome, traumatic brain injury (TBI), and even dementia. Less severe cognitive conditions include attention deficit disorder (ADD), dyslexia (difficulty reading), dyscalculia (difficulty with math), and learning disabilities in general. In some jurisdictions, cognitive disability refers to intellectual disability.

General descriptor


### Cognitive impairment

Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of

General descriptor

# Dementia

Dementia is a collective name for progressive degenerative brain syndromes which affect memory, thinking, behavior and emotion. Symptoms may include: loss of memory, difficulty in finding the right words or understanding what people are saying, difficulty in performing previously routine tasks, and personality and mood changes.

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. Dementia is caused when the brain is damaged by diseases, such as Alzheimer’s disease or a series of strokes. Dementia is progressive, which means the symptoms will gradually get worse.

Dementia is a term that characterizes the progressive loss of brain function that occurs with certain neuropathological diseases or trauma and is often associated with aging. It is marked by memory disorders, personality and behavioral changes, and impaired reasoning. Dementia is not a disease itself, but rather a group of symptoms that are caused by various degenerative brain diseases or conditions, such as Alzheimer’s disease, stroke, or other brain trauma. Alzheimer’s disease is the most prevalent cause, associated with some two-thirds of the instances of dementia. There are different types of dementias, among them Alzheimer’s dementia, vascular dementia, fronto-temporal dementia, Lewy body dementia are the most prevalent. Dementia related to a brain disease, such as Alzheimer’s, generally has a progressive nature so that over time the individual affected continually loses more cognitive and functional skills and eventually is totally unable to function independently.

Dementia is defined as “a progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational function.”

Dementia is the loss of cognitive functioning—thinking, remembering, and reasoning—to such an extent that it interferes with a person’s daily life. Dementia is not a disease itself, but rather a set of symptoms. Memory loss is a common symptom of dementia, although memory loss by itself does not mean a person has dementia. Alzheimer’s disease is the most common form of dementia, accounting for the majority of all diagnosed cases.

## General descriptor

1. Dementia: About dementia. (n.d.) Alzheimer’s Disease International. [https://www.alz.co.uk/about-dementia](https://www.alz.co.uk/about-dementia)

## Dementia screen

Screening) is undertaken to increase the precision of a decision by reducing subjectivity and increasing objectivity. The properties of an ideal screening scale would be that it is valid, that is, it has *face validity* (experts like clinicians, patients and carers would agree that the questions are relevant and important), that it has *construct validity* (it measures the construct it was designed to measure), *concurrent validity* (when used alongside a gold standard assessment like a very well validated scale or an expert clinical assessment, it performs well), that it shows reliability – typically *inter-rater* Sheenhan, B. (2012). Assessment scales in dementia. Ther Adv Neurol Disord (2012) 5(6) 349 –358.
reliability (two or more raters using the scale in the same subjects and conditions come up with the same result) and test–retest reliability (the same rater using the scale on another occasion in the same subject comes up with the same result). Importantly, it should be practical to use – in practice, this often depends on it being short (so it can be used in busy clinical practice ... (and) participants are not overburdened by long interviews) and acceptable – so it does not upset, exhaust or embarrass the patient or assessor.

### Dementia assessment

The most important diagnostic tools are the informant interview and office-based clinical assessment. Physicians should interview both the patient and a reliable informant and inquire into the patient's current condition, medical and medication history, patterns of alcohol use, and living arrangements. Use of standardized informant-based instruments will help determine lapses in memory and language use, the ability to learn and retain new information, handle complex tasks, demonstrate sound judgment, and show usual behavior. Reported changes should be compared with the person's past performance. Evidence of decline from previous functioning and impairment in multiple cognitive domains confirms the diagnosis. There should a comprehensive physical examination, including a brief neurological and mental status evaluation and a laboratory evaluation, generally including a complete blood cell count, blood chemistries, liver function tests and determination of thyroid-stimulating hormone and vitamin levels. Other laboratory tests should be ordered if suggested by history or physical examination. Imaging studies are optional but recommended by many clinicians and experts.

Guides diagnosis


### Dementia diagnosis – mild cognitive impairment

**Diagnostic criteria for mild cognitive impairment (MCI)**

MCI is diagnosed when there is concern regarding a decline in cognition reported by the patient, informant, or clinician, and there is objective evidence of cognitive deficits in 1 or more domains (typically memory) and most important there is preservation of independence in functional abilities. The differentiation of dementia from MCI rests on whether there is substantial interference in the ability to function at work or in usual daily activities. This is a clinical judgment. Further evaluation examines the pathogenesis of MCI, focusing on ruling out vascular, traumatic, and medical causes, and consideration of AD genetic factors.

Guides the choice of tests/assessments and offers guidance for consensus clinical diagnosis conferencing


### Dementia diagnosis – probable dementia

**Diagnostic criteria for probable Alzheimer’s dementia (AD)**

Probable AD is diagnosed when the criteria for dementia are met, and symptoms have a gradual onset over months to years, not suddenly over hours or days, and there is clear worsening of cognition. Additionally, the initial and most prominent cognitive deficits are usually amnestic (associated with impairment in learning and recall of recently learned information) or less commonly nonamnestic (when language deficits are most prominent, e.g., word-finding difficulties). Deficits should also occur in other domains such as visuospatial abilities (face or object recognition) and executive function (reasoning, judgment, problem solving). The diagnosis of probable AD guides the choice of tests/assessments and offers guidance for consensus clinical diagnosis conferencing

## Dementia diagnosis – possible dementia

**Diagnostic criteria for possible Alzheimer’s dementia (AD)** A diagnosis of possible AD should be made when the criteria for AD are met (regarding the nature of cognitive deficits) but the disease follows an atypical course (eg, there is a sudden onset of cognitive impairment and cognitive decline is not gradual), or when criteria for AD are met but there is evidence of a mixed presentation, such as concomitant cerebrovascular disease, or the patient has clinical features of dementia with Lewy bodies, has another comorbidity (medical or neurologic), or is using medication that could have a substantial effect on cognition.

Guides the choice of tests/assessments and offers guidance for consensus clinical diagnosis conferencing


## Dementia diagnosis – people with ID

Diagnosis in people with ID is generally on the basis of meeting criteria ICD-10 (World Health Organization, 1992), DSM-IV-TR (American Psychiatric Association, 2000).

Guides the choice of tests/assessments and offers guidance for consensus clinical diagnosis conferencing


## Dementia screening – people with ID

Reactive screening is the assessment of functioning and exploring the reasons for observed deterioration in any adult with intellectual disabilities after concerns have been raised; recommended to establish a baseline for every adult with Down’s syndrome whilst they are healthy – ideally at age 30 – and then undertaking prospective screening for dementia for adults with Down’s syndrome conducted at intervals from the age of 30 onwards. Prospective screening (monitoring) entails checking for early signs of dementia by repeating the baseline assessment at regular interval and the frequency of prospective screening (monitoring) for dementia should be matched to the rising risk with age.

Guides the choice of tests/assessments and offers guidance for consensus clinical diagnosis conferencing


## Dementia due to Alzheimer’s disease

Dementia when there are cognitive or behavioral (neuropsychiatric) symptoms that:
1. Interfere with the ability to function at work or at usual activities; and
2. Represent a decline from previous levels of functioning and performing; and
3. Are not explained by delirium or major psychiatric disorder;
4. Cognitive impairment is detected and diagnosed through a combination of (1) history-taking from the patient and a knowledgeable informant and (2) an objective cognitive assessment, either a “bedside” mental status examination or neuropsychological testing. Neuropsychological testing should be performed when the routine history and bedside mental status examination cannot provide a confident diagnosis.
5. The cognitive or behavioral impairment involves a minimum of two of the following domains:
   - Impaired ability to acquire and remember new information—symptoms include: repetitive questions or conversations, misplacing personal belongings, forgetting events or appointments, getting lost on a familiar route.
   - Impaired reasoning and handling of complex tasks, poor judgment—symptoms include: poor understanding of safety risks, inability to manage...
<table>
<thead>
<tr>
<th><strong>Dementia and intellectual disability</strong></th>
<th>Adults with an intellectual disability affected by dementia as those who:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>• have intellectual limitations that significantly limit the person’s ability to successfully participate in normal day-to-day activities such as self-care, communication, work, or going to school, and</td>
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<tr>
<td></td>
<td>• developed the intellectual limitation during the ‘developmental period’ (before approximately age 22), and</td>
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<tr>
<td></td>
<td>• the limitation is anticipated to result in long term adaptive or functional support needs, and/or</td>
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<tr>
<td></td>
<td>• are eligible for State or Federal public support programs because they have been diagnosed as having an intellectual disability; and</td>
</tr>
<tr>
<td></td>
<td>• are affected by dementia, and meet the criteria of having been diagnosed with possible, probable, or definitive dementia, or have mild cognitive impairment, as defined by the World Health Organization’s International Classification of Diseases or meet the diagnostic criteria of the American Psychiatric Association’s Diagnostic and Statistical Manual.</td>
</tr>
</tbody>
</table>

**Dementia stages**

1. Dementia can be divided in three stages:  
   • early stage – first year or two  
   • middle stage – second to fourth or fifth years  
   • late stage – fifth year and after  
These periods are given as an approximate guideline and not all persons with dementia will display the same symptoms.

2. The middle and later stages of dementia in people with Down’s syndrome are similar to these stages in the general population. There is some evidence that dementia in people with Down’s syndrome progresses more rapidly and that they may have earlier loss of basic skills such as walking, becoming incontinent, and having swallowing difficulties.

**Dementia symptoms – Down syndrome**

1. The symptoms of dementia in people with Down syndrome are broadly similar to those seen in the general population, although there are some differences. Changes in behavior and personality (e.g., becoming more stubborn, irritable or withdrawn) or loss of daily living abilities are common. Memory loss, the most common early symptom of Alzheimer’s disease among older people generally, is seen less often as an early
symptom in people with Down syndrome. This may be because most people with Down syndrome will already have poor short-term memory.

[2] The symptoms of Alzheimer’s disease might be expressed differently among adults with Down syndrome. For example, in the early stages of the disease, memory loss is not always prominent. In addition, not all symptoms ordinarily associated with Alzheimer’s disease will occur. Generally, changes in activities of daily living skills occur, and the person with Down syndrome might begin to have seizures when he or she had not had them in the past. Changes in mental processes—such as thinking, reasoning, and judgment—also might be present, but they often are not readily noticeable because of limitation of the individual’s functioning in general.

[3] The symptoms of Alzheimer’s disease show wide differences between people with Down syndrome. In the early stage of the disease, memory loss is not always seen, and not all the symptoms associated with Alzheimer’s disease will be recognizable. Generally, changes in activities of daily living and work habits are noticed first. Epileptic seizures may occur early or late in the course of the disease. Cognitive changes are frequently present but they are difficult to evaluate because of limitations in the individual’s language, communication and related intellectual abilities.

[4] Clinical symptoms at first are increasing depression, indifference and a decline in social communication. Later symptoms are: seizures in previously unaffected persons, changes in personality, loss of memory and general functions, long periods of inactivity or apathy, hyperactive reflexes, loss of activity of daily skills, visual retention deficits, loss of speech, disorientation, increase in stereotyped behavior and abnormal neurological signs. Average age of onset is 54 years and average interval from diagnosis to death is less than 5 years.

Dementia symptoms – intellectual disability

[1] The symptoms of dementia in people with an intellectual disability (other than Down syndrome) can vary widely. For those with mild intellectual disability and dementia seems to appear and progress similarly to dementia in the general population. For those with more severe intellectual disability, the initial symptoms of dementia are often less typical, possibly involving changes in personality or behavior, which can make diagnosing dementia more difficult.

[2] Warning signs of Alzheimer’s disease for adults with intellectual and developmental disabilities include loss of activity of daily living skills; difficulty with well-learned abilities, changes in personality; more withdrawn, frustrated; periods of inactivity or apathy, disinterest in activities the individual previously enjoyed; development of seizures not previously seen; disorientation to time and place; increase in stereotyped behaviors; hyperactive reflexes; visual retention deficits; speech difficulties, not able to use words or speech that is not clear.


**Diagnosing Alzheimer’s disease in Down syndrome**

1. The process of making a diagnosis of Alzheimer’s disease in someone with Down syndrome is the same as making a diagnosis of Alzheimer’s disease in anyone else. Diagnosis is based on a detailed history of progressive change over time in thinking, memory and daily living skills, physical examination, tests of thinking and memory, and investigations (blood tests and brain scans) to rule out other causes of decline in functioning.

2. Making a diagnosis of Alzheimer’s disease can be difficult when the person has Down syndrome for a number of reasons:
   - People with Down syndrome are susceptible to a number of reversible conditions that can be mistaken for Alzheimer’s disease. These include hypothyroidism and depression. The side effects of some medications can also mimic Alzheimer’s disease
   - The usual skill tests used for diagnosis do not take into account the existing problems of a person with Down syndrome
   - The limited communication skills of some people with Down syndrome may affect the assessment.

**Early onset Alzheimer’s disease**

1. Younger-onset (also known as early-onset) Alzheimer’s disease affects people younger than age 65.

2. The early-onset form of Alzheimer’s disease most often shows up in the 40s and 50s; in some persons it may show in the 30s.

**Early onset Dementia – people with Down syndrome**

1. Age-related cognitive decline and frontal lobe dementia appear to be more prevalent in the younger age groups (30–49 years of age) of adults with Down syndrome, and frontal lobe dementia appears to be more prevalent in those adults with more severe intellectual disability. Early-onset presents with more frontal symptoms and this may represent a different clinical subtype of Alzheimer’s disease in Down’s syndrome.

2. As adults with Down syndrome live, on average, 55 to 60 years, they are more likely to develop younger-onset Alzheimer’s (Alzheimer’s occurring before age 65) than older-onset Alzheimer’s (Alzheimer’s occurring at age 65 or older). Autopsy studies show that by age 40, the brains of almost all individuals with Down syndrome have significant levels of plaques and tangles, abnormal protein deposits considered Alzheimer’s hallmarks. But despite the presence of these brain changes, not everyone with the syndrome develops Alzheimer’s symptoms.

3. Studies have also shown that by the age of about 40, almost all people with Down’s syndrome develop changes in the brain associated with Alzheimer’s disease. However, not all go on to develop clinical symptoms of dementia. The reason for this increased risk has not been fully identified.
Frontotemporal dementia

1. Frontotemporal dementia (FTD) or frontotemporal degenerations refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes (the areas behind the forehead) or its temporal lobes (the regions behind the ears).

2. Frontotemporal degeneration (FTD) is a disease process that results in progressive damage to the temporal and/or frontal lobes of the brain. It causes a group of brain disorders that share many clinical features. FTD is also commonly referred to as frontotemporal dementia, fronto-temporal lobar degeneration (FTLD), or Pick's disease.

Lewy-body dementia

1. Lewy body dementia, also known as dementia with Lewy bodies, is the second most common type of progressive dementia after Alzheimer's disease dementia. Protein deposits, called Lewy bodies, develop in nerve cells in the brain regions involved in thinking, memory and movement (motor control). Lewy body dementia causes a progressive decline in mental abilities. People with Lewy body dementia may experience visual hallucinations, and changes in alertness and attention. Other effects include Parkinson's disease-like symptoms such as rigid muscles, slow movement and tremors.

2. A new category of features “suggestive” of DLB includes rapid eye movement sleep behavior disorder (RBD), severe neuroleptic sensitivity, and abnormal dopamine transporter neuroimaging imaging... If one or more of these suggestive features are present, in addition to one or more core features (i.e., fluctuating cognition with pronounced variations in attention and alertness; recurrent visual hallucinations that are typically well formed and detailed; and spontaneous motor features of parkinsonism), a diagnosis of probable DLB could be made. Possible DLB was to be diagnosed if one or more suggestive features were present in a patient with dementia even in the absence of any core features.

Mild cognitive impairment

Mild cognitive impairment (MCI) causes a slight but noticeable and measurable decline in cognitive abilities, including memory and thinking skills. A person with MCI is at an increased risk of developing dementia due to Alzheimer's disease or dementia due to other neuropathology.

Mild cognitive impairment due to Alzheimer's disease

MCI—Criteria for the clinical and cognitive syndrome

Concern regarding a change in cognition

There should be evidence of concern about a change in cognition, in comparison with the person's previous level. This concern can be obtained from the patient, from an informant who knows the patient well, or from a skilled clinician observing the patient.

Impairment in one or more cognitive domains

There should be evidence of lower performance in one or more cognitive domains that is greater than would be expected for the patient's age and educational background. If repeated assessments are

Specific diagnostic descriptor


available, then a decline in performance should be evident over time. This change can occur in a variety of cognitive domains, including memory, executive function, attention, language, and visuospatial skills. An impairment in episodic memory (i.e., the ability to learn and retain new information) is seen most commonly in MCI patients who subsequently progress to a diagnosis of AD dementia.

**Preservation of independence in functional abilities**

Persons with MCI commonly have mild problems performing complex functional tasks which they used to perform previously, such as paying bills, preparing a meal, or shopping. They may take more time, be less efficient, and make more errors at performing such activities than in the past. Nevertheless, they generally maintain their independence of function in daily life, with minimal aids or assistance. It is recognized that the application of this criterion is challenging, as it requires knowledge about an individual’s level of function at the current phase of their life. However, it is noteworthy that this type of information is also necessary for the determination of whether a person is demented.

**Neurodegenerative disorders**

1. Disorders involving diseases in which cells of the central nervous system stop working or die. Neurodegenerative disorders usually get worse over time and have no cure. They may be genetic or be caused by a tumor or stroke. Neurodegenerative disorders also occur in people who drink large amounts of alcohol or are exposed to certain viruses or toxins. Examples of neurodegenerative disorders include Alzheimer's disease and Parkinson's disease.

2. Neurodegenerative disease is an umbrella term for a range of conditions which primarily affect the neurons in the human brain. Neurons are the building blocks of the nervous system which includes the brain and spinal cord. Neurons normally don’t reproduce or replace themselves, so when they become damaged or die they cannot be replaced by the body. Examples of neurodegenerative diseases include Parkinson’s, Alzheimer’s, and Huntington’s disease. Neurodegenerative diseases are incurable and debilitating conditions that result in progressive degeneration and/or death of nerve cells. This causes problems with movement (called ataxias), or mental functioning (called dementias).

**Neurodevelopmental disorders**

Neurodevelopmental disorders are a group of disorders in which the development of the central nervous system is disturbed. This can include developmental brain dysfunction, which can manifest as neuropsychiatric problems or impaired motor function, learning, language or non-verbal communication.

**Parkinson disease dementia**

Parkinson disease dementia (PDD) is defined as cognitive impairment that has reached the stage of dementia and which appears in the context of preexisting PD. Visual hallucinations, autonomic, and sleep disturbances are common. A number of authors consider dementia with Lewy bodies (DLB) and PDD as two syndromes within the same disease spectrum.

**Rapidly progressive dementia**

Rapidly progressive dementia is a rare condition with a large number of possible causes. Rapidly progressive dementia has been poorly defined in specific diagnostic descriptor.

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the literature. Although Creutzfeldt-Jakob disease is a prominent cause, care must be taken to identify potentially treatable conditions, such as unsuspected vascular disease, reversible structural pathogenesis (26% of RPDs), infections, and immunologically mediated disorders. RPD is a condition that develops within 12 months after the appearance of the first cognitive symptoms.

Vascular dementia

[1] Vascular dementia occurs when the brain is damaged because of problems with the supply of blood to the brain, and results in symptoms such as memory loss and difficulties with thinking, problem-solving or language. When the vascular system within the brain becomes damaged - so that the blood vessels leak or become blocked - then blood cannot reach the brain cells and they will eventually die and this can cause problems with memory, thinking or reasoning.

[2] Vascular dementia is a syndrome comprising ischemic and hemorrhagic etiologies. The dominant feature of the cognitive syndrome is an abnormal executive function that interferes with social or occupational functioning. The term vascular cognitive impairment (VCI) was devised to incorporate conditions in any cognitive domain with a vascular origin or impaired brain perfusion and encompasses a slow, progressive, clinical course and the contributions of vascular disease to cognitive impairment (CI) as does vascular cognitive disorder (VCD).

Specific diagnostic descriptor


General social care terms

Advanced care planning

Advance care planning (ACP) is a process of discussing and sharing planning for future health care. For the purposes of this framework, ACP focuses on the person with dementia and involves both that person and the health care professionals responsible for their care. ACP may also involve the person with dementia’s family if that is the person’s wish. ACP helps the person with dementia identify their personal beliefs and values and incorporate these beliefs and values into plans for their future health care. It provides people with the opportunity to develop and express their preferences for care, informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available. ACP may result in the person with dementia choosing to write an advance care plan (see above) and/or advance directive and/or to appoint an enduring power of attorney (see below). If the person has strong views or preferences about medical treatments and procedures, they should be advised to consider completing an advance directive.

Dementia capable

Dementia capable encompasses an ability (a combination of staff knowledge, skills, and competency as well as available programs and services) to fulfill the needs of adults with dementia and their caregivers. The concept applies to workforces, programs, services, and systems. Both the “dementia-friendly” approach led by the European Union countries and the dementia-capable approach carried out in the United States apply to similar ends. The dementia-friendly approach focuses on the living.
experience/user experience, whereas the dementia-capable approach focuses on special needs. With a focus on the living experience/user experience, the dementia-friendly normalization process requires modifications of the living environment (involving people, resources, places, activities, cultures, technologies, and so on) to ensure that adults with dementia and their families can enjoy a normal life in their communities for as long as possible. With a focus on special needs, the dementia-capable approach adapts the U.S. language and philosophy of care for persons with disabilities to serve adults with dementia and their families and ensure their needs are met. Both approaches encourage inclusion and acceptance, but the difference is that the dementia friendly approach attempts to include adults with dementia and their families in the community directly, whereas the dementia capable approach uses a two-step approach (where Step 1 involves inclusion into the disability community and Step 2 promotes inclusion into the society at large through being a member of the disability community).

| Dementia capability | A model system:  
|---|---|
| 1. Educates the public about brain health. This would include information about the risk factors associated with developing dementia, first signs of cognitive problems, management of symptoms if individuals have dementia, support programs, and opportunities to participate in research.  
| 2. Identifies people with possible dementia and recommend that they see a physician for a timely, accurate diagnosis and to rule out reversible causes of dementia or conditions that resemble it.  
| 3. Ensures that program eligibility and resource allocation take into account the impact of cognitive disabilities.  
| 4. Ensures that staff communicate effectively with people with dementia and their caregivers and provide services that: a) are person- and family-centered, b) offer self-direction of services, and c) are culturally appropriate.  
| 5. Educates workers to identify possible dementia, and understand the symptoms of dementia and appropriate services.  
| 6. Implements quality assurance systems that measure how effectively providers serve people with dementia and their caregivers.  
| 7. Encourages development of dementia-friendly communities, which include key parts of dementia-capability  
| Dementia-capable service systems recognize that  
| 1) people with dementia use more and different services than people with physical disabilities  
| 2) rely on caregivers to remain in their communities | Guidance for care planning and the design of services  

| Dementia friendly community | In dementia-friendly communities, residents, agencies, businesses, and service providers are learning about dementia through education and awareness efforts, and providing assistance to people with the condition and their caregivers as they go about their daily lives. These efforts go beyond developing dementia-capable health and long-term services and Guidance for care planning and the design of services  
|---|---|
supports. Dementia friendly communities involve improved customer service at participating agencies and businesses, supportive faith or spiritual communities, emergency services that understand dementia, and suitable transportation and public spaces.

### Dementia friendly environment

1. To maintain as much independence as possible, a person with Alzheimer’s dementia needs to live in as familiar an environment as possible, with people who are as familiar to them as possible. This is not a time to introduce drastic changes into a person’s life; it is a time to start thinking about ways to enable them to keep their independence as long as possible. The environment should be as stress-free and calm as possible, and designed with a person’s sensory and other problems in mind.

   - Daily routines should be maintained.
   - Flooring should be one color throughout, as changes in color and texture can be seen as steps or obstacles. Flooring should not be shiny, as this can look like water. Patterned flooring can appear ‘frightening’ in dim light (to someone with dementia, it can look as if there are moving insects/objects on the floor at night-time).
   - Pictures and signs can be used to help a person find their way around the house, the toilet door could be painted a bright color to make it easy to find.
   - Mirrors can be removed or covered, as a person may not recognize their own reflection, lighting should not glare.
   - People with whom the person spends time, including other people with intellectual disabilities, should be helped to understand the condition and how they can be involved in the person’s support.

2. Dementia-friendly environments are created using a flexible approach that maximizes the person with dementia’s individual requirements for freedom and involvement and minimizes regimentation.

### Dementia ready - residential

Living situations that may include living with family, living on one’s own or with a partner/friend, living in a small supervised setting, living in a large supervised setting or living in a dementia specific setting. Modifications/changes may be needed to support continuation of the living situation (see Table 6 from Jokinen et al., 2013))

### Guidance for care planning and the design of services


Dementia-ready – day programs

1 Dementia-ready day programs evolve when dementia becomes more prominent and there is a need to reorganize to better support small group activities and flexibility in hours of involvement for the individual with

Guidance for care planning and the design of services

Dementia (e.g. partial versus full days) (Table 8). Such day programs work more closely with aging and Alzheimer/dementia specific service providers and begin to focus on maintaining the individual’s previously learned skills and enjoyable activities rather than the addition of new skills and experiences. Staffing becomes dementia-capable and training is offered with attention to address wandering management, health related concerns, and incontinence to reduce the likelihood that people with dementia will be discharged and no longer able to attend the program. Greater interaction with social and medical day care programs and with dementia specific programs and senior centers in the community likely increases the value of day programs in an overall intellectual disabilities and dementia strategy and create opportunities for cross-programming and shared resources.

Day program descriptors

<table>
<thead>
<tr>
<th>Environment</th>
<th>Programming</th>
</tr>
</thead>
<tbody>
<tr>
<td>Small group and one-on-one spaces</td>
<td>Multi-sensory in approach; both stimulating and calming</td>
</tr>
<tr>
<td>Dementia appropriate lighting (reducing shadows), noise abatement, floor plan (reducing glare and avoiding patterns), wayfinding cues</td>
<td>Support of existing skills and memories rather than teaching new things</td>
</tr>
<tr>
<td>Fully accessible with adaptive toilets and bathroom area (able to deal with toileting accidents)</td>
<td>Tailored to the likes and dislikes and previous experiences</td>
</tr>
<tr>
<td>Spacious living areas, sitting areas</td>
<td>Reminiscence, trips in the community, walks, simple exercise, music, games, flowers, horticulture, art, music, aromatherapy, hair/make-up/personal grooming (activity not training oriented)</td>
</tr>
<tr>
<td>Gardens, kitchen, snack area, memory room, beauty salon</td>
<td>Offered by staff trained in dementia care practices</td>
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</table>

Dementia trained staff

1. Staff who are trained to understand how to communicate with people with dementia and respond to BPSD, the complexity of the condition which combines features of chronic neurological disease, mental illness and physical frailty, and function within integrated care. Staff can spot the early symptoms of dementia, understand how to interact with people with dementia and signpost to the most appropriate care and support.

2. Staff who are trained in the following areas: Alzheimer’s & dementia disease awareness; strategies for caring for the person with dementia; communication and understanding behavior; social needs and activities;


<p>| | |</p>
<table>
<thead>
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<tbody>
<tr>
<td>eating well; reducing pain; falls; wandering; restraint-free care, and end-of-life care.</td>
<td></td>
</tr>
</tbody>
</table>

Note: AD: Alzheimer’s disease; ID: intellectual disability
## Appendix C: Examples of terms used in reference to dementia and ID within a convenience sample of articles and documents

<table>
<thead>
<tr>
<th>Citation</th>
<th>Paper focus</th>
<th>Subject pool</th>
<th>Terminology used/cited</th>
<th>Defined/undefined?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reference</td>
<td>Description</td>
<td>Comparison</td>
<td>Diagnosis</td>
<td>Note</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
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</tr>
<tr>
<td>Millichap, Oliver, McQuillan, Kalsy, Lloyd &amp; Hall (2003)</td>
<td>Descriptive functional analysis of behavioral excesses shown by adults with Down syndrome and dementia. [Int J Geriatr Psychiatry. 2003 Sep;18(9):844-54]</td>
<td>Behavior - Behavioral excesses</td>
<td>Down syndrome</td>
<td>“… a clinical diagnosis of AD outlined by Holland (1999), which included the presence of gradual decline and cognitive impairment in the absence of significant health or sensory problems.”</td>
</tr>
<tr>
<td>Margallo-Lana, Moore, Kay, Perry, Ried, Berney, &amp; Tyrer (2007)</td>
<td>Fifteen-year follow-up of 92 hospitalized adults with Down’s syndrome: incidence of cognitive decline, its relationship to age and neuropathology. [JIDR, 2007, 51(6), 463-477]</td>
<td>Behavior - Cognitive decline</td>
<td>Down syndrome</td>
<td>“…diagnosis of dementia requires a decline from a previous level of cognitive functioning sufficient to impair personal activities of daily living that is not due to other non-organic causes such as physical illness or depression.” “Alzheimer-type dementia, as described in ICD-10”</td>
</tr>
<tr>
<td>Reference</td>
<td>Care practices</td>
<td>Intellectual disability</td>
<td>Dementia</td>
<td>Term not defined</td>
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<td>-----------</td>
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<td>-----------------</td>
</tr>
<tr>
<td>Courtenay, K., Jokinen, N.S., &amp; Strydom, A. (2010). Caregiving and adults with intellectual disabilities affected by dementia. Journal of Policy and Practice in Intellectual Disabilities, 2010, 7(1), 26 - 33.</td>
<td>Care practices</td>
<td>Intellectual disability</td>
<td>Dementia, dementia-related caregiving, early-state dementia, dementia care mapping</td>
<td>“... dementia care mapping is used to observe and evaluate the quality of life and care of people living with dementia. It consists of three phases where trained “mappers” carry out detailed observations of behavior and care provision and assign “well-being” or “ill-being” ratings.” “...dementia is a progressive condition associated with slowly increasing care needs and carer burden...” Other terms not defined</td>
</tr>
<tr>
<td>Reference</td>
<td>Source</td>
<td>Diagnosis</td>
<td>Intellectual Disability</td>
<td>Dementia</td>
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</tr>
<tr>
<td>Jaycock, Persaud &amp; Johnson (2006).</td>
<td>Care practices – Dementia care mapping</td>
<td>Intellectual disability</td>
<td>Dementia care mapping, dementia, dementia services</td>
<td></td>
</tr>
<tr>
<td>Nagdee (2011)</td>
<td>Diagnostics</td>
<td>Intellectual disability</td>
<td>Dementia</td>
<td></td>
</tr>
</tbody>
</table>

"...dementia care mapping (DCM, 7th edition: Bradford Dementia Group, 1997.) “DCM (Kitwood and Bredin, 1992) is a developmental evaluation tool measuring the quality of care from the perspective of the recipient.”

Term not defined explicitly; references to IASSID-AAMR criteria and processes and by behavioral description

“The progressive deterioration of cognitive functions and verbal communication, the inability to perform previously rewarding activities along with changes in perception, content of thought, mood and behavior, render troublesome the use of reliable and comparable criteria for evaluating QoL relative to the person and his social context during the course of dementia.” Others not defined

No explicit definitions, but some allusions to Alzheimer’s neuropathology and behavioral
<table>
<thead>
<tr>
<th>Source</th>
<th>Study Title</th>
<th>Authors</th>
<th>Year</th>
<th>Page Range</th>
<th>Journal</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strydom, A. (2015).</td>
<td>A genetic cause of Alzheimer disease: mechanistic insights from Down syndrome.</td>
<td>Nature Reviews: Neuroscience, 16 (Sept), 564-574.</td>
<td></td>
<td></td>
<td></td>
<td>(BPSD), dementia, early-onset Alzheimer disease (EOAD), descriptors of dementia in Down syndrome (e.g., “...development of amyloid plaques and neurofibrillary tangles (NFTs), which are typical of AD brain neuropathology...”; “... decline in memory and language skills that may be present...”). BPSD is described as ‘non-cognitive’ changes *** are associated with deficits in executive functioning and with frontal antraphy...”. EOAD is defined as “Occurrence of Alzheimer disease before the age of 65 years.”</td>
</tr>
<tr>
<td>Prasher &amp; Krishman (1993)</td>
<td>Age of onset and duration of dementia in people with Down’s syndrome.</td>
<td>International Journal of Geriatric Psychiatry, 1993, 8(11), 915-922</td>
<td></td>
<td></td>
<td></td>
<td>Dementia not defined; however, dx statement was provided: “The diagnosis of clinical dementia was based on the authors of each report but included changes in personality, loss of intellectual and social skills, presence of neurological signs (e.g., seizures), and resulting death not due to some other medical disorder.”</td>
</tr>
</tbody>
</table>
### REPORT OF THE SUMMIT WORKING GROUP ON NOMENCLATURE AND DEMENTIA & INTELLECTUAL DISABILITY

<table>
<thead>
<tr>
<th>Title</th>
<th>Section</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
<td>Type</td>
<td>Domain</td>
</tr>
<tr>
<td>--------</td>
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<td>--------</td>
</tr>
<tr>
<td>Jozsvai, E. (2006).</td>
<td>Epidemiology</td>
<td>Down syndrome</td>
</tr>
<tr>
<td>Janicki &amp; Dalton (2000)</td>
<td>Epidemiology</td>
<td>Intellectual disability</td>
</tr>
<tr>
<td>Watchman, Kerr &amp; Wilkinson (2010)</td>
<td>Guidance document</td>
<td>“Learning difficulty”</td>
</tr>
</tbody>
</table>
| Shooshtari, Martens, Burchill, Dik, & Naghipur (2011) | Health (Depression) | Developmental disabilities | Dementia | “Dementia is a mental disorder characterized by a loss of intellectual abilities of sufficient
<table>
<thead>
<tr>
<th>Reference</th>
<th>Summary</th>
<th>Health</th>
<th>Diagnosis</th>
<th>Comment</th>
</tr>
</thead>
</table>

... diagnosed as having “Dementia in Alzheimer’s disease” according to DCR-10 criteria (WHO, 1993)...
Puri, Ho, & Singh (2001)  
Age of seizure onset in adults with Down’s syndrome.  

<table>
<thead>
<tr>
<th>Seizures (Age of onset)</th>
<th>Down syndrome</th>
<th>Alzheimer’s disease</th>
<th>Cited DSM-III-R dx criteria</th>
</tr>
</thead>
</table>

Menendez (2005)  
Down syndrome, Alzheimer’s disease and seizures.  

<table>
<thead>
<tr>
<th>Seizures</th>
<th>Down syndrome</th>
<th>Alzheimer-type abnormalities, dementia, Alzheimer’s disease, Advanced Alzheimer’s disease</th>
<th>No terms defined</th>
</tr>
</thead>
</table>

d’Orsi & Specchio (2014)  
[Progressive myoclonus epilepsy in Down syndrome patients with dementia. [J Neurol, 2014, 261(8), 1584-1597]

<table>
<thead>
<tr>
<th>Seizures (myoclonus epilepsy)</th>
<th>Down syndrome</th>
<th>Alzheimer’s disease (undefined); dementia;</th>
<th>“Diagnosis of dementia was generated using the modified ICD-10 criteria for adults with intellectual disabilities based on DSM-IV-TR.”</th>
</tr>
</thead>
</table>

Lott, Doran, Walsh & Hill (2006)  
Telemedicine, dementia and Down syndrome: implications for Alzheimer disease.  

<table>
<thead>
<tr>
<th>Telemedicine</th>
<th>Down syndrome</th>
<th>Alzheimer’s disease, dementia of the Alzheimer’s type (DAT)</th>
<th>No terms defined</th>
</tr>
</thead>
</table>

Note: This table represents a completely unscientific and unsystematic sampling of articles and documents dealing with ‘dementia’ and ID. Conceivable they can serve as a reasonable sample of papers found in the field and reflect the terms used.

References (for Appendix C)


REPORT OF THE SUMMIT WORKING GROUP ON NOMENCLATURE AND DEMENTIA & INTELLECTUAL DISABILITY


<table>
<thead>
<tr>
<th>Source</th>
<th>website</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Down Syndrome International (INT)</td>
<td><a href="https://ds-int.org/resource/adults-18-ageing">https://ds-int.org/resource/adults-18-ageing</a></td>
<td>“Dementia is a frequently voiced concern about people with Down syndrome. There is a tendency for people with Down syndrome to develop dementia at a younger age than in the general population. However, research indicates that the overall percentage of adults with Down syndrome who develop dementia is similar to that of the population who do not have Down syndrome. It is not inevitable that those with Down syndrome will develop dementia.”</td>
</tr>
<tr>
<td>Down’s Syndrome Association (UK)</td>
<td><a href="http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/getting-older/alzheimers-disease/">http://www.downs-syndrome.org.uk/for-families-and-carers/health-and-well-being/getting-older/alzheimers-disease/</a></td>
<td>“Alzheimer’s disease is a type of dementia that gradually destroys brain cells, affecting a person’s memory and their ability to learn, make judgments, communicate and carry out basic daily activities. Alzheimer’s disease is characterized by a gradual decline that generally progresses through three stages: early, middle and late stage disease.” “Dementia is not a disease in its own right. Dementia is an umbrella term covering more than 100 different conditions associated with a cognitive decline. One of these conditions is Alzheimer’s disease.”</td>
</tr>
<tr>
<td>National Down Syndrome Society (USA)</td>
<td><a href="http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/An-Introduction-to-Alzheimers-Disease/">http://www.ndss.org/Resources/Aging-Matters/Alzheimers-Disease/An-Introduction-to-Alzheimers-Disease/</a></td>
<td>“Alzheimer’s disease is a type of dementia that gradually destroys brain cells, affecting a person’s memory and their ability to learn, make judgments, communicate and carry out basic daily activities. Alzheimer’s disease is characterized by a gradual decline that generally progresses through three stages: early, middle and late stage disease. These three stages are distinguished by their general features, which tend to progress gradually throughout the course of the disease. Alzheimer’s disease is not inevitable in people with Down syndrome. While all people with Down syndrome are at risk, many adults with Down syndrome will not manifest the changes of Alzheimer’s disease in their lifetime. Although risk increases with each decade of life, at no point does it come close to reaching 100%. This is why it is especially important to be careful and thoughtful about assigning this diagnosis before looking at all other possible causes for why changes are taking place with aging. Estimates show that Alzheimer’s disease affects about 30% of people with Down syndrome in their 50s. By their 60s, this number comes closer to 50%.”</td>
</tr>
<tr>
<td>Down Syndrome Australia (AUS)</td>
<td><a href="http://www.dowsindrome.org.au/documents/Ageing_Resource_Health_Check.pdf">http://www.dowsindrome.org.au/documents/Ageing_Resource_Health_Check.pdf</a></td>
<td>“Alzheimer’s disease is a progressive degenerative condition of the brain that results in a gradual change, over years, in a person’s ability to think, remember and perform tasks of daily living. In ways that scientists don’t yet understand, the extra copies of genes present in people with Down syndrome cause developmental problems and health issues. Scientists think that the increased risk of dementia in individuals with Down syndrome may also result from the extra gene present on chromosome 21. Some studies suggest that 30 per cent of people with Down syndrome aged in their 50’s have Alzheimer’s disease and more than 75 per cent aged 65 and older have Alzheimer’s disease.”</td>
</tr>
</tbody>
</table>