PCAD Project

Working Resources List on Dementia Care Management and Intellectual Disability

Preparing Community Agencies for Adults Affected by Dementia - "PCAD" Project

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PCAD Project
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Working Resources List on Dementia Care

Adams,D., Oliver,C., Kalsy, S., Peters, S., Broquard, M., Basra, T., Konstandinidi, E., & McQuillan, S.
Behavioural characteristics associated with dementia assessment referrals in adults with Down syndrome.
Journal of Intellectual Disability Research. 2008 Apr;52(Pt 4):358-68. Epub 2008 Jan 22.
Abstract: Behavioral changes associated with dementia in Down syndrome are well documented, yet little is known about the effect of such behaviors on carers and referral. By comparing the behavioral and cognitive profiles of individuals referred for a dementia assessment with those of individuals not referred, some insight can be gained into behavioral characteristics that initiate referral for specialist support or interventions. Forty-six adults with Down syndrome were divided into two groups dependent upon method of entry into the study; post-referral to a specialist service for older adults with intellectual disabilities and Down syndrome for a dementia assessment (n = 17) or after receiving information sent out to day centers and residential homes (n = 29). These groups were compared on established measures of dementia alongside two informant measures of behavior. Those referred for a dementia assessment evidenced scores indicative of cognitive decline on both informant and direct Neuropsychological Assessments and showed more behavioral excesses, but not deficits, and lower socialization and coping skills than those in the comparison group. Carers of those referred for a dementia assessment reported a greater impact of behavioral excesses on staff than on the individual showing the behavior in contrast to the comparison group. The behavioral differences between those referred and the comparison group suggest that two factors are involved in the instigation of a referral for a dementia assessment: the nature of the behavioral presentation (excesses rather than deficits) and the effect of that behavioral change upon the care staff.

Alzheimer's Association
Guidelines for dignity: Goals of specialized Alzheimer/dementia care in residential settings
47 pp.
Chicago: The Alzheimer's Association [919 North Michigan Avenue, Suite 1000, Chicago, IL 60611-1676] (1992)
Abstract: Standards for care and structure of care settings housing persons affected by Alzheimer's disease. Includes sections on philosophy, pre-admission activities, admission, care planning and implementation, adapting to changes in condition, staffing and training, physical environment and "success indicators."

Alzheimer's Australia
Down syndrome and Alzheimer's disease
12 pp.
[Place of publication not provided] (no date)
Source: http://www.cddh.monash.org/assets/dsad-booklet-final.pdf
Abstract: Informational booklet on dementia and people with Down syndrome jointly issued by Alzheimer's Australia, Down Syndrome Victoria, and Centre for Developmental Disability Health Victoria. Contains three main sections: (1) About Alzheimer's disease and Down syndrome, (2) Diagnosis, and (3) Support, as well as a section on local resources.

Alzheimer's Disease International
Planning and design guide for community based day care centres
21 pp.
London: Alzheimer's Disease International [45/46 Lower Marsh, London SE1 7RG, United Kingdom (www.alz.co.uk)] (1999)
Abstract: An illustrated 21-page booklet highlighting main design issues and suggestions for organizing an effective environment for adults with dementia - with applications for residential environment.

Alzheimer's Disease Society
Safe as houses -- Living alone with dementia (A resource booklet to aid risk management)
London: Alzheimer's Disease Society [Gordon House, 10 Greencoat Place, London SW1P 1PH, United Kingdom] (1994)
30 pp.
Abstract: A 30 page booklet designed for the carer who is concerned about an older person with early to mid-stage dementia who may be living on their own. The booklet examines risks that the older adult may encounter and suggests how they could be minimized. The intent of the booklet is to aid the older person remain functional at home, with as minimal risk, for as long as possible. Covers personal care, finances, wandering, security, medication, utilities, and household safety. Whilst information is generic, resource information is geared toward the UK.

Alzheimer's Society
Learning disabilities and dementia
6 pp,
Alzheimer's Society UK
[Place of publication not provided] (2011)
Source:
http://alzheimers.org.uk/site/scripts/document_pdf.php?documentID=103
Abstract: Web-based booklet produced in the UK on the topic of intellectual disabilities and dementia. Contains background information, as well as diagnosis, identificatiion of symptoms and support and care services.

Antonangeli, J.M.
Of two minds: A guide to the care of people with the dual diagnosis of Alzheimer's Disease and mental retardation.
167 pp.
Malden, Mass.: Cooperative for Human Services [110 Pleasant Street, Malden, MA 02148] (1995)
Abstract: Written in training manual format, this text covers a range of topics related to dementia among persons with intellectual disabilities, including the notions behind dementia, structuring physical environments, safety and control issues, communication strategies, assessing and aiding with activities of daily living, behavior management strategies, medical concerns, and aiding carers. Much of the text is drawn from general practice in the Alzheimer's field with reference to application for settings with persons with intellectual disabilities.

Antonangeli. J.M.
The Alzheimer project: formulating a model of care for persons with Alzheimer's disease and mental retardation
American Journal of Alzheimer's Disease, 1995, 10(4), 13-16.
Abstract: Article speaks to a pilot project conducted in Massachusetts to increase staffing, education and Alzheimer case management supports. Special supports were designed and offered to a number of adults with Down syndrome affected by dementia, including specialize assessments, team care planning meetings, home adaptations and behavior loss supports.

Aylward, E., Burt, D., Thorpe, L., Lai. & Dalton, A.J.
Diagnosis of dementia in individuals with intellectual disability: report of the task force for development of criteria for diagnosis of dementia in individuals with mental retardation
Journal of Intellectual Disability Research, 1997, 41, 152-164
Abstract: The foremost impediment to progress in the understanding and treatment of dementia in adults with intellectual disability is the lack of standardized criteria and diagnostic procedures. Standardized criteria for the diagnosis of dementia in individuals with intellectual disability are proposed, and

their application is discussed. In addition, procedures for determining whether or not criteria are met in individual cases are outlined. It is the intention of the authors, who were participants of an International Colloquium on Alzheimer Disease and Mental Retardation, that these criteria be appropriate for use by both clinicians and researchers. Their use will improve communication among clinicians and researchers, and will allow researchers to test hypotheses concerning discrepancies in findings among research groups (e.g. dementia prevalence ranges and age of onset). [This report is available also on www.aamr.org at the following URL: http://161.58.153.187/Bookstore/Downloadables/index.shtml]

Ball, S.L., Holland, A.J., Hon, J., Huppert, F.A., Treppner, P., & Watson, P.C.
Personality and behaviour changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study.
International Journal of Geriatric Psychiatry, 2006, 21(7), 661-673
Abstract: Research based on retrospective reports by carers suggests that the presentation of dementia in people with Down syndrome may differ from that typical of Alzheimer's disease (AD) in the general population, with the earliest changes tending to be in personality or behavior rather than in memory. This is the first long-term prospective study to test the hypothesis that such changes, which are more typical of dementia of frontal type (DFT) in the general population, mark the preclinical stage of AD in DS. A previously identified population sample of older people with DS, first assessed in 1994 and followed-up 18 months later, were reassessed after a further 5 years. This study focuses on the 55 individuals who took part in the second follow-up. Dementia diagnosis was made using the modified CAMDEX informant interview and neuropsychological assessment was undertaken using the CAMCOG. Progression in clinical presentation was examined and degree of cognitive decline over time (on the CAMCOG and derived measures of executive function (EF) and memory) was compared across groups based on diagnosis and age: AD, DFT, personality/behavior changes insufficient for a diagnosis of DFT (PBC), no diagnosis <50 years and no diagnosis 50 + years. Progression was observed from early changes in personality and behavior to an increase in characteristics associated with frontal lobe dysfunction and/or a deterioration in memory, prior to the development of full AD. Individuals who met criteria for DFT were significantly more likely to progress to a diagnosis of AD over the following 5 years than those who did not and those with PBC were significantly more likely to progress to a more severe diagnosis (DFT or AD) than those without. In the 5 years prior to diagnosis, participants with PBC and DFT had shown a degree of global cognitive decline intermediate between those with no dementia and those with AD. Both these groups had shown a significant decline in EF but not in memory, while the AD group had shown significant decline on both measures, with a significantly greater degree of decline in memory. Older participants without informant reported changes showed a more generalized pattern of decline. These findings confirm that the early presentation of AD in DS is characterized by prominent personality and behavior changes, associated with executive dysfunction, providing support for the notion that the functions of the frontal lobes may be compromised early in the course of the disease in this population. This has important implications for the diagnosis, treatment and management of dementia in people with DS.

Ball, S.L., Holland, A.J., Treppner, P., Watson, P.C., & Huppert, F.A.
Executive dysfunction and its association with personality and behaviour changes in the development of Alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities.
British Journal of Clinical Psychology, 2008, 47(Pt 1), 1-29.
Abstract: Recent research suggests that preclinical Alzheimer's disease (AD) in people with Down syndrome (DS) is characterized by changes in personality/behavior and executive dysfunction that are more prominent than deterioration in episodic memory. This study examines the relationship between executive dysfunction and the clinical and preclinical features of AD in DS. To determine the specificity of this relationship, performance on executive function (EF) measures is contrasted with performance on memory measures. One hundred and three people with DS (mean age 49 years, range 36-72) with mild to moderate learning disabilities (LD) took part. Dementia diagnosis was based on the CAMDEX informant interview conducted with each participant's main carer. Reported changes in personality/behavior and memory were recorded. Participants completed six EF and six memory measures (two of which also had a strong executive component) and the BPVS (as a measure of general intellectual ability). First, performance was compared between those with and without established dementia of Alzheimer's type (DAT), controlling for age and LD severity using ANCOVA. Next, the degree to which informant-reported changes predicted cognitive test performance was examined within the non-DAT group using multiple regression analyses. The DAT group (N=25) showed a consistent pattern of impaired performance relative to the non-DAT group (N=78), across all measures. Within the non-DAT group, number of informant-reported personality/behavior changes was a significant predictor of performance on two EF and two 'executive memory' tests (but not on episodic memory tests). Informant-reported memory changes, however, were associated with impaired performance on a delayed recall task only. These findings provide further evidence for a specific impairment in frontal-lobe functioning in the preclinical stages of AD in DS.

Bauer, A.M., & Shea, T.M.
Alzheimer's disease and Down syndrome: A review and implications for adult services
Education and Training of the Mentally Retarded, 1986, 21, 144-150
Abstract: In this article, the diagnosis of Alzheimer's disease and its progressive behavioral impact on persons with Down syndrome is discussed. Several implications and suggestions for care and service provision for adults with Down syndrome are presented, including that Alzheimer's disease in an adult with Down syndrome has an impact on the carer, adjusting communication strategies to correspond to the stage of dementia, aiding families to seek assistance from social agencies, stressing the remaining abilities and skills, aiding families and carers to develop realistic methods of providing care, and adapting the persons care and environment to help them cope with losses stemming from dementia. The authors also suggest proactive strategies for anticipating decline among adults with Down syndrome associated with dementia.

Bishop KM, Hogan M, Janicki MP, Keller SM, Lucchino R, Mughal DT, Perkins EA, Singh BK, Service K, Wolfson S; Health Planning Work Group of the National Task Group on Intellectual Disabilities and Dementia Practices.
Guidelines for dementia-related health advocacy for adults with intellectual disability and dementia: national task group on intellectual disabilities and dementia practices.
Intellect Dev Disabil. 2015 Feb;53(1):2-29. doi: 10.1352/1934-9556-53.1.2
Abstract: Increasing numbers of adults with intellectual disabilities (ID) are living into old age. Though this indicates the positive effects of improved health care and quality of life, the end result is that more adults with ID are and will be experiencing age-related health problems and also exhibiting symptoms of cognitive impairment and decline, some attributable to dementia. Early symptoms of dementia can be subtle and in adults with ID are often masked by their lifelong cognitive impairment, combined with the benign effects of aging. A challenge for caregivers is to recognize and communicate symptoms, as well as find appropriate practitioners familiar with the medical issues presented by aging adults with lifelong disabilities. Noting changes in behavior and function and raising suspicions with a healthcare practitioner, during routine or ad hoc visits, can help focus the examination and potentially validate that the decline is the result of the onset or progression of dementia. It can also help in ruling out reversible conditions that may have similar presentation of symptoms typical for Alzheimer's disease and related dementias. To enable caregivers, whether family members or staff, to prepare for and advocate during health visits, the National Task Group on Intellectual Disabilities and Dementia Practices has developed guidelines and recommendations for dementia-related health advocacy preparation and assistance that can be undertaken by provider and advocacy organizations.

Bittles, A.H., & Glasson, E.J.
Clinical, social, and ethical implications of changing life expectancy in Down syndrome
Developmental Medicine & Child Neurology, 2004, 46, 282-286.
Abstract: Increased life expectancy generates greater ethical and legal dilemmas in the treatment of people with Down syndrome. Assumptions that younger cohorts of people with DS will experience healthier lives when compared to previous generations may not be realized as specific health issues associated with DS are genetically encoded and thus contemporary generations may face the same adverse health issues. With respect to dementia, authors note that by age 60 years, dementia involving memory loss, cognitive decline, and changes in adaptive behavior may be present in at least 56% of adults with DS and that some the neuropathological features of Alzheimer disease may be evident as early as age 40.

Bowers, B., Webber, R., & Bigby, C.
Aging and health related changes of people with intellectual disabilities living in group homes in Australia.
Journal of Policy and Practice in Intellectual Disabilities, 2009, 6(2), 98. [SINGLE PAGE]
Abstract: Group homes for people with ID are based on social models, emphasizing inclusion, engagement in community, and quality of life. As age related changes occur, group home staff members are faced with decisions about how to respond, how to support people experiencing health problems, and whether or for how long people can remain in the group homes. This study explored how group home staff members respond to aging and age related health conditions in group home residents and to identify factors that put people at risk of premature or inappropriate relocation. Using a longitudinal design in order to observe, over time, the onset of health problems, the initial responses of housing staff to health, the development of health conditions, the consequences of their initial responses, and the outcomes for both staff and residents were considered. In-depth interviews were conducted—at three 6-month intervals with 18 clusters of the housing manager, family member, the person with the disability, and in some cases, healthcare providers. A total of 91 interviews were completed, transcribed, and analyzed and in keeping with the theory-generating approach, early interviews were open and exploratory, evolving over time to facilitate comparative analysis across groups, strategies, conditions, and care issues. Staff and family members agreed that aging and the development of associated health conditions was increasingly becoming an issue for them. Significantly, there was wide variation among housing staff in terms of philosophy of care, with some believing that people should be supported to remain at the group homes for as long as possible. This, however, required the acquisition of new resources, a range of organizational changes to support staff and residents, changes to staffing patterns and levels, and a change in recruiting as a strategy to alter skill mix of house workers. Authors concluded that problems identified by most housing staff included: (a) inability of residents to retire despite age and health status; (b) risk of premature moves to aged care; and © disruption to general house activities and routines of other residents. Staff members' experienced altered work routines, concerns about the safety of residents and themselves, and frequent turnover. Availability of resources, such as equipment and home modifications, flexibility of staffing to accommodate changing resident needs, and philosophy of care all had a significant impact on residents' ability to "stay home."

Bowey, L. & McGlaughlin, A.
Adults with a learning disability living with elderly carers talk about planning for the future: Aspirations and concerns. *British Journal of Social Work*, 2005, 35(8), 1377-1392. DOI: https://doi.org/10.1093/bjsw/bch241
Abstract: The majority of adults with an intellectual disability live with family carers, many of whom are ageing and have support needs of their own. Planning for the future thus becomes the key to preventing a crisis situation when family care is no longer viable because of death or ill health. Existing knowledge and practice are largely based upon the perspective of professionals and carers. This study explored the views, aspirations and concerns of adults with an intellectual disability, about living at home and planning for the future. Findings show that participants were very aware of the need for alternative housing or support in the future and had clear preferences about their future options. However, they also showed extensive concern for their family carers and this often impacted on their willingness to plan for the future or to move to alternative housing. Their demonstrable awareness of the inevitable death or ill health of family carers, and willingness to engage with the implications, emphasize the importance of involving adults with intellectual disability in planning for their future, as well as providing them with bereavement support.

Brawley, E.C.
Designing for Alzheimer's disease - Strategies for creating better care environments.
313 pp.
New York: Wiley (1997)
Abstract: 20 chapter general text on adapting homes and living environments for persons with dementia; applicable to home and other residential situations for adults with intellectual disabilities and dementia. Chapter sections include Aging and Alzheimer's disease, Sensory environment (light and aging vision, lighting, impact of color, patterns and texture, acoustical changes, and wayfinding guidelines), Special care settings (creating a home feeling, designing spaces, therapeutic gardens and outdoor spaces), Implementing effective interior design (furniture and fabrics, floor-covering, wall and ceiling finishes, windows and window treatments), and the Design process. Contains a directory of resources and a glossary of terms.,

Burt, D.B., & Aylward, E.
Assessment methods of diagnosis of dementia
In M.P. Janicki & A.J. Dalton (Eds.), Dementia, Aging, and Intellectual Disabilities.
pp. 141-156
Philadelphia: Brunner-Mazel (1999)
Abstract: Standardized diagnostic criteria and procedures are proposed to further progress in the understanding and treatment of dementia in adults with intellectual disabilities. This book chapter is a revised summary of previous reports prepared by participants of an international working group, which was conducted under the auspices of the International Association on Intellectual Disability and the American Association on Mental Retardation. Similarities in diagnostic issues between adults with intellectual disability and those in the general population are discussed, followed by a summary of issues unique to adults with intellectual disability. A brief overview of the application of ICD-10 diagnostic criteria to adults with intellectual disability is presented, including a description of procedures for determining whether criteria are met in individual cases. Finally, clinical and research recommendations are made.

Cairns, D., Kerr, D., Chapman, A.
Difference realities: a training guide for people with Down's syndrome and Alzheimer's disease
pp. 54
University of Stirling (Dementia Services Development Centre), Stirling, Scotland FK9 4LA
A working guide for staff who are working with people with intellectual disabilities affected by Alzheimer's disease. Topical sections cover the definitions of dementia and deal with diagnostic suggestions, as well as dealing with communication, helping maintenance of skills, dealing with challenging behaviors, structuring activities, and overall management of dementia. Written in an easy style, this guide is a very useful addition to any materials given to staff to help them understand and related to people affected by dementia.

Cairns, V., Lamb, I., & Smith, E.
Reflections upon the development of a dementia screening service for individuals with Down's syndrome across the Hyndburn and Ribble Valley area.
British Journal of Learning Disabilities, 2011, 39(3), 198-208.
Abstract: The high prevalence of dementia in individuals with Down's syndrome has led intellectual disability services in the Hyndburn and Ribble Valley (HRV) area of England to develop a screening service to address this need. The authors offer reflections upon this process by its members after the first 12 months of operation. A multidisciplinary team, comprising professionals from intellectual disability psychology, intellectual disability speech and language therapy, intellectual disability community nursing and older adults psychiatry, has developed, and begun to implement, screening care pathways. The service conducts routine screening assessments, provides intervention for individuals where concerns arise and delivers training to carers. At the point of writing, 27 service users have received screening assessments and six have been identified as at moderate–high risk of developing dementia. Reflection and feedback has highlighted issues for consideration throughout the service development process, and an evaluation of the training provided by the service has found this to be effective in increasing carers understanding about dementia and intellectual disabilities.

Carfi, A., Antociccio, M., Brandi, V., Cipriani, C., Fiore, F., Mascia, D., Vetrano, D.L., Onder, G..
Down syndrome in adulthood: A disease for geriatricians
European Geriatric Medicine, 2014, 5(Supp 1), 549.
Abstract: Authors evaluated 89 adults with Down syndrome at a clinic in Rome, Italy, using a range of physiological and neurological methods, including nutritional and sensory assessments. The S's mean age was 42 years (range 18 to 72); 51% were females. Authors found behavioral disorders (53%), mood disorders (43%), seizures (22%), osteoporosis (40%), hypothyroidism (53%), diastolic dysfunction (80%), OSAS (90%), and hearing impairment (82%). Authors noted severe cognitive impairments in 67%, BMI greater than 25 in 66%, and low scores on physical performance measures (50%). Authors conclude that the pattern of diseases and conditions noted resemble those of other older adults and recommend that a mandatory geriatric evaluation be undertaken in older adults with Down.

Carmeli, E., Ariav, C., Bar-Yossef, T., & Levy, R.
Movement skills in persons with Down syndrome decrease with aging
International Journal on Disability and Human Development, 2010, 9(1), 29–34.
Abstract: Persons with Down syndrome (DS) are comparatively physically inactive, which could accelerate the onset of disease, resulting in symptoms associated with aging that are detrimental to health. The aim was to evaluate movement abilities across the life span in persons with DS. Eleven persons with DS (>50 years, mean age 58 years), and 10 younger persons with DS (<49 years, mean age 28 years) who resided in a residential living center were included in the study. Age- and gender-matched people without DS (n=22) served as control group. Five sensory-motor tasks that involved the integration of hand movements with visual information were used, as well as the posture scale analyzer system to examine postural stability. Results showed that the older persons with DS had more medical problems than the young persons with and without DS. The hand coordination and postural stability of the older adults with DS were more impaired in comparison with the young group and both control groups. It is postulated that their poor motor function and slower responses might be explained by a less active lifestyle, that could accelerate the onset of disease, resulting in symptoms associated with aging that are detrimental to health. Our observations could have significant implications for understanding the mechanisms underlying movement dysfunction in older adults with DS and might offer new approaches for possible prevention.

Carling-Jenkins, R., Torr, J., Iacono, T., & Bigby, C.
Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments.
Journal of Intellectual and Developmental Disability, 2012, 37(1), 54-60.
Abstract: Australian research addressing the experiences of families of adults with Down syndrome and Alzheimer's disease in seeking diagnosis and gaining support is limited. The aim of this study was to gain a greater understanding of these processes by exploring the experiences of families and carers in supporting people with Down syndrome and Alzheimer's disease who had lived most or all of their lives with family. Three detailed case studies were created from multiple data sources, and then analyzed thematically. Families of adults with Down syndrome experienced stress and confusion as they negotiated a service system poorly equipped to meet their needs and professionals more focused on longstanding disability than the recent diagnosis of Alzheimer's disease. Such overshadowing led to mismanagement by services. Authors conclude that this research advances understandings of the support needs of people with Down syndrome and Alzheimer's disease and their families and exposes gaps in the service system.

Carr, J., & Collins, S.
Ageing and dementia in a longitudinal study of a cohort with Down syndrome.
Journal of Applied Research in Intellectual Disabilities, 2014, 27(6), 555-563.
Abstract: A population sample of people with Down syndrome has been studied from infancy and has now been followed up again at age 47 years. Intelligence and language skills were tested and daily living skills assessed. Memory/cognitive deterioration was examined using two test instruments. Scores on verbal tests of intelligence changed little. Those on a non-verbal test, on self-help skills and on both memory tests showed some decline, even when the scores of those already suffering from dementia were discounted. At age 47, scores on most tests of even the majority of the cohort (i.e. those not definitely diagnosed with dementia) showed some decline. While this includes the scores of people who may subsequently develop dementia, it may also reflect the normal ageing process in this population.

Castro, P., Zaman, S., & Holland, A.
Alzheimer's disease in people with Down's syndrome: the prospects for and the challenges of developing preventative treatments.
Journal of Neurology, 2017, Apr;264(4), 804-813. doi: 10.1007/s00415-016-8308-8. Epub 2016 Oct 24.
Abstract: People with Down's syndrome (DS) are at high risk for developing Alzheimer's disease (AD) at a relatively young age. This increased risk is not observed in people with intellectual disabilities for reasons other than DS and for this reason it is unlikely to be due to non-specific effects of having a neurodevelopmental disorder but, instead, a direct consequence of the genetics of DS (trisomy 21). Given the location of the amyloid precursor protein (APP) gene on chromosome 21, the amyloid cascade hypothesis is the dominant theory accounting for this risk, with other genetic and environmental factors modifying the age of onset and the course of the disease. Several potential therapies targeting the amyloid pathway and aiming to modify the course of AD are currently being investigated, which may also be useful for treating AD in DS. However, given that the neuropathology associated with AD starts many years before dementia manifests, any preventative treatment must start well before the onset of symptoms. To enable trials of such interventions, plasma, CSF, brain, and retinal biomarkers are being studied as proxy early diagnostic and outcome measures for AD. In this systematic review, we consider the prospects for the development of potential preventative treatments of AD in the DS population and their evaluation.

Centre for Developmental Disability Health Victoria
Dementia and Intellectual Disability – A guide to supporting people with intellectual disabilities through their journey with dementia: Online Learning for Disability Support Workers
http://www.cddh.monash.org/online-learning/
Abstract: These are on-line learning modules for disability staff supporting people who were at risk of developing, or had already been identified as having, dementia. There are four 16 minute nodules in the series addressing key questions you may have when supporting someone with dementia. They cover helpful information related to dementia and ID. Module 1: Understanding dementia and intellectual disability; Module 2: Taking action – The role of the support worker in assessment; Module 3: Supporting someone with intellectual disability and dementia; and Module 4: Supporting people through environment and activity. There are also a series self-taking test questions.

Chaput, J.L.
Housing people with Alzheimer disease as a result of Down syndrome: a quality of life comparison between group homes and special care units in long term care facilities.
Master's thesis, Department of City Planning, University of Manitoba (1998)
Abstract: Report of study to determine which form of housing, group homes or special care units (SCUs), provided an enhanced quality of life for individuals with Down syndrome (DS) and Alzheimer disease (AD). Ten long term care (LTC) facilities with SCUs for people with AD in the Winnipeg, Canada area and ten group homes for people with DS and AD across Canada participated in the study. Results indicated that the group homes seemed to provide an enhanced quality of life for adults with DS and AD because they provided a home-like environment and they operated according to a therapeutic philosophy of care. In addition, costs for caregiving seemed to be more economical in group homes than in SCUs because group homes utilized lower staff wages and medical costs. Report provides information on practices and costs.

Chaput, J.L. & Udell, L.
Housing people with Alzheimer disease as a result of Down syndrome: a quality of life comparison between group homes and special care units in long term care facilities.
Journal of Intellectual Disability Research, 2000, 44, 236 (abstract No. 186)
[Paper presented at the 11th World Congress of the International Association for the Scientific Study of Intellectual Disabilities, Seattle, Washington (USA), August 1-6, 2000]
Abstract: The purpose of the study was to determine which form of housing, i.e., group homes or special care units (SCUs), provided a better quality of life for individuals with Alzheimer disease (AD) as a result of Down syndrome (DS). The study also provided Winnserv Inc. (a non-profit housing organization that houses people with mental disabilities) with important information. Using the study results, Winnserv Inc. was able to determine that their group homes were suitable to maintain individuals with DS and AD and that their group homes were more cost-effective than SCUs in terms of caregiving. Twenty caregivers from both group homes and SCUs were selected to participate in this study. Ten long term care (LTC) facilities with SCUs for people with AD were selected in the Winnipeg area and ten group homes for people with Down syndrome and AD were chosen in Winnipeg and across Canada. The results indicated that the group homes seemed to provide the best quality of life for people with AD as a result of Down syndrome because they provided a home-like environment and they operated according to a therapeutic philosophy of care. In addition, costs for caregiving seemed to be more economical in group homes than in SCUs because group homes utilized lower staff wages and medical costs. Based on the results, it was recommended that Winnserv Inc. continue to house people with DS and AD.

Chaput, J.L.
Adults with Down syndrome and Alzheimer's disease: Comparisons of services received in group homes and in special care units
Journal of Gerontological Social Work, 2002, 38, 197-211
Abstract: An increasing number of people with Down syndrome are at risk of

dementia resulting from Alzheimer's disease. Many reside in community group homes. When they are affected by dementia, the challenge to agencies providing group homes is how to best provide continued housing and provide effective dementia-related care management. In the general population, long term care is typically provided in nursing facilities, often in special care units (SCUs). This study evaluated select factors found in group homes and SCUs to determine which is able to provide a better quality of life for people with Down syndrome affected by dementia. Interviews, using quality of life indicators, were conducted at 20 sites, equally selected from group homes and SCUs, on the basis of their experience with people with dementia. Results indicate that group homes can provide conditions associated with better quality of life and, additionally, operate with lower staffing costs due to the non-utilization of medical staff.

Ciprianim G., Danti, S., Carlesi, C., & DiFiorino, M.
Aging with Down syndrome: the dual diagnosis - Alzheimer's disease and Down syndrome
American Journal of Alzheimer's Disease & Other Dementias, 2018, 33(4), 253-262.
Abstact: People with Down syndrome (DS) enjoy a longer life expectancy now than they ever have before and are therefore at greater risk of developing conditions associated with aging, including dementia. Authors undertook at review to explore the phenomenon of dementia in DS. Medline and Google Scholar searches were conducted for relevant articles, chapters, and books published until 2017. Search terms included Alzheimer's disease, cognitive impairment, dementia, DS, and trisomy 21. Publications found through this indexed search were reviewed for further references. Authors concluded that virtually, all subject aged 35 to 40 show key neuropathologic changes characteristic of Alzheimer's disease, but only a part of them show clinical signs of dementia, usually around the age of 50 years. Early signs of dementia in people with DS may be different from those experienced by the general population. Failure to recognize this can delay diagnosis and subsequent interventions

Cleary, J., & Doody, O.
Professional carers' experiences of caring for individuals with intellectual disability and dementia: A review of the literature.
Journal of Intellectual Disabilities, [2016] e-print
Abstract: The number of people with intellectual disability living into old age and developing dementia continues to increase. Dementia presents a wide range of challenges for staff due to progressive deterioration. This article presents the findings from a narrative literature review of professional caregivers' experiences of caring for individuals with intellectual disability and dementia. Seven electronic databases were searched using Boolean operators and truncation to identify relevant literature. Search results were combined and narrowed to articles relevant to staff working with individuals with intellectual disability and dementia, and 14 articles met the criteria for review. Themes outlined in the review include staff knowledge of dementia, staff training in dementia, caregiving, challenging behavior, pain management, mealtime support and coping strategies. Overall carers must review and adjust their care delivery and support to people with intellectual disability and dementia, not only in terms of identifying and responding to their health needs but also through collaborative team working within and across services.

Cleary J, & Doody O.
Nurses' experience of caring for people with intellectual disability and dementia. Journal of Clinical Nursing, 2017, 26(5-6), 620-631. doi: 10.1111/jocn.13431. Epub 2016 Nov 14.
Abstract: The authors endeavored to explore nurses' experiences of caring for older people with intellectual disability and dementia. Ageing and dementia prevalence is increasing along with the life expectancy of people with intellectual disability. As a population group, people with intellectual disability have a high prevalence of dementia, which is higher within the subpopulation of Down syndrome. People with intellectual disability live in residential care, community or residential settings, and nurses are required to adapt their practices to meet the changed needs of the individual. A qualitative Husserlian descriptive phenomenological methodology was undertaken by the researchers so as to be able to become absorbed in the quintessence of meaning and explore nurses' experience of working with older people with intellectual disability and dementia. Ethical approval was obtained, and data were collected utilizing semistructured interviews (n = 11). Interviews were transcribed and analyzed using Colaizzi's framework for data analysis. The authors extracted three key themes were identified: 'knowledge of dementia', 'person-centred care' and 'transitioning within the service'. The study highlights the need for proactive planning, life story books of the patient, and funding to support client and staff. The authors concluded that overall, the study highlights the importance of knowing the person, supporting the individual and recognizing presenting behaviors as outside the control of the individual. The article presents the experiences of nurses caring for the older person with intellectual disability and dementia. Transitions are often very difficult for both the person and their peers, and they experience benefit from the efforts of a multidisciplinary team facilitating a person-centered approach.

Cohen, U., & Wiesman, G.D.
Holding on to home: Designing environments for people with dementia.
181 pp.
Baltimore: Johns Hopkins University Press (1991)
Abstract: General text on adapting homes and living environments for persons with dementia; applicable to home and other residential situations for adults with intellectual disabilities and dementia.

Collacott R.A.
Epilepsy, dementia and adaptive behaviour in Down's syndrome.
Journal of Intellectual Disability Research, 1993, 37(2), 153-60.
Abstract: Widespread inquiry identified 378 adults with Down's syndrome resident in Leicestershire, England. The immediate carer of 351 of these (92.8%) was interviewed for the purpose of establishing a past history of seizures, including the age at which the seizures began. The immediate carer was also invited to provide information to enable the completion of an Adaptive Behaviour Scale (A.B.S.) rating. Individuals with a history of seizures were divided into two groups on the basis of whether or not seizures commenced prior to or after age 35 years. Two control groups of individuals with Down's syndrome, but without a history of seizures were selected. Adaptive Behaviour Scale scores for those in whom seizures commenced at a younger age were similar to those who had no recorded history of seizures. However, in those in whom seizures began in later life, scores on all domains of the A.B.S. were significantly reduced compared to both young epileptic patients and their controls. Adaptive Behaviour Scale scores for the older control group held an intermediate position, suggesting that late-onset epilepsy may be a late manifestation of a dementing process. A clinical diagnosis of dementia recorded in the case records was significantly associated with the presence of late-onset epilepsy. This is supportive of the hypothesis that late-onset epilepsy in individuals with Down's syndrome is associated with Alzheimer's disease.

Coppus A , Evenhuis H, Verberne GJ, Visser F, van Gool P, Eikelenboom P, van Duijin C.
Dementia and mortality in persons with Down's syndrome.
Journal of Intellectual Disability Research, 2006, 50(10), 768-77.
Abstract: Numerous studies have documented that persons with Down's syndrome (DS) are at an increased risk of Alzheimer's disease (AD). However, at present it is still not clear whether or not all persons with DS will develop dementia as they reach old age. We studied 506 people with DS, aged 45 years and above. A standardized assessment of cognitive, functional and physical status was repeated annually. If deterioration occurred, the patients were examined and the differential diagnosis of dementia was made according to the revised Dutch consensus protocol and according to the ICD-10 Symptom Checklist for Mental Disorders. We compared our findings with those reported in the literature. The overall prevalence of dementia was 16.8%. Up to the age of 60, the prevalence of dementia doubled with each 5-year interval. Up to the age of 49, the prevalence is 8.9%, from 50 to 54, it is 17.7%, and from 55 to 59, it is 32.1%. In the age category of 60 and above, there is a small decrease in prevalence of dementia to 25.6%. The lack of increase after the age of 60 may be explained by the increased mortality among elderly demented DS patients (44.4%) in comparison with non-demented patients (10.7%) who we observed during a 3.3-year follow-up. There was no decrease in incidence of dementia in the age group of 60 and above. Our findings are very similar to those published in the literature. Patients with dementia were more frequently treated with antiepileptic, antipsychotic and antidepressant drugs. The history of depression was strongly associated with dementia. Our study is one of the largest population-based studies to date. We found that despite the exponential increase in prevalence with age, the prevalence of dementia in the oldest persons with DS was not higher than 25.6%.

Coppus, A.M.W , Evenhuis, H.M, Verberne, G-J., Visser, F.E., Oostra, B.A. Eikelenboom, P., van Gool, W.A., Cecile, A., Janssens, J.W. , van Duijn, C.M.
Survival in elderly persons with Down syndrome.
Journal of the American Geriatrics Society, 2008, 56(12), 2311 - 2316.
Abstract: The longer life expectancy now experienced by persons with Down syndrome (DS) makes it necessary to know the factors influencing survival in older persons with this syndrome. In a prospective longitudinal cohort study of dementia and mortality, 506 persons with DS aged 45 and older were followed for a mean of 4.5 years (range 0.0–7.6 years). Cognitive and social functioning were tested at baseline and annual follow-up. The diagnosis of dementia was determined according to a standardized protocol. Cox proportional hazards modeling was used for survival analysis. Relative preservation of cognitive and functional ability is associated with better survival in this study population. Clinically, the most important disorders in persons with DS that are related to mortality are dementia, mobility restrictions, visual impairment, and epilepsy -- but not cardiovascular diseases. Also, level of intellectual disability and institutionalization were associated with mortality.

Cooper, S-A.
High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome. Psychological Medicine, 1997, 27(3), 609-616.
Abstract: For many years, it has been known that dementia can occur in people with learning disabilities, but there have been few research studies. Studies that do quote rates for dementia show these to be high, but this important fact has received remarkably little attention. Comprehensive psychiatric and medical assessments were undertaken on the whole population (ascertained as far as is possible) of people with learning disabilities aged 65 years and over living in Leicestershire, UK (N=134), in order to ascertain rates of DCR defined dementia, and associated factors. Dementia was diagnosed in 21·6%, against an expected prevalence of 5·7%, for a group with this age structure. The rate of dementia increased in successive age cohorts: 15·6% aged 65-74 years; 23·5% aged 65-84 years; and 70·0% aged 85-94 years. People with dementia tended to be older, female, with more poorly controlled epilepsy, a larger number of additional physical disorders, less likely to be smokers and had lower adaptive behavior scores than did the elderly people without dementia. They were more likely to live in health service accommodation. Dementia occurs at a much higher rate among elderly people with learning disabilities than it does among the general population; this is independent of the association between dementia and Down's syndrome. Whether this relates etiologically to genetics, lack of brain 'reserve' or history of brain damage is yet to be determined.

Coppus, A., Evenhuis, H., Verberne, G.J., Visser, F., van Gool, P., Eikelenboom, P., & van Duijin, C.
Dementia and mortality in persons with Down's syndrome.
Journal of Intellectual Disability Research, 2006, Oct;50(Pt 10):768-77.
Abstract: Numerous studies have documented that persons with Down syndrome (DS) are at an increased risk of Alzheimer's disease (AD). However, at present it is still not clear whether or not all persons with DS will develop dementia as they reach old age. The authors studied 506 people with DS, aged 45 years and above. A standardized assessment of cognitive, functional and physical status was repeated annually. If deterioration occurred, the patients were examined and the differential diagnosis of dementia was made according to the revised Dutch consensus protocol and according to the ICD-10 Symptom Checklist for Mental Disorders. We compared our findings with those reported in the literature. The overall prevalence of dementia was 16.8%. Up to the age of 60, the prevalence of dementia doubled with each 5-year interval. Up to the age of 49, the prevalence is 8.9%, from 50 to 54, it is 17.7%, and from 55 to 59, it is 32.1%. In the age category of 60 and above, there is a small decrease in prevalence of dementia to 25.6%. The lack of increase after the age of 60 may be explained by the increased mortality among elderly demented DS patients (44.4%) in comparison with non-demented patients (10.7%) who we observed during a 3.3-year follow-up. There was no decrease in incidence of dementia in the age group of 60 and above. Our findings are very similar to those published in the literature. Patients with dementia were more frequently treated with antiepileptic, antipsychotic and antidepressant drugs. The history of depression was strongly associated with dementia. The authors concluded that their study is one of the largest population-based studies to date. We found that despite the exponential increase in prevalence with age, the prevalence of dementia in the oldest persons with DS was not higher than 25.6%.

Coppus AM, Evenhuis HM, Verberne GJ, Visser FE, Eikelenboom P, van Gool WA, Janssens AC, van Duijn CM.
Early age at menopause is associated with increased risk of dementia and mortality in women with Down syndrome.
J Alzheimers Dis. 2010;19(2):545-50. doi: 10.3233/JAD-2010-1247.
Abstract: In a prospective longitudinal cohort study of dementia and mortality in persons with Down syndrome aged 45 years and older, 85 postmenopausal women were followed for a mean follow-up time of 4.3 years (range 0.0 to 7.4 years). The effect of age at menopause on age at diagnosis of dementia and survival was estimated using correlation analysis and Cox Proportional Hazard Model. We found a significant correlation between age at menopause and age at diagnosis of dementia (rho=0.52; p< 0.001), and between age at menopause and age at death (rho=0.49; p=0.01). Early age at menopause is associated with a 1.8 fold increased risk of dementia: Hazard Ratio (HR): 1.82 (95% Confidence Interval (CI): 1.31-2.52) and with risk of death: HR: 2.05 (95% CI: 1.33-3.16). Our study suggests that age at menopause in women with Down syndrome is a determinant of age at onset of dementia and mortality.

Cosgrave, M.P., Tyrrell, J., McCarron, M., Gill, M., & Lawlor, B.A.
Determinants of aggression, and adaptive and maladaptive behavior in older people with Down's syndrome with and without dementia.
Journal of Intellectual Disability Research, 1999, 43(5), 393-399.
Abstract: In a cross-sectional study of aggression, and adaptive and maladaptive behavior in 128 subjects with Down's syndrome (DS), 29 of whom had dementia, the current authors found that the presence of dementia was not predictive of aggression or maladaptive behavior. However, the level of adaptive behavior was shown to be lower in subjects with dementia, and in those with lower levels of cognitive functioning, as measured on a rating instrument, the Test for Severe Impairment. Although the presence of aggressive behaviors is not higher in subjects with dementia and DS on cross-sectional review, it remains to be seen whether aggression will increase in individual cases with the onset or progression of dementia. The decline in adaptive behavior shown in the present study confirms the findings of previous studies and indicates a direction for service development for persons with the dual diagnosis of dementia and DS.

Cosgrove, M.P., Tyrrell, J., McCarron, M., Gill, M., & Lawlor, B.A.
Age at onset of dementia and age of menopause in women with Down;s syndrome.
Journal of Intellectual Disability Research, 1999, 43(6), 461-465.
Abstract: Menstrual status and the age of menopause were investigated in 143 Irish females with Down's syndrome (DS). The average age of menopause in 42 subjects (44.7 years) was younger than in the general population. The age at onset of dementia correlated with the age of menopause. This finding may be a manifestation of accelerated ageing in DS or point to oestrogen deficiency being an independent risk factor for the development of Alzheimer's

Courtenay, K., Jokinen, N.S., & Strydom, A.
Caregiving and adults with intellectual disabilities affected by dementia
Journal of Policy and Practice in Intellectual Disabilities, 2010, 7(1), 26 - 33.
Abstract: Authors conducted a systematic review of the available Dutch, English, and German language literature for the period 1997–2008 on the current knowledge on social-psychological and pharmacological caregiving with respect to older adults with intellectual disabilities (ID) affected by dementia. Authors note that caregiving occurs on a personal level between the person and their carer and organizational and interorganizational supports have an impact on the quality of care provided. However, the lack of robust evidence to meet the needs of adults with ID affected by dementia means that service organizations often have to extrapolate from the evidence base of dementia care practices in the general population. The review showed that concerns over staff burden, behavioral interventions, and staff training, and applications of models of care were emerging, but were not systematically studied. Authors noted that pharmacological agents and nonpharmacological, psychosocial techniques were being used to assist carers manage behavior, but the evidence base of both nonpharmacological and pharmacological interventions that can help people with ID and dementia and their carers is insufficient because of the absence of systematic and robust studies. The authors note a need for an international research agenda that begins to address gaps in knowledge. With more adults projected to be affected by dementia, a robust evidence-based body of literature on dementia care in people with ID can help with planning for and providing quality dementia-capable services.

Cox, S.
Home solutions: Housing & support for people with dementia
London: The Housing Associations Charitable Trust [78 Quaker Street, London, England E1 6SW; e/m: hact@hact.org.uk] (1998)
112 pp.
Abstract: Publication details some 10 case studies of housing options and accommodations for persons affected by dementia (and applicable to adults with intellectual disabilities). Models covered include: support in a person's own home, support in a shared home, specialist dementia support with communal facilities, and different types and levels of support on one site. Sections also deal with housing and support solutions for people with dementia from ethnic minority communities and the repair, remodeling, adaptation and renovation of ordinary housing. Case models contain full descriptions of settings and accommodations.

Cutler, N.R., Heston, L.L., Davies, P., Haxby, J.V., & Schapiro, M.B.
NIH Conference. Alzheimer's disease and Down's syndrome: new insights.
Annuals of Internal Medicine, 1985,103(4), 566-578.
Abstract: Neuropathologic and neurochemical studies of older adults with Down's syndrome and those with Alzheimer's disease reveal striking similarities. Genetic studies indicate that near relatives of patients with Alzheimer's disease are at increased risk of developing Alzheimer's disease, and the risk appears to be age specific. These families with familial Alzheimer's disease have also been found to have a high incidence of Down's syndrome. Neurochemical data suggest that a cholinergic deficiency must be present for dementia to develop, and serial assessments of brain metabolic function with positron emission tomography in Alzheimer's disease have shown that the parietal lobe has reductions in metabolic function before the onset of neuropsychologic deficits in this brain region. Neuropsychologic testing indicates that patients with Down's syndrome over 35 years old have poorer cognitive skills than do younger patients. Brain metabolic function is excessively reduced in the demented adults with Down's syndrome.

Dalton, A.J., Mehta, P.D., Fedor, B.L. & Patti, P.J.
Cognitive changes in memory precede those in praxis in aging persons with Down syndrome.
*Journal of Intellectual & Developmental Disability,*1999, *24*(2), 169-187.
Abstract: Experimental tests of cognitive functions were developed and standardised to detect the onset and progression of the early stage of Alzheimer disease in persons with Down syndrome. The aim was to determine whether or not there was a specific sequence of cognitive changes over a 3-year period for the test measures. When compared with a young group (17-39years of age at the start), an old group of persons with Down syndrome (40-58years of age at the start) showed small but statistically significant changes over time suggestive of "pre-clinical signs" of dementia. When the data were sorted into 4 subgroups on the basis of age, a more detailed analysis revealed that the subgroup that was 50 years of age and older at the start showed changes in scores which were of a magnitude more clearly indicative of early dementia on the test measures. Deterioration in learning/ memory functions began at a mean age of 54.2 years, followed later by deterioration in movement-related functions (praxis) at a mean age of 56.9 years. Deterioration in scores on an informant-based behavior rating scale (MOSES) occurred at an intermediate age of 55.0 years. The results provide preliminary support for the hypothesis that persons with Down syndrome who are 50 years of age and older may develop a specific sequence of functional changes during the early stage of dementia. They also illustrate ways in which small sample norms can be effectively used to increase the practical usefulness of tests intended to evaluate dementia in persons with intellectual disabilities.

Davis, D.R.
A parent's perspective
In M.P. Janicki & A.J. Dalton (Eds.), Dementia, aging, and intellectual disabilities.
pp. 42-50
Philadelphia: Brunner-Mazel (1999)
Abstract: Book chapter that provides an account of the experiences of a family with an adult son with Down syndrome who eventually succumbs to dementia of the Alzheimer's type. Includes a discussion of the difficult early years of the son's life and the challenges the family faced as he aged. It also examines the family's problems in recognizing that their son was experiencing the onset of dementia and his gradual decline until his death at age 46.

Day, K., Carreon, D., & Stump, C.
The therapeutic design of environments for people with dementia: A review of the empirical research
The Gerontologist, 2000, 40, 397-416
Abstract: Design of the physical environment is increasingly recognized as an important aid in caring for people with dementia. This article reviews the empirical research on design and dementia, including research concerning facility planning (relocation, respite and day care, special care units, group size), research on environmental attributes (noninstitutional character, sensory stimulation, lighting, safety), studies concerning building organization (orientation, outdoor space), and research on specific rooms and activity spaces (bathrooms, toilet rooms, dining rooms, kitchens, and resident rooms). The analysis reveals major themes in research and characterizes strengths and shortcomings in methodology, theoretical conceptualization, and application of findings.

Davies, M., McGllade, A., & Bickerstaff, D.
A needs assessment of people in the Eastern Health and Social Services Board (Northern Ireland) with intellectual disability and dementia
Journal of Learning Disabilities, 2002, 6, 23-33.
Abstract: Article details a study undertaken by the Eastern Health and Social Services Board (Northern Ireland) which aimed to identify the number of people with intellectual disability within this area who were diagnosed with or were thought to have dementia. The objectives of the study were to collate demographic details and to profile the needs of this group. Key workers were asked to provide this information and were invited to comment on gaps in existing service provision and on future needs. A number findings emerged: diagnostic services were patchy; people with dementia were living in a range of residential settings; carers wished to care for their clients for as long as practically possible, but they required extra resources and training to do so; and some individuals with an intellectual disability were excluded from elderly services. A report was compiled incorporating 12 recommendations.

De Vreese, L. P., Mantesso, U., De Bastiani, E., Weger, E., Marangoni, A.C., & Gomiero, T.
Procedures on Cognition and behavior in older adults with intellectual disabilities: A 3-year follow-up study.
Journal of Policy and Practice in Intellectual Disabilities, 2012, 9(2), 92-102.
Abstract: Dementia appears at a higher rate among some adults with intellectual disabilities (ID) and this potentially poses a greater risk of nursing home admission. Yet, to date, there is no evidence on the efficacy of general dementia-derived environment-, personnel-, and patient-oriented intervention strategies in delaying onset of dementia or in slowing down its rate of progression in this population. To investigate the feasibility and efficacy of a multicomponent nonpharmacological approach, the authors studied a sample of 14 adults with worsening cognition and everyday functioning who were no longer manageable by their family or staff in day centers or, and who were relocated in a model special care unit (SCU) designed to proactively accommodate the needs of people with ID and dementia. Baseline level and rate of decline across a 3-year period were assessed by means of the Dementia Questionnaire for Persons with Intellectual Disabilities and compared to two control groups not in dementia-capable programs matched for age, sex, and severity of ID. After 3 years, the authors found some improvement in cognition and stabilization in everyday functioning and behaviors in the SCU residents and a worsening in the control groups. The authors noted that enrollment in a dementia-capable program facilitated daily practice of residents' residual skills and abilities, enhancing their memory and verbal communication, that the prosthetic environment contributed to activity maintenance and appropriate intellectual challenges, and that the greater participation on an individual level added to the skill maintenance. Although the interpretation of these positive findings is not straightforward, they confirm the validity of this "in-place progression" model and provide a platform for continuing progress in person-centered services and care for aging persons with ID.

De Vreese, L.P. Mantesso, U., de Bastiani, E., Marangoni, A., & Gomiero, T.
Psychometric evaluation of the Italian version of the AADS questionnaire: A caregiver-rated tool for the assessment of behavioral deficits and excesses in persons with intellectual disabilities and dementia
International Psychogeriatrics, 2011, 23, 1124-1132.
Abstract: The aim of this study was to verify the reliability and validity of the Italian version of the Assessment for Adults with Developmental Disabilities

(AADS-I), the only available measure specifically designed to assess the frequency, management difficulties and impact on the quality of life (QoL) of positive and negative non-cognitive symptoms in persons with intellectual disabilities (ID) and dementia. AADS-I was administered to professional carers of 63 aging ID individuals. We computed the internal consistency separately of the frequency, management difficulty and effect on the QoL subscales of Behavioral Excesses and Behavioral Deficits and their inter-rater and test-retest reliabilities. Homogeneity of AADS-I was found to range from good to excellent: Cronbach's a coefficients were 0.77, 0.83 and 0.82, respectively for frequency, management difficulty and effect on the QoL of Behavioral Excesses, and 0.82, 0.76 and 0.79 of Behavioral Deficits. Intraclass correlation coefficients (ICC) between two independent carers were 0.67, 0.79 and 0.73 and 0.67, 0.67 and 0.67 for frequency, management difficulty and effect on the QoL of Behavioral Excesses and Deficits, respectively. Corresponding ICC for test-retest reliability were 0.80, 0.75, 0.78 and 0.70, 0.81, 0.81. Age, sex and typology of ID did not correlate with the AADS-I subscale scores, whereas the severity of ID related only with the frequency subscale of Behavioral Deficits. This subscale also correlated with the Dementia Questionnaire for Persons with Intellectual Disabilities. Behavioral deficits are more frequent in subjects with dementia. These results confirm the reliability and validity of the Italian version of AADS.

De Vreese, L.P., Uberti, M., Mantesso, U., De Bastiani, E., Weger, E., Marangoni, A.C., Weiner, M.F. & Gomiero, T.
Measuring quality of life in intellectually disabled persons with dementia with the Italian version of the quality of life in late-stage dementia (QUALID) scale. Journal of Alzheimer's Disease and Parkinsonism, 2012, 2:104e. doi:10.4172/2161-0460.1000104
Abstract: The aim of this study is to verify a cross-cultural adaptation of an Italian version of the Quality of Life in Late-Stage Dementia (QUALID) scale in a sample of aging people with intellectual disabilities (ID). The QUALID was translated according to standardized procedures. Internal consistency was analyzed using Cronbach's alpha. A Principal Component Analysis verified its multidimensionality. Inter-rater and test-retest reliabilities were also assessed using the Intraclass Correlation Coefficient (ICC). Convergent validity was probed by Spearman's correlations among the QUALID score and the six sub-scores of the Assessment for Adults with Development Disabilities (AADS), a proxy-based questionnaire rating behavioral excesses and deficits commonly found in people with intellectual disabilities and dementia. Clinical validity was assessed by comparing QUALID scores obtained by subjects with and without dementia using the Mann-Whitney U test. A total of 40 adults/older people with ID at five ID-specific centers in the province of Trento and Cremona participated in the study. Findings show optimal levels of internal consistency (a = 0.80) and confirm the factors identified in the Spanish validation study (symptoms of discomfort, positive social interaction and depression). The scale has high inter-rater (ICC = 0.95) and good test-retest reliabilities (ICC = 0.89). The total QUALID score correlates significantly with the AADS sub-scores for behavioral excesses, but does not differ between individuals with and without dementia, though two out of the three identified factor scores are significantly higher in the dementia subgroup. The authors conclude that the Italian version of the QUALID is a reliable and valid instrument for estimating quality of life in aging adults with ID and dementia.

Deb, S., Hare, M.A., Prior, L., & Bhaumik, S.
Dementia screening questionnaire for individuals with intellectual disabilities. *British Journal of Psychiatry,* 2007, 190, 440-444.
Abstract: Many adults with Down syndrome develop Alzheimer's dementia relatively early in their lives, but accurate clinical diagnosis remains difficult. The authors set out too develop a user-friendly observer-rated dementia screening questionnaire with strong psychometric properties for adults with intellectual disabilities. They used qualitative methods to gather information from carers of people with Down syndrome about the symptoms of dementia. This provided the items for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) which was then tested for its psychometric properties. The DSQIID was administered to carers of 193 adults with Down syndrome, 117 of whom were examined by clinicians who confirmed a diagnosis of dementia for 49 according to modified ICD-10 criteria. They established that a total score of 20 provides maximum sensitivity (0.92) and optimum specificity (0.97) for screening. The DSQIID has sound internal consistency ($\propto$=0.91) for all its 53 items, and good test-retest and interrater reliability. The authors established a good construct validity by dividing the questionnaire items into four factors. The authors conclude that the DSQIID is valid, reliable and user-friendly observer-rated questionnaire for screening for dementia among adults with Down syndrome.

Deb, S., Hare, M. & Prior, L.
Symptoms of dementia among adults with Down's syndrome: a qualitative study.
Journal of Intellectual Disability Research, 2007, 51, 726-739.
Abstract: Dementia is common among adults with Down's syndrome (DS); yet the diagnosis of dementia, particularly in its early stage, can be difficult in this population. One possible reason for this may be the different clinical manifestation of dementia among people with intellectual disabilities.
The aim of this study was to map out the carers' perspective of symptoms of dementia among adults with DS in order to inform the development of an informant-rated screening questionnaire. Unconstrained information from carers of people with DS and dementia regarding the symptoms, particularly the early symptoms of dementia, was gathered using a qualitative methodology. Carers of 24 adults with DS and dementia were interviewed. The interviews were recorded and fully transcribed. The transcripts were then analyzed using qualitative software. There appeared to be many similarities in the clinical presentation of dementia in adults with DS and the non-intellectually disabled general population. Like in the non-intellectually disabled general population, forgetfulness especially, impairment of recent memory combined with a relatively intact distant memory and confusion were common, and presented early in dementia among adults with DS. However, many 'frontal lobe'-related symptoms that are usually manifested later in the process of dementia among the general population were common at an early stage of dementia among adults with DS. A general slowness including slowness in activities and speech, other language problems, loss of interest in activities, social withdrawal, balance problems, sleep problems, loss of pre-existing skills along with the emergence of emotional and behavior problems were common among adults with DS in our study. This study highlighted the similarities in the clinical presentation of dementia among the general population and people with DS with a particular emphasis on the earlier appearance of symptoms associated with the frontal lobe dysfunction among adults with DS.

Dekker, A.D., Strydom, A., Coppus, A,M,W., Nizetic, D., Vermeiren,, Y., Naude, P.J.W., Van Dam, D., Potier, M-C., Fortea, J., De Deyn, P.P.
Behavioural and psychological symptoms of dementia in Down syndrome: Early indicators of clinical Alzheimer's disease?
Cortex, 2015, 75, 36-61.
Abstract: Behavioral and psychological symptoms of dementia (BPSD) are a core symptom of dementia and are associated with earlier institutionalization and accelerated cognitive decline for adults with Down syndrome (DS) and increased caregiver burden. Despite the extremely high risk for DS individuals to develop dementia due to Alzheimer's disease (AD), BPSD have not been comprehensively assessed in the DS population. Due to the great variety of DS cohorts, diagnostic methodologies, sub-optimal scales, covariates and outcome measures, it is questionable whether BPSD have always been accurately assessed. However, accurate recognition of BPSD may increase awareness and understanding of these behavioral aberrations, thus enabling adaptive caregiving and, importantly, allowing for therapeutic interventions. Particular BPSD can be observed (long) before the clinical dementia diagnosis and could therefore serve as early indicators of those at risk, and provide a new, non-invasive way to monitor, or at least give an indication of, the complex progression to dementia in DS. This review found that various BPSD appear to be altered in demented DS individuals, but study results have not always been consistent. From childhood to adulthood, externalizing behavior likely decreases and internalizing behavior increases. Frontal lobe symptoms have been suggested as early signs of AD in DS. Disinhibition and apathy, as well as executive dysfunction, seem to be omnipresent in the prodromal phase, whereas reports are inconsistent for depression. Regarding activity disturbances, studies indicated decreasing hyperactivity levels towards adulthood. Excessive activity in demented DS individuals should be a fairly easy observable sign, however, general slowness has been reported and apathy itself might cause reduced activity. Agitation appears to be more prevalent in demented than in non-demented DS individuals, but reports on aggression are inconsistent, though aggression seems to be reduced in the overall DS population. Sleep disturbances are markedly present in both demented and non-demented DS individuals. Although sleep disorders may not yet differentiate between those with and without AD, they are important to consider as such sleep disorders may aggravate cognitive decline and BPSD.

Devenny, D.A., Krinsky-McHale, S.J., Sersen, G., & Silverman, W.P.
Sequence of cognitive decline in dementia in adults with Down's syndrome.
Journal of Intellectual Disability Research 2000, 44, 654-665.
Abstract: Because of lifelong intellectual deficits, it is difficult to determine the earliest signs and characteristics of age-associated decline and dementia among adults with Down syndrome. In a longitudinal study in which all participants were healthy at the time of their entry into the study, the present authors compared the amount of decline on the subtests of the WISC-R to determine the sequence of cognitive decline associated with varying stages of dementia. Twenty-two individuals with varying degrees of cognitive decline were compared to 44 adults with DS who have remained healthy. All participants functioned in the mild or moderate range of intellectual disability at initial testing. On each subtest of the WISC-R, the amount of change experienced by the healthy participants over the study period was compared to the amount of change found for each of the groups with decline. Out of the individuals who showed declines, 10 adults with DS were classified as having 'questionable' decline based on the presence of memory impairment, and five and seven adults with DS were classified as in the 'early stage' and 'middle stage' of DAT, respectively, based on the presence of memory impairment, score on the Dementia Scale for Down Syndrome and a physician's diagnosis. It was found that participants who were identified as 'questionable', in addition to the memory loss that determined their classification, also showed significant declines on the Block Design and Coding subtests. The five adults in the early stage of dementia showed declines on these subtests, and in addition, on the Object Assembly, Picture Completion, Arithmetic and Comprehension subtests. The seven adults in the middle stage of dementia showed declines on these subtests, plus declines on Information, Vocabulary and Digit Span subtests. The Picture Arrangement and Similarities subtests were not useful in distinguishing between the groups because of baseline floor effects for a substantial proportion of participants. The present longitudinal study showed a sequence of cognitive decline associated with DAT, beginning with a possible 'pre-clinical' stage, and progressing through the early and middle stages. This approach begins to define the sequence of declining cognitive capacities that contributes to the observed functional deterioration caused by Alzheimer's disease and that is likely to reflect the involvement of cortical areas as the disease progresses.

Dick, M.B., Doran, E., & Phalen, M., & Lott,I.
Cognitive profiles on the Severe Impairment Battery are similar in Alzheimer disease and down syndrome with dementia
Alzheimer Disease and Associated Disorders, 2015, Dec 22 [Epub ahead of print]
Abstract: Previous research has revealed similarities in the neuropathology, clinical presentation, and risk factors between persons with Alzheimer disease from the general population (GP-AD) and those with Down syndrome (DS-AD). Less is known, however, about the extent of similarities and differences in the cognitive profiles of these 2 populations. Fifty-one moderate to severely demented GP-AD and 59 DS-AD individuals participated in this study which compared the cognitive profiles of these 2 populations on the Severe Impairment Battery (SIB), controlling for sex as well as level of functional ability using a modified version of the Bristol Activities of Daily Living Scale. Overall, the neuropsychological profiles of the higher-functioning individuals within the DS-AD and advanced GP-AD groups, as represented by mean difference scores on the SIB as a whole and across the 9 separate cognitive domains, were very similar to one another after adjusting for sex and functional impairment. To our knowledge, this is the first study to directly compare the cognitive profiles of these 2 populations on the SIB. Findings suggest that the underlying dementia in GP-AD and DS-AD may have corresponding and parallel effects on cognition.

Dodd, K.
Supporting people with Down's syndrome and dementia
Tizard Learning Review, 2003, 8(4), 14-18
Abstract: Brief review of literature and concepts dealing with the prevalence of dementia among people with Down syndrome in England, ethical issues in assessment and diagnosis, the value of early diagnosis, and an explication of service options and management strategies. Review concludes with a prognosis for services in the future.

Dodd, K., Watchman, K., Janicki, M.P., Coppus, A., Gaertner, C., Fortea, J., Santos, F. H., Keller, S.M., & Strydom. A.
Consensus Statement of the International Summit on Intellectual Disability and Dementia related to post-diagnostic support
Aging & Mental Health, 2018, 22(11), 1406-1415. DOI: 10.1080/13607863.2017.1373065
Abstract: Post diagnostic support (PDS) has varied definitions within mainstream dementia services and different health and social care organizations, encompassing a range of supports that are offered to adults once diagnosed with dementia until death. An international summit on intellectual disability and dementia held in Glasgow, Scotland in 2016 identified how PDS applies to adults with an intellectual disability and dementia. The Summit proposed a model that encompassed seven focal areas: post-diagnostic counseling; psychological and medical surveillance; periodic reviews and adjustments to the dementia care plan; early identification of behavior and psychological symptoms; reviews of care practices and supports for advanced dementia and end of life; supports to carers/ support staff; and evaluation of quality of life. It also explored current practices in providing PDS in intellectual disability services. The Summit concluded that although there is limited research evidence for pharmacological or non-pharmacological interventions for people with intellectual disability and dementia, viable resources and guidelines describe practical approaches drawn from clinical practice. Post diagnostic support is essential, and the model components in place for the general population, and proposed here for use within the intellectual disability field, need to be individualized and adapted to the person's needs as dementia progresses. Recommendations for future research include examining the prevalence and nature of behavioral and psychological symptoms (BPSD) in adults with an intellectual disability who develop dementia, the effectiveness of different non-pharmacological interventions, the interaction between pharmacological and non-pharmacological interventions, and the utility of different models of support.

Donaldson S.
Work stress and people with Down syndrome and dementia.
Down's Syndrome, Research and Practice, 2002, 8(2), 74-78.
Abstract: Author assessed how staff ratings of challenging behavior for people with Down syndrome and dementia affected the self-reported well-being of care staff. Data were collected from 60 care staff in 5 day centers in a large city in England. The data were collected by use of a questionnaire. There was no significant difference between those who cared for individuals with Down syndrome and dementia and those caring for service users with other non-specified learning disabilities without dementia, regarding their self-reported well-being. Self-reported well-being did correlate with staff rating of challenging behavior in both those who cared for people with Down syndrome and dementia and those who did not care for such service users, with well-being declining as perceived challenging behavior increased. The findings indicate that challenging behavior prevention and reduction may be of benefit to both service users and care staff well-being.

Dunne, P., Reilly, E., Judge, R., Lowe, F. & McCarron, M.
Giving meaning to life - the role of digital life Stories in supporting people with intellectual disability and dementia
Journal of Intellectual Disability Research, 2019, 63(8), 643.
Abstract: Over a four-year period individuals with an intellectual disability (ID) in a large service provider in the Republic of Ireland were supported to create their personalized digital life story using selected multi media apps. An easy read survey was distributed to 380 people with ID to gauge their readiness and interest in engaging in digital life story. A bespoke training course was developed to support the introduction of digital life story activities. The use of the personalized digital life stories by the individuals and their support staff, family and social network was captured through recorded observations and individual use was tracked through a developed audit tool. Over the four-year period eighty people with an ID commenced their digital life story. Case studies within this cohort showed a variety of use which varied depending on degree of ID and stage of dementia. In all cases life stories were instrumental to enhanced communication and social interactions. Key factors in uptake and sustainability were staff training, iPad clubs and champions across the organization Implications: Digital life stories were key in supporting meaningful interactions across the continuum of dementia both in day to day interactions with family, staff, volunteers, and peers and as a tool for social engagement through digital life story clubs.

Eisner, D.A.
Down's syndrome and aging: Is senile dementia inevitable?
Psychological Reports 1983, 52(1), 119-124.
https://doi.org/10.2466/pr0.1983.52.1.119

Abstract: Numerous studies have reported that in elderly Down's Syndrome individuals there is a high preponderance of senile dementia. An examination of these investigations shows that, while there is accelerated neurological aging, there is not a high incidence of behavioral or overt senile dementia. Changes in cognitive functioning for Down's Syndrome persons are similar to those found in non-Down's retarded populations.

Engdahl, J.M.K.
Alzheimer's disease & Down syndrome: A practical guide for caregivers.
36 pp.
Bozeman, Montana: Author [723 South 13th Street, Bozeman, MT 59715] (1995)
Abstract: Training manual developed to provide primary information about care practices for parents and other primary carers of adults with Down syndrome affected by Alzheimer's disease. Covers, in brief format, recognizing signs and symptoms, diagnostic advice, care management practice (communication, dealing with problem behaviors, helping with activities of daily living, promoting alternative activities) and help for carers.

ENIDA
Face to face: Respectful coping with dementia in older people with intellectual disability
52 minutes
Working Group on Coping with Dementia in Older People with Intellectual Disability, European Network on Intellectual Disability and Ageing [ENIDA - c/o Patricia Noonan Walsh, Ph.D., Director, Centre for the Study of Developmental Disabilities, University College Dublin, Belfield, Dublin 4, IRELAND -- e-mail: patricia.walsh@ucd.ie] (2000)
Abstract: A 52-minute video with an accompanying information booklet, which uses a number of case vignettes from France, Belgium and the Netherlands to illustrate the various symptoms and stages of dementia among older people with intellectual disability. Examples of practices to promote "respectful coping" with dementia, death and dying on the part of direct support professionals and clinicians are presented. Devised for staff training and development, Face to Face may be viewed in short segments. A version with English subtitles and English booklet is available in formats suitable for Europe and for North America. Developed with funding and support from: ENIDA, Fondation de France, the European Union, and University College Dublin, Ireland.

Ericksson, M., & Sundin, M.
Developing early detection of dementia with people with intellectual and developmental disabilities
Poster presented at the 27th Annual Conference of Alzheimer Europe, Berlin, Germany, October 3, 2017. (PO3.26)
Abstract: In Finland there is a lack of a unified approach to the early detection of dementia for people with intellectual and developmental disabilities (IDD). The aim of this presentation is to describe a currently underway collaboration project, which responds to this challenge. In our opinion, there are two essential elements in early detection of dementia with people with IDD: 1) an overall description of the psychosocial functioning of the person and 2) a screening method for dementia, which developed for persons with IDD. These two components are shortly outlined. Psychosocial functioning: Early detection of neurocognitive disorders in people with IDD is multidisciplinary teamwork. The Finnish Association of Intellectual and Developmental Disabilities (FAIDD) has published two methods for this purpose (the Toimi and the Psyto), and we recommend using these methods in the assessment of dementia in people with IDD as well. For example, it is important to distinguish the symptoms of dementia from other possible psychological disorders (like mood disorders and psychotic symptoms). Translation of the National Task Group Early Detection Screen for Dementia (NTG-EDSD): Commonly used assessment methods (like the Cerad and the Mini-Mental) may not be applicable for people with IDD. In our project, we decided to translate the NTG-EDSD into Finnish. The EDSD is already available online in many other languages (www.aadmd.org/ntg/screening). As the authors write, the NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by people who know the client well. The Finnish version of the NTG-EDSD is being introduced into practice in 2017. FAIDD trains staff and other people working with people with IDD in using the screen within the perspective of psychosocial functioning.

Esbensen, A.J.
Health conditions associated with aging and end of life of adults with Down syndrome.
International Review of Research in Mental Retardation, 2010, 39c, 107–126.
Abstract: Expectations for the life course of individuals with Down syndrome (DS) have changed, with life expectancy estimates increasing from 12 in 1949 to nearly 60 years of age today. Along with this longer life expectancy comes a larger population of adults with DS who display premature age-related changes in their health. There is thus a need to provide specialized health care to this aging population of adults with DS who are at high risk for some conditions and at lower risk for others. This review focuses on the rates and contributing factors to medical conditions that are common in adults with DS or that show changes with age. The review of medical conditions includes the increased risk for skin and hair changes, early onset menopause, visual and hearing impairments, adult onset seizure disorder, thyroid dysfunction, diabetes, obesity, sleep apnea and musculoskeletal problems. The different pattern of conditions associated with the mortality of adults with DS is also reviewed.

Esbensen, A.J., Boshkoff Johnson, E., Amaral, J.L., Tan, C.M., & Macks, R.
Differentiating aging among adults with Down syndrome and comorbid psychopathology.
American Journal on Intellectual and Developmental Disabilities, 2016, 121 (1), 13-24.
Abstract: Differences were examined between three groups of adults with Down syndrome in their behavioral presentation, social life/activities, health, and support needs. We compared those with comorbid dementia, with comorbid psychopathology, and with no comorbid conditions. Adults with comorbid dementia were more likely to be older, have lower functional abilities, have worse health and more health conditions, and need more support in self-care. Adults with comorbid psychopathology were more likely to exhibit more behavior problems and to be living at home with their families. Adults with no comorbidities were most likely to be involved in community employment. Differences in behavioral presentation can help facilitate clinical diagnoses in aging in Down syndrome, and implications for differential diagnosis and service supports are discussed.

Esbensen, A.J., Mailick, M.R., & Silverman, W.
Long-term Impact of parental well-being on adult outcomes and dementia status in individuals with Down syndrome.
American Journal on Intellectual and Developmental Disabilities, 2013, 118(4), 294-309.
Abstract: Parental characteristics were significant predictors of health, functional abilities, and behavior problems in adults with Down syndrome (n = 75) over a 22-year time span, controlling for initial levels and earlier changes in these outcomes. Lower levels of behavior problems were predicted by improvements in maternal depressive symptoms. Higher levels of functional abilities were predicted by prior measures of and improvements in maternal depressive symptoms. Better health was predicted by prior measures of maternal depressive symptoms, paternal positive psychological well-being, relationship quality between fathers and their adult children, and improvements in maternal positive psychological well-being. Dementia status was also predicted by parental characteristics. The study suggests the importance of the family context for healthy aging in adults with Down syndrome.

Evenhuis H.M.
The natural history of dementia in Down's syndrome.
Arch Neurol. 1990 Mar;47(3):263-7.
Abstract: In a prospective longitudinal study with death as the end point in 17 middle-aged patients with Down's syndrome, dementia was clinically diagnosed in 15 patients, by means of careful observations in daily circumstances. Autopsies were performed in 10 cases: 8 demented patients and 2 nondemented patients. Neuropathologically, Alzheimer-type abnormalities were demonstrated in 9 patients, both demented and nondemented, and combined Alzheimer-type abnormalities with infarctions were demonstrated in 1 patient. In the 14 demented patients who did not show evidence of cerebrovascular or systemic vascular disease, dementia had an early onset and was rapidly progressive (mean age at onset, 51.3 years in the moderately retarded patients and 52.6 years in the severely retarded patients; mean duration of symptoms, respectively, 4.9 and 5.2 years). Cognitive and behavioral decline corresponded to symptoms of dementia of the Alzheimer's type in patients without Down's syndrome, but often were not recognized early. In the present group of patients, there was a remarkably high incidence of gait and speech deterioration. Also, the incidence of epileptic seizures and myoclonus was about eightfold, as compared with dementia of the Alzheimer's type in patients without Down's

syndrome.

Forbat, L., & Service, K.P.
Who cares? Contextual layers in end-of-life care for people with intellectual disability and dementia, Dementia, 2005, 4(3), 413-431.
Abstract: The complexity of the relationship between intellectual disability (ID) and dementia is increasingly acknowledged. In order to operationalize a route towards person-centered care, we introduce the hierarchy model (Pearce, 1999) as a tool to focus the attention of policy and practice on all aspects of caregiving. This tool, which is taken from the family therapy literature, enables practitioners to examine the broad systems that impact on the delivery and receipt of care. In this article, we focus on its utility in scrutinizing end-of-life and later stages of dementia by illustrating its use with three key areas in dementia care. These three areas provide some of the most challenging situations at the end stages, because of the possible treatment options, they are: nutrition, medical interventions, and the location of care provision. This model enables a focused approach to understanding how meaning is created within social interaction. The article draws out implications for practice and policy and has applications for practice internationally.

Foundation for People with Learning Disabilities
Down's syndrome and dementia - Briefing for Commissioners
London: The Foundation for People with Learning Disabilities [c/o Mental Health Foundation, 20/21 Cornwall Terrace, London, England NW1 4QL; e/m mhf@mhf.org.uk; www.learningdisabilities.org.uk] (February 2001)
8 pp.
Abstract: Backgrounder document, written for funders of services in the United Kingdom, outlines the epidemiology of dementia and Down's syndrome and identifies key support services necessary as part of a package of local services to be established for persons affected by dementia and intellectual disabilities (ID). While titled for dementia and Down's syndrome applicable for all persons with ID. Written in brief style, covers main issues and funding considerations and serves as an excellent planning tool for establishing services. Also covers basic clinical diagnostic information and basis for care management decision making. Routes the reader to associated organizations for further information

Fray, M.T.
Caring for Kathleen: A sister's story about Down's syndrome and dementia.
Kidderminster, United Kingdom: British Institute of Learning Disabilities [BILD, Wolverhampton Road, Kidderminster, Worcestershire, UK DY10 3PP -- www.bild.demon.co.uk] (2000)
44 pp.
Abstract: Biographical monograph on the aging and eventual decline and death of a woman with Down syndrome as told by her sister. Provides many insights in service barriers and successes, while also providing a vivid case example of how Alzheimer's disease affects a family carer of a person with an intellectual disability.

Fredericksen, J. & Fabbre, V.
Down syndrome and Alzheimer's disease: Issues and implications for social work.
Journal of Gerontological Social Work, 2018, 61(1), 4-10. DOI: 10.1080/01634372.2017.1393480.
Owing to recent medical advancements, people with Down Syndrome (DS) are now able to live considerably longer lives and thus experience a variety of complex issues as they age. Alzheimer's Disease (AD) frequently occurs in older adults who have DS, but few practice guidelines exist to inform social work practice with older adults who have this dual diagnosis. This commentary will highlight the connection between these two conditions within a neurobiological framework and discuss implications for practice based on the available literature on this intersection of ability status, cognitive status, and age.

Gitlin, L.N., and Corcoran, M.
Making homes safer: environmental adaptations for people with dementia
Alzheimer's Care Quarterly, 2000, 1(1), 50-58
Abstract: Evaluating the safety of the home environment is an important component of clinical care for persons with dementia. This article discusses safety concerns for persons with dementia living at home alone or with family members, specific modifications to the physical environment to address these issues, and guiding principles for implementing environmental changes. A wide range of environmental strategies can be introduced to maximize home safety. Different adaptations may need to be implemented with progressive memory loss thus necessitating periodic reevaluation of the home.

Hammond, B., & Beneditti, P.
Perspectives of a care provider
In M.P. Janicki & A.J. Dalton (Eds.), Dementia, Aging, and Intellectual Disabilities.
pp. 32-41
Philadelphia: Brunner-Mazel (1999)
Abstract: Book chapter that provides a descriptive chronology of a middle-aged woman with Down syndrome who, once diagnosed with Alzheimer disease, follows a classic course of decline and eventual debilitation and death. Staff of her residence chronicled the progression of her dementia and provide some insights into the care management practices used in providing for her care. The authors place the course of her disease in perspective and offer comments on the stresses and strains on agency resources. Suggestions are offered for agencies facing similar challenge in providing day to day care for adults with dementia.

Handen, B.L.
The search for biomarkers of Alzheimer's Disease in Down Syndrome
American Journal of Intellectual and Developmental Disabilities, 2020,125(2), 97-99. doi: 10.1352/1944-7558-125.2.97.
Adults with Down syndrome are at high risk for Alzheimer's disease (AD), with most individuals developing clinical dementia by their late 60s. This increased risk for AD has been attributed, at least in part, to triplication and overexpression of the gene for amyloid precursor protein (APP) on chromosome 21, leading to elevated levels of amyloid ß peptides. This article offers a brief overview of our current knowledge of AD in the DS population. In addition, the NIA/NICHD-funded, multicenter longitudinal study of biomarkers of AD in adults with DS is explored.The Alzheimer's Biomarkers Consortium–Down Syndrome (ABC-DS) is a longitudinal study of Alzheimer Disease biomarkers in adults with Down syndrome supported by federal grants from the National Institute on Aging (NIA) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). The primary goal of ABC-DS is to understand the factors that moderate the relationship between Aß, neurodegeneration and dementia in DS and biomarkers for those factors that could be critically important in the design of effective therapeutic trials for AD, not only in DS, but in the general population as well.

Hassiotis, A., Strydom, A., Allen, K., & Walker, Z.
A memory clinic for older people with intellectual disabilities
Aging & Mental Health, 2003, 7(6), 418-423
Abstract: Cognitive decline in older people with intellectual disabilities (ID) is often under-recognized. Following the publication of the National Service Framework for Older People and the white paper Valuing People, older people with intellectual disabilities of all aetiologies should have access to a systematic assessment of their cognitive function in order to detect decline in cognition and adaptive skills and implement appropriate treatments as early as possible. The development of a memory clinic for older people with ID is described, including instruments used and characteristics of attendees. Such projects are in line with current UK government policies and can contribute to the improvement of standards of care and support research in this vulnerable group of people.

Head, E., Powell, D., Gold, B.T., Schmitt, F.A..
Alzheimer's Disease in Down Syndrome
European Journal of Neurodegenerative Diseases, 2012, 1(3): 353–364.
Abstact: A key challenge to adults with Down syndrome (DS) as they age is an increased risk for cognitive decline, dementia, and Alzheimer disease (AD). In DS persons ranging from 40-49 years of age, 5.7-55% may be clinically demented and between 50-59 years, dementia prevalence ranges from 4-55% (reviewed in [1]). Despite the wide ranges reported for dementia prevalence, a consistent feature of aging in DS is the progressive accumulation of AD brain pathologies. By the age of 40 years, virtually all have sufficient senile plaques and neurofibrillary tangles for a neuropathological diagnosis of AD [2]. Thus, there is dissociation between the age of onset of AD neuropathology (40 years) and increasing signs of clinical dementia. We discuss the hypothesis that frontal impairments are a critical factor affecting cognitive function and are associated with white matter (WM) and AD neuropathology. While these may be an early sign of conversion to dementia, we also review several other clinical comorbidities that may also contribute to dementia onset.

Hellen, C.R.
Alzheimer's disease - activity-focused care (2nd Ed.)
Boston: Butterworth-Heinemann (1998)
436 pp.
Abstract: A 13-chapter text that provide voluminous information on developing and provision of activities for persons affected by Alzheimer's disease and related dementias - with application to persons with intellectual disabilities. Written from a practitioner viewpoint, it is designed to promote an individual's cognitive, physical and psychosocial well-being. It includes forms and profiles for use by program personnel, presents a holistic intervention program, features content on refocusing activities for physically combative or violent situations. Contains chapters on communication, daily living care activities, aiding at mealtimes, facilitating physical wellness (mobility and exercise), addressing dementia induced behaviors, creating meaningful activities for daily life, and aiding in terminal care, among others.

Higgins, L., & Mansell, J.
Quality of life in group homes and older persons' homes.
British Journal of Learning Disabilities, 2009, 37, 207–212
Abstract: Older people with intellectual disabilities sometimes live in older people's homes rather than homes for people with intellectual disabilities. Little is known about their quality of life in these homes. A non-equivalent comparison group design was used to compare the quality of life of 59 people in three groups; older people without an intellectual disability living in older people's homes (n = 20), older people with an intellectual disability living in older people's homes (n = 19) and older people with an intellectual disability living in intellectual disability homes (n = 20). Data were collected on participant characteristics, adaptive behavior and three aspects of quality of life; community involvement, participation in domestic living and choice making. The three groups were comparable in terms of gender, ethnicity and additional impairments but the older people without an intellectual disability were older and had more adaptive skills than the other groups. Older people with an intellectual disability experienced better quality of life outcomes in terms of participation in meaningful activity and community access when they lived in intellectual disability homes compared with older people's homes. It was not possible to achieve reliability on the measure of choice-making. This study provides some evidence to suggest that older people with an intellectual disability may be best served in intellectual disability homes rather than older people homes and that it is an area of research which needs further exploration.

Holland, A.J.
Ageing and its consequences for people with Down's syndrome
Fact Sheet Series - Learning about intellectual disabilities and health
Accessed 24 August 2004 at
http:www.intellectualdisability.info/lifestages/ds_ageing.htm
Down Syndrome Association (UK) and the Department of Mental Health & Learning Disability at St. George's Hospital Medical School, University of London.
9 pp.
Abstract: Fact sheet outlines the evidence which suggests that ageing and t he problems of old age are particularly relevant to people with Down syndrome as some of these age-related problems develop earlier in life than would normally be the case. Topics covered include: aging and the brain, aging and dementia, behavioral features of dementia in people with Down syndrome, apparent decline in later life - cases to consider, difficulties in detecting dementia in people with intellectual disabilities, differential diagnosis - which conditions mimic dementia, common causes of decline in later life in people with Down syndrome, genetic mechanisms, treatment, supporting the individual, and the future.

Holland, A.J., Karlinsky, H. & Berg, J.M.
Alzheimer's disease in persons with Down syndrome: Diagnostic and management considerations
In J.M. Berg, H. Karlinsky, A.J. Holland (Eds.), Alzheimer's Disease, Down Syndrome, and Their Relationship.
pp. 96-114
Oxford: Oxford University Press (1993)
Abstract: Book chapter that examines the implications of Alzheimer's disease for adults with Down syndrome, including assessment and diagnosis and specialty service provision. Authors note that assigning a tenable diagnosis of Alzheimer disease requires careful and comprehensive data assembly, including medical history, clinical examination, neuropsychological assessment and laboratory investigations. Once the diagnosis is established, effective ongoing management should focus on supporting not only the affected individual (including advocacy for his or her rights) but also the family and professional carers. During the course of the illness various medical, psychiatric and psychological interventions can be helpful as can changes in the environment. A wide range of services for persons with Down syndrome who develop Alzheimer's disease makes it possible for affected individuals, despite deterioration, to remain in the family home or in community residential settings. Authors proffer some general suggestions for services and adaptations.

Holland, A.J., Hon, J., Huppert, F.A., & Stevens, F.
Journal of Intellectual Disability Research, 2000, 44(2), 138-146.
Incidence and course of dementia in people with Down's syndrome: findings from a population-based study.
Journal of Intellectual Disability Research, 2000, ;44(2), 138-146.
Abstract: The prevalence rate of Alzheimer's disease (AD) in people with Down's syndrome (DS) increases significantly with age. However, the nature of the early clinical presentation, course and incidence rates of dementia are uncertain. The aims of the present study were to investigate the characteristics of age-related clinical changes and incidence rates for dementia in a population-based sample of people with DS aged 30 years and older at the age of risk for dementia. A modified version of the Cambridge Examination for Mental Disorders of the Elderly informant interview was used to determine the extent and nature of changes in memory, personality, general mental functioning and daily living skill 18 months after a similar assessment At the time of the first assessment, the initial changes reported were predominately in behaviour and personality. At the second assessment, overall estimated incidence rates for frontal-like dementia were high (0.24), mainly in the younger groups, with incidence rates of AD, meeting both ICD-10 and DSM-IV criteria, of 0.04 predominately in the older groups. The present authors have hypothesized that the observed personality changes and the high estimated incidence rates of frontal-like dementia in the younger groups may indicate that functions served by the frontal lobes are the first to be compromised with the progressive development of Alzheimer-like neuropathology in people with DS.

Hom, C.
AAIC 2020, Poster presentation, July 29, 2020.
https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Paper/43299
Abstract: Past attempts to characterize the earliest cognitive changes as individuals with Down Syndrome (DS) transition from cognitively stable to mild cognitive impairment (MCI) have been equivocal (Garcia-Alba et al., 2019; Lautarescu et al., 2017). Difficulties identifying MCI in this population are complicated by variability in pre-morbid cognitive abilities, the use of neuropsychological tests that were created for the neurotypical population, and participants scoring at floor on the baseline assessment (Krinsky-McHale and Silverman, 2013). We examined data from 151 individuals with Down Syndrome (M age=50.25, SD age=6.94). Their pre-morbid level of intellectual impairment ranged from mild to severe. All participants received comprehensive evaluations. Following data collection, the clinical status of each participant was rated at consensus review that considered performance on a core neuropsychological test battery and the clinical data for each participant. Data from the non-demented and MCI groups are examined: Cognitive Stable (N=107, 70.9%) and MCI-DS (N=44, 29.1%). The full battery consists of 27 subtests that were hypothesized a priori to measure five cognitive domains: language, memory, executive function, visuospatial reasoning, and motor coordination. Factor analysis revealed 7 principal components that maximally discriminated between test scores in older adults with DS who have not reached clinical AD status: (1) general intelligence (2) sensorimotor, (3) memory, (4) language comprehension and expression, (5) executive function/speed, (6) attention/language expression, and (7) visuomotor. Cluster analysis for the MCI group produced 3 distinct groups: (1) dysexecutive (n=4), (2) dysnomic/visuospatial impaired (n=28), and (3) amnestic/motor impaired (n=12). Author concludes that the neuropsychological battery assesses 7 distinct cognitive functions in older adults with DS. It can also capture cognitive decline, as we were able to empirically identify three distinct neuropsychological subtypes of MCI: amnestic/visuomotor impaired, dysexecutive, and dysnomic. These subtypes are generally consistent with those that have been found within the neurotypical population (Edmonds et al., 2015; Dick et al., 2016), strengthening the evidence that AD has a similar course in the DS population and late onset AD.

Horvath,S,. Garagnani,P., Bacalini, M.G., Pirazzini,C., Salvioli,S., Davide, G.,Di Blasio, A.M., Giuliani,C., Tung,S., Vinters, H.V., & Franceschi, C.
Accelerated epigenetic aging in Down syndrome
Aging Cell, 2015, 1–5, eprint. Doi: 10.1111/acel.12325
Abstract: Down syndrome (DS) entails an increased risk of many chronic diseases that are typically associated with older age. The clinical manifestations of accelerated aging suggest that trisomy 21 increases the biological age of tissues, but molecular evidence for this hypothesis has been sparse. Here, we utilize a quantitative molecular marker of aging (known as the epigenetic clock) to demonstrate that trisomy 21 significantly increases the age of blood and brain tissue (on average by 6.6 years, P = 7.0 3 10 $^{-14}$).

Huxley, A., Van-Schaik, P., & Witts, P.
A comparison of challenging behavior in an adult group with Down's syndrome and dementia compared with an adult Down's syndrome group without dementia.
British Journal of Learning Disabilities, 2005, 33(4), 188-193.
Abstract: This study investigated the frequency and severity of challenging behavior in adults with Down's syndrome with and without signs of dementia. Care staff were interviewed using the Aberrant Behavior Checklist-Community version (M.G. Aman & N.N. Singh, Slosson, East Aurora, NY, 1994), to investigate the frequency and severity of challenging behavior. Individuals' 'dementia status' was assessed by using the Dementia Scale for Down's Syndrome (Gedye Research and Consulting, Vancouver, 1995). The results showed that the dementia group displayed more frequent and severe forms of challenging behavior than the nondementia group. The difference in reported levels of challenging behavior of both groups with the general learning disabilities population was not considered to be clinically significant and levels fell predominantly within the 'normal range'. The findings of this study suggest that frequent and severe forms of challenging behavior in adults with Down's syndrome is more likely to be a behavioral symptom associated with the onset of a dementing illness and not due to normal aging alone.

Iacono, T., Bigby, C., Carling-Jenkins, R., & Torr, J.
Taking each day as it comes: Staff experiences of supporting people with Down syndrome and Alzheimer's disease in group homes,
Journal of Intellectual Disability Research, 2013; 58(6). DOI:10.1111/jir.12048.
Abstract: Disability staff are being increasingly required to support adults with Down syndrome who develop Alzheimer's disease. They have little understanding of the nature of care required, and may lack input from aged care and dementia services, which lack knowledge of intellectual disability. The aim of this study was to report on the experiences of disability staff in group homes supporting residents with Down syndrome and Alzheimer's disease in relation to their under understanding of what was happening to these residents, their responses to them, and how they felt about their support role. Disability support staff for nine adults with Down syndrome who had a diagnosis of Alzheimer's disease were interviewed twice, over intervals of 6-9 months. Interviews were transcribed and analyzed for themes. Authors foiund that three key themes emerged - (I) struggling to understand change, (ii) taking each day as it comes, and (iii) he's got a disability and that's our job. Staff had only limited understanding of how Alzheimer's disease impacted the adults with Down syndrome, their responses to changes were ad hoc, and they used strategies on a trial and error basis. They were committed to providing care, but at the risk of rejecting input and support. The need for collaboration across disability, and aged and disability care was evident to facilitate aging-in-place and planned care transitions.

Ilacqua, A., Benedict, J., Shoben, A., Skotkp, B.G., Mathews, T. Benson, B., & Allain, D.C.
Alzheimer's disease development in adults with Down syndrome: Caregivers' perspectives
American Journal of Medical Genetics, 2020, 182(1), 104-114
Abstract: Research about Alzheimer's disease (AD) in individuals with Down syndrome (DS) has predominantly focused on the underlying genetics and neuropathology. Few studies have addressed how AD risk impacts caregivers of adults with DS. This study aimed to explore the perceived impact of AD development in adults with DS on caregivers by assessing caregiver knowledge, concerns, effect on personal life, and resource utilization via a 40-question (maximum) online survey. Survey distribution by four DS organizations and two DS clinics resulted in 89 caregiver respondents. Only 28 caregivers correctly answered all three AD knowledge questions. Caregivers gave an average AD concern rating of 5.30 (moderately concerned) and an average impact of possible diagnosis rating of 6.28 (very strong impact), which had a significant negative correlation with the age of the adult with DS (p = .009). Only 33% of caregivers reported utilization of resources to gain more information about the AD and DS association, with low levels of perceived usefulness. Our data reveal caregivers' misconceptions about AD development in DS, underutilization of available resources, and substantial concerns and perceived impacts surrounding a possible AD diagnosis. This study lays the foundation for how the medical community can better serve caregivers of aging adults with DS.

Jacbs, J., Schwartz, A., McDougle, C.J., & Skotko, B.G.
Rapid clinical deterioration in an individual with Down syndrome
American Journal of Medical Genetics, Part A 9999A:1-4 DOI 10.1002/ajmg.a.37674
Abstract: A small percentage of adolescents and young adults with Down syndrome experience a rapid and unexplained deterioration in cognitive, adaptive, and behavioral functioning. Currently, there is no standardized work-up available to evaluate these patients or treat them. Their decline typically involves intellectual deterioration, a loss of skills of daily living, and prominent behavioral changes. Certain cases follow significant life events such as completion of secondary school with friends who proceed on to college or employment beyond the individual with DS. Others develop this condition seemingly unprovoked. Increased attention in the medical community to clinical deterioration in adolescents and young adults with Down syndrome could provide a framework for improved diagnosis, evaluation, and treatment. This report presents a young adult male with Down syndrome who experienced severe and unexplained clinical deterioration, highlighting specific challenges in the systematic evaluation and treatment of these patients.

Jamieson-Craig, R., Scior, K., Chan, T., Fenton, C., & Strydom, A.
Reliance on carer reports of early symptoms of dementia among adults with intellectual disabilities
Journal of Policy and Practice in Intellectual Disabilities, 2010, 7(1), 34 - 41.
Abstract: As clinicians often rely on carer reports to identify adults with intellectual disabilities (ID) with early signs of dementia, this study focused on carer-reported symptoms to ascertain whether carer reports of decline in everyday function would be a more effective screening method to detect possible cases of dementia than reports of memory decline in older adults with ID. Subjects were 154 participants who were reassessed along with their carers two to three years after baseline. A questionnaire for carer-reported change in everyday function and the Dementia Questionnaire for Persons with Mental Retardation (DMR) were used to assess carer views of everyday function and memory. The diagnosis of dementia was confirmed by two psychiatrists working independently. Participants who developed dementia displayed both everyday function and memory decline. Overall, decline in everyday function appeared to be the best indicator of new dementia cases. Retrospective carer report of change in everyday function was as good as, if not better than, prospective ratings to identify dementia; however, in those with mild ID, memory change was a better indicator of dementia, while in those with more severe ID, decline in everyday function was a better indicator. Decline in everyday function (whether prospective change from baseline or reported retrospectively by carers) appears to be a better screening method for dementia than memory decline, particularly for participants with moderate/severe ID.

Janicki, M.P.
Quality outcomes in group home dementia care for adults with intellectual disabilities.
Journal of Intellectual Disability Research, 2011, 55(8), 763-776.
[doi: 10.1111/j.1365-2788.2011.01424.x].
Abstract: Dementia, as a public health challenge, is a phenomenon vexing many care organizations providing specialized residential and family supports for older adults with intellectual disabilities. With increasing survivorship to ages when risk is greatest, expectations are that many more adults in service will present with cognitive decline and diagnosed dementia as they grow older. As persons with dementia present with new needs, there is often a call for a reorientation of services. With respect to residential supports, agencies may need to adapt current methods of care, with particular attention to providing care in small group homes. However, dementia-related care also must be quality care and applicable standards need to be met. The author reviewed relevant policy and practice organizational guidelines and applied research literature addressing components of care and service provision that were critical to quality care and

that were consistent with professional practice. Examined were the nuances and contributing factors of quality dementia care and it was proposed that quality of care criteria need to be universally applicable and serve as a framework for adapting extant residential environments and make them 'dementia-capable'. It is proposed that efforts to evaluate dementia-related care provision with respect to quality need to consider quality of care provision components such as (1) clinically relevant early and periodic assessment; (2) functional modifications in the living setting; (3) constructive staff education and functionality for stage-adapted care; and (4) flexible long-term services provision that recognizes and plans for progression of decline and loss of function.

Janicki, M.P.
On-going activities of the National Task Group on Intellectual Disabilities and Dementia Practices
The Gerontologist, 2018, 56(Suppl_3), 573.
Abstract: The National Task Group on Intellectual Disabilities and Dementia Practices (NTG), organized in 2011, has been actively involved in stimulating development of services for people with intellectual disabilities (ID) affected by dementia. The NTG has created several sets of practice guidelines, a screening and early detection instrument for use by families and agencies, web-based informational materials,and a national curriculum on ID and dementia, and has undertaken the provision of workforce development workshops across the US on dementia and ID. The NTG works to compliment the activities being undertaken under the National Plan to Address Alzheimer's Disease and consults with various national organizations focusing on dementia and lifelong disabilities. The goal of the NTG is to continue to affect change and improve the quality of community dementia care provision corresponding with National Plan updates.

Janicki, M..P.
Community-based housing and NPI-care practices for adults with intellectual disability and dementia
AAIC 2020 Conference, Poster presentation, July 30. 2020.
https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Paper/47061.
Abstract: Aging persons with intellectual disability (ID) represent a vulnerable population with respect to cumulative neuropathological conditions, including dementia. Adults with Down syndrome (DS), a subset, have a recognized high risk for Alzheimer's disease. With dementia present, how to provide post-diagnostic supports is challenging. Dementia care group homes (GHs) along with NPIs are emerging as a mode for providing out-of-home community supports. Data from a longitudinal study provide insights on what care organizations need to consider when organizing specialty group home care. The study, begun in 2011, followed three co-located homes providing NPIs to 15 adults with dementia. Findings revealed trajectories of changes over time, housing need/function level patterning, and health status outcomes. Key findings noted 3 age-of-admission clusters (?=50.5; ?=57.1; ?=66.8); overall mortality (?age-death=65.4; ID=69.3; DS=56.3) – half of original entrants died within 7 years; age at entry (?= 59.1); years from entry to death (?= 5.4 yrs); LOS (?=49.4 months/4.12 yrs); morbidities (number of co-morbidities decreased among survivors). In same period, 8/15 deaths in GHs vs 3/15 deaths in Controls. NPI-related practices included day program activities (adults in mid- to later stages were engaged in regular off-site day activities that agency provided; adults with advanced dementia remained in homes), staffing patterns differed based on level of care – more staff assigned to homes with residents with advanced dementia, and staff training included dementia capable communications, engagement, and managing daily routines. Trends showed adults with Down syndrome were admitted to homes earlier but had more life-years in the GHs than older adults admitted at later age but who succumbed earlier to disease complications. Dementia care GHs should expect varied trajectories of decline; mortality linked to complexity of pre-existing conditions and progression of dementia; changes in the focus of care needs over time (including advanced dementia and end-of-life care). Dementia care GHs can enable provision of in-community group housing and quality care in accord with stage-defined functional changes and needs if structured in a planful way (factoring in dementia-stage, dementia type, mortality expectations, health status, patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents).

Janicki,M.P., Dalton, A.J., McCallion, P., Davies Baxley, D., & Zendell, A.
Group home care for adults with intellectual disabilities and Alzheimer's disease
Dementia, 2005, 4, 361-385.
Abstract: The growing numbers of individuals with intellectual disabilities affected by Alzheimer disease and related dementias has raised new challenges for community care providers. This paper examines means of providing community group home-based care in a sample of care providers in five different countries. The aim is to identify trends that have emerged. Two samples of group homes for adults with intellectual disabilities affected by dementia were studied to determine: (1) what are the physical characteristics of the homes; (2) what physical environmental adaptations have been made in response to behavioral deterioration expressed by residents with dementia, and (3) what are the demands on staff resulting from dementia care. The first sample of group homes in five countries provided comparative international data on home designs, staffing, costs, and residents. The second sample, drawn from homes in the USA and the UK, provided data on the impact of dementia. Findings revealed staffing and design of homes varied but generally abided by general practices of dementia care; homes relied on existing resources to manage changes posed by dementia care; programmatic and environmental adaptations were implemented to address progression of dementia; and residents with dementia presented more demands on staff time with respect to hygiene maintenance and behavior management when compared to other residents not affected by dementia.

Janicki, M. P., Heller, T., Seltzer, G., & Hogg, J.
Practice guidelines for the clinical assessment and care management of Alzheimer's disease and other dementias among adults with intellectual disability
Journal of Intellectual Disability Research, 1996, 40, 374-382
Abstract: The AAMR/IASSID practice guidelines, developed by an international workgroup, provide guidance for stage-related care management of Alzheimer's disease, and suggestions for the training and education of carers, peers, clinicians, and program staff. The guidelines suggest a three step intervention activity process, that includes: (1) recognizing changes, (2) conducting assessments and evaluations, and (3) instituting medical and care management. They provide guidance for public policies that reflect a commitment for aggressive care of people with Alzheimer's disease and intellectual disability, and avoidance of institutionalization solely because of a diagnosis of dementia. [This report is available also on www.aamr.org at the following URL: http://161.58.153.187/Bookstore/Downloadables/index.shtml]

 **Janicki, M.P., McCallion, P., & Dalton, A.J.**
Supporting people with dementia in community settings.
In M.P. Janicki & A.F. Ansello (Eds.), Community Supports for Aging Adults with Lifelong Disabilities.
pp. 387-413
Baltimore, Maryland: Paul H. Brookes Publishing (2000)
Abstract: Due to the "greying" of the nation's population, dementia associated with Alzheimer's disease and other causes, has become another challenge for providers of services to adults with intellectual disabilities. In this book chapter, the authors explore the factors, policies, and support structures that can help agencies provide continued "aging-in-place" dementia-capable care, develop "in-place progression" dementia specific programs, or chose alternative care settings. It also explores some features of dementia-related behaviors that may need to be taken into account in program design and makes suggestions for staff training and planning for dementia programs.

Janicki, M.P., McCallion, P., & Dalton, A.J.
Dementia-related care decision-making in group homes for persons with intellectual disabilities
Journal of Gerontological Social Work, 2002, 38(½), 179-196.
Abstract: The number of age-associated pathologies is increasing, with the increase in the number of elderly persons. One such age-associated condition, Alzheimer's disease and related dementias, affects a significant number of adults with intellectual disability (ID), in particular those with Down syndrome. Many affected adults live in small community group homes or with their families. How to provide sound and responsive community care is becoming a challenge for agencies faced with an increasing number of affected adults. This study reports the outcome of a survey of group homes serving adults with ID and dementia, explores the onset, duration and effects of dementia and their impact on planning for community care of adults with ID. It also examines emerging community care models that provide for "dementia capable" supports and services. Two models, "aging in place," and "in place progression" are examined with regard to care practices and critical agency decision making. An approach, the ECEPS model, for responding to dementia is offered.

Janicki, M.P. & Dalton A.J.
Care management, diagnostic and epidemiologic considerations in adults with intellectual disabilities and Alzheimer disease
British Journal of Developmental Disabilities, 1996, 42(Supplement), s84
Abstract: Review of the process and outcome of the Invitational International Colloquium on Alzheimer Disease among Persons with intellectual Disabilities held in Minneapolis, Minnesota (USA) and the subsequent development of a set of international practice guidelines and reports on the assessment, epidemiology, and care management of adults with intellectual disabilities affected by dementia.

Janicki, M.P., & Dalton, A.J.
Dementia in developmental disabilities
In N. Bouras (Ed.), Psychiatric and Behavioral Disorders in Developmental Disabilities and Mental Retardation (1999)
pp. 121-153
Cambridge: Cambridge University Press
Abstract: This book chapter provides a brief overview of the current status of knowledge about dementia and its relationship to intellectual disability, touching on current developments in the evaluation of possible comorbid psychiatric, medical and age-associated conditions. The clinical presentation of dementia is examined as well as relevant contemporary issues related to diagnosis, assessment, and care management. Lastly, questions of dementia policy and suggestions for training programs on dementia and intellectual disability are addressed.

Janicki, M.P., & Dalton, A.J.
Dementia and public policy considerations
In M.P. Janicki & A.J. Dalton (eds.), Dementia, Aging, and Intellectual Disabilities (1999)
pp. 388-414
Philadelphia: Brunner-Mazel
Abstract: This book chapter examines a number of the major public policy considerations related to the aging of adults with intellectual disabilities who evidence change due to dementia. Specifically addressed is the changing structure of at-risk adult populations with intellectual disabilities in service systems, the programmatic and policy issues raised by providers attempting to cope with these changes, needs for further training, education and dissemination of information on aging, and lastly, the challenges and policy imperatives to be confronted with the new millennium.

Janicki, M.P., & Dalton, A.J.
Dementia, aging, and intellectual disabilities: A handbook
488pp.
Philadelphia: Brunner-Mazel [http://www.taylorand francis.com] (1999)
Abstract: 21 chapter text on dementia issues and intellectual disabilities. Six parts: Introduction, Biomedical considerations, Assessment considerations, Clinical considerations, Program considerations, and Education and policy considerations. Text provides most up-to-date information available about Alzheimer's disease and related dementias as they affect persons with mental disabilities. Text examines biology and physiology of dementia, neurological and medical complications associated with dementia, best practices to meet the needs of aging persons with intellectual disabilities, policy issues raised by the growing number of older adults with ID, and case studies of affected individuals. Contains glossary of terms, and appendices with AAMR/IASSID practice guidelines for dementia diagnosis and care management in adults with intellectual disabilities, as well as Newroth & Newroth guidelines for coping with Alzheimer's disease in persons with Down syndrome.

Janicki, M.P., & Dalton, A.J.
Prevalence of dementia and impact on intellectual disability services
Mental Retardation, 2000, 38, 277-289.
Abstract: A statewide survey, conducted to ascertain the administrative prevalence of dementia in adults with an intellectual disability, found a prevalence of about 3% of the adult service population over the age of 40 years (a rate of 28/1000), 6.1% of the population over the age of 60 years, and 12.1% of the population over the age of 80 years (or rates of 68.7/1000 and 121.3/1000, respectively). The rate of dementia was consistent with that for adults in the general population, except for those adults with Down syndrome (who made up a third of the overall group) who had a much higher rate: 22.1% among adults age 40 and older and 56.4% among adults age 60 and older. Onset was observed to occur in the mid-60s (early 50s for Down syndrome). Alzheimer-type dementia was the most frequent diagnosis. Late-onset seizures were reported in about 12% of the cases. With the occurrence of dementia expected to rise proportionately with the increase of longevity among adults with an intellectual disability, it is clear that care systems will have to raise the "index of suspicion" among staff and families, adapt to become "dementia capable," and improve their diagnostic and technical resources, as well as their community-based care management supports.

Janicki, M.P., McCallion. P., Splaine, M., Santos, F.H., Keller, S.M., & Watchman, K.
Consensus statement of the international summit on intellectual disability and dementia related to nomenclature
Intellectual and Developmental Disabilities, 2017, 55(5), 338–346. DOI: 10.1352/1934-9556-55.5.338.
Abstract: A working group of the 2016 International Summit on Intellectual Disability and Dementia was charged to examine the terminology used to define and report on dementia in publications related to intellectual disability (ID). A review of related publications showed mixed uses of terms associated with dementia or causative diseases. Like general applications, language related to dementia in ID field often lacked precision and could lead to a misunderstanding of the condition(s) under discussion. Most articles related to ID and dementia reporting clinical or medical research generally provided a definition of dementia or related terms; social care articles tended toward term use without definition. Toward terminology standardization within studies/ reports on dementia and ID, the Summit recommended (a) gaining familiarity with dementia-related diagnostic, condition-specific, and social care terms (as identified in the working group's report), (b) creating a guidance document on accurately defining and presenting information about individuals or groups referenced, and (c) that in reports on neuropathologies or cognitive decline or impairment, definitions are used and data include subjects' ages, sex, level of ID, residential situation, basis for dementia diagnosis, presence of Down syndrome (or other risk conditions), years from diagnosis, and if available, scores on objective measures of changing function.

Janicki, M.P. Zendell, A., & DeHaven. K.
Coping with dementia and older families of adults with Down syndrome.
Dementia, 2010, 9(3), 391-407.
Abstract: The authors studied a group of older carers of aging adults with Down syndrome (DS) to ascertain what effects such caregiving may have on them given the presence or possibility of age-associated decline or dementia. The study also examined the comparative levels of care provided, key signs noted when decline was beginning, the subjective burden experienced, and what were the key associated health factors when carers faced a changed level of care. The authors found that this group was made up of long-term, committed carers who had decided early to look after their relative with DS over their lifetime. When faced with the onset and ongoing progression of dementia, their commitment was still evident as evidenced by adopting physical accommodations and finding ways to continue to provide care at home, while also seeking help from outside sources. Most saw a family or group home environment as the place of choice for their relative with DS when they decided they could no longer offer care. The study did not ascertain any burn-out or significant health related problems associated with their continued caregiving save for their concerns about day-to-day strain and what will happen in the future.

Janicki, M.P., & McCallion, P.
A group home cluster model for providing community-based dementia care.
Paper presented at the 21st annual conference of Alzheimer Europe, Warsaw, Poland. (2011, October).
Abstract: Paper reports on a study undertaken of an innovation group home program operated by a provider organization serving older adults with intellectual disabilities. The provider built three co-located group homes for five adults within a neighborhood setting. Each of the adults resident at the homes have some degree of diagnosed dementia. The adults were both males and females, all were age 50+, and some had Down syndrome. The homes are staffed by paid staff working 24/7. The residents were studied for health co-morbidities, program activities, and degrees of impairment and compared with a matched group of adults without dementia. The study examined administrative and programmatic factors related to the operation of the homes, as well as shifts in characteristics related to their intellectual disability and the effects of dementia
.

Jaycock, S., Persaud, M. & Johnson, R.

The effectiveness of dementia care mapping in intellectual disability residential services: A follow-up study.
Journal of Intellectual Disabilities, 2006, 10(4), 365-375.
Abstract: The authors present a follow-up to exploratory work published in the Journal of Intellectual Disabilities in 2001. This article describes a study that aimed to assess the effectiveness of dementia care mapping in supporting practice improvement in intellectual disability residential services. An average of 9 hours of observational data were collected using dementia care mapping in relation to 14 adults with severe or profound intellectual disabilities (but who not have dementia). Sixteen interviews were also undertaken with staff over a 4 month period.The findings provided a detailed picture of the activities and interactions between the participants involved in the study and raised some issues about 'organizational culture' when developing person-centered approaches. These data have helped strengthen the case that care mapping has the potential to be a useful addition to the existing repertoire of tools to support effective practice improvement and person-centered planning.

Jervis, N., & Prinsloo, L.
How we developed a multidisciplinary screening project for people with Down's syndrome given the increased prevalence of early onset dementia
British Journal of Learning Disabilities, 2008, 36 (1), 13–21.
Abstract: Much research has identified an increased prevalence of dementia in adults with Down syndrome when compared with the general population. Neuropathological changes associated with Alzheimer's dementia in the brain have been found in most people with Down syndrome who die over the age of 35 years. Given the limitations of many assessments for dementia in relation to people with Down syndrome for a single completion, it has been recommended that all people with Down syndrome are assessed at least once in early adulthood in order that they have their own baseline which can be compared with in the future if changes in skills and abilities occur. The authors have had many requests from other services enquiring about their project and how a similar initiative could be set up. Therefore, this article focuses on the way the Manchester Learning Disability Partnership approached screening 135 adults with Down syndrome and details the assessments used, practical considerations, what has been learned and future service implications.

Johannsen, P., Christensen, J.E.J., & Mai, J.
The prevalence of dementia in Down syndrome
Dementia, 1996, 7(4), 221-225.
Abstract: The authors assess the prevalence of clinical dementia in three age groups of persons with Down syndrome in the county of Aarhus, Denmark. Group 1 was composed of 14-16 year olds (n=13), group 2 was composed of 23-29 year olds (n=34), and group 3 was composed of 50-60 year olds (n=25). Of the 85 subjects, 72 (85%) participated. Carers were interviewed and a neurological examination was performed. An EEG was recorded in 50 of the Ss. Definite clinical dementia was defined as a acquired and progressive decline in 4 or more out of 17 items that are considered to indicate dementia in people with Down syndrome. Possible dementia was considered when 1-3 items were affected. Six adults (24%) in group 3 had definite clinical dementia and 6 adults in group 3 and 2 (6%) in group 2 had possible dementia. Authors note that this was the first Danish population-based study of the prevalence of dementia in people with Down syndrome.

Johansson, M., Holst,G., & G Ahlström
Signs in people with intellectual disabilities: Interviews with managers and staff on the identification process of dementia
Journal of Intellectual Disabilty Research, 2019, 63(8), 649.
Abstract: An increasing number of people with intellectual disability (ID) are reaching older ages and an increased risk of dementia diseases. Staff and managers give support in daily living and can deliver information about residents' changes in behavior. The aim of this Swedish study was to explore the identification process employed by staff and managers to detect signs of suspected dementia in people with ID within intellectual disability services (ID-services). Twenty managers and 24 staff within ID-service were interviewed and qualitative latent content analysis was applied. A model consisting of three themes on three levels of resources for the identification process of signs of suspected dementia emerged from the analysis. On the first level was the time and continuity in the care relationship, which is crucial for identifying and responding to changes in cognitive ability that indicate dementia. On the second level, the staff identifies deficiencies in their own knowledge, seek support from colleagues and managers within their workplace and, on the third level, outside their workplace. Staff and managers expressed needs for guidance and education from specialists in dementia and primary healthcare. This finding indicates an urgent need for intervention research and digital support for staff in dementia care.

Johnson, N., Fahey, C., Chicoine, B., Chong, G., & Gitelman, D.
Effects of donepezil on cognitive functioning in Down syndrome
American Journal on Mental Retardation, 2003,108(6), 367-372
Abstract: This study to determined whether donepezil, an acetylcholinesterase inhibitor, would improve cognitive functioning in 19 subjects with Down syndrome and no dementia. They were assigned to either a donepezil or placebo group. Cognitive functioning and caregiver ratings were measured at baseline, 4 weeks, and 12 weeks. With the exception of one area (language), no improvement was noted in any of the cognitive subtests, behavioral scores, or caregiver ratings. Subjects in the donepezil group showed an improvement in language scores compared to subjects in the placebo group. The results suggest that donepezil may improve language performance in subjects with Down syndrome and no dementia, but further studies need to be done on a larger group to confirm this result.

Jokinen, N.S., Janicki,M.P., Hogan,M., & Force, L.T.
The middle years and beyond: Transitions and families of adults with Down syndrome
Journal on Developmental Disabilities, 2012, 18(2), 59-69.
Abstract: Normally expected transitions connect the various periods of life. Often these transitions are prompted by life events that require adaptation to a changed circumstance and may challenge both individual and family quality of life. Such transitions may be *planful* (proactive) or *demand* (reactive). Little, however, has been written about the nature of such transitions and how they specifically affect older-aged families of adults with Down syndrome. Such families are often predominate lifelong carers of adults with Down syndrome. Drawing on research and experience, the authors examined three transition points from a family perspective. Each of these points of change requires that people adapt and may lead to various outcomes, including at times outcomes that are unexpected, stressful, and challenging. The three points of transition examined include moving away from the parental home, changes occurring within a residential service (e.g., staff changes, relocations), and the reactions to the onset and course of dementia. Vignettes and quotes illustrate the complexities of these transitions and show that, even with planful management, often such transitions can go awry and produce unpredictable outcomes.

Jokinen, N.
The content of available practice literature in dementia and intellectual disability.
Dementia: The International Journal of Social Research and Practice, 2005, 4(3), 327-339.
Abstract: Adults with intellectual disability are living to ages seen within the general population and they, too, are at risk of developing dementia. This review was to conducted to identify the nature and content of the literature related to adults with intellectual disability and dementia and bring together guidelines for services and staff providing care. The preponderance of work between 1995 and 2004 focuses on the biomedical, diagnosis and assessment aspects of the disease. Although guidelines exist, there is a lack of published literature on the efficacy of practice strategies to guide the provision of daily care. Future research is discussed that could support continued community living and high quality of life during all stages of the disease.

Jokinen, N., Service, K., Marsack-Topolewski, C., & Janicki, M.P.
Support-staging model for caregivers of adults with intellectual disability affected by dementia
AAIC2020,Poster presentation, July 30, 2020.
https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Paper/47274
Abstract: Adults with intellectual disability (ID) and dementia are a sub-population of persons who are often un- or underserved. Most adults with ID are integrated within the general community (living autonomously, or in apartments/group residences); but significant numbers also reside with their families, particularly adults with Down syndrome. Family help/counseling approaches, such as the New York University-Caregiver Intervention (NYUCI), might benefit from a support-staging model assessment focus on what specific aid a family requires to meet their needs. Patterns of such needs have been identified that can help with providing dementia-capable care. Objective needs include: (a) information on signs and symptoms, (b) diagnostic advice, (c) understanding behavioral changes and managing dementia-related behaviors, (d) adapting homes, (e) determining daily routines most conducive to calming, (f) planning for the future, (g) finding and navigating resources, and (h) responding to end-of-life needs. Subjective needs include: (a) being informed at time of

diagnosis and throughout the course of dementia, (b) coping with a profound sense of loss from knowing the diagnosis, (c) fearing the future [including financial concerns], (d) formulating long-term plans, (e) accessing community-based coordinated care, (f) facing difficulties from the medical community, (g) feeling overwhelmed by caregiving demands, (h) feeling a sense of isolation and abandonment, and (i) facing end-of-life issues. A working group emanating from the 2016 Glasgow Summit on Intellectual Disability and Dementia organized a schema encapsulating these concerns into a support-staging model. The schema suggested four fluid stages: Diagnostic (seeking cause of changes in function, abilities, personality), Explorative (exploring dementia capable interventions), Adaptive (coping with and managing the symptoms/changes), and Closure (resolving / relief from responsibilities). Using this schema, a process (utilizing the NYUCI) is underway to operationalize a support-staging assessment instrument which would enable counseling staff to frame the state of a family's concerns, build relationships through this knowledge of the caregiver and provide tailored services to them. The outcome will enable systematic coding and organizing both objective and subjective data so that specific interventions and counseling can be adapted to meet both intermittent and continuous caregiver needs.

Jokinen, N., Janicki, M.P., Keller, S.M., McCallion, P., Force,L.T., & National Task Group on Intellectual Disabilities and Dementia Practices
Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia
Journal of Policy and Practice in Intellectual Disabilities, 2013, 10(1), 1–24.
Abstract: To assist families and organizations in their planning for extended care that accompanies the diagnosis of dementia, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States adopted a set of practice guidelines covering the period from when suspicions are aroused to when care ends with eventual death. These guidelines are drawn from the research literature as well as clinical experiences and demonstrated best practices. The guidelines delineate what actions should be undertaken and are presented in a manner that reflects the progressive nature of prevalent dementias. To enable the development of the most appropriate and useful services and care management for adults with intellectual disabilities affected by dementia, the NTG adopted the staging model generally accepted for practice among generic dementia services. The staging model follows the flow from a prediagnosis stage when early recognition of symptoms associated with cognitive decline are recognized through to early, mid, and late stages of dementia, and characterizes the expected changes in behavior and function. In keeping with the National Plan to Address Alzheimer's Disease recommendations for earlier and more widespread efforts to detect possible symptoms, the guidelines cite the application of the NTG-Early Detection Screen for Dementia as a first step in documenting early signs of cognitive and functional changes among people with intellectual disabilities. The guidelines also provide information on nonpharmacological options for providing community care for persons affected by dementia as well as commentary on abuse, financial, managing choice and liability, medication, and nutritional issues.

Jokinen, N., Gomiero, T., Watchman, K., Janicki, M.P. Hogan, M., Larsen, F., Service, K., & Crowe, J .
Perspectives on family caregiving of people aging with intellectual disability affected by dementia: Commentary from the International Summit on Intellectual Disability and Dementia
Journal of Gerontological Social Work, 61(4), 411-431. DOI: 10.1080/01634372.2018.1454563
Abstract: This article, an output of the 2016 International Summit on Intellectual Disability and Dementia, examines familial caregiving situations within the context of a support-staging model for adults with intellectual disability (ID) affected by dementia. Seven narratives offer context to this support-staging model to interpret situations experienced by caregivers. The multidimensional model has two fundamental aspects: identifying the role and nature of caregiving as either primary (direct) or secondary (supportive); and defining how caregiving is influenced by stage of dementia. We propose staging can affect caregiving via different expressions: (1) the "diagnostic phase," (2) the "explorative phase," (3) the "adaptive phase," and (4) the "closure phase." The international narratives illustrate direct and indirect caregiving with commonality being extent of caregiver involvement and attention to the needs of an adult with ID. We conclude that the model is the first to empirically formalize the variability of caregiving within families of people with ID that is distinct from other caregiving groups, and that many of these caregivers have idiosyncratic needs. A support-staging model that recognizes the changing roles and demands of carers of people with ID and dementia can be useful in constructing research, defining family-based support services, and setting public policy.

Kalsy, S., McQuillan, S., Oliver. C., Hall, S.
Manual for the "Assessment for Adults with Developmental Disabilities" (A.A.D.S.) Questionnaire
School of Psychology, University of Birmingham, Edgbaston, Birmingham B15 2TT (2000).
Scales designed to assess behaviors associated with dementia and levels of caregiving. American version is available for download from www.uic.edu/orgs/rrtcamr/dementia.

Kalsy, S., Heath, R., Adams, D., & Oliver, C.
Effects of training on controllability attributions of behavioural excesses and deficits shown by adults with Down syndrome and dementia.
Journal of Applied Research in Intellectual Disabilities, 2007, 20(1), 64 -68.
Abstract: Whereas there is a knowledge base on staff attributions of challenging behavior, there has been little research on the effects of training, type of behavior and biological context on staff attributions of controllability in the context of people with intellectual disabilities and dementia. A mixed design was used to investigate the effects of three factors on care staff attributions of the controllability of challenging behavior. Pre- and post-training measures were administered to participants (n = 97) attending training on ageing, dementia and people with intellectual disabilities. Authors found no significant effects of diagnosis or type of behavior on attributions were found. There was a significant increase in knowledge after training ($P < 0.001$) and training was found to significantly decrease the attribution of controllability ($P < 0.001$). Conclusion was that the results suggest that training that focuses on aspects of change relevant to behavior can favorably influence care staff's knowledge and attributions of controllability within the context of people with Down syndrome and dementia.

Keater, D.B., Phelen, M.J., Taylor, L., Doran, E., Krinsky-McHale, S., Price, J., Ballard, E.E., Kreisl, W.C., Hom, C., Nguyen, D., Pulsifer, M., Lai, F., Rosas, D.H., Brickman, A.M., Schupf, N., Yassa, M.A., Silverman, W., & Lott, I.T.
Down syndrome: Distribution of brain amyloid in mild cognitive impairment
Alzheiimer's Dementia: Diagnosis, Assessment & Disease Monitoriing, 2020, 12(1), e12013. https://doi.org/10.1002/dad2.12013
Abstract: Down syndrome (DS) is associated with a higher risk of dementia. We hypothesize that amyloid beta (Aß) in specific brain regions differentiates mild cognitive impairment in DS (MCI-DS) and test these hypotheses using cross-sectional and longitudinal data. 18F-AV-45 (florbetapir) positron emission tomography (PET) data were collected to analyze amyloid burden in 58 participants clinically classified as cognitively stable (CS) or MCI-DS and 12 longitudinal CS participants. The study confirmed our hypotheses of increased amyloid in inferior parietal, lateral occipital, and superior frontal regions as the main effects differentiating MCI-DS from the CS groups. The largest annualized amyloid increases in longitudinal CS data were in the rostral middle frontal, superior frontal, superior/middle temporal, and posterior cingulate cortices. Authors note that this study helps us to understand amyloid in the MCI-DS transitional state between cognitively stable aging and frank dementia in DS. The spatial distribution of Aß may be a reliable indicator of MCI-DS in DS.

Kerins, G., Petrovic, K., Bruder, M.B., & Gruman, C.,
Medical conditions and medication use in adults with Down syndrome: A descriptive analysis.
Down Syndrome Research and Practice, 2008, 12(2), 141-147. [http://www.down-syndrome.org/reports/2009/reports-2009.pdf]
Abstract: Authors the presence of medical conditions and medication use within a sample of adults with Down syndrome. The author employed a retrospective chart review using a sample of 141 adults with Down syndrome and age range of 30 to 65 years. They identified 23 categories of commonly occurring medical conditions and 24 categories of medications used by adults with Down syndrome. From their work, the authors concluded that approximately 75% of older adults with Down syndrome in their sample experienced memory loss and dementia. Hypothyroidism, seizures, and skin problems also occurred commonly. The prevalence of cancer (i.e., solid tumors) and hypertension was extremely low. Older adults with Down syndrome used anticonvulsants more often than younger adults with Down syndrome. The use of multivitamins and medications such as pain relievers, prophylactic antibiotics, and topical ointments was common

Kerr, D.
Down's syndrome and dementia
76 pp.
Birmingham, UK: Venture Press (1997)
Abstract: Text providing a comprehensive review of issues and practices relative to adults with Down syndrome affected by Alzheimer's disease. Covered are a range of topics related to care management, including assessment of need, communication, creating a therapeutic environment, how to maintain skills, and dealing with challenging behaviors. Also covered are specific interventions and supporting carers.

Kirk, L.J., Hick, R., & Laraway, A.
Assessing dementia in people with learning disabilities: The relationship between two screening measures.
Journal of Intellectual Disabilities, 2006, 10(4), 357-364.
Abstract: As life expectancy increases for people with intellectual disabilities, the impact of dementia on people with intellectual disabilities and their families, carers and services is becoming more apparent. Psychological services for intellectual disabilities are receiving an increasing number of referrals requesting dementia assessment. Health and social care services are adapting to the diverse needs of an ageing population with intellectual disabilities. The authors describe a study investigating the relationship between two assessments for dementia in people with intellectual disabilities. Carers of people with intellectual disabilities over the age of 50 (or 40 if the individual had Down syndrome) completed the Dementia Questionnaire for Mentally Retarded People (DMR) and the Adaptive Behavior Scale–Residential and Community (ABS). Overall, the two questionnaire measures showed significant relationships. However, results suggested that both assessments have clinical value in informing individual needs and aiding diagnosis. The authors discuss the Implications for both clinical and social care services.

Koenig, B.R.
Aged and dementia care issues for people with an intellectual disability: Best practices (vol. 2).
80 pp.
Brighton, South Australia: MINDA, Inc. (1995)
Abstract: Text covering a range of useful topics related to service provision for dementia among persons with intellectual disabilities. Highly detailed chapters cover health issues, physical decline, behavioral changes, and social aspects. Specific remedial information is provided on communication issues and adapting the environment. A chapter also addresses counseling strategies, examining a diverse range of approaches.

Kozma, C.
Down syndrome and dementia.
Topics in Geriatric Rehabilitation, 2008, 24(1), 41–53.
Abstract: Down syndrome (DS) is one of the most common genetic conditions with an estimated incidence of 1 in 750 in the general population. It results from an extra chromosome 21 with the total chromosome count being 47 instead of the normal 46. The classic features of DS include hypotonia, atypical facial characteristics, an increased incidence of major and minor anomalies, vision and hearing deficits, other health problems, and intellectual disabilities. People with DS are living longer and experiencing premature aging, specifically Alzheimer disease (AD). The incidence of AD among adults with DS varies significantly according to studies averaging between 11% to 22% for people aged 40 to 49 years, 24.9% for people aged 50 to 59 years, and 25.6% to 77% for people older than 60 years. All studies indicate an early onset of AD as well as an exponential increase in prevalence with age. Furthermore, senile plaques and neurofibrillary tangles, the neuropathological characteristics of AD, are seen in the brain of all people with DS. Annual screening for AD should become part of routine medical practice of older adults with DS, because an early diagnosis is important for comprehensive care.

Krinsky-McHale SJ, & Silverman W.
Dementia and mild cognitive impairment in adults with intellectual disability: issues of diagnosis.
Developmental Disabilities Research Reviews, 2013,18(1).31-42. doi: 10.1002/ddrr.1126.
Abstract: Individuals with intellectual disability (ID) are now living longer with the majority of individuals reaching middle and even "old age." As a consequence of this extended longevity they are vulnerable to the same age-associated health problems as elderly adults in the general population without ID. This includes dementia, a general term referring to a variety of diseases and conditions causing substantial loss of cognitive ability and functional declines; adults with Down syndrome are at especially high risk. A great deal of recent effort has focused on the very earliest detectable indicators of decline (and even prodromal stages of dementia-causing diseases). A condition called mild cognitive impairment (MCI) has been conceptually defined as a decline in functioning that is more severe than expected with typical brain aging but not severe enough to meet criteria for a diagnosis of dementia. Consensus criteria for both dementia and MCI have been developed for typically developing adults but are of limited applicability for adults with ID, given their pre-existing cognitive impairments. Early diagnosis will continue to be of growing importance, both to support symptomatic treatment and to prevent irreversible neuropathology when interventions are developed to slow or halt the progression of underlying disease. While the intellectual and developmental disabilities field has for some time recognized the need to develop best-practices for the diagnosis of MCI and dementia, there remains a pressing need for empirically based assessment methods and classification criteria.

Lin LP, Hsu SW, Hsia YC, Wu CL, Chu C, Lin JD.
Association of early-onset dementia with activities of daily living (ADL) in middle-aged adults with intellectual disabilities: the caregiver's perspective.
Research in Developmental Disabilities, 2014, 35(3), 626-631. doi: 10.1016/j.ridd.2013.12.015. Epub 2014 Jan 24.
Abstract: Few studies have investigated in detail which factors influence activities of daily living (ADL) in adults with intellectual disabilities (ID) comorbid with/without dementia conditions. The objective of the present study was to describe the relation between early onset dementia conditions and progressive loss of ADL capabilities and to examine the influence of dementia conditions and other possible factors toward ADL scores in adults with ID. This study was part of the "Healthy Aging Initiatives for Persons with an Intellectual Disability in Taiwan: A Social Ecological Approach" project. We analyzed data from 459 adults aged 45 years or older with an ID regarding their early onset symptoms of dementia and their ADL profile based on the perspective of the primary caregivers. Results show that a significant negative correlation was found between dementia score and ADL score in a Pearson's correlation test ($r=-0.28$, $p<0.001$). The multiple linear regression model reported that factors of male gender ($ß=4.187$, $p<0.05$), marital status ($ß=4.79$, $p<0.05$), education level (primary: $ß=5.544$, $p<0.05$; junior high or more: $ß=8.147$, $p<0.01$), Down's syndrome ($ß=-9.290$, $p<0.05$), severe or profound disability level ($ß=-6.725$, $p<0.05$; $ß=-15.773$, $p<0.001$), comorbid condition ($ß=-4.853$, $p<0.05$) and dementia conditions ($ß=-9.245$, $p<0.001$) were variables that were able to significantly predict the ADL score ($R(2)=0.241$) after controlling for age. Disability level and comorbidity can explain 10% of the ADL score variation, whereas dementia conditions can only explain 3% of the ADL score variation in the study. The present study highlights that future studies should scrutinize in detail the reasons for the low explanatory power of dementia for ADL, particularly in examining the appropriateness of the measurement scales for dementia and ADL in aging adults with ID.

Llewellyn, P.
The needs of people with learning disabilities who develop dementia, A literature review
Dementia (London), 2011, 10(2), 235-247.
https://doi.org/10.1177/1471301211403457
Abstract: People with learning disabilities are living longer and are increasingly developing age related conditions including dementia. If this occurs, their medical and social needs pose many challenges for services. A literature review was undertaken of articles published between 1996— 2006. Data was collected relating to the needs of people with learning disabilities and dementia, their carers and their peers. The primary medical need is for timely and accurate diagnosis. There is a multitude of diagnostic tools and advice is available as to which are most suitable for different client groups. The needs of carers are intertwined with those of people with learning disabilities and dementia and meeting their needs for education, training and increased staff numbers, has proved beneficial. Although multiple services will be responsible for the needs of this client group, there is a consensus that learning disability services should be at the heart of service provision.

Lloyd, V. , Kalsy, S., & Gatherer, A.
The subjective experience of individuals with Down syndrome living with dementia
Dementia, 2007, 6(1), 63-88.
Abstract: An increasing number of studies have begun to explore the subjective

experience of individuals with dementia. However, despite the increased prevalence of dementia in individuals with Down syndrome, no such published research has been undertaken within this population. The aim of this study was to explore the perspectives and subjective experiences of six individuals with Down syndrome and dementia. Semi-structured interview accounts were analyzed using Interpretative Phenomenological Analysis, in order to gain a level of understanding concerning the impact of dementia upon respondents' lives and sense of self. Five main themes emerged: (1) Self-image, (2) The Relational Self, (3) Making Sense of Decline,(4) Coping Strategies and (5) Emotional Experience. Whilst the process of adjusting to dementia appeared comparable to the general population, the content of this was influenced by multiple levels of context specific to having a concomitant intellectual disability.

Lloyd, V., Kalsy, S., & Gatherer, A.
Impact of dementia upon residential care for individuals with Down syndrome
Journal of Policy and Practice in Intellectual Disabilities, 2008, 5(1), 33-38.
Abstract Despite the increased prevalence of dementia in individuals with Down syndrome, relatively little is known about its impact upon care provision. Carers may be familiar with the demands of assisting a person with Down syndrome, but generally have little knowledge about the course or impact of dementia. This dissonance may lead to stress, which can have a detrimental effect on the carer and the quality of care for the recipient. In this exploratory study, the authors examined the objective and subjective impact of dementia upon paraprofessional paid carers of individuals with Down syndrome working in residential settings. The study used the Caregiver Activities Scale—Intellectual Disabilities (CAS-ID), the Caregiver Difficulties Scale—Intellectual Disabilities (CDS-ID), and the Maslach Burnout Inventory (MBI). Responses given for these measures by paraprofessional carers of individuals with Down syndrome and dementia (n = 9) were compared with responses from those caring for recipients with Down syndrome and no additional cognitive decline (n = 11). No significant differences were found in the responses from these sets of carers on measures of objective (CAS-ID) or subjective burden (CDS-ID). However, the MBI revealed that carers of individuals with Down syndrome and dementia reported significantly increased levels of emotional exhaustion. Findings suggested that, while even when there is little difference in the level of caregiving tasks or the subjective difficulties of caregiving, the onset of dementia in individuals with Down syndrome resulted in increased emotional exhaustion for carers. Additional factors not considered within this study, such as challenging behavior, may also be pertinent to carer burden.

Llewellyn, P.
The needs of people with learning disabilities who develop dementia: A literature review.
Dementia: The International Journal of Social Research and Practice, 2011, 10(2), 235-247.
Abstract: People with intellectual disabilities (ID) are living longer and are increasingly developing age related conditions including dementia. If this occurs, their medical and social needs pose many challenges for services. A literature review was undertaken of articles published between 1996–2006. Data were collected relating to the needs of people with ID and dementia, their carers and their peers. The primary medical need is for timely and accurate diagnosis. There is a multitude of diagnostic tools and advice is available as to which are most suitable for different client groups. The needs of carers are intertwined with those of people with ID and dementia and meeting their needs for education, training and increased staff numbers, has proved beneficial. Although multiple services will be responsible for the needs of this client group, there is a consensus that ID services should be at the heart of service provision.

Lott, J.D.
The rate of decline of social skills across dementing and non-dementing individuals with intellectual disabilities: A longitudinal study.
Dissertation Abstracts International: Section B: The Sciences and Engineering, 2007, 67(8-B), 2007, 4715.
The author sought to establish rate of decline of adaptive skills in a population of individuals with intellectual disability (ID) with dementia compared to similar adults with ID and without dementia, as well as examining the variability of positive and negative social behaviors across diagnostic classes. The participants were matched for age, sex, Down syndrome, and level of ID. The control group was screened for the presence of dementia with the Early Signs of Dementia Checklist. Rate of decline within groups was assessed by the Vineland Adaptive Behavior Scales and changes in positive and negative behaviors were measured by the Matson Evaluation of Social Skills for the Severely Retarded. (MESSIER) Prior to a diagnosis of dementia groups were equivalent. No significant differences were found for adaptive behaviors. Visual analysis of plotted means supports predicted decline in skills for both groups. Significant differences were found across time for positive social skills. Significant correlations were observed between the VABS and the MESSIER Positive domains. The findings provide support for the diagnostic utility of the MESSIER with dementia. However, no support was observed for different variances of negative behaviors across diagnostic groups. This would suggest that the measure of negative behaviors is not supported as a diagnostic tool at this time.

Lynggard, H., & Alexander, N.
'Why are my friends changing?' Explaining dementia to people with learning disabilities
British Journal of Learning Disabilities, 2004, 32(1), 30-34.
Abstract: Many publications seek to explain the causes and effects of dementia to the general population and there is evidence of the benefit of supporting carers and of establishing support groups. However, there is much less published material aimed at people with intellectual disabilities, and little focus on the specific needs of people who share their homes and lives with other people with learning disabilities who develop dementia. This article, based on group work, describes residents who had expressed bewilderment at the gradual changes they were witnessing in two of their housemates with dementia with whom they had shared a home and friendships over many years. Employing a wide range of visual aids, equipment, role plays and exercises, we sought to make the explanation of dementia as accessible and concrete as possible. The group also provided a forum for the residents to talk about the effects of living with others who develop dementia. Evaluation showed how a relatively short intervention can result in positive changes for both the people with learning disabilities who develop dementia and their peers.

MacDonald, S., & Summers, S.J.
Psychosocial interventions for people with intellectual disabilities and dementia: A systematic review
Journal of Applied Research in Intellectual Disabilities, 27 February 2020
https://doi.org/10.1111/jar.12722
Abstract: People with intellectual disability experience a higher prevalence of dementia, at an earlier age, than the general population. The aim of this review was to establish the psychological interventions and outcomes for individuals with intellectual disability and dementia. A search of eight electronic databases and reference lists of all included articles was conducted using PRISMA guidelines. Data were synthesized using an integrative method. Initial searching produced 2,331 papers. Twenty-one studies met the inclusion criteria. Interventions were deductively categorized into behavioural, systemic and therapeutic. All studies reported positive findings for individuals and for the systems which support them, but limited by methodological issues and neglect of the direct experience and impact on individuals themselves. The lack of a synthesis of psychosocial interventions within clinical practice, and the associated evidence, has invariably led to a lack of knowledge in practice. This is clearly evidenced by the omission of psychosocial interventions within established intellectual disability and dementia care pathways. The findings are discussed in relation to the wider literature and evidence base. Future research should aim to adopt methodologically robust designs that are inclusive of the individual experience of people with intellectual disability. The authors also posit that this review will provide essential knowledge for enacting policies that all individuals diagnosed with dementia and their carers have access to meaningful post-diagnostic care, including social and psychological care and support.

Manji, S.W.L.U.
Aging with dementia and an intellectual disability: A case study of supported empowerment in a community living home.
Dissertation Abstracts International Section A: Humanities and Social Sciences, 2009, 70(1-A), 352.
Abstract: Case study explored the qualitative experience of 4 adults with intellectual disability (ID) and dementia residing in a specializing dementia support group home. Participant observation, daily living log notes, and interviews with family/friend carers, direct-care staff, and administrators were used to obtain data. The three study questions were: (I) how the onset of dementia in people with ID changes their needs, what adjustments have to be made in the support practices, and what service barriers and successes are experienced; (ii) how adults with ID and dementia experience living in a home specializing in dementia support and how stakeholders perceive this model of

support; and (iii) what are the ways policymakers can better respond to the changing needs of people with ID and dementia. Two social processes were identified: 'marginalization' and 'supported empowerment'. Marginalization depicted how dementia affected adults with ID as they incurred multiple losses in ability, home, and community. Despite losses, the adults maintained their 'selfhood' with good health support, decision-making, self-agency, and autonomy as the home provided an individualized transition process, consistent and person-centered support, and elevated empathy to facilitate freedom of choice. Supported empowerment was found as an empowering social model with micro-practices that harnessed elements of empowerment necessary to support people with dual disabilities. Seven policy considerations that prevent premature placement in nursing homes, enable aging in place, and maintain a participatory life in community were recommended.

Margallo-Lana M.L., Moore, P.B., Kay, D.W., Perry, R.H., Reid, B.E., Berney, T.P., Tyrer, S.P.
Fifteen-year follow-up of 92 hospitalized adults with Down's syndrome: incidence of cognitive decline, its relationship to age and neuropathology
Journal of Intellectual Disability Research, 2007, 51, 463-477.
Abstract: The clinical and neuropathological features associated with dementia in Down's syndrome (DS) are not well established. To examine clinico-pathological correlations and the incidence of cognitive decline in a cohort of adults with DS. A total of 92 hospitalized persons with DS were followed up from 1985 to December 2000. At outset, 87 participants were dementia-free, with a median age of 38 years. Assessments included the Prudhoe Cognitive Function Test (PCFT) and the Adaptive Behavior Scale (ABS), to measure cognitive and behavioral deterioration. Dementia was diagnosed from case records and caregivers' reports. Eighteen (21%) patients developed dementia during follow-up, with a median age of onset 55.5 years (range 45-74). The PCFT demonstrated cognitive decline among those with a less severe intellectual disability (mild and moderate) but not among the profoundly disabled people (severe and profound). Clinical dementia was associated with neuropathological features of Alzheimer's disease, and correlated with neocortical neurofibrillary tangle densities. At the age of 60 years and above, a little more than 50% of patients still alive had clinical evidence of dementia. Authors concluded that clinical dementia associated with measurable cognitive and functional decline is frequent in people with DS after middle age, and can be readily diagnosed among less severely intellectually disabled persons using measures of cognitive function such as the PCFT and behavioral scales such as the ABS. In the more profoundly disabled people, the diagnosis of dementia is facilitated by the use of behavioral and neurological criteria. In this study, the largest prospective DS series including neuropathology on deceased patients, the density of neurofibrillary tangles related more closely to the dementia of DS than senile plaques. In people with DS surviving to middle and old age, the development of dementia of Alzheimer type is frequent but not inevitable, and some people with DS reach old age without clinical features of dementia.

Marler, R., & Cunningham, C.
Down's Syndrome and Alzheimer's Disease: A Guide for Carers.
39 pp.
London: Down's Syndrome Association [155 Mitcham Road, London, UK SW17 9PG] (1994).
Abstract: This booklet for community carers and agency staff covers some of the fundamentals concerning adults with Down syndrome and Alzheimer's disease, including information on obtaining diagnoses, approaches to care management, and securing services in the UK. Contains some vignettes and a small glossary and references.

Mascarenhas Fonseca, L., Prado Mattar, G., Guerra Haddad, G., Burduli, E., McPherson, S.M., Maria de Figueiredo Ferreira Guilhoto, L., Busatto Filho, G., Sanches Yassuda, M., Bottino, C.M.C , Queiroz Hoexter, M. & Chaytor, N.S.
AAIC2020, Poster presentation, July 29, 2020.
https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Paper/47603
Abstract: Neuropsychiatric symptoms (NPS) are significant manifestations of dementia, with important consequences for patients and caregivers. Despite the established genetic link between Down syndrome (DS) and Alzheimer's disease (AD), studies investigating NPS in individuals with DS and dementia are scarce. The Neuropsychiatric Inventory (NPI) was developed to identify symptoms of dementia and while it is widely used for the assessment of individuals with dementia in the general population, we have found no studies using the NPI in those with DS. The aim of this study is to characterize NPS in a sample with DS with heterogeneous cognitive profiles using the NPI Participants (N=92) with DS, =30 years of age were assessed with the Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities (CAMDEX-DS). They were classified by a psychiatrist into three categories: AD, prodromal dementia, and stable cognition. Another psychiatrist blinded to the CAMDEX-DS dementia diagnosis, evaluated the participants using the NPI. Chi-square tests were used to check for significant differences in frequency of symptoms. Thirteen participants (14.1%) had AD, 17 (18.4%) were classified as prodromal dementia and 62 (67.5%) were in the stable cognition group. Prevalence of delusion, depression, anxiety, disinhibition, irritability, appetite abnormalities and total NPI did not differ between groups. Anxiety and irritability were common across all groups (~50% of the total), while euphoria was not present in any participant. Hallucination, agitation, apathy, aberrant motor behaviour and night-time behaviour disturbance showed significant difference among the groups ($p<0.05$), with higher prevalence in the group with AD. Authors note that the results indicate that individuals with DS and AD have some of the symptoms that are characteristically present among the general population with AD. Future studies are needed to understand if AD in DS is associated with a similar pattern of NPS observed among people with AD in the general population or may follow a specific NPS pattern. The high frequency of some NPS in individuals with DS and stable cognition should be considered in the diagnostic process in order to reduce the odds of generating a false positive.

Mattheys, K., Boustead, I., Doyle, A., & Watchman, K.
'Life through a lens': understanding the impact of dementia, a participatory action project led by people with intellectual disability
Journal of Intellectual Disability Research, 2019, 63(8), 650.
Abstract: Co-researchers with an intellectual disability are part of a team looking at the effects of non-drug interventions with people who have dementia, including people with Down syndrome. Photovoice is a method of data collection and analysis combining photography with social action supporting the inclusion of people typically excluded from research. Three co-researchers with intellectual disabitly working on the 'Life through a Lens' research project attended training in photovoice methodology and use of the camera, followed by a series of practice exercises. Each engaged in participant observation to understand the impact of non-drug interventions on peers with an intellectual disabitly and dementia. Photographs were then taken that represented their feelings about the intervention followed by a group discussion with wider research team. Two of the co-researchers believed that their peers benefitted from the non-drug interventions. For example, after observing changes to the home environment of one participant, the co-researcher discussed the relaxing and calming effect this created and how it helped her to be safer at home; his photography reflected the security he observed. Such photography can help with reflecting perceptions of the effect of non--drug interventions in dementia care, offering greater authority to co-researchers with intellectual disability.

May, H.L., Fletcher, C., Alvarez, N., Zuis, J., & Cavallari, S.G.
Alzheimer's disease and Down syndrome: A manual of care
Wrentham, Mass.: Alzheimer's Committee of Wrentham Developmental Center (1996)
89 pp.
Abstract: A 9-chapter staff training manual covering the basic issues related to the occurrence of Alzheimer's disease in adults with Down syndrome. Chapters include an introduction, Alzheimer's disease and Down syndrome, assessment, family and guardian considerations, early Alzheimer's disease, mid-stage Alzheimer's disease, feeding and nutrition concerns, and understanding difficult behaviors. Appendix contains a "Level of Capacity Scale," and table outlining implications and treatment suggestions for persons with intellectual disabilities affected by dementia.

McBrien, J., Whitwham, S., Olverman, K., & Masters, S.
Screening adults with Down's syndrome for early signs of Alzheimer's disease.
Tizard Learning Disability Review, 2005, 10(4), 23-32.
Abstract: Given the now well-recognized risk of Alzheimer's Disease (AD) for adults with Down's Syndrome (DS) as they reach middle age, services for people with learning disability (LD) need to meet this new challenge. Good practice guidance from the Foundation for People with Learning Disabilities recommended that every service for people with learning disability should set up a register of adults with DS, conduct a baseline assessment of cognitive and adaptive functioning before the age of 30 years, develop specialist skills in this area, offer training to other professionals, front-line staff and carers, and seek high-quality co-ordination between agencies. This article reports the progress of one LD service in meeting these challenges, highlighting the successes and

difficulties that may guide other teams considering such a development.

McCallion, P.
Maintaining communication
In M.P. Janicki & A.J. Dalton (Eds.), Dementia, Aging, and Intellectual Disabilities
pp. 261-277
Philadelphia: Brunner-Mazel (1999)
Abstract: This book chapter is based on the premise that progression of dementia among persons with intellectual disabilities appears to be similar to that in the general population. Therefore, it explores how existing service models and programs may be adapted for the population with intellectual disabilities. A five part program, Maintaining Communication and Independence (MCI), is proposed which adapts an existing program for persons with dementia to better meet the needs of persons with intellectual disabilities. The five parts to MCI are: (1) strengths identification and deficit assessment, (2) environmental modification, (3) good communication, (4) memory aids, and (5) taking care of the carer.

McCallion, P., & Janicki, M.P.
Intellectual disabilities and dementia (Computer-based Course)
2 CD-Rom set
Center for Excellence in Aging Services, School of Social Welfare, Richardson 208, University at Albany, Albany, New York 12222 (2002)
Abstract: 2 disk set - usable on Windows 9.X/2000 on 233 MHZ Pentium or faster with audio/video playback. Instructional course on aging, intellectual disabilities and dementia. Contains digital video version of "Dementia and People with Intellectual Disabilities– What Can We Do?"

McCallion, P., Nickle, T., & McCarron, M.
A comparison of reports of caregiver burden between foster family care providers and staff caregivers in other settings: A pilot study
Dementia (London), 2005, 4(3), 401-412
https://doi.org/10.1177/1471301205055034
Abstract: There has been increasing concern about the impact of dementia symptoms on the lives and on the care being provided for persons with intellectual disability (ID) in out-of-home settings. One such setting that has received little attention is foster family care homes. These settings in the USA replicate family living and while some supports and resources are provided, they are not designed to meet intensive care needs. As a preliminary step in understanding family experiences and to expand the range of interest in Alzheimer's disease (AD) in persons with ID beyond traditional out-of-home settings, a pilot study was initiated that included aging persons with ID and symptoms of AD who were living in foster family care settings in two regions of New York State as well as more traditional out-of-home care subjects. Comparisons of matched samples on subjective and objective burden measures suggest that there are few differences in experiences. The limitations of these findings are considered and recommendations made for future, related research.

McCarron, M.
Some issues in caring for people with the dual disability of Down's syndrome and Alzheimer's dementia
Journal of Learning Disabilities for Nursing, Health and Social Care, 1999, 3(3), 123-129
Abstract: Virtually all individuals with Down's syndrome over the age of 35 years have neurological changes characteristic of Alzheimer's disease. It has become increasingly recognized that people with Down's syndrome and dementia have very special needs, and those who care for them require specialist knowledge and skills. This paper aims to explore some important issues in caring for persons with this dual disability. It commences with a brief outline on the prevalence of dementia in this population. Diagnostic issues and the clinical presentation of dementia in persons with Down's syndrome are reviewed. In an attempt to help staff respond to the opportunities and challenges they encounter, issues discussed, include: promoting well-being, developing a shared vision on which to build practice, mealtimes -- a therapeutic event, reality orientation and validation therapy, communication, activity and entertainment.

McCarron, M., Gill, M., Lawlor, B., & Begley, C.
Time spent caregiving for persons with the dual disability of Down's syndrome and Alzheimer's dementia: Preliminary findings
Journal of Learning Disabilities, 2002, 6(3), 263-279
Abstract: Persons with Down's syndrome (DS) are at increased risk of Alzheimer's type dementia (AD) compared with the general population. Little attention has been paid to the current and future impact of AD on caregivers and clients in residential and community settings. This study sought to test if the Caregiver Activity Survey-Intellectual Disability (CAS-ID) would be useful in measuring time spent by professional caregivers aiding persons with DS and AD. Preliminary findings suggest that staff caregiving time increases significantly when a person with DS experiences symptoms of dementia. No significant differences were reported in time spent caregiving for subjects at mid-stage versus end-stage dementia; however, the nature and tasks of caregiving change as dementia progresses. This study supports the utility of the CAS-ID in measuring time spent caregiving for persons with AD and DS. Care providers must plan appropriate models of health and social care to effectively address these needs.

McCarron, M., Gill, M., Lawlor, B., & Beagly, C.
A pilot study of the reliability and validity of the Caregiver Activity Survey – Intellectual Disability (CAS-ID)
Journal of Intellectual Disability Research, 2002, 46, 605-612
Abstract: Authors undertook to amend the Caregiver Activity Survey (Davis et al., 1997) and apply it for use with caregivers of persons with intellectual disabilities. Under this study, the CAS-ID was tested with 30 adults and convergent validity was assessed by comparing the CAS-ID with other measures of cognitive and functional impairment of adults with intellectual disabilities. Final version of the CAS-ID contains 8 items: dressing, bathing/showering, grooming, toileting, eating and drinking, housekeeping, nursing care-related activities, and supervision/behavior management. Authors content that the CAS-ID has the potential for identifying and measuring care and resource requirements for people experiencing decline associated with dementia.

McCarron, M., Gill, M., McCallion, P., & Begley, C.
Health co-morbidities in ageing persons with Down syndrome and Alzheimer's dementia.
Journal of Intellectual Disability Research, 2005, 49(7), 560-566.
Abstract: Consideration of the relationship between physical and mental health co-morbidities in ageing persons with Down syndrome (DS) and Alzheimer's dementia (AD) is of clinical importance both from a care and resource perspective. Aim: To investigate and measure health co-morbidities in ageing persons with Down syndrome with and without AD. Methods: Recorded physical and mental health needs were ascertained for 124 persons with DS >35 years through a systematic and detailed search of individual medical and nursing case records. Differences in persons with and without AD were investigated, by stage of dementia and by level of intellectual disability (ID). A summed score for health co-morbidities was created and compared using r-tests. Results: Persons with AD had significantly higher co-morbidity scores than persons without AD ® = -8.992, d.f. = 121, P<0.0001). There was also a significant difference in summed co-morbidity scores for persons at end-stage vs. persons at midstage AD (t = -6.429, d.f. = 56, P < 0.0001). No differences were found by level of ID. Conclusions: Increasing health co-morbidities in persons with DS and AD have important implications for care and resources. Appropriate environmental supports combined with competent skilled staff are crucial and will have an important impact on the quality of life for this increasingly at risk population.

McCarron, M., & Lawlor, B.A.
Responding to the challenge of ageing and dementia in intellectual disability in Ireland
Aging and Mental Health, 2003, 7(6), 413-417
Abstract: The intellectual disability (ID) population in Ireland is ageing and the number of older persons with the dual disability of ID and dementia is increasing. In spite of these demographic trends, as in other countries adequate policy and service provision for this population are lacking. This paper draws upon data available on the population with ID and dementia, reviews both generic and ID specific literature, considers the policy context and argues for a specific model of service provision. A service model is proposed for the development of multidisciplinary specialist teams within ID, delivered through mobile regional ID dementia clinics.

McCarron, M., Gill, M., Mccallion, P., Begley, C.
Alzheimer's dementia in persons with Down's syndrome: predicting time spent on day-to-day caregiving.
Dementia, 2005, 4(4), 521-538.

Abstract: The aim of this study was to investigate the amount of time formal caregivers spend addressing activities of day-to-day care activities for persons with Down's syndrome (DS) with and without Alzheimer's dementia (AD). Caregivers completed for 63 persons with DS and AD, and 61 persons with DS without AD, the Caregiving Activity Survey-Intellectual Disability (CAS-ID). Data was also gathered on co-morbid conditions. Regression analysis was used to understand predictors of increased time spent on day-to-day caregiving. Significant differences were found in average time spent in day-to-day caregiving for persons with and without AD. Mid-stage and end-stage AD, and co-morbid conditions were all found to predict increased time spent caregiving. Nature and tasks of day-to-day caregiving appeared to change as AD progressed. The study concluded that staff time to address day-to-day caregiving needs appeared to increase with onset of AD and did so most dramatically for persons with moderate intellectual disability. Equally, while the tasks for staff were different, time demands in caring for persons at both mid-and end-stage AD appeared similar.

McCarron, M., McCallion, P., Fahey-McCarthy, E., Connaire, K., & Dunn-Lane, J.
Supporting persons with Down syndrome and advanced dementia: Challenges and care concerns
Dementia, 2010, 9, 285-298.
Abstract: To understand staff perceptions of critical issues in caring for persons with intellectual disability (ID) and advanced dementia. There has been growing interest in addressing resource, training, and service redesign issues including an increase in collaborative practices in response to the growing incidence of dementia among persons with ID. Most recently this has included consideration of the specific issues in advanced dementia. Thirteen focus group interviews were held involving staff in six ID services and one specialist palliative care provider in Ireland. A qualitative descriptive approach was taken to analysis. Staff identified three key themes: (1) readiness to respond to end of life needs, (2) the fear of swallowing difficulties, and (3) environmental concerns and ageing in place. Four underlying issues that emerged in this study offer clues to solutions: (a) differences in staff preparation associated with settings, (b) lack of understanding and lack of collaboration with palliative care services, © uncertainties about the ability to transfer existing palliative care models to persons with ID and dementia and (d) the need to develop training on end stage dementia and related care approaches

McCarron, M. McCallion, P., Fahey-McCarthy, E., & Connaire, K.
Staff perceptions of essential prerequisites underpinning end-of-life care for persons with intellectual disability and advanced dementia.
Journal of Policy and Practice in Intellectual Disabilities, 2010, 7(2), 143–152.
Abstract To better address palliative care and end-of-life issues for persons with intellectual disability (ID) and dementia, work was undertaken to understand the perspectives of agency staff in both the ID services and specialist palliative care fields. A qualitative descriptive design composed of 13 focus group interviews involved 50 participants drawn from six ID service providers and seven participants from one specialist palliative care service. Analysis was an iterative process; codes were identified and through thematic analysis, collapsed into two core themes: building upon services' history and personal caring—offering quality and sensitive care, and supporting comfort and optimal death in persons with ID and advanced dementia. Challenges were raised for service systems in the areas of aging in place, person-centered care, and interservice collaboration. Authors recommend both more practice relationship based and collaborative approaches to care and a stronger evidence-based research program on the timing and the efficacy of palliative care for persons with ID and dementia.

McCarron, M., McCallion, P., Fahey-McCarthy, E., & Connaire, K.
The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia.
Journal of Applied Research in Intellectual Disabilities, 2011, 24, 189–198.
Abstract: To better describe the role and timing of palliative care in supporting persons with intellectual disabilities and advanced dementia (AD). Specialist palliative care providers have focused mostly on people with cancers. Working with persons with intellectual disabilities and AD offers opportunities to expand such palliative care to other populations and disease conditions and to better understand the timing and role of palliative care delivery. Thirteen focus group interviews were held involving staff in six intellectual disability services and one specialist palliative care provider in Ireland. A qualitative descriptive approach was taken to analysis. Specialist palliative care staff recognized that person-centered care delivered in intellectual disability services was consistent with palliative approaches, but staff in intellectual disability services did not consider advanced dementia care as 'palliative care'. Both groups were unsure about the role of palliative care at early stage of dementia but appreciated specialist palliative care contributions in addressing pain and symptom management challenges. Successful extension of palliative care principles, philosophy and services to persons with intellectual disabilities and AD will require in-depth understanding of prevailing care philosophies and agreement regarding timing and the unique contributions of specialist palliative care services.

McCarron, M., & Riley, E.
Supporting persons with intellectual disability and dementia: Quality dementia care standards - A guide to practise
39 pp.
Dublin, Ireland: Trinity College Dublin (2010)
Source: http://www.docservice.ie/includes/documents/Dementia%20Publication%202011.pdf
Abstract: Document contains a series of six standards covering a range of areas concerned with care affecting adults with intellectual disabilities affected by dementia. Drawn from standards affecting the general population, this document groups together focal areas under six main categories reflecting person-centered dementia care. The standards consist of statements, indicators, and criteria for assessing evidence. The standards cover (1) appropriately trained staff and service development, (2) memory assessment services, (3) health and personal care, (4) communication and behavior, (5) promoting well-being and social connectedness, and (6) supporting persons with advanced dementia.

McCarron, M., Reilly, E., & Dunne, P.
Achieving quality environments for person centred dementia care
45 pp.
Dublin, Ireland: Daughters of Charity Service
Abstract: Provides an overview of principles and practices designed to enable the operation of small group homes, including covering the planning process, design of private and public spaces, as well as therapeutic uses. Illustrated by two Daughters of Charity homes established for dementia specific care for people with ID. One home offers care for people with moderate dementia and includes 4 permanent beds and 2 respite beds for people both living with their families in the community and community group homes. Home also has a 6 bed step-down palliative care unit for people with ID in the later stages of dementia. These purpose built facilities were designed to be responsive to the changing needs of persons across the continuum of dementia. The home-like environments support people with dementia and staff to participate and complete tasks together, as well as informal impromptu unplanned activities. The homes are designed so that each resident has his or her own bedroom, with numerous communal areas including sitting rooms and garden areas.

McGuire, B. E.; Whyte, N. , & Hardardottir, D.
Alzheimer's disease in Down Syndrome and intellectual disability: A review.
The Irish Journal of Psychology, 2006, 27(3-4), 114-129.
The authors review the literature on Alzheimer's disease (AD) in persons with general intellectual disabilities and those with Down syndrome. It focuses on the prevalence, clinical manifestations, diagnosis and management of AD in these populations. The literature indicates that people with Down syndrome have a greatly increased risk of dementia from their early 40s, while people with general intellectual disabilities have similar rates of AD to the general population. Taking into account the life expectancy of people with intellectual disabilities and those with Down syndrome, guidelines are provided for estimating the proportion of service users in a population that are at risk of developing dementia. The difficulties around diagnosis are reviewed and a particular emphasis is placed on the range of psychometric measures that may contribute to assessment and diagnosis. The management of service users who develop dementia is also reviewed and the implications for service providers are highlighted.

McKenzie, K., Harte, C., Patrick, S., Matheson, E., & Murray, G.C.
The assessment of behavioural decline in adults with Down's syndrome
Journal of Learning Disabilities, 2002, 6, 175-184
Abstract: Article reports study the examined two methods of using the Vineland Adaptive Behavioral Scales (VABS) to measure behavioral change in adults with

Down syndrome who were surmised to be at-risk of Alzheimer's disease. The first approach used the VABS within a semi-structured interview and all areas of behavioral change identified by staff were noted. The second approach used the basal rule of the VABS as indicated in the Scales' manual. Comparison of the two approaches indicated that using the second approach highlighted significant decline in scores (for adults meeting the criteria for "probable Alzheimer's disease) on a number of domains between baseline and 12-24 months. One limitation of this approach that was noted was that this scoring method appeared to miss more subtle changes on behavior, which may be indicative of early Alzheimer's disease – which were picked up by the first approach. Authors recommend flexibility in using the VABS for assessment purposes and caution researchers to be explicit in reporting how the VABS was used in studies assessing dementia.

McKenzie, K., Metcalfe, D., Michie, A., & Murray, G.
Service provision in Scotland for people with an intellectual disability who have, or who are at risk of developing, dementia.
Dementia (London), 2020, 19(3), 736-749. doi: 10.1177/1471301218785795.
Abstract: This research aimed to identify current national provision by health services in Scotland in relation to proactive screening and reactive assessment for people with an intellectual disability in Scotland who have, or are at risk of developing, dementia. Staff from 12 intellectual disability services, representing the 11 health board areas in Scotland, completed an online questionnaire which asked about proactive screening and reactive assessment for people with intellectual disability who had, or were at risk of developing, dementia as well as suggested areas for improvement. All of the areas provided services for people with intellectual disability who have, or are at risk of developing, dementia, but differed as to whether this was reactive, proactive or both. Nine services offered intervention following diagnosis. The most common elements used across both proactive screening and reactive assessment were conducting a health check, using a general dementia questionnaire designed for people with an intellectual disability and direct assessment with the person. Clinical psychology and community learning disability nurses were the professions most likely to be involved routinely in both proactive screening and reactive assessments. The psychometric properties of the most commonly used assessments of cognitive and behavioral functioning were mixed. The areas of improvement suggested by practitioners mainly related to ways of improving existing pathways. This research represents the first step in providing an overview of service provision in Scotland. There was some inconsistency in relation to the general and specific components which were involved in proactive screening and reactive assessment. Implications for service provision are discussed.

McQuillan, S., Kalsy, S., Oyebode, J., Millichap, D., Oliver, C., & Hall, S.
Adults with Down's syndrome and Alzheimer's disease
Tizard Learning Review, 2003, 8(4), 4-13
Abstract: Adults with Down's syndrome are at risk of developing Alzheimer's disease in later life. This paper gives an overview of the current research in the area and discusses the implications it raises for individuals, carers, and service providers. Information on the link between Down's syndrome and Alzheimer's disease and prevalence rates are given. The clinical symptoms of Alzheimer' disease and a stage model documenting the progression of the disease are presented. Attention is drawn to the problems inherent in assessing and diagnosing Alzheimer's disease in a person with a pre-existing intellectual disability. Also discussed are the management of Alzheimer's disease, a focus on care management practices, and recommendations for service provision (including guidelines for supporting individuals which include maintaining skills, adapting a person-centered approach, implementing psychosocial interventions, and multi-disciplinary care management. Recommendations for the future include increasing education and awareness, implementing screening services, improving assessment methods, and developing appropriate services.

Menéndez M.
Down syndrome, Alzheimer's disease and seizures.
Brain Development, 2005, 27(4), 246-252.
Abstract: Neuropathologically, Alzheimer-type abnormalities are demonstrated in patients with Down syndrome (DS), both demented and nondemented and more than a half of patients with DS above 50 years develop Alzheimer's disease (AD). The apolipoprotein E epsilon4 allele, oestrogen deficiency, high levels of Abeta1-42 peptide, elevated expression of BACE2, and valine polymorphism of prion protein gene are associated with earlier onset of dementia in DS individuals. Advanced AD alone may be an important risk factor for new-onset seizures in older adults and age above 60 years is a recognized risk factor for poor outcome from convulsive and nonconvulsive status epilepticus. DS patients aged over 45 years are significantly more likely to develop Alzheimer's disease than those less than 45 years and up to 84% demented individuals with DS develop seizures. Late-onset epilepsy in DS is associated with AD, while early-onset epilepsy is associated with an absence of dementia. In AD patients with a younger age of dementia onset are particularly susceptible to seizures. DS adults with epilepsy score significantly higher overall on the adaptive behaviour profile. Language function declined significantly more rapidly in AD patients with seizures and there is a good correlation between the severity of EEG abnormalities and cognitive impairment whereas in DS slowing of the dominant occipital rhythm is related to AD and the frequency of the dominant occipital activity decreases at the onset of cognitive deterioration.

Millichap, D., Oliver, C., McQuillan, S., Kalsy, S., Lloyd, V., & Hall, S.
Descriptive functional analysis of behavioral excesses shown by adults with Down syndrome and dementia.
International Journal of Geriatric Psychiatry, 2003, 18, 844-854.
Abstract: The study examined the hypothesis that a functional relationship exists between social environmental events and behavioral excesses in individuals with Down syndrome and dementia. Design: A case-series design was employed (n = 4) using an direct observation-based descriptive functional assessment procedure. Methods: Observations were conducted in the natural environments of four participants over periods ranging from 11 to 15.4 hours. Data were collected on non-verbal and verbal behavioral excesses, appropriate engagement and verbal interaction with others. Social environmental events observed including both staff and peer behavior. Results: Analysis of co-occurrence for behavioral excesses and social environmental events indicated significant relationships for some behaviors consistent with operant reinforcement processes. Sequential analysis showed that changes in the probability of social contact occurred in the period directly preceding and following verbal behaviors. Conclusions: Results support the hypothesis that, consistent with literature for older adults with dementia in the general population, some behavioral excesses were functional in nature and not randomly occurring events. No relationship was found between appropriate engagement and staff.

Mohan, M., Bennet, C., & Carpenter, P.K.
Rivastigmine for dementia in people with Down syndrome
Cochrane Systemic Review - Intervention, 2009, 1.
https://doi.org//10.1002/14651858.CD007658
Abstract: Alzheimer's dementia (AD) is the most common form of dementia in people with Down Syndrome (DS). Acetylcholine is a chemical found in the brain that has an important role in memory, attention, reason and language. Rivastigmine is a "pseudo-irreversible" inhibitor of acetylcholinesterase, which is thought to maintain levels of acetylcholine. Rivastigmine can improve cognitive function and slow the decline of AD in the general population over time. It is important to note that people with DS tend to present with AD at a much younger age than the normal population as well as having subtle differences in physiology (e.g. metabolism and heart rate) and may therefore have different requirements from the general population. The authors sought to determine the effectiveness and safety of rivastigmine for people with DS who develop AD by using the following search methods, CENTRAL, MEDLINE, EMBASE, CINAHL, PsycINFO, BIOSIS, SCI, SSCI and the NRR, up to October 2008. They also contacted the manufacturers of rivastigmine as well as experts in the field, to ask about reports of unpublished or ongoing trials. Selection criteria included randomised controlled trials of participants with DS and AD in which treatment with rivastigmine was administered compared with a placebo group. Authors found that no study was identified which met inclusion criteria for this review and

concluded that as there are no included trials, recommendations cannot be made about rivastigmine for AD in DS. Well-designed, adequately powered studies are required.

Moran, J.A., Rafii, M.S., Keller, S.M., Singh, B.K., Janicki, M.P.
The National Task Group on Intellectual Disabilities and Dementia Practices consensus recommendations for the evaluation and management of dementia in adults with intellectual disabilities.
Mayo Clinic Proceedings, 2013 Aug;88(8):831-840. doi: 10.1016/j.mayocp.2013.04.024. Epub 2013 Jul 10.
Abstract: Adults with intellectual and developmental disabilities (I/DD) are increasingly presenting to their health care professionals with concerns related to growing older. One particularly challenging clinical question is related to the evaluation of suspected cognitive decline or dementia in older adults with I/DD, a question that most physicians feel ill-prepared to answer. The National Task Group on Intellectual Disabilities and Dementia Practices was convened to help formally address this topic, which remains largely under-represented in the medical literature. The task group, comprising specialists who work extensively with adults with I/DD, has promulgated the following Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities as a framework for the practicing physician who seeks to approach this clinical question practically, thoughtfully, and comprehensively.

Moss, S., Lambe, L., & Hogg, J.
Physical and mental health
Ageing Matters - Pathways for Older People with Learning Disabilities: Manager's Reader.
pp. 41-60
Kidderminster: British Institute of Learning Disabilities [Wolverhampton Road, Kidderminster, Worcestershire DY10 3PP United Kingdom] (1998)
Abstract: This unit, one of six that is used for training staff, covers briefly some of the key issues related to physical and mental health, and touches on dementia. Although not specifically developed for care management of adults with dementia, the text, in total, can be a useful resource for staff working in care settings when one or more of the adults in the setting are affected by dementia.

Moss, S., & Patel, P.
Dementia in older people with intellectual disability: symptoms of physical and mental illness, and levels of adaptive behavior.
Journal of Intellectual Disability Research, 1997, 41(1), 60-69.
Abstract: Detailed data on health and functional ability of 101 people with intellectual disability over 50 years of age are presented. Using a combination of informant interviewing, observation and measurement of cognitive change over a 3-year period, 12 of these individuals were identified as suffering from dementia. Their data are compared to those of the non-dementia sufferers. The people suffering from dementia had a greater number of chronic physical health problems and chronic disability resulting from physical health problems. Their capacity for self-directed activity was lower. The subjects had a reduced capacity to enjoy things, and were more irritable and more prone to violence. However, the outlook is somewhat different from a strategic perspective. The population of people with intellectual disability shows considerable epidemiological changes across the lifespan because of the effects of differential survival. The interaction of these factors tends to mask the impact of dementia-related skill loss in this population

Mullins, D., Daly, E., Simmons, A., Beacher, F., Foy, C.M.L., Lovestone, S.,, Hallahan, B., Murphy, K.C., & Murphy, D. G.
Dementia in Down's syndrome: an MRI comparison with Alzheimer's disease in the general population.
Journal of Neurodevelopmental Disorders 2013, 5, 19-00. doi:10.1186/1866-1955-5-19.
Abstract: Down's syndrome (DS) is the most common genetic cause of intellectual disability. People with DS are at an increased risk of Alzheimer's disease (AD) compared to the general population. Neuroimaging studies of AD have focused on medial temporal structures; however, to our knowledge, no *in vivo* case–control study exists comparing the anatomy of dementia in DS to people with AD in the general population. We therefore compared the *in vivo* brain anatomy of people with DS and dementia (DS+) to those with AD in the general population. Using MRI in 192 adults, we compared the volume of whole brain matter, lateral ventricles, temporal lobes and hippocampus in DS subjects with and without dementia (DS+, DS-), to each other and to three non-DS groups. These included one group of individuals with AD and two groups of controls (each age-matched for their respective DS and general population AD cohorts). AD and DS+ subjects showed significant reductions in the volume of the whole brain, hippocampus and temporal lobes and a significant elevation in the volume of the lateral ventricle, compared to their non-demented counterparts. People with DS+ had a smaller reduction in temporal lobe volume compared to individuals with AD. DS+ and AD subjects have a significant reduction in volume of the same brain regions. We found preliminary evidence that DS individuals may be more sensitive to tissue loss than others and have less 'cognitive reserve'

Nagdee, M.
Dementia in intellectual disability: a review of diagnostic challenges.
African Journal of Psychiatry, 2011, 14, 194-199.
Abstract: The evaluation of dementia in individuals with intellectual disability, which will guide subsequent intervention, care and management depends on the systematic review of a number of factors: (1) the individual historical context, obtained from multiple sources, (2) evaluation of the pre-existing cognitive, behavioral, psychiatric, medical and adaptive skill profile, (3) the constellation, and pattern of evolution, of presenting signs and symptoms, (4) results of focused investigations, and (5) refinement of the differential diagnosis. In patients with ID, standard clinical methods need to be supplemented by careful, longitudinal behavioral observations, and individually tailored assessment techniques. Co-morbidity, multiple biological, psychological and socioenvironmental factors, and complex interactions among events, are the reality for many ageing people with ID. Determining the various influences is often a formidable clinical task, but should be systematically carried out using medical, cognitive, behavioral, neuropsychiatric and psycho-social frameworks.

National Task Group on Intellectual Disabilities and Dementia Practices.
My thinker's not working': A national strategy for enabling adults with intellectual disabilities affected by dementia to remain in their community and receive quality supports.
42pp.
National Task Group on Intellectual Disabilities and Dementia Practices [www.aadmd.org/ntg]. (2012).
Abstract: 'My Thinker's Not Working' is the short title for the 42-page summative report issued by the National Task Group on Intellectual Disabilities and Dementia Practices, a planning and advocacy group organized to produce a national plan on dementia and intellectual disabilities. The report offers 20 recommendations for the improvement of services nationally and locally and suggests that its findings and recommendations be considered and integrated into the reports and plans being developed by the federal Advisory Council on Alzheimer's Research, Care, and Services -- under the National Alzheimer's Project Act. The document reviews the main issue facing adults with intellectual disabilities as they age when they are affected by dementia, as well as their families and provider organizations. The document is composed of 7 sections (Charge and Purpose, The Population, Challenges Facing the Population, Community Services, Education and Training, Financing, and Possible Solutions) and the National Dementia and Intellectual Disabilities Action Plan.

NAMHI
Alzheimer's Dementia in persons with intellectual disabilities: Some common questions and concerns
NAMHI, 5 Fitzwilliam Place, Dublin 2, Ireland
Abstract: 28 page booklet with 18 sections/question areas outlining basic

information about Alzheimer's disease and people with ID, diagnostic resources, and service to help cope with the course of the disease. Developed by Dr. Mary McCarron of Trinity College Dublin.

Nelson L.D., Orme, D., Osann, K., & Lott, I.T.
Neurological changes and emotional functioning in adults with Down Syndrome.
Journal of Intellectual Disability Research, 2001, 45, 450-456.
Abstract: Study examined emotional changes in adults with Down Syndrome (DS) over time and to determine whether changes in these psychological variables were associated with brain atrophy on MRI scan and the presence of pathological reflexes on the neurological examination. Participants were 26 adults with DS and their caregivers. Caregivers completed a measure of emotional functioning about individuals with DS at two different time points (1 year apart). Levels of cognitive functioning were measured and neurological and MRI examinations were performed on all subjects at initial testing. Significant group effect separated those with and without pathological findings on MRI and neurological exam across three different scales: depression, indifference, and pragmatic language functioning. Problems of poor pragmatic language functioning appeared later in the course of suspected Alzheimer's disease (AD), as demonstrated by a significant group effect at time 2, but not at initial testing. In these subjects, the primary emotional change was a decline in social discourse (e.g. conversational style, literal understanding, verbal expression in social contexts). These emotional levels were stable over time, regardless of degree of cognitive decline. Specific emotional changes occur during the course of AD which were associated with abnormal findings from MRI and from neurological examination. These results, along with abnormalities in brain imaging and the presence of pathological reflexes, suggested that frontal lobe dysfunction is likely to be an early manifestation of Alzheimer's Disease in Down Syndrome.

New York State Developmental Disabilities Planning Council
When people with developmental disabilities age
18 minutes
New York State Developmental Disabilities Planning Council [155 Washington Avenue, Albany, New York 12222] (1992).
Abstract: A 18-minute video outlining the major physical and social change issues affecting adults with intellectual and developmental disabilities as they age, including a brief mention of Alzheimer's disease and Down syndrome. Available in VHS and CD-Rom format.

New York State Developmental Disabilities Planning Council
Dementia and people with intellectual disabilities – What can we do?
23 minutes
New York State Developmental Disabilities Planning Council [155 Washington Avenue, Albany, New York 12222] (2001).
Abstract: An instructional video which covers the basics of how dementia affects adults with intellectual disabilities, and provides information on diagnostics and suggestions on providing supports and services in community care settings. Produced by the University at Albany, this video can serve as primer on dementia and intellectual disabilities and provides information on basic design and service issues. Available in VHS and CD-Rom format.

Newroth, S., & Newroth, A.
Coping with Alzheimer disease: a growing concern.
28 pp.
Downsview: Ontario: National Institute on Mental Retardation (Kinsmen NIMR Building, York University Campus, 4700 Keele Street, Ontario, Canada, M3J IP3) (1981)
Abstract: Monograph describing one residential program's experience in caring for persons with Down syndrome who developed Alzheimer's disease; includes a chart of observations and guidelines for care. The guidelines are reproduced as an appendix in Janicki & Dalton (1999).

Nieuwenhuis-Mark, R.E.
Diagnosing Alzheimer's dementia in Down syndrome: Problems and possible solutions.
Research in Developmental Disabilities, 2009, 30(5), 827-838.
Abstract: It is widely accepted that people with Down syndrome are more likely than the general population to develop Alzheimer's dementia as they age. However, the diagnosis can be problematic in this population for a number of reasons. These include: the large intra-individual variability in cognitive functioning, the different diagnostic and methodological procedures used in the field and the difficulty in obtaining baseline levels of cognitive functioning in this population with which to assess cognitive and behavioral change. Recent researchers have begun to suggest ways around these difficulties. This review explores these recent developments and provides recommendations which may aid clinicians in their attempts to diagnose Alzheimer's dementia in the early stages in the Down syndrome population.

Noelker, E.A. & Somple, L.C.
Adults with Down syndrome and Alzheimer's
In K.A. Roberto (Ed.), The Elderly Caregiver: Caring for Adults with Developmental Disabilities.
pp. 81-92
Newbury Park: SAGE Publications (1993)
Abstract: Book chapter providing a brief summary of significant assessment and care issues affecting adults with Down syndrome who have Alzheimer's disease. Noted are the needs for education of carers and families, as well as specialty care provision and community services.

O'Caoimh, R., Clune, Y., & Molloy, D.W.
Screening for Alzheimer's disease in Downs syndrome
Journal of Alzheimers Disease Parkinsonism, 2013, S7;
http://dx.doi.org/10.4172/2161-0460.S7-001
Abstract: Down syndrome (DS), is associated with an increased incidence of Alzheimer's disease (AD). Although pathological changes are ubiquitous by 60 years of age, prevalence rates are lower. The diagnosis of AD in persons with DS is challenging, complicated by atypical presentations, baseline intellectual disability and normal age associated cognitive decline. Effective screening is limited by a paucity of diagnostic criteria, cognitive screening instruments and screening programs. Both observer-rated questionnaires and direct neuropsychological testing are suggested to screen for cognitive impairment, each with different strengths and weaknesses. This paper reviews commonly used screening instruments and explores the unique challenges of screening for AD in persons with DS. It concludes that single, one-dimensional screening tools and opportunistic evaluations are insufficient for detecting dementia in this population. These should be replaced by batteries of tests, incorporating informant questionnaires, direct neuropsychological testing, assessment of activities of daily living and behaviors, measured at baseline and reassessed at intervals. Developing these strategies into organized screening programs should improve diagnostic efficiency and management.

O'Dwyer, M., Finnerty, S., Henman, M., Carroll, R., McCallion, P., & McCarron, M.
Prevalence and treatment of dementia in older adults with intellectual disability in Ireland
Journal of Intellectual Disability Research, 2019, 63(8), 645.
Abstract: High rates of dementia have been reported among older adults with intellectual disability (ID), particularly those with Down Syndrome. As the use of dementia drugs in this patient group lacks an evidence base, their rates of use are of interest. Incidence and prevalence rates were determined using a combined dementia variable for three waves of the IDS-TILDA study, a nationally representative study of older adults with ID in Ireland. Incidence of dementia was defined as participants newly reporting a diagnosis and/or newly receiving dementia drug(s) at each wave. Prevalence of dementia was defined those who had reported a diagnosis at a previous wave and/or received dementia drug(s) at a previous wave. Drugs for dementia were included as a proxy for dementia diagnosis, in those with no diagnosis. Dementia incidence remained similar across Waves: 5.0% at Wave 1, 4.3% at Wave 3. Prevalence increased, 5% at Wave 1, to 9.6% by Wave 3. Those receiving receiving

dementia drug(s) decreased, from 54.1% of those with dementia at Wave 1 to 28.8% at Wave 3. Three dementia drugs were reported: donepezil, memantine and rivastigmine. It was found that use of drugs for dementia decreased, despite an increased incidence. Further research into efficacy of use of a drugs is
needed.

Oliver, C., & Holland, A.J.
Down's syndrome and Alzheimer's disease: a review.
Psychological Medicine, 1986, 16(2), 307-322.
Abstract: Neuropathological change found in nearly all individuals with Down syndrome over the age of 35 years closely resembles that of Alzheimer's disease. The extent to which dementia occurs as a result of this change is unclear, and the studies which have investigated presumed cognitive deficits are reviewed. The theories put forward to explain the association between these two disorders and their possible significance to the understanding of the aetiology of Alzheimer's disease are discussed.

Oliver, C., Crayton, L., Holland, A., & Hall, S.
Cognitive deterioration in adults with Down syndrome: effects on the individual, caregivers, and service use
American Journal on Mental Retardation, 2000, 103, 455-465
Abstract: Individuals with Down syndrome (N = 49) who had participated in serial neuropsychological assessments were assigned to one of three groups comparable in level of premorbid intellectual disability: (1) those showing cognitive deterioration, (2) those comparable in age but not showing cognitive deterioration and (3) those not showing cognitive deterioration but younger. Those experiencing cognitive deterioration were less likely to receive day services, had more impoverished life experiences, and required more support compared to groups without cognitive deterioration. When age was controlled for, cognitive deterioration was significantly positively associated with carer difficulties and service use and negatively associated with life experiences for the individual. Results suggest a potential role for carer difficulties in influencing life experiences of adults with Down syndrome showing cognitive decline.

Oliver, C., Kalsy, S., McQuillan, S., & Hall, S.
Behavioural excesses and deficits associated with dementia in adults who have Down syndrome.
Journal of Applied Research in Intellectual Disabilities, 2011, 24, 208–216.
Abstract: Informant-based assessment of behavioral change and difference in dementia in Down syndrome can aid diagnosis and inform service delivery. To date few studies have examined the impact of different types of behavioral change. The Assessment for Adults with Developmental Disabilities (AADS), developed for this study, assesses behavioral excesses (11 items) and deficits (17 items) associated with dementia. Inter-informant reliability, internal consistency and concurrent validity were evaluated and found to be robust. A comparison of the AADS subscale scores for three groups (n = 12) of adults with Down syndrome demonstrated more frequent deficits and excesses and greater management difficulty and effects on the individual in a dementia group than age comparable and younger groups. The AADS is a promising dementia specific measure for people with intellectual disability. Further research should evaluate change as dementia progresses and the nature of management difficulty and effects on the individual.

Olsen, R.V., Ehrenkrantz, E., & Hutchings, B.L.
Creating the movement-access continuum in home environments for dementia care
Topics in Geriatric Rehabilitation, 1996, 12(2): 1-8
Abstract: Since the majority of people with Alzheimer's disease receive some care at home, the environment of that home must be safe and supportive. In-depth interviews of 90 "seasoned" caregivers identified tactics for creating these settings through home modifications and technology. A successful modification strategy follows a three-stage movement-access continuum that responds to the disease course -- assistance, restriction with compensation, and wheelchair accessibility. Approaching home modifications along this continuum encourages independence and movement when appropriate while providing safety and control. With a sensitive and ongoing modification strategy, the home environment can become an asset rather than a liability for caregiving.

Olsen, R.V., Ehrenkrantz, E., & Hutchings, B.
Creating supportive environments for people with dementia and their caregivers through home modifications
Technology and Disability, 1993, 2(4): 47-57
Abstract: Article examines what caregivers did to enhance or modify their homes when a spouse or other family member had dementia. Authors address controlling access (using locking techniques, blocking access with gates and partial doors, and the like, as examining modifications to kitchens, bathrooms, and furniture. Data showed that many built ramps, double railings, hand grips, as well as extending landings for ease of wheelchair use, reducing riser heights, removing steps, and installing electric chair lifts. Home owners also reconfigured space and rooms. Authors conclude that home owners modified spaces to increase access and independence in some life areas and to limit or curtail access in others. Article is a good source of information for how the process and outcome of families tackle home modifications

 **Olsen, R.V., Ehrenkrantz, E., & Hutchings, B.**
Homes that help: Advice from caregivers for creating a supportive home (Alzheimer's and Related Dementias)
77 pp.
Newark, New Jersey: New Jersey Institute of Technology [Architecture and Building Science Research Group, School of Architecture, NJIofT, University Heights, Newark, New Jersey 07102-1982] (1993)
Abstract: Manual that details examples of how to adapt a home for persons affected by dementia, covering care management techniques, physical adaptations, and personal monitoring strategies.

Owens, D., Dawson, J. C., & Losin, S.
Alzheimer's disease in Down's syndrome.
American Journal of Mental Deficiency, 1971, 75, 606–612.
Abstract: Although neuropathologists describe Alzheimer's changes in the brains of all victims of Down's syndrome over 35 yr. of age, only 3 cases of clinical dementia in such individuals are described in the literature. In order to establish clinical correlates of Alzheimer's disease, psychiatric and neurologic findings obtained from a middle-aged group were compared to those of Down's syndrome patients in their early 20s. The older group exhibited significantly greater incidence of abnormality in (a) object identification, (b) snout reflex, (c) Babinski sign, and (d) palmomental sign. Both groups displayed mild hypertonia rather than hypotonia, and face-hand test was abnormal in 75% of Ss tested. While dementia is uncommon, subtle neurological changes reflect neuropathological findings present in aging sufferers of Down's syndrome.

Pape, S.
Dementia diagnostic criteria in persons with [IDD}.
Journal of Intellectual Disability Research, 2019, 63(8), 641.
Abstract: Dementia is a common clinical presentation among older adults with IDD, particularly those with Down syndrome. The presentation of dementia may differ compared with typical Alzheimer's disease, and criteria thus require validation in IDD populations. Data from memory assessments in individuals with Down syndrome were presented to expert raters who rated the case as dementia or no dementia using ICD-10, DSM-IV-TR and DSM-5 criteria and their own clinical judgement. Estimates were then made of the concurrent validity and reliability of clinicians' diagnoses of dementia against these manualised diagnoses. Validity of clinical diagnoses were explored by establishing the stability of diagnoses over time. Similar data from previous studies in other individuals with intellectual disabilities were compared. It was found that clinical diagnoses of dementia in Down syndrome were valid and reliable and could be used as the standard against which new criteria such as the DSM-5 are measured. Criteria had good inter-rater reliability but concurrent validity varied. Implications: Author cautions that clinicans should consider the reliability and validity of dementia diagnostic criteria when applying these in clinical settings.

Patti, P., Amble, K. & Flory, M.
Placement, relocation and end of life issues in aging adults with and without Down's syndrome: A retrospective study.
Journal of Intellectual Disability Research, 2010, 54(6), 538-546.
Abstract: Aging adults with Down's syndrome (DS) experience more relocations and other life events than adults with intellectual disabilities aged 50 and older without DS. Age-related functional decline and the higher incidence of dementia were implicated as the contributing factors that led to relocation and nursing home placement. A retrospective study of adults with intellectual disabilities who were born prior to the year 1946 was conducted to analyze the number of relocations experienced over a 5- and 10-year period. The cohort consisted of 140 individuals (61 with DS between ages 50–71 years, and 79 without DS between ages 57–89 years) who had been referred to a diagnostic and research clinic. Analyses revealed the number of relocations over a 5- and 10-year period were significantly greater in the DS group. Placement in a nursing home for end of life care was significantly higher in the DS group whereas the majority (90%) in the non-DS group remained in a group home setting. Mortality was significantly earlier in the DS group with the mean age at death to be 61.4 years compared with 73.2 years in the non-DS group. The authors concluded that the present results suggest that aging adults with DS encounter more relocations, and are more likely to have their final placement for end of life care in a nursing home. In contrast, the adults without DS were subjected to less relocation and remained in the same group home setting

Persaud, M., & Jaycock, S.
Evaluating care delivery: the application of dementia care mapping in learning disability residential services
Journal of Learning Disabilities, 2001, 5(4), 345-352
Abstract: Measurement and evaluation in intellectual disability services is still in its infancy. This report explores how good practice in relation to quality of care initiatives in dementia care transpose into intellectual disability settings. The authors applied dementia care mapping (DCM) to evaluate its effectiveness and efficiency in generic intellectual disability settings. Results showed that the application of the method to be partially successful. The data produced compared favorably in quality, quantity and detail with those collected in dementia care areas. Analysis of data revealed great potential for the method; however, result indices and coding frameworks need to be modified and adapted in future studies. No subject had dementia.

Peterson, M.E., & O'Bryant, S.E.
Blood-base biomarkers for Down syndrome and Alzheimer's disease: A systematic review
Developmental Neurobiology, 2019, 79(7), 699-710.
https://doi.org/10.1002/dneu.22714
Abstract: Down syndrome (DS) occurs due to triplication of chromosome 21. Individuals with DS face an elevated risk for development of Alzheimer's disease (AD) due to increased amyloid beta (Aß) resulting from the over-expression of the amyloid precursor protein found on chromosome 21. Diagnosis of AD among individuals with DS poses particular challenges resulting in an increased focus on alternative diagnostic methods such as blood-based biomarkers. The aim of this review was to evaluate the current state of the literature of blood-based biomarkers found in individuals with DS and particularly among those also diagnosed with AD or in prodromal stages (mild cognitive impairment [MCI]). A systematic review was conducted utilizing a comprehensive search strategy. Twenty-four references were identified, of those, 22 fulfilled inclusion criteria were selected for further analysis with restriction to only plasma-based biomarkers. Studies found Aß to be consistently higher among individuals with DS; however, the link between Aß peptides (Aß1-42 and Aß1-40) and AD among DS was inconsistent. Inflammatory-based proteins were more reliably found to be elevated leading to preliminary work focused on an algorithmic approach with predominantly inflammatory-based proteins to detect AD and MCI as well as predict risk of incidence among DS. Separate work has also shown remarkable diagnostic accuracy with the use of a single protein (NfL) as compared to combined proteomic profiles. This review serves to outline the current state of the literature and highlights the potential plasma-based biomarkers for use in detecting AD and MCI among this at-risk population.

Prasher, V.
End-stage dementia in adults with Down syndrome
International Journal of Geriatric Psychiatry, 1995, 10(12), 1067-1069.
https://doi.org/10.1002/gps.930101213
Abstract: End-stage dementia in adults with Down syndrome has not been fully investigated. Available information, 6 months prior to death, for 20 adults with Down syndrome who had died with Alzheimer's disease was reviewed. A terminal stage of severe intellectual deterioration, marked personality and mood changes, loss of sphincter control, seizure activity, immobility with hypertonia and complete loss of self-care skills was found. These findings have important clinical and service implications.

Prasher, V.P.
Review of donepezil, rivastigmine, galantamine and memantine for the treatment of dementia in Alzheimer's disease in adults with Down syndrome: implications for the intellectual disability population
International Journal of Geriatric Psychiatry, 2004, 19, 509 - 515
Abstract: The management of dementia in Alzheimer's disease has dramatically changed since the development of anti-dementia drugs. However, there is limited information available regarding the bio-medical aspects of the differing drugs; particularly relating to adults with intellectual disability. Indeed the information available for the intellectual disabled population is limited to adults with Down syndrome. This review highlights the important pharmacological and clinical aspects of donepezil, rivastigmine, galantamine and memantine and supports the view that such drugs play an important part in the management of dementia in adults with intellectual disability. Future clinical and research issues are discussed.

Prasher, V., Farooq, A. & Holder, R.
The Adaptive Behavior Dementia Questionnaire (ABDQ): screening questionnaire for dementia in Alzheimer's disease in adults with Down syndrome.
Research in Developmental Disabilities, 2004, 25(4), 385-397.
Abstract: The diagnosis of dementia in Alzheimer's disease remains at times problematic in adults with intellectual disability. The analysis of 5-year consecutive data developed a researched-based clinical screening tool for dementia in Alzheimer's disease in adults with Down syndrome. The Adaptive Behavior Dementia Questionnaire (ABDQ) is a 15-item questionnaire, which is used to detect change in adaptive behavior. The scale has good reliability and validity, with an overall accuracy of 92%. It is one of the first clinical tools designed specifically to screen for dementia in Alzheimer's disease in adults with Down syndrome.

Prasher, V.P.,& **Filer, A.**
Behavioural disturbance in people with Down's syndrome and dementia.
Journal of Intellectual Disabilities Research, 1995, 39(5), 432-436.
Abstract: Behavioral disturbance associated with dementia in people with Down syndrome has not been fully researched. This study investigated such problems in subjects with Down syndrome and dementia and controls with Down syndrome but free of dementia. Changes in mood, difficulty with communication, gait deterioration, loss of self-care skills, sleep disturbance, day-time wandering and urinary incontinence were found to be associated with dementia. Problems giving the greatest cause for concern to carers were restlessness, loss of communication skills, urinary incontinence and wandering. Care provision specifically focused on management of behavioral disturbance in individuals who develop dementia is recommended.

Prasher, V.P., Mahmood, H., & Mitra, M.
Challenges faced in managing dementia in Alzheimer's disease in patients with Down syndrome.
Degenerative Neurological and Neuromuscular Disease, 2016, 6, 85-94.
Abstract: Dementia in Alzheimer's disease (DAD) is more common in adults with Down syndrome (DS), with characteristically an earlier onset. The treatment of

DAD is not too dissimilar in the general population and in people with intellectual disabilities. However, the underlying intellectual disability can make the management of DAD more challenging in older adults with DS. This literature review aimed to look at the management of DAD in people with DS. The management of dementia is holistic. This includes treating reversible factors, aiming to slow the cognitive decline, psychological therapies, ensuring that the environment is appropriate, and use of psychotropic medication when necessary to manage behavioral problems, psychotic symptoms, depressive 69symptoms, and sleep difficulty. Antidementia medications have a role to play but remain limited. The management of DAD in the DS population can be at times challenging, but good clinical practice should involve accurate diagnosis of dementia, treating any reversible additional factors, consideration of psychological and behavioral management, use of antidementia medication, and a multidisciplinary team approach.

Prasher, V.P., Metseagharun, T., & Haque, S.
Weight loss in adults with Down syndrome and with dementia in Alzheimer's disease.
Research in Developmental Disabilities, 2004 Jan-Feb;25(1):1-7.
Abstract: An association between weight loss and Alzheimer's disease has been established in the general population but little information is available regarding this association in people with intellectual disabilities. A 4-year longitudinal study of adults with Down syndrome with and without Alzheimer's disease was undertaken. Age-associated weight loss was seen in virtually all older adults with Down syndrome. A significant association between weight loss and Alzheimer's disease was found for older adults with Down syndrome. This study highlights important research and clinical issues regarding weight loss and nutrition in Down syndrome adults with dementia.

Proveda, B., & Broxholme, S.
Assessments for dementia in people with learning disabilities: Evaluation of a dementia battery developed for people with mild to moderate learning disabilities
Learning Disability Practice, 19(1), 31-40. doi.org/10.7748/ldp.19.1.31.s23
Abstract: An intellectual disabilities' dementia battery was developed to assess cognitive abilities in individuals referred to the intellectual disabilities service because of concerns of possible dementia. The present study aimed to establish concurrent validity with previously validated measures of cognitive ability and its clinical effectiveness in detecting dementia in this population. Fifty-five individuals aged 29 and over (range: 29 to 71), received a baseline and a follow-up assessment using the dementia battery between 2000 and 2010. Differences in performance between individuals allocated to 'probable', 'unsure' and 'no' dementia groupings were investigated at domain and subtest level, as well as overall performance. Results on the battery were compared with clinically relevant measures of dementia also included in the local assessment protocol. Significant differences in overall performance were found between the 'probable' and 'no' dementia groups as well as cognitive domain-specific differences. No differences were found at subtest level. Good concurrent validity was found between the battery and comparable measures of change within the dementia assessment protocol, namely the VABS, DMR and BPVS II. The intellectual disabilities' dementia battery appears to be a good measure, which can be used longitudinally, to detect change in individuals and help establish a diagnosis of dementia. It is also comparable with other measures of change incorporated in the dementia assessment protocol. Subtests included in the language domain appear to be the most relevant at detecting significant changes between baseline and follow up. Future studies should attempt to standardize this measure and establish cut-off scores.

Puri, B.K., Ho, K.W., & Singh, I.
Age of seizure onset in adults with Down's syndrome.
International Journal of Clinical Practice, 2001, 55(7), 442-444.
Abstract: In a cohort of 68 adults (35 males and 33 females) with Down's syndrome aged 29-83 years, a history of seizures was found in 26.5%. The overall mean age of onset of seizures was 37 years, males (22 years) being significantly younger than females (51 years). The age of onset was bimodally distributed, with the first peak occurring in the first two decades, and a late-onset peak occurring in the fifth and sixth decades. A strong association between Alzheimer's disease and seizures was confirmed. Of those with a history of seizures, those aged over 45 years were significantly more likely to develop Alzheimer's disease than those younger than 45. It is suggested that late-onset epilepsy in Down's syndrome is associated with Alzheimer's disease, while early-onset epilepsy is associated with an absence of dementia.

Rafii, M. S.
Tau PET imaging for staging of Alzheimer's disease in Down syndrome
Developmental Neurobiology, 2019, 79(7), 711- 715.
https://doi.org/10.1002/dneu.22658
Abstract: Alzheimer's disease (AD) pathology and early-onset dementia develop almost universally in Down syndrome (DS). AD is defined neuropathologically by the presence of extracellular plaques of aggregated amyloid ß protein and intracellular neurofibrillary tangles (NFTs) of aggregated hyperphosphorylated tau protein. The development of radiolabeled positron emission tomography (PET) ligands for amyloid plaques and tau tangles enables the longitudinal assessment of the spatial pattern of their accumulation in relation to symptomatology. Recent work indicates that amyloid pathology develops 15–20 years before neurodegeneration and symptom onset in the sporadic and autosomal dominant forms of AD, while tau pathology correlates more closely with symptomatic stages evidenced by cognitive decline and dementia. Recent work on AD biomarkers in DS illustrates similarities between DS and sporadic AD. It may soon be possible to apply recently developed staging classifications to DS to obtain a more nuanced understanding of the development AD in DS and to provide more accurate diagnosis and prognosis in the clinic.

Reid, A. H., & Aungle, P. G.
Dementia in ageing mental defectives: A clinical psychiatric study. Journal of *Mental Deficiency Research,* 1974, 18, 15–23. Doi: 10.1111/j.1365-2788.1974.tb01214.x
Abstract: Review of literature on dementia and Down to date.

Robertson, J., Hatton, C., Emerson, E., Baines, S.
Prevalence of epilepsy among people with intellectual disabilities: A systematic review.
Seizure, 2015, 29, 46-62. doi: 10.1016/j.seizure.2015.03.016.
Abstract: Epilepsy is more common in people with intellectual disabilities than in the general population. However, reported prevalence rates vary widely between studies. This systematic review aimed to provide a summary of prevalence studies and estimates of prevalence based on meta-analyses. Studies were identified via electronic searches using Medline, Cinahl and PsycINFO and cross-citations. Information extracted from studies was tabulated. Prevalence rate estimates were pooled using random effects meta-analyses and subgroup analyses were conducted. A total of 48 studies were included in the tabulation and 46 studies were included in meta-analyses. In general samples of people with intellectual disabilities, the pooled estimate from 38 studies was 22.2% (95% CI 19.6-25.1). Prevalence increased with increasing level of intellectual disability. For samples of people with Down syndrome, the pooled estimate from data in 13 studies was 12.4% (95% CI 9.1-16.7), decreasing to 10.3% (95% CI 8.4-12.6) following removal of two studies focusing on older people. *Prevalence increased with age in people with Down syndrome and was particularly prevalent in those with Alzheimer's/dementia.* Epilepsy is highly prevalent in people with intellectual disabilities. Services must be equipped with the skills and information needed to manage this condition.

Robinson, A., Spencer, B., & White, L.
Understanding difficult behaviors: Some suggestions for coping with Alzheimer's disease and related illnesses
80 pp.
Geriatric Education Center of Michigan (Alzheimer's Education Program, Eastern Michigan University, P.O. Box 981337, Ypsilanti, MI 48198-1337; www.emich.edu/public/alzheimers) (1999 rev.)
Abstract: Manual format publication providing detailed information on

addressing difficult behaviors and understanding their causes and environmental relationships. Specific detailed sections on angry, agitated behavior; hallucinations and paranoia; incontinence; problems with bathing, dressing, eating, sleeping and wandering; repetitive actions, screaming and verbal noises, and wanting to go home. Appendix contains selected readings, and audio-visual materials. Does not specifically focus on intellectual disabilities, but is good generic resource.

Ryan, C., MacHale, R., & Hickey, E.
"Forgetting familiar faces": Staff perceptions of dementia in people with intellectual disabiliities
British Journal of Learning Disabilities, 2018, 46(3), 155-162.[On-line version of 29 May 2018]; https://doi.org/10.1111/bld.12233
Abstract: Living with dementia is challenging, but poses unique difficulties for adults with an intellectual disability. The demands of dementia are also challenging for family, carers, and friends. The authors explored the impact of dementia on direct care staff using a focus group methodology. Thematic analysis was used to investigate the staff narratives. There were four key themes that emerged: (a) the difficulty of recognizing symptoms of dementia in people with intellectual disability, (b) the process of diagnosis, (c) the challenge of dementia for the person, (d) the emotional impact of dementia for other people. The authors concluded that the themes identified a number of important potential targets for supporting staff and peers when dementia is present in an adult witih an intellectual disability.

Santos, F.H., Watchman, K., Janicki, M.P. and the Summit on Intellectual Disability and Dementia.
Highlights from the International Summit on Intellectual Disability and Dementia Implications for Brazil
Dementia & Neuropsychologia, 2018, 12(4), 329-336. doi: 10.1590/1980-57642018dn12-040001
Abstract: In October of 2016, an interdisciplinary group representing North and South American and European countries met in Glasgow, Scotland, to scrutinize universal issues regarding adults with intellectual disability (ID) affected by dementia and to produce recommendations and guidelines for public policy, practice, and further research. The aim of this paper is to apprise relevant outcomes of the Summit targeting Brazilian researchers, clinicians, and nongovernmental organizations in the field of ageing and dementia that are committed to developing the Brazilian national dementia plan. Three core themes were covered by the Summit: i) human rights and personal resources, ii) personalized services and caregiver support, and iii) advocacy and public impact. The exploration of the themes highlighted variations across countries, and revealed consensual views on matters such as international networks, guidance for practices, and advocacy on behalf of both people with ID affected by dementia, and their families. The authors outline the challenges Brazil must confront regarding ageing and dementia and proffer recommendations to address the needs of adults with ID affected by dementia within this scenario; both of which would help in developing the Brazilian national dementia plan.

Schaap, F.D., Dijkstra, G.J., Finnema, E.J., & Reijneveld, S..A.
The first use of dementia care mapping in the care for older people with intellectual disability: a process analysis according to the RE-AIM framework
Aging & Mental Health, 22(7), 912-919. DOI: 10.1080/13607863.2017.1401582
Abstract: The aging of the population with intellectual disability (ID), with associated conseqences as dementia, creates a need for evidence-based methods to support staff. Dementia Care Mapping (DCM) is perceived to be valuable in dementia care and promising in ID-care. The aim of this study was to evaluate the process of the first use of DCM in ID-care. DCM was used among older people with ID and care-staff in 12 group homes of six organisations. We obtained data on the first use of DCM in ID-care via focus-group discussions and face-to-face interviews with: care-staff (N = 24), managers (N = 10), behavioural specialists (N = 7), DCM-ID mappers (N = 12), and DCM-trainers (N = 2). We used the RE-AIM framework for a thematic process-analysis. All available staff (94%) participated in DCM (reach). Regarding its efficacy, staff considered DCM valuable; it provided them new knowledge and skills. Participants intended to adopt DCM, by continuing and expanding its use in their organisations. DCM was implemented as intended, and strictly monitored and supported by DCM-trainers. As for maintenance, DCM was further tailored to ID-care and a version for individual ID-care settings was developed, both as standards for international use. To sustain the use of DCM in ID-care, a multidisciplinary, interorganisational learning network was established. DCM tailored to ID-care proved to be an appropriate and valuable method to support staff in their work with aging clients, and it allows for further implementation. This is a first step to obtain an evidence-based method in ID-care for older clients.

Schaap, F.D., Finnema, E.J., Dijkstra, G.J., & Reijneveld, M.
What can we learn from dementia care in the care of older people with intellectual disability?
Journal of Intellectual Disability Reserach, 2019, 63(8), 645-646.
Abstract: The ageing of people with intellectual disability (ID) increases rates of dementia, starting earlier and are more prevalent than in the general population. ID-care staff call for methods, knowledge, and skills to support their older residents. Person-centred methods derived from dementia care can fill this gap, but are often used unsystematically, and not adapted to ID-care. Moreover, their effectiveness in ID-care is not yet clear. One person-centred method adapted to ID-care, is Dementia Care Mapping (DCM). The aim of this study is to examine the experiences of care staff with DCM. We assessed this after two applications of DCM in twelve group homes for older people with ID, with a qualitative study (N = 24) and a quantitative study on care-staff (N = 136). Our study showed that DCM provided better understanding of the behaviour of their residents with and without dementia, more reflection and awareness of their own professional behaviour, and new knowledge and (dementia-care) skills. Furthermore, relating the needs and interpretation of the behaviour of residents to the theory of person-centred care provided care-staff a rationale and significance in daily care. Finally, DCM led to more team coordination of care. Authors concluded that evidence from dementia care can improve the quality of care for older people with ID, if adequately embedded in ID-care.

Schlamb, C.D., & Moriconi, C.D.
Betsy: A case study of a client with Down's syndrome and dementia
Advancing Care Excellence for Seniors.
http://dx.doi.org/http://www.nln.org/facultyprograms/facultyresources/aces/Betsy/betsy.pdf
This case study is about an aging woman experiencing Down syndrome (DS) and dementia. People with Down syndrome are living longer than ever before. Since the 1980s their life expectancy has doubled and many now live into their 60s, most likely because of advances in medical treatment and improved living conditions. Adults with DS and dementia typically experience several residential relocations during their lifetime and these may be traumatic events for these individuals. This study explores the complex needs of aging clients with intellectual disabilities. Target students for this teaching strategy have completed medical-surgical or geriatric nursing.

Schupf, N., Kapell, D., Nightingale, B, Rodriguez, A., Tycko, B., & Mayeux, R.
Earlier onset of Alzheimer's disease in men with Down syndrome.
Neurology, 1998, 50(4), 991-995.
Abstract: Virtually all individuals with Down syndrome (DS) have neuropathologic changes characteristic of Alzheimer's disease (AD) beginning at 40 years of age. Few studies have examined factors that influence age at onset of AD in DS. We investigated whether sex differences in age at onset and risk of AD among adults with DS are similar to those observed in the general population and whether the effect of sex on risk of AD is modified by apolipoprotein E(*APOE*) genotype. A community-based sample of 111 adults with cytogenetically confirmed DS (34 to 71 years of age) was ascertained through the New York State Developmental Disabilities system. A semi-structured interview with caregivers and review of medical records was used to ascertain the presence or absence of AD. *APOE* genotyping was carried out without knowledge of the subject's medical history or clinical diagnosis. Both male gender and the presence of an *APOE* ?4 allele were associated with an earlier onset of AD. Compared with women, men with DS were three times as

likely to develop AD. Compared with those with the *APOE* 3/3 genotype, adults with DS with the 3/4 or 4/4 genotypes were four times as likely to develop AD. No individual with an *APOE* ?2 allele developed AD. No evidence of interaction of sex and *APOE* genotype was found in risk of AD. The higher risk of AD in men may be related to differences in hormonal function between men and women with DS that are distinct from those in the general population.

Schupf N., Kapell D, Nightingale B, Rodriguez A, Tycko B, Mayeux R.
Earlier onset of Alzheimer's disease in men with Down syndrome.
Neurology, 1998, 50(4), 991-995.
Abstract: Virtually all individuals with Down syndrome (DS) have neuropathologic changes characteristic of Alzheimer's disease (AD) beginning at 40 years of age. Few studies have examined factors that influence age at onset of AD in DS. We investigated whether sex differences in age at onset and risk of AD among adults with DS are similar to those observed in the general population and whether the effect of sex on risk of AD is modified by apolipoprotein E (APOE) genotype. A community-based sample of 111 adults with cytogenetically confirmed DS (34 to 71 years of age) was ascertained through the New York State Developmental Disabilities system. A semistructured interview with caregivers and review of medical records was used to ascertain the presence or absence of AD. APOE genotyping was carried out without knowledge of the subject's medical history or clinical diagnosis. Both male gender and the presence of an APOE epsilon4 allele were associated with an earlier onset of AD. Compared with women, men with DS were three times as likely to develop AD. Compared with those with the APOE 3/3 genotype, adults with DS with the 3/4 or 4/4 genotypes were four times as likely to develop AD. No individual with an APOE epsilon2 allele developed AD. No evidence of interaction of sex and APOE genotype was found in risk of AD. The higher risk of AD in men may be related to differences in hormonal function between men and women with DS that are distinct from those in the general population.

Schupf N, Winsten S, Patel B, Pang D, Ferin M, Zigman WB, Silverman W, Mayeux R. (2006). Bioavailable estradiol and age at onset of Alzheimer's disease in postmenopausal women with Down syndrome.
Neuroscience Letter, 2006, Oct 9,406(3). 298-302.
Abstract: Several lines of evidence suggest that loss of estrogen after menopause may play a role in the cognitive declines associated with Alzheimer's disease (AD). Women with Down syndrome (DS) experience early onset of both menopause and AD. This timing provides a model to examine the influence of endogenous estrogen deficiency on risk of AD. We hypothesized that low serum levels of bioavailable estradiol (E2) would be associated with increased risk of AD. One hundred and nineteen postmenopausal women with DS, 42-59 years of age, were ascertained through the New York State developmental disability service system and followed at 18-month intervals. Information from cognitive assessments, caregiver interviews, medical record review and neurological examination was used to establish the diagnosis of dementia. Women with DS who developed AD had lower levels of bioavailable E2, lower levels of total estradiol, higher levels of sex-hormone binding globulin, and lower levels of dehydroepiandrosterone sulfate at baseline than women who remained dementia free over the course of follow-up. Women who had low levels of bioavailable E2 at baseline were four times as likely to develop AD (HR=4.1, 95% CI: 1.2-13.9) and developed AD, on average, 3 years earlier, than those with high levels of bioavailable E2, after adjustment for age, level of mental retardation, ethnicity, body mass index, history of hypothyroidism or depression and the presence of the apolipoprotein varepsilon4 allele. Our findings support the hypothesis that reductions in estrogen following menopause can contribute to the cascade of pathological processes leading to AD.

Schupf N, Pang D, Patel BN, Silverman W, Schubert R, Lai F, Kline JK, Stern Y, Ferin M, Tycko B, Mayeux R.
Onset of dementia is associated with age at menopause in women with Down's syndrome.
Annuals of Neurology, 2003, 54(4), 433-438.
Abstract: Women with Down's syndrome experience early onset of both menopause and Alzheimer's disease. This timing provides an opportunity to examine the influence of endogenous estrogen deficiency, indicated by age at menopause, on risk of Alzheimer's disease. A community-based sample of 163 postmenopausal women with Down's syndrome, 40 to 60 years of age, was ascertained through the New York State Developmental Disability service system. Information from cognitive assessments, medical record review, neurological evaluation, and caregiver interviews was used to establish ages for onset of menopause and dementia. We used survival and multivariate regression analyses to determine the relation of age at menopause to age at onset of Alzheimer's disease, adjusting for age, level of mental retardation, body mass index, and history of hypothyroidism or depression. Women with early onset of menopause (46 years or younger) had earlier onset and increased risk of Alzheimer's disease (AD) compared with women with onset of menopause after 46 years (rate ratio, 2.7; 95% confidence interval [CI], 1.2-5.9). Demented women had higher mean serum sex hormone binding globulin levels than nondemented women (86.4 vs 56.6 nmol/L, p = 0.02), but similar levels of total estradiol, suggesting that bioavailable estradiol, rather than total estradiol, is associated with dementia. Our findings support the hypothesis that reductions in estrogens after menopause contribute to the cascade of pathological processes leading to AD.

Scottish Down's Syndrome Association
What is dementia? - A booklet about dementia for adults who have a learning disability.
14pp
Edinburgh: Scottish Down's Syndrome Association [158-160 Balgreen Road, Edinburgh, Scotland EH11 3AU; e/m: info@sdsa.org.uk; www.sdsa.org.uk] [n.d.]
[Source: http://www.rrtcadd.org/TA/Dementia_Care/Resources/Info.html]
Abstract: Written for the Scottish Down's Syndrome Association by Diana Kerr and Mo Innes this A4 size booklet is designed to explain dementia and its nuances to persons with intellectual disabilities (termed "learning disabilities in Scotland). Using drawings and easy language this booklet covers many of the symptoms and behaviors classically associated with Alzheimer's disease.

Service, K.P.
Considerations in care for individuals with intellectual disability with advanced dementia
Journal of Gerontological Social Work, 2002, 38, 213-224.
Abstract: A number of physical, psychosocial, or ethical issues related to the care of the individual with advanced dementia are reviewed and related to individuals with intellectual disabilities. The sources used include the published literature and illustrations drawn from personal observations. The author notes that through anticipation and early planning, advanced directives and service planning (which looks to adaptation of services and other care management interventions), can effectively impact care at the end. Areas that need to be addressed include technical information, including a review of and, as appropriate, adaptation of general advanced dementia resources, relief, rest, support, reassurance, receipt of on-going information, participation in planning, a sense of humor, and appreciation. Also noted, are the differences experienced because of the presence of paid staff as carers and residence outside of the family home. It is concluded that, although the goals of quality care is the same for all people with advanced dementia, the process by which to reach these goals often needs further consideration and adaptation for people with intellectual disabilities.

Service, K..P., & Clifford, C.J.
What do I really need? Assessment of caregiver supports for people with intellectual and developmental disability and dementia.
AAIC 2020 Conference (Amsterdam, NL - virtual), Poster presentation, July 30. 2020. https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Person/47602
Abstract: The increased needs of people with an intellectual and developmental disability (IDD) and a dementia related disorder can strain caregivers and existing community support systems. The project team, comprised of IDD and Aging experts and funded, in part, through a federal grant, conducted a needs assessment on the awareness and use of typical community-based resources

such as senior centers. The assessment consisted of both telephone interviews and home visits with group home, shared living, and family caregivers. Nurse Practitioner (NP) conducted a total of 95 interviews with 54 site visits, and the evaluator completed 40 interviews with caregivers of people with IDD and dementia diagnosis. Analysis included both qualitative and quantitative data. Caregivers were asked about the following: functional and health status of person with IDD since dementia diagnosis, receipt of dementia specific caregiving training, care confidence levels, perceived barriers to care, and access to community-based aging resources. Caregiver's most frequent concerns included lack of suitable day programming, planning for the person's future, and caregiver burnout and stress. 78% reported feeling confident providing care currently and 68% were confident about providing care in the future. Most caregivers are aware of local community resources such as senior centers, Alzheimer's Association Counseling and an on-line training series on aging, but rarely used the resources. Authors note that caregivers generally relied on support from provider agencies indicating a need for increased collaboration across the IDD and Aging human service support systems. Trainings, delivered to both aging advocates and caregivers of people with IDD, and designed to improve communication and collaboration focused on dementia capable care, state systems, and available community resources. In addition, a series of web-based resources were developed with a focus on IDD and dementia. Results of the assessment will continue to guide resource and training development to improve collaboration and support the relationship between the Aging and IDD communities.

 **Service, K.P., Lavoie, D. Herlihy, J.E.**
Coping with losses, death and grieving
In M.P. Janicki & A.J. Dalton (eds.), Dementia, Aging, and Intellectual Disabilities.
pp. 330-351
Philadelphia: Brunner-Mazel (1999)
Abstract: This book chapter uses a composite case to demonstrate strategies to address the issues related to losses and death for people with intellectual disability and the diagnosis of dementia and for their families and staff. Dealing with the diagnosis and the changes are explained in the framework of the stages of death and dying as developed by Kubler-Ross. The responses to the losses of dementia which are manifested by affected individuals and members of their personal networks are reflective of a number of factors. The dilemma related to personal value systems, professional roles, and philosophies of care is explored in the context of ethical concerns. The impact of program considerations such as rules, regulations, policies, and economics is examined. Bereavement work for peers and housemates can be further developed for carers, family, and staff. Recommendations for research and interventions for public policy are given.

Service, K., Watchman, K., Hogan, M., Janicki, M.P., Cadovius, N., & Beránková, A.
Dying well with an intellectual disability and dementia
Journal of Dementia Care, 2017, 25(4), 25-31.
Abstract: An international summit on intellectual disability and dementia identified three areas where the added complexity of advanced dementia warrants particular attention around end-of-life services in people with an intellectual disability. The three areas were: (a) ascertainment of advanced stage of dementia, (b) place of care, and (c) active support. The authors discuss each of these three issues and note the particular challenges that arise when someone with dementia also has an intellectual disability. The summit proffered a series of recommendations that included ongoing exchange of experiences and skills across professions, development of tools and scales that facilitate understanding of the progression of dementia, and more equitable access to palliative care and hospice services with increased and timely referral.

Sheehan, R., Sinai, A., Bass, N., Blatchford, P., Bohnen, I,, Bonell, S., Courtenay, K., Hassiotis, A., Markar, T., McCarthy, J., Mukherji, K., Naeem, A,. Paschos, D., Perez-Achiaga, N., Sharma, V., Thomas, D., Walker, Z., Strydom, A.
Dementia diagnostic criteria in Down syndrome.
International Journal of Geriatric Psychiatry, 2015, 30(8). 857-863. doi: 10.1002/gps.4228.
Abstract: Dementia is a common clinical presentation among older adults with Down syndrome. The presentation of dementia in Down syndrome differs compared with typical Alzheimer's disease. The performance of manualised dementia criteria in the International Classification of Diseases (ICD)-10 and Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision (DSM-IV-TR) is uncertain in this population. We aimed to determine the concurrent validity and reliability of clinicians' diagnoses of dementia against ICD-10 and DSM-IV-TR diagnoses. Validity of clinical diagnoses were also explored by establishing the stability of diagnoses over time. The authors used clinical data from memory assessments of 85 people with Down syndrome, of whom 64 (75.3%) had a diagnosis of dementia. The cases of dementia were presented to expert raters who rated the case as dementia or no dementia using ICD-10 and DSM-IV-TR criteria and their own clinical judgement. The authors found that clinician's judgement corresponded best with clinically diagnosed cases of dementia, identifying 84.4% cases of clinically diagnosed dementia at the time of diagnosis. ICD-10 criteria identified 70.3% cases, and DSM-IV-TR criteria identified 56.3% cases at the time of clinically diagnosed dementia. Over time, the proportion of cases meeting ICD-10 or DSM-IV-TR diagnoses increased, suggesting that experienced clinicians used their clinical knowledge of dementia presentation in Down syndrome to diagnose the disorder at an earlier stage than would have been possible had they relied on the classic description contained in the diagnostic systems. The authors concluded that clinical diagnosis of dementia in Down syndrome is valid and reliable and can be used as the standard against which new criteria such as the DSM-5 are measured.

Sheehan. R., Sinai, A., Bass, N., Blatchford, P., Bohnen, I,, Bonell, S., Courtenay, K., Hassiotis, A., Markar, T., McCarthy, J., Mukherji, K., Naeem, A,. Paschos, D., Perez-Achiaga, N., Sharma, V., Thomas, D., Walker, Z., Strydom, A.
Dementia diagnostic criteria in Down syndrome.
International Journal of Geriatric Psychiatry., 2014 Nov 3. doi: 10.1002/gps.4228. [Epub ahead of print]
Abstract: Dementia is a common clinical presentation among older adults with Down syndrome. The presentation of dementia in Down syndrome differs compared with typical Alzheimer's disease. The performance of manualised dementia criteria in the International Classification of Diseases (ICD)-10 and Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision (DSM-IV-TR) is uncertain in this population. We aimed to determine the concurrent validity and reliability of clinicians' diagnoses of dementia against ICD-10 and DSM-IV-TR diagnoses. Validity of clinical diagnoses were also explored by establishing the stability of diagnoses over time. The authors used clinical data from memory assessments of 85 people with Down syndrome, of whom 64 (75.3%) had a diagnosis of dementia. The cases of dementia were presented to expert raters who rated the case as dementia or no dementia using ICD-10 and DSM-IV-TR criteria and their own clinical judgement. The authors found that clinician's judgement corresponded best with clinically diagnosed cases of dementia, identifying 84.4% cases of clinically diagnosed dementia at the time of diagnosis. ICD-10 criteria identified 70.3% cases, and DSM-IV-TR criteria identified 56.3% cases at the time of clinically diagnosed dementia. Over time, the proportion of cases meeting ICD-10 or DSM-IV-TR diagnoses increased, suggesting that experienced clinicians used their clinical knowledge of dementia presentation in Down syndrome to diagnose the disorder at an earlier stage than would have been possible had they relied on the classic description contained in the diagnostic systems. The authors concluded that clinical diagnosis of dementia in Down syndrome is valid and reliable and can be used as the standard against which new criteria such as the DSM-5 are measured.

Sheehan, R., Sinai, A., Bass, N., Blatchford, P., Bohnen, I., Bonell, S., ... Strydom, A.
Dementia diagnostic criteria in Down syndrome
International Journal of Geriatric Psychiatry, 2015, 30(8), 857–863.

Abstract: Dementia is a common clinical presentation among older adults with Down syndrome. The presentation of dementia in Down syndrome differs compared with typical Alzheimer's disease. The performance of manualized dementia criteria in the International Classification of Diseases (ICD)-10 and Diagnostic and Statistical Manual of Mental Disorders-IV-Text Revision (DSM-IV-TR) is uncertain in this population. The authors aimed to determine the concurrent validity and reliability of clinicians' diagnoses of dementia against ICD-10 and DSM-IV-TR diagnoses. Validity of clinical diagnoses were also explored by establishing the stability of diagnoses over time. We used clinical data from memory assessments of 85 people with Down syndrome, of whom 64 (75.3%) had a diagnosis of dementia. The cases of dementia were presented to expert raters who rated the case as dementia or no dementia using ICD-10 and DSM-IV-TR criteria and their own clinical judgement. The authors found that clinician's judgement corresponded best with clinically diagnosed cases of dementia, identifying 84.4% cases of clinically diagnosed dementia at the time of diagnosis. ICD-10 criteria identified 70.3% cases, and DSM-IV-TR criteria identified 56.3% cases at the time of clinically diagnosed dementia. Over time, the proportion of cases meeting ICD-10 or DSM-IV-TR diagnoses increased, suggesting that experienced clinicians used their clinical knowledge of dementia presentation in Down syndrome to diagnose the disorder at an earlier stage than would have been possible had they relied on the classic description contained in the diagnostic systems. Clinical diagnosis of dementia in Down syndrome is valid and reliable and can be used as the standard against which new criteria such as the DSM-5 are measured.

Shultz, J.M., Aman, M.G., & Rojahn, J..
Psychometric evaluation of a measure of cognitive decline in elderly people with mental retardation.
Research in Developmental Disabilities, 1998, 19, 63-71.
Abstract: Forty elderly persons with mental retardation were assessed by their care providers on a modified version of the Short Informant Questionnaire on Cognitive Decline in The Elderly (IQCODE) an instrument designed to quantify cognitive decline in elderly people in the general population. They were also assessed for IQ, aberrant behavior, and current mental status; test-retest and interrater reliability were evaluated as well. Internal consistency, as assessed by coefficient alpha, was moderately high (alpha = .86). Test-retest reliability was mediocre and interrater reliability levels did not reach statistical significance. The Short IQCODE was not correlated with a variety of demographic features or with behavior ratings, showing evidence of divergent validity. However, the Short IQCODE was only weakly (nonsignificantly) correlated with a measure of current mental status, which challenges its concurrent validity. The Short IQCODE probably needs to be modified further for satisfactory psychometric performance in people with mental retardation. However, some features of this study may have resulted in suboptimal estimates of the Short IQCODE's psychometric characteristics.

Sigal, M.J,, & Levine, N.
Down's syndrome and Alzheimer's disease.
Journal of the Canadian Dental Association, 1993, 59(10), 823-5, 829.
Abstract: Individuals with Down's syndrome (DS) who live to be 40 years of age will demonstrate neuropathological changes that are consistent with Alzheimer's disease (AD). Due to modern medical intervention, we are now observing an aging DS population. Middle-aged Down's syndrome adults are actually considered to be "very old," and it is not uncommon to observe a progressive loss of cognitive function and a decline in the ability to perform daily tasks consistent with that seen in Alzheimer's disease. At this stage, the DS individual will not be able to perform daily preventive dental care and may be unable to cooperate for professional dental care. Clinicians who care for DS adults must be aware of this problem when preparing their dental treatment plans, which must emphasize preventive care prior to the onset of dementia and the maintenance of that program during their patients' cognitive decline. In the latter stages of AD, it may be necessary to extract all the remaining teeth due to the inability of the individual or care giver to provide adequate oral hygiene to prevent dental caries or periodontal disease.

Simard, M., & van Reekum, R.
Dementia with Lewy bodies in Down's syndrome.
International Journal of Geriatric Psychiatry, 2001, Mar;16(3), 311-20.
Abstract: The association between Down's syndrome (DS) and Alzheimer's disease is well established. This paper presents a review of the literature, suggesting a possible association between DS and the more recently recognized dementia with Lewy bodies (DLB). Patients with DLB frequently present with changes in affect and behavior, and in particular with psychotic symptoms. The literature suggests a possible role for atypical neuroleptics in the management of psychosis in DLB.

Soliman, A, & Hawkins, D.
The link between Down's syndrome and Alzheimer's disease: 1.
British Journal of Nursing, 1998, Jul 9-22;7(13):779-784.
Abstract: This article, the first of two parts, considers the link between Down's syndrome and Alzheimer's disease and how this link has been a significant factor with regards to research into the aetiology of Alzheimer's disease. It describes some of the suggested causes of Alzheimer's disease in people with Down's syndrome. The diagnosis, signs and symptoms of Alzheimer's disease are briefly discussed. The second article concludes with the implications of Alzheimer's disease in people with Down's syndrome for family careers, services and nurses.

Soliman, A., & Hawkins, D.
The link between Down's syndrome and Alzheimer's disease: 2.
British Journal of Nursing, 1998, Jul 23-Aug 12;7(14):847-850.
Abstract: In this article, the second of two parts, the needs of family and professional carers of people with Down's syndrome and Alzheimer's disease are examined. Substantial numbers of people with Down's syndrome survive to the age of 50 and beyond and so work still needs to be done on finding solutions to the problems faced by this client group and its carers. As well as the difficulties faced by any family carer of a person with dementia, those caring for someone with Down's syndrome and Alzheimer's disease may also have to deal with additional worries and problems. Consideration is given to service provision and the implications for nursing. A case study will illustrate some of the points made.

Strydom, A.
Clinical trials to prevent or delay Alzheimer's disease in individuals with Down syndrome
Journal of Intellectual Disability Research, 2019, 63(8), 640-641.
Abstract: Adults with Down syndrome (DS) have neuropathological features identical to individuals with sporadic Alzheimer's disease (AD) and this discovery played an important role in the identification of the amyloid precursor protein gene on chromosome 21. Individuals with DS have a lifetime risk for dementia in excess of 90% and DS is now acknowledged to be the most common genetic cause of AD, but this group is often excluded from AD medication trials. This review will discuss primary and secondary prevention trials for AD in DS and the potential barriers and solutions to such trials. It will include a brief overview of the epidemiology, diagnosis and outcome measurement issues pertinent to prevention trials, as well as important ageing-related co-morbidities that need to be considered in the design of such trials. Ddescribed is the work of the Europe-wide Horizon21 Consortium and other efforts to establish DS clinical trials networks, as well as to consider the methodological issues for trials to prevent or delay AD in DS. It was noted that individuals with DS could benefit from treatments to prevent or delay AD. Improved knowledge of pathogenic processes and their clinical consequences in DS will hopefully lead to new clinical trials.

Strydom, A., & Hassiotis, A.
Diagnostic instruments for dementia in older people with intellectual disability in clinical practice
Aging & Mental Health, 2003, 7(6), 431-437
Abstract: There is a need for simple and reliable screening instruments for dementia in the intellectual disability (ID) population that can also be used to follow their progress, particularly if they are being treated with anti-dementia drugs. Commonly used tests for the general population such as the Mini Mental

State Examination (MMSE) are not appropriate for many people with ID. This paper is a literature review of alternative instruments that have been used in research or recommended by experts since 1991 and have the potential to be used as screening instruments. Two types of tests have been identified: those administered to informants, and those that rely on direct assessment of the individual. The most promising informant rated screening tool in most adults with ID including Down syndrome (DS) diagnosis is the Dementia Questionnaire for Persons with Mental Retardation (DMR). However, sensitivity in single assessments is variable and cut-off scores need further optimization. In those with DS, the Dementia Scale for Down Syndrome (DSDS) has good specificity but mediocre sensitivity. The Test for Severe Impairment and Severe Impairment Battery are two direct assessment tools that show promise as screening instruments, but need further evaluation.

Strydom, A., & Hassiotis, A., **Livingston, G., & King, M.**
Prevalence of dementia in older adults with intellectual disability without Down syndrome
Journal of Applied Research in Intellectual Disabilities, 2006, 19, 253.
Abstract: The aim of this study was to determine the prevalence of dementia in older adults with intellectual disability(ID) without Down syndrome. The authors identified the total population of adults with ID aged 60+ in the five London boroughs served through local social services registers, ID teams and residential services providers and then screened the Ss with a simple object memory task, information about functional status, and the Dementia Questionnaire for Persons with Mental Retardation (DMR). Screen positives on the DMR, or those with unexplained functional decline or memory deficits underwent detailed examination. Full assessment of cognitive and physical function was undertaken and additional information was collected from informants and medical records. All information was summarized to determine dementia status with IDC-10, DSM-IV, and DC-LD criteria. The authors identified 264 adults with ID and 222 (84%) participated in the study. One in four screened positive. The prevalence rate for ICD-10 or DSM-IV was 12%. Prevalence differed between those with mild and severe ID, and between diagnostic criteria. The authors concluded that dementia is common in older adults with ID without DS, but prevalence in severe ID deviated from prediction and the use of diagnostic criteria needs to be reviewed.

Strydom, A., Hassiotis, A., & Livingston, G.
Mental health and social care needs of older people with intellectual disabilities
Journal of Applied Research in Intellectual Disabilities, 2005, 18(3), 229-235.
Abstract: Older people with intellectual disabilities (ID) are a growing population but their age-related needs are rarely considered and community services are still geared towards the younger age group. We aimed to examine the mental health and social care needs of this new service user group. We identified all adults with ID without Down syndrome (DS) aged 65+ living in the London boroughs of Camden and Islington. The Psychiatric Assessment Schedule for Adults with a Developmental Disability (PASADD) checklist was used to detect psychiatric disorder, the Vineland Behavior Scale (maladaptive domain) for problem behaviors and the Dementia Questionnaire for Persons with Mental Retardation (DMR) to screen for dementia. Carers reported health problems and disability. Needs were measured with the Camberwell Assessment of Need for adults with Intellectual Disabilities (CANDID-S). A total of 23 older people with ID (13 had mild ID and nine more severe ID) and their carers participated in the survey. In which, 74% had one or more psychiatric symptoms; 30% were previously known with a diagnosis of mental illness. One-third of the older people screened positive for dementia (range: 17-44%, depending on sensitivity of DMR scores used). Three quarters of the group had physical health problems, 74% had poor sight, 22% had hearing loss and 30% had mobility problems. Carers rated unmet needs for accommodation (22%), day activities, and eyesight and hearing. The people with ID rated unmet needs to be social relationships (44%), information and physical health. Authors concluded that older people with ID without DS have considerable prevalence of health problems and psychiatric disorders, including symptoms of functional decline and dementia. Such symptoms are often not recognized and further research into their needs is a priority.

Strydom, A., Livingston, G., King, M., & Hassiotis. A.
Prevalence of dementia in intellectual disability using different diagnostic criteria.
British Journal of Psychiatry, 2007, 191, 150-157.
Abstract: Diagnosis of dementia is complex in adults with intellectual disability owing to their pre-existing deficits and different presentation. To describe the clinical features and prevalence of dementia and its subtypes, and to compare the concurrent validity of dementia criteria in older adults with intellectual disability. The Becoming Older with Learning Disability (BOLD) memory study is a two-stage epidemiological survey of adults with intellectual disability without Down syndrome aged 60 years and older, with comprehensive assessment of people who screen positive. Dementia was diagnosed according to ICD–10, DSM–IV and DC–LD criteria. The DSM–IV dementia criteria were more inclusive. Diagnosis using ICD–10 excluded people with even moderate dementia. Clinical subtypes of dementia can be recognized in adults with intellectual disability. Alzheimer's dementia was the most common, with a prevalence of 8.6% (95% CI 5.2–13.0), almost three times greater than expected. Dementia is common in older adults with intellectual disability, but prevalence differs according to the diagnostic criteria used. This has implications for clinical practice.

Strydom, A., Hassiotis, A., King, M., Livingston, G.
The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID.
Psychological Medicine, 2008, 15, 1-9.
Abstract: Previous research has shown that adults with intellectual disability (ID) may be more at risk of developing dementia in old age than expected. However, the effect of age and ID severity on dementia prevalence rates has never been reported. We investigated the predictions that older adults with ID should have high prevalence rates of dementia that differ between ID severity groups and that the age-associated risk should be shifted to a younger age relative to the general population. A two-staged epidemiological survey of 281 adults with ID without Down syndrome (DS) aged 60 years; participants who screened positive with a memory task, informant-reported change in function or with the Dementia Questionnaire for Persons with Mental Retardation (DMR) underwent a detailed assessment. Diagnoses were made by psychiatrists according to international criteria. Prevalence rates were compared with UK prevalence and European consensus rates using standardized morbidity ratios (SMRs). Dementia was more common in this population (prevalence of 18.3%, SMR 2.77 in those aged 65 years). Prevalence rates did not differ between mild, moderate and severe ID groups. Age was a strong risk factor and was not influenced by sex or ID severity. As predicted, SMRs were higher for younger age groups compared to older age groups, indicating a relative shift in age-associated risk. Criteria-defined dementia is 2-3 times more common in the ID population, with a shift in risk to younger age groups compared to the general population.

Strydom, A., Shooshtari, S., Lee, L., Raykar, V., Torr, J., Tsiouris, J., Jokinen, N., Courtenay, K., Bass, N., Sinnema, M., & Maaskant, M.
Dementia in older adults with intellectual disabilities—epidemiology, presentation, and diagnosis
Journal of Policy and Practice in Intellectual Disabilities, 2010, 7(2), 96-110.
Abstract: As life expectancy of people with intellectual disabilities (ID) extends into older age, dementia is an increasing cause of morbidity and mortality. To update and summarize current knowledge on dementia in older adults with ID, the authors conducted a comprehensive review of the published literature from 1997–2008 with a specific focus on: (1) epidemiology of dementia in ID in general as well as in specific genetic syndromes; (2) presentation; and (3) diagnostic criteria for dementia. The review drew upon a combination of searches in electronic databases Medline, EMBASE, and PsycINFO for original research papers in English, Dutch, or German. The authors report that varied methodologies and inherent challenges in diagnosis yield a wide range of reported prevalence rates of dementia. Rates of dementia in the population with intellectual disability not because of Down syndrome (DS) are comparable with or higher than the general population. Alzheimer's disease onset in DS appears earlier and the prevalence increases from under 10% in the 40s to more than 30% in the 50s, with varying prevalence reported for those 60 and older. Incidence rates increase with age. Few studies of dementia in other genetic

syndromes were identified. Presentation differs in the ID population compared with the general population; those with DS present with prominent behavioral changes believed to be because of frontal lobe deficits. Authors recommend large-scale collaborative studies of high quality to further knowledge on the epidemiology and clinical presentation of dementia in this population.

Strydom A., Coppus A., Blesa R., Danek. A., Fortea J.,Hardy.J., Levin, J., Nuebling G., Rebillat A.S.., Ritchie, C., van Duijn, C., Zaman, S., & Zetterberg, H.
Alzheimer's disease in Down syndrome: An overlooked population for prevention trials.
Alzheimers Dementia (N Y), 2018, 13(4), 703-713. doi: 10.1016/j.trci.2018.10.006.
Abstract: The discovery that adults with Down syndrome (DS) have neuropathological features identical to individuals with sporadic Alzheimer's disease (AD) played a key role in the identification of the amyloid precursor protein gene on chromosome 21 and resulted in the amyloid cascade hypothesis. Individuals with DS have a lifetime risk for dementia in excess of 90%, and DS is now acknowledged to be a genetic form of AD similar to rare autosomal-dominant causes. Just as DS put the spotlight on amyloid precursor protein mutations, it is also likely to inform us of the impact of manipulating the amyloid pathway on treatment outcomes in AD. Ironically, however, individuals with DS are usually excluded from AD trials. This review will discuss primary and secondary prevention trials for AD in DS and the potential barriers and solutions to such trials and describe the Europe-wide Horizon21 Consortium to establish a DS-AD prevention clinical trials network.

Stuart, C.
Estimating the number of people with Down's syndrome in Scotland and the cohort at elevated risk of early onset dementia.
Tizard Learning Disability Review, 2017, 22(3), 164-171
https://doi.org/10.1108/TLDR-11-2016-0041
Abstract: The purpose of this study was to ascertain the size of the population of adults with Down syndrome in Scotland and provide a basis for estimating their number and age ranges with dementia. Data were requested from all general practitioners (GP) in Scotland on people with an identified READ code denoting Down syndrome. A statistical weighting model was then applied to account for non-response bias. Findings were that there were 3,261 adults with Down estimated by the application of a statistical weighting model. Of these, 1,118 (34%) were aged between 40 and 59. This age group includes those adults with the highest incidence of early onset dementia. It was not possible to apply a benchmark to the percentage of observed data so as to determine the accuracy of the estimates. Adults with Down have an elevated risk of developing dementia significantly earlier than the general population and require specific age appropriate supports and services to meet their needs both pre- and post-diagnosis. The reality of this is currently not fully realized in either standard practice or national policy concerning the issue.

Sung, H., Hawkins, B.A., Eklund, S.J., Kim, K.A., Foose, A., May, M.E., Rogers, N.B.
Depression and dementia in aging adults with Down syndrome: a case study approach.
Mental Retardation, 1997, 35(1), 27-38. https://doi: 10.1352/0047-6765(1997)035<0027:DADIAA>2.0.CO;2
Abstract: Patterns of symptoms associated with depression and dementia were examined in 3 aging adults with Down syndrome. A case study approach (Yin, 1994) was employed to identify and link these symptoms. Results of the case analyses provide further insight into distinguishing between depression and dementia in older persons with Down syndrome.

Temple, V., & Konstantareas, M.M.
A comparison of the behavioural and emotional characteristics of Alzheimer's dementia in individuals with and without Down syndrome.
Canadian Journal of Aging, 2005, 24(2), 179-190
Abstract: The behavioral and emotional changes associated with Alzheimer's disease (AD) are compared for individuals with Down syndrome and AD and individuals with AD from the general population (AD-only). The primary caregivers of 30 people with Down syndrome and AD and 30 people with AD-only completed the BEHAVE-AD and the Apathy subscale of the CERAD. As well, behavioral observations at adult day programs were undertaken with selected participants (n=26). The Down syndrome group experienced fewer delusions and had lower total scores on the BEHAVE-AD, indicating fewer problem behaviors overall. Day program observations suggested that the AD-only group were more likely to be sedentary and observe the activities of others, while the Down syndrome group were more physically active. Improving our understanding of the similarities and differences between these two groups may help facilitate the integration of individuals with Down syndrome into adult day programs for the general population.

Temple, V., Jozsvai, E., Konstantareas, M.M., & Hewitt, T.A.
Alzheimer dementia in Down's syndrome: the relevance of cognitive ability.
Journal of Intellectual Disability Research, 2001, 45, 47-55.
Abstract: More years of education have been found to be associated with a lower rate of Alzheimer disease (AD) in individuals without intellectual disability. It has been proposed that education reflects greater 'synaptic reserve' and that greater synaptic reserve may defer the development of AD. The present study compared individuals with Down's syndrome (DS) who were found to have symptoms of dementia with those who remained symptom-free to determine if the two groups differed in their level of education, employment, recreational activities, years in an institution or overall level of cognitive functioning. Thirty-five adults with DS aged between 29 and 67 years were assessed. The participants were recruited from a community health facility and included individuals with a wide range of ability levels. Neuropsychological testing, caregiver report and the Dementia Scale for Down Syndrome (Gedye 1995) were used to identify decline in participants over periods of 6 months to 3 years. After the effect of age was statistically removed, multiple regression analyses revealed that level of cognitive functioning was significantly associated with decline such that a higher level of cognitive functioning predicted less decline. None of the environmental variables (i.e. educational level, years in an institution and employment) were directly associated with decline; however, a post hoc regression using level of cognitive functioning as the outcome variable revealed that level of cognitive functioning itself was associated with these environmental variables. A higher level of cognitive functioning was associated with fewer cases of dementia in individuals with DS, and level of cognitive functioning appears to be associated with environmental factors such as level of education, years in an institution and employment. The present findings suggest that environmental interventions aimed at improving level of cognitive functioning may also be useful in deferring the onset of dementia.

The Arc
Developmental disabilities and Alzheimer disease: what you should know.
43 pp.
Silver Spring, Maryland: The Arc of the United States [1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910 -- www.TheArc.org] (1995)
Abstract: A booklet covering some of the fundamentals concerning adults with intellectual disabilities and Alzheimer's disease including what is Alzheimer's disease, its course and outcome, diagnostic suggestions, care considerations, and how to obtain assistance. Contains resource list and glossary.

Thompson, D.J., Ryrie, I., & Wright, S.
People with intellectual disabilities living in generic residential services for older people in the UK
Journal of Applied Research in Intellectual Disabilities, 2004, 17, 101-108
Abstract: As part of a UK program of work focusing on older people with ID, the circumstances of those who reside in generic services for older people were investigated. Some 215 people with ID were identified living in 150 homes. They were significantly younger than other residents and were placed in these homes more because of organizational change or the aging/death of family carers, rather than due to their own needs. Of the residents, 24 adults had Down syndrome, 8 of whom were noted to have dementia. Of the 215, 45 had dementia. Average age of people with DS upon entry was 60 and those

remaining at the homes was about 65.

Torr, J., Strydom, A., Patti, P. & Jokinen N.
Aging in Down syndrome: Morbidity and mortality.
Journal of Policy and Practice in Intellectual Disabilities, 2010, *7*, 70-81.
Abstract: The life expectancy of adults with Down syndrome has increased dramatically over the last 30 years, leading to increasing numbers of adults with Down syndrome now living into middle and old age. Early-onset dementia of the Alzheimer type is highly prevalent in adults with Down syndrome in the sixth decade, and this has overshadowed other important conditions related to aging among adults with Down syndrome. The authors' aim was to update and summarize current knowledge on these conditions, and examine causes of morbidity and mortality in older people with Down syndrome by conducting a systematic review of the published literature for the period: 1993–2008. They reviewed English-language literature drawn from searches in the electronic databases Medline, CINAHL, and PsycINFO, as well as supplementary historical papers. The authors conclude that functional decline in older adults with Down syndrome cannot be assumed to be due only to dementia of the Alzheimer type (which is not inevitable in all adults with Down syndrome). Functional decline may be the result from a range of disorders, especially sensory and musculoskeletal impairments. Given the high rates of early-onset age-related disorders among adults with Down syndrome, programmatic screening, monitoring, and preventive interventions are required to limit secondary disabilities and premature mortality. With respect to assessment and treatment, in the absence of specialist disability physicians, geriatricians have a role to play.

Tsiouris, J.A., & Patti, P.J.
Drug treatment of depression associated with dementia or presented as "pseudodementia" in older adults with Down syndrome.
Journal of Applied Research in Developmental Disabilities, 1997, *10* (4), 312-322.
Abstract: The response to antidepressant drugs, mainly the selective serotonin reuptake inhibitors (SSRIs), was evaluated in adults with intellectual disability (ID) and Down syndrome (DS) who presented with depression and decline in activities of daily living (ADL) skills. Among other patients with ID referred to a specialised clinic for diagnostic work-up, 37 adults with DS over the age of 40 and a mean age of 51.4 years were evaluated and 34 were followed-up. Depression associated with dementia was diagnosed in 16 cases, and depression presented as functional decline 'pseudodementia' was found in 4 cases. Recommendations for treatment with antidepressants were followed in 10 cases with a marked improvement in functioning compared to a rapid decline in 10 cases where treatment was refused. Treatment with the SSRI antidepressant drugs resulted in improved quality of life, differentiated 'pseudodementia' from dementia, and possibly delayed the dementing process in adults with DS and presentation of depression associated with dementia.

Tsiouris, J.A., Patti, P.J., Tipu, O. & Raguthu, S..
Adverse effects of phenytoin given for late-onset seizures in adults with Down syndrome.
Neurology, 2002 *59,* 779-780.
Summary (no abstract): A brief report that indicates the adverse effects of therapeutic levels of phenytoin and the improvement observed when phenytoin was replaced with other antiepileptics in 17 adults with DS, Alzheimer disease (AD) and late-onset seizures (LOS). The reported deterioration in the patients' condition was found to be due to the adverse effects from phenytoin and not to AD. It was suggested that practitioners avoid prescribing phenytoin to treat LOS in persons with DS and AD. If phenytoin is already prescribed, it should be replaced with another anticonvulsive agent.

Tyler, C.V., & Shank, J.C.
Dementia and Down syndrome
The Journal of Family Practice, 1996, 42(6), 619-621
Abstract: Case report of a 43-year old woman with Down syndrome and progressive decline over three years that was attributed to dementia of the Alzheimer's type. Authors describe the medical conditions evident during decline, whilst living with her family. Identifies typical features associated with decline for persons with Down syndrome and defines areas for concern during examinations by physicians.

Tyrrell, J., Cosgrave, M., McCarron, M., McPherson, J., Calvert, J., Kelly, A., McLaughlin, M., Gill, M.,& Lawlor, B.A.
Dementia in people with Down's syndrome.
International Journal of Geriatric Psychiatry, 2001, Dec;16(12):1168-74.
Abstract: To determine the prevalence of dementia in an Irish sample of people with Down's syndrome (DS) and to examine associated clinical characteristics of dementia in this group. Some 285 people with DS (Age 35-74 years, mean age +/- SD 46.5 +/- 8.2 years) were included in this cross-sectional study. The diagnosis of dementia was made using modified DSMIV criteria. Cognitive tests used were the Down's Syndrome Mental Status Examination (DSMSE), Test for Severe Impairment (TSI) and adaptive function was measured by the Daily Living Skills Questionnaire (DLSQ). The overall prevalence of dementia was 13.3%. The presence of dementia was associated with epilepsy, myoclonus, and head injury. The demented DS group were significantly older (n = 38, mean age 54.7 years SD +/- 7.5) than the non-demented (n = 246, mean age 45.6, SD +/- 7.3). The TSI and DLSQ had a satisfactory spread of scores without 'floor' or 'ceiling' effects in people with moderate and severe learning disability. Median scores in demented versus the non-demented groups were significantly different for each measure of function. Authors conclude that dementia had a prevalence of 13.3% and occurred at a mean age of 54.7 years. The combination of DLSQ score, age and presence of epilepsy were found to predict presence of dementia.

Udell, L.
Supports in small group home settings
In M.P. Janicki & A.J. Dalton (Eds.), Dementia, Aging, and Intellectual Disabilities.
pp. 316-329
Philadelphia: Brunner-Mazel (1999)
Abstract: This book chapter covers what organizations that provide residential supports to adults with an intellectual disability need to consider in terms of planning and implementing program changes. Covered are areas that examine the nature of dementia and its possible impact on service provision, Its particular focus is on how agencies that decide to support people with dementia in small group home settings can accommodate their organizational and operational structure and offers insight ion the perspectives and questions that agencies need to consider. Suggestions are offered on how to address some of the difficulties that organizations will encounter.

University of Maryland School of Medicine
Hi Buddy... The developmentally delayed individual with Alzheimer disease
19 minutes
VideoPress, the University of Maryland School of Medicine [100 North Greene Street, Suite 300, Baltimore, Maryland USA (1 800 328 7450; fax: 1 410 706 8471; www.videopress.org)]
Abstract: Video on the subject of Alzheimer's disease and adults with developmental disabilities.

University of Stirling
Building networks - Conference on learning disabilities and dementia
58 pp.
Dementia Services Development Centre, Department of Applied Social Science, Faculty of Human Sciences, University of Stirling, Stirling, Scotland FH9 4LA (2000).
Abstract: Proceedings of conference on community dementia care and people with intellectual disabilities held in Dunblane, Scotland (November 11, 1999). The report summarizes the main points made by the numerous speakers at the conference. The conference highlighted the need for wider awareness among managers and service personnel of the need for (and for resources and developing expertise on) training staff in residential and home support services on responding to the needs of people with intellectual disabilities who have

dementia. The 16 papers range from the theoretical to the practical.

Urv, T.K., Zigman, W.B., & Silverman,W.
Psychiatric symptoms in adults with down syndrome and Alzheimer's disease.
American Journal on Intellectual and Developmental Disabilities, 2010, 115(4), 265-276.
Abstract: Changes in psychiatric symptoms related to specific stages of dementia were investigated in 224 adults 45 years of age or older with Down syndrome. Findings indicate that psychiatric symptoms are a prevalent feature of dementia in the population with Down syndrome and that clinical presentation is qualitatively similar to that seen in Alzheimer's disease within the general population. Psychiatric symptoms related to Alzheimer's disease vary by the type of behavior and stage of dementia, but do not seem to be influenced by sex or level of premorbid intellectual impairment. Some psychiatric symptoms may be early indicators of Alzheimer's disease and may appear prior to substantial changes in daily functioning. Improvements in understanding the progression of dementia in individuals with Down syndrome may lead to improved diagnosis and treatment.

Verbeek H, van Rossum E, Zwakhalen SM, Kempen GI, Hamers JP.
Small, homelike care environments for older people with dementia: a literature review.
International Psychogeriatrics, 2009, 21(2), 252-264.
Abstract: There is large cross-national variation in the characteristics of small, domestic-style care settings which emphasize normalized living. However, a systematic overview of existing types is lacking. This study provides an international comparison of the care concepts which have adopted a homelike philosophy in a small-scale context. Insight into their characteristics is vital for theory, planning and implementation of such dementia care settings. A literature search was performed using various electronic databases, including PubMed, Medline, CINAHL and PsycINFO. In addition, “gray” literature was identified on the internet. Concepts were analyzed according to five main characteristics: physical setting, number of residents, residents' characteristics, domestic characteristics and care concept. 75 papers were included covering 11 different concept types in various countries. Similarities among concepts reflected a focus on meaningful activities centered around the daily household. Staff have integrated tasks and are part of the household, and archetypical home-style features, such as kitchens, are incorporated in the buildings. Differences among concepts were found mainly in the physical settings, numbers of residents and residents' characteristics. Some concepts have become regular dementia care settings, while others are smaller initiatives. The care concepts are implemented in various ways with a changing staff role. However, many aspects of these small, homelike facilities remain unclear. Future research is needed, focusing on residents' characteristics, family, staff and costs.

Visootsak, J., & Sherman, S.
Neuropsychiatric and behavioral aspects of trisomy 21
Current Psychiatry Reports, 2007, 9(2), 135-140.
Abstract: Down syndrome (DS), or trisomy 21, is the most common identifiable genetic cause of mental retardation. The syndrome is unique with respect to its cognitive, behavioral, and psychiatric profiles. The well-known cheerful and friendly demeanor often creates a personality stereotype, with parents and observers commenting on the positive attributes. Despite these strengths, approximately 20% to 40% of children with DS have recognized behavioral problems. Such problems persist through adulthood, with a decrease in externalizing symptoms of aggressiveness and attention problems and the emergence of internalizing symptoms of depression and loneliness. In adulthood, the presence of early-onset dementia of the Alzheimer type and cognitive decline may pose a challenge in recognizing these internalizing symptoms. Understanding the age-related changes in cognitive functioning and behavioral profiles in individuals with DS provides insight into clinical and treatment implications.

Walaszek, A., Schroeder, M., Krainer, J., Pritchett, G., Wilcenski, M., Endicott, S. , Albrecht, T., Carlsson, C.M., & Mahoney, J.
Effectively training professional caregivers to screen and refer persons with dementia and intellectual/developmental disability
AAIC 2020 Conference, Poster presentation, July 30. 2020.
https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Paper/37966
Abstract: By age 40, almost all people with Down syndrome, the most common cause of intellectual/developmental disability (I/DD), have neuropathological changes consistent with Alzheimer’s disease; by age 60, about half have dementia. Detecting dementia in persons with I/DD can be challenging because baseline cognitive impairment can be severe and because persons with I/DD may have difficulty reporting symptoms. The National Task Group Early Detection Screen for Dementia (NTG-EDSD) was developed to aid detection of cognitive impairment in adults with I/DD. We implemented an educational curriculum to increase the ability of professional caregivers to screen for dementia in persons with I/DD using the NTG-EDSD. In November 2018 to April 2019, we held five training sessions for professional caregivers of persons with I/DD, partnering with various managed care organizations (MCO), aging and disability resource centers, adult day programs, and adult family homes. We assessed knowledge and attitudes at baseline, immediately after training, and one week, one month and six months after training. Participants (N=154) included direct care workers, case managers, healthcare providers, and other social services staff. Participants reported a marked increase in confidence in their ability to detect changes associated with mild cognitive impairment or dementia ($p<0.001$), decline in activities of daily living ($p=0.02$), and changes in behavior and affect ($p<0.001$). Satisfaction with the training was very high, and 94.0% of participants agreed or strongly agreed they could use the NTG-EDSD tool with their clients. Following the training, one MCO we partnered with, serving 62 of 72 counties in Wisconsin, made the NTG-EDSD a standard part of the assessment of adults with Down syndrome starting at age 40. Authors note that a wide variety of social services and healthcare professionals can be effectively trained to screen for dementia in persons with I/DD using a standardized screening tool, the NTG-EDSD. Satisfaction with the training was high, and use of the NTG-EDSD was thought to be feasible. This educational intervention led to change in practice at a systems level within an MCO. Next steps could include assessing impact of such training on the quality of life and healthcare outcomes of persons with I/DD.

Walker, C.A., & Walker, A.
Uncertain Futures: people with learning difficulties and their ageing family carers
54 pp.
Brighton, UK: Pavilion Publishing (1998)
Abstract: This monograph provides an overview of research, policy and practice relating to service responses to adults with learning difficulties living at home with older family carers in the UK. The authors’ premise is that as life expectancy increases, a growing proportion of people with learning difficulties continues to live with family members, most frequently parents, whose caring role is being extended into their own advanced old age. Highlighted are some of the issues raised by service users, carers and service providers, including care for someone with diminishing abilities. The text argues that there is urgent need for the paid service sector to work with families to provide the necessary support and planning to take the uncertainty out of the future.

Wallace, E., Harp, J., Van Pelt,K.I., Koehl, L., Caban-Holt, .A.M,., Anderson-Mooney, A.J., Robertson, W., Lightner, D., Jicha, G.A., Head, E., & A Schmitt, F.A.
Validity of the Severe Impairment Battery, Brief Praxis Test, and Dementia Questionnaire for Persons with Intellectual Disabilities in differentiating dementia status in individuals with Down syndrome
AAIC2020, Poster presentation, July 29, 2020.
https://alz.confex.com/alz/20amsterdam/meetingapp.cgi/Paper/44227
Abstract: Idividuals with Down syndrome (DS) are at high risk for dementia, specifically Alzheimer’s disease (AD). However, many measures regularly used for the detection of AD in the general population are not suitable for individuals with DS. Some measures, including the Severe Impairment Battery (SIB), Brief Praxis Test (BPT), and Dementia Questionnaire for Persons with Intellectual Disabilities (DMR), have been used in clinical trials and other research with this

population. Validity research is limited, however, particularly regarding identification of predementia symptoms in the DS population. The current project presents baseline cross-sectional SIB, BPT, and DMR performance in order to characterize their ability to discriminate normal cognition, possible AD, and probable AD in DS. Baseline SIB, BPT, and DMR performances from 117 individuals were analyzed as part of a large longitudinal cohort of aging individuals with DS. Receiver operating characteristic (ROC) curves were calculated to investigate accuracy in differentiating levels of dementia status. In comparing no/possible AD vs. probable AD, the SIB and BPT exhibited fair discrimination ability (AUC = .78 and .79, respectively). In comparing no/possible AD vs. probable AD, the DMR exhibited good discrimination ability (AUC = .89), with qualitatively similar performance of the DMR-Cognitive and DMR-Social subscales (AUC = .89 and .83, respectively). In comparing no AD vs. possible AD, the SIB and BPT failed to differentiate these groups (AUC = .53 and .55, respectively), whereas the DMR exhibited good differentiation (AUC = .80). Au thors note that the results suggest that the SIB, BPT, and DMR are able to discriminate between levels of dementia status in individuals with DS, supporting their continued use in the clinical assessment of dementia in DS. Specifically, the DMR, based on informant ratings of social and cognitive behaviors of daily living, outperformed the SIB and BPT, tests of cognitive performance, in discriminating no/possible AD vs. probable AD as well as no AD vs. possible AD. Such findings suggest that the DMR is better equipped to identify symptoms of overt dementia as well as predementia in this population. Findings reinforce the importance of including informant behavior ratings in assessment of this population.

Wark, S., Hussain, R., & Parmenter, T.
Down syndrome and dementia: Is depression a confounder for accurate diagnosis and treatment?
Journal of Intellectual Disabilities, 2014, 18(4), 305-314
Abstract: The past century has seen a dramatic improvement in the life expectancy of people with Down syndrome. However, research has shown that individuals with Down syndrome now have an increased likelihood of early onset dementia. They are more likely than their mainstream peers to experience other significant co-morbidities including mental health issues such as depression. This case study reports a phenomenon in which three individuals with Down syndrome and dementia are described as experiencing a rebound in their functioning after a clear and sustained period of decline. It is hypothesized that this phenomenon is not actually a reversal of the expected dementia trajectory but is an undiagnosed depression exaggerating the true level of functional decline associated with the dementia. The proactive identification and treatment of depressive symptoms may therefore increase the quality of life of some people with Down syndrome and dementia.

Watchman, K., Kerr, D., & Wilkinson, H.
Supporting Derek: A new resource for staff working with people who have a learning difficulty and dementia.
58 pp.
York, United Kingdom: Joseph Rountree Foundation (2010)
Access: http://www.jrf.org.uk/publications/supporting-derek
Abstract: This resource pack published by the Joseph Rowntree Foundation in partnership with the University of Edinburgh, is aimed at staff supporting people with intellectual disability who develop dementia. Its focus in on helping care staff and training officers from intellectual disability and dementia care settings, as well as community, housing and health care staff. The pack is composed of 10 topic area (chapters), including basics on dementia, understanding behavior, development care environments, pain, communication, meaningful activities, friends with dementia, nutrition and hydration, night-time care, and palliative care. The pack includes a DVD and training materials which cover many of the key issues related to diagnosing and responding to dementia in people with intellectual disabilities. A short drama included on the DVD (acted by people with an intellectual disability) provides an insight into the reality of dementia and how it might feel to the individual affected.

Watchman, K.
Critical issues for service planners and providers of care for people with Down's syndrome and dementia.
British Journal of Learning Disabilities, 2003, 31(2), 81-84.
Abstract: This discussion paper raises critical issues that need to be addressed along with suggestions as to how they may be met with. Author notes that the role of service planners and providers of care is one that cannot be understated while considering the future needs of people with Down's syndrome and dementia. Discussed are appropriateness of accommodations, care management, diagnosis, and training.

Watchman, K.
Why wait for dementia?
Journal of Learning Disabilities, 2003, 7, 221-230
Abstract: Adults with Down syndrome living in supported accommodation, who develop dementia, may also experience other preventable difficulties caused by the environment in which they live. This can result in their enforced move to a different accommodation. Yet it is known that it is beneficial for people with intellectual disabilities and dementia to remain in familiar surroundings for as long as possible. This article puts forward a new set of guidelines suggesting the modification of the living environment of adults with Down syndrome before they develop dementia. The guidelines are discussed along with possible barriers to their implementation.

Watchman, K.
Intellectual Disability and Dementia: Research into Practice.
336 pp.
London/Philadelphia: Jessica Kingsley Publishers (2014).
Abstract: In 16 chapters, this edited text offers a balanced appraisal of the evidence base on people with intellectual disabilities who develop dementia. It includes a range of resources, and is split into three sections that address the following: (1) The association between intellectual disabilities and dementia: what do we know? (2) Experiences of dementia in people with intellectual disabilities: how do we know?, and (3) Service planning: what are we going to do? Section one explores issues such as defining and diagnosing dementia in people with intellectual disabilities, prevalence and incidence and treatment options. The authors explain the differing theories about why people with Down's syndrome are more likely to experience dementia, which provides a useful foundation for discussions about the use of medication. Section two explores the perspectives of people with learning disabilities and their families and the experiences of families via case studies. This section also explores some checklists for use with family members to help plan for the future. Section three focuses on service planning by describing a framework that can be used by practitioners for discussing diagnosis and prognosis of dementia. This section also considers the issues related to ageing in place and dementia-specific services and suggests that training is important for staff supporting those with learning disabilities and dementia.

Watchman, K., Janicki, M.P., and the members of the International Summit on Intellectual Disability and Dementia
The intersection of intellectual disability and dementia: Report of the international summit on intellectual disability and dementia
The Gerontologist, (2019),;59(3), 411-419. doi: 10.1093/geront/gnx160.
Abstract: An International Summit on Intellectual Disability and Dementia, held in Glasgow, Scotland (October 13-14, 2016) drew individuals and representatives of numerous international and national organizations and universities with a stake in issues affecting adults with intellectual disability (ID) affected by dementia. A discussion-based consensus process was used to examine and produce a series of topical reports examining three main conceptual areas: (1) human rights and personal resources (applications of the Convention for Rights of People with Disabilities and human rights to societal inclusion, and perspectives of persons with ID), (2) individualized services and clinical supports (advancing and advanced dementia, post-diagnostic supports, community supports and services, dementia-capable care practice, and end-of-life care practices), and (3) advocacy, public impact, family caregiver issues (nomenclature/ terminology, inclusion of persons with ID in national

plans, and family caregiver issues). Outcomes included recommendations incorporated into a series of publications and topical summary bulletins designed to be international resources, practice guidelines, and the impetus for planning and advocacy with, and on behalf of, people with ID affected by dementia, as well as their families. The general themes of the conceptual areas are discussed and the main recommendations are associated with three primary concerns.

Watchman, K., Janicki, M.P., Splaine, M., Larsen, F.K., Gomiero, T., & Lucchino, R.
International summit consensus statement: intellectual disability inclusion in national dementia plans.
American Journal of Alzheimer's Disease & Other Dementias, 2017, 1-8, https://doi.org/10.1177/1533317517704082
Abstract: The World Health Organization (WHO) has called for the development and adoption of national plans or strategies to guide public policy and set goals for services, supports, and research related to dementia. It called for distinct populations to be included within national plans, including adults with intellectual disability (ID). Inclusion of this group is important as having Down's syndrome is a significant risk factor for early-onset dementia. Adults with other ID may have specific needs for dementia-related care that, if unmet, can lead to diminished quality of old age. An International Summit on Intellectual Disability and Dementia, held in Scotland, reviewed the inclusion of ID in national plans and recommended that inclusion goes beyond just description and relevance of ID. Reviews of national plans and reports on dementia show minimal consideration of ID and the challenges that carers face. The Summit recommended that persons with ID, as well as family carers, should be included in consultation processes, and greater advocacy is required from national organizations on behalf of families, with need for an infrastructure in health and social care that supports quality care for dementia.

Watchman, K., Janicki MP, Udell L, Hogan M, Quinn S, Beránková A.
Consensus statement of the International Summit on Intellectual Disability and Dementia on valuing the perspectives of persons with intellectual disability. Journal of Intellectual Disabilities, 2018, Jan 1:1744629517751817. doi: 10.1177/1744629517751817.
Abstract: The International Summit on Intellectual Disability and Dementia covered a range of issues related to dementia and intellectual disability, including the dearth of personal reflections of persons with intellectual disability affected by dementia. This article reflects on this deficiency and explores some of the personal perspectives gleaned from the literature, from the Summit attendees and from the experiences of persons with intellectual disability recorded or scribed in advance of the two-day Summit meeting. Systemic recommendations included reinforcing the value of the involvement of persons with intellectual disability in (a) research alongside removing barriers to inclusion posed by institutional/ethics review boards, (b) planning groups that establish supports for dementia and (c) peer support. Practice recommendations included (a) valuing personal perspectives in decision-making, (b) enabling peer-to-peer support models.

Watchman, K., Mattheys, K., & McKernon, M.
Effects of the implementation of non-drug Interventions on behaviour and psychosical smptoms of dementia in people who have an Intellectual disability
Journal of Intellectual Disability Research, 2019, 63(8), 647.
Abstract: This three-year study investigates if non-drug interventions result in positive changes in behaviour associated with dementia in people with intellectual disability. People with intellectual disability are involved as advisors (n = 1) and co-researchers (n = 4) in both cycles. Cycle 1 (concluded) included 7 participants with intellectual disability in the early stage of dementia (4 with Down syndrome) and 12 support staff. Cycle 2 (ongoing) includes participants who have a more profound intellectual disability, and/or are experiencing advanced dementia. In both cycles, a goal-setting tool firstly helped to identify individualised non-drug interventions. In Cycle 1, a pre- and post-behaviour change tool (NPI-Q), was completed alongside semi-structured interviews, a bespoke tool to measure 'in the moment' changes, intervention diaries, and photovoice. Cycle 1 interventions included reminiscence, life story, music playlists, cookery, aromatherapy, environmental design change, exercise and cognitive games. Of 239 separate intervention over a 6-month period in Cycle 1, 193 resulted in positive behaviour change with 75% of goals being achieved or exceeded. The study offers insight into the support of people with intellectual disability and dementia. Use of non-drug supports in response to distress has led to cultural change within participating organizations with less reliance on medication as a first response.

Warner, M.L.
The complete guide to Alzheimer's-proofing your home.
470 pp.
West Lafayette, Indiana: Purdue University Press (1998)
Abstract: General text on adapting homes and living environments for persons with dementia; applicable to home and other residential situations for adults with intellectual disabilities and dementia.

Webber, R., Bowers, B. McKenzie-Green, B.
Staff responses to age-related health changes in people with an intellectual disability in group homes.
Disability and Society, 2010, 25(6), 657-671.
Abstract: The purpose of this study was to explore how supervisors in group homes caring for people with intellectual disability responded to the development of age-related health changes in their residents. Ten group home supervisors working in the disability sector were interviewed once. Data were analyzed using Dimensional Analysis. The study identified several factors related to whether a resident could stay 'at home' or would need to be moved to residential aged care (nursing home) including: nature and extent of group home resources, group home staff comfort with residents' health changes, staff skill at navigating the intersection between the disability and ageing sectors, and the supervisor's philosophy of care. The ability of older people with an intellectual disability to 'age in place' is affected by staff knowledge about and comfort with age-related illnesses, staff skills at navigating formal services, staffing flexibility, and the philosophy of group home supervisors. Despite the growing international concern for the rights of people with disability, particularly in relation to decision making, questions about the older person's choice of residence and participation in decision making about what was best for them, were almost nonexistent. Rather, decisions were made based on what was considered to be in 'the best interest

Whitehouse, R., Chamberlain, P., & Tunna, K.
Dementia in people with learning disability: a preliminary study into care staff knowledge and attributions
British Journal of Learning Disabilities, 2000, 28(4) 148- 153
Abstract: This paper describes the findings of a pilot study funded by the NHS Executive Primary and Community Care Research Initiative Small Projects Scheme that investigated the knowledge and attributions of dementia held by care staff who work with older adults with learning disability. Meetings took place with 21 members of care staff identified as "keyworkers" to older adults with learning disability living in residential houses provided by Solihull Healthcare NHS Trust, Solihull, UK. The results suggest that staff have knowledge of ageing at a similar level to that of college students. Forgetfulness was the sign that they would most expect to see if they thought someone was suffering from dementia. When a change in behavior was attributed to dementia, it was most likely to be viewed as 'stable, uncontrollable' with staff feeling pessimistic about being able to change the behavior.

Whittick, J.E.
Dementia and mental handicap: attitudes, emotional distress and caregiving
British Journal of Medical Psychology, 1989, 62, 181-189
Abstract: Against the current climate of hospital closure programs and community care, attitudes to caregiving were examined in three groups of carers, namely mothers caring for a mentally handicapped child, mothers caring for a mentally handicapped adult and daughters caring for a parent with dementia. An 'attitude questionnaire' was developed by the author and

administered, postally, to the three groups. Daughters were found to be more likely than the mothers to see their caring role in a negative way and were more inclined to favor institutional care. Possible reasons for this are discussed. The relationship between attitudes and emotional distress (as measured by the GHQ-30) were also examined for the sample as a whole. Negative and pro-institutional attitudes towards the caregiving situation were associated with elevated levels of emotional distress. Implications at both a local and a national level for all those involved with carers are discussed in the light of these findings.

Wilkinson, H., Janicki, M.P., & Edinburgh Working Group on Dementia Care Practices (EWGDCP).
The Edinburgh Principles with accompanying guidelines and recommendations.
Journal of Intellectual Disability Research, 2002, 46, 279-284.
Abstract: A panel of experts attending a 3-day meeting held in Edinburgh, UK, in February 2001 was charged with producing a set of principles outlining the rights and needs of people with intellectual disability (ID)and dementia, and defining service practices which would enhance the supports available to them. The Edinburgh Principles, seven statements identifying a foundation for the design and support of services to people with ID affected by dementia, and their carers, were the outcome of this meeting. The accompanying guidelines and recommendations document provides an elaboration of the key points associated with the Principles and is structured toward a four-point approach: (1) adopting a workable philosophy of care; (2) adapting practices at the point of service delivery; (3) working out the coordination of diverse systems; and (4) promoting relevant research. It is expected that the Principles will be adopted by service organizations world-wide, and that the accompanying document will provide a useful and detailed baseline from which further discussions, research efforts and practice development can progress.

Wilkinson, H., Kerr, D., & Rae, C.
People with a learning disability: their concerns about dementia
Journal of Dementia Care, 2003, 11(1), 27-29.
Abstract: With people with a learning disability live longer, more of them are developing dementia. In planning the services they need, an important first step is to ask them what they think. Author report information from surveying a group of older adults with intellectual disabilities.

Wilkinson, H., Kerr, D., & Cunningham, C.
Equipping staff to support people with an intellectual disability and dementia in care home settings.
Dementia -,The International Journal of Social Research and Practice, 2005, 4(3), 387-400.
Abstract: The knowledge, experiences and skills of direct care staff working in care home settings are essential in ensuring a good quality of life and care for a person with an intellectual disability (ID) who develops dementia. Drawing on the findings of a wider study, the issues of training, support and the wider needs of staff when trying to support a resident who develops dementia are explored, specifically as relating to the role played by staff and the need to determine their experiences and related training needs. Following an introduction to the policy and practice context for working with people with an ID and dementia, and a brief description of the research method, the authors discuss the attitudes and practices of staff; supportive changes at an organizational level; and the knowledge and training needs of staff and specific gaps in knowledge. The authors argue that, within the policy and practice context of aiming to support residents to 'age in place', support for staff is a crucial aspect of ensuring that such an approach is effective and provides a coordinated approach to planning, resourcing and support.

Whitwham, S., McBrien, J., & Broom, W.
Should we refer for a dementia
assessment? A checklist to help know when to be concerned about dementia in adults with Down syndrome and other intellectual disabilities.
British Journal of Learning Disabilities, 2011, 39(1), 17-21.
Abstract: The aim of this research was to develop a simple screening checklist to help carers and professionals know when to make a referral for a dementia assessment. A checklist was completed for all new referrals to a dementia service for people with intellectual disabilities. The obtained scores were compared to the diagnostic outcome of a comprehensive dementia assessment. The data (n = 159) indicate a higher score on the checklist correlates significantly with a subsequent diagnosis of dementia. Cut-off scores are explored. The checklist appears to be a useful tool to prompt referrals for a full dementia assessment. By helping the referrer to know when to be concerned about dementia, it may reduce the number of people referred late or not at all.

Wisniewski, K., Howe, J., Williams, D. G., & Wisniewski, H. M.
Precocious aging and dementia in patients with Down's
syndrome.
Biological Psychiatry, 1978,13, 619–627.
Abstract: Studied 50 unselected institutionalized patients with Down's syndrome to determine the clinical course of precocious aging and mental and neurological deterioration. Significant differences were established in neurological and psychiatric abnormalities and mental deterioration in patients below and above age 35, indicating progressive changes in the CNS. Demonstrated were higher incidence of recent memory loss, impairment of short-term visual retention, frontal release signs, hypertonia, hyperreflexia, long-tract signs, and psychiatric problems. Also noted was the presence of external features of precocious aging. Down's syndrome appears to be a human chromosomal abnormality in which genetically determined biochemical defects leading to precocious aging and dementia can be studied.

Woods, R.T., Moniz-Cook, E., Lliffe, S., Campion, P., Vernooij-Dassen, M., Zanetti, O., & Franco, M.
Dementia: Issues in early recognition and intervention in primary care.
Journal of the Royal Society of Medicine, 2003, 96, 320-324.
Abstract: Generic article about the need for quality and accurate screening and assessment of adults suspected of showing signs of Alzheimer's disease and the need for psychosocial interventions and family carer supports. Authors note need for better training of medical practitioners who may be screening for dementia, indicating that there is a need for timely detection and diagnosis that will prevent crises, facilitate adjustment and provide access to treatments and supports.

Zeilinger, E.L., Gärtner, C, Janicki, M.P., Esralew, L., Weber, G.
Practical applications of the NTG-EDSD for screening adults with intellectual disability for dementia: A German-language version feasibility study.
Journal of Intellectual and Developmental Disability, 2016, 41(1), 42-49.
Abstract: Authors evaluated the feasibility of using the German-language version of a recently developed screening tool for dementia for persons with intellectual disability (ID): the National Task Group – Early Detection Screen for Dementia (NTG-EDSD). Some 221 paid carers of ageing persons with ID were asked to use the NTG-EDSD and report back on its utility and on 4 feasibility dimensions, and to provide detailed feedback on aspects deemed critical or missing. All feasibility dimensions were rated good to very good, and 80% of respondents found the NTG-EDSD useful or very useful for the early detection of dementia. This highlights a high acceptability of this instrument by the main target group. The positive feasibility evaluation of the NTG-EDSD indicates the usability and adequacy of this instrument for application of early detection of dementia in persons with ID.

Zigman, W.B,, & Lott. I.T.
Alzheimer's disease in Down syndrome: Neurobiology and risk.
Mental Retardation and Developmental Disabilities Research Reviews, 2007, 13, 237–246.
Abstract: Down syndrome (DS) is characterized by increased mortality rates, both during early and later stages of life, and age-specific mortality risk remains higher in adults with DS compared with the overall population of people with mental retardation and with typically developing populations. Causes of increased mortality rates early in life are primarily due to the increased incidence of congenital heart disease and leukemia, while causes of higher mortality rates later in life may be due to a number of factors, two of which are an increased risk for Alzheimer's disease (AD) and an apparent tendency toward premature

aging. In this article, we describe the increase in lifespan for people with DS that has occurred over the past 100 years, as well as advances in the understanding of the occurrence of AD in adults with DS. Aspects of the neurobiology of AD, including the role of amyloid, oxidative stress, Cu/ZN dismutase (SOD-1), as well as advances in neuroimaging are presented. The function of risk factors in the observed heterogeneity in the expression of AD dementia in adults with DS, as well as the need for sensitive and specific biomarkers of the clinical and pathological progressing of AD in adults with DS is considered.

Zigman, W.B., .Devenny, D.A., Krinsky-McHale, S.J., Jenkins, E.C., Urv, T.K., Wegiel, J., Schupf, N., & Silverman, W.
Alzheimer's disease in adults with Down syndrome.
International Review of Research in Mental Retardation, 2008, 36, 103-145.
Abstract: Down syndrome is associated with increased mortality rates due to congenital cardiac defects and leukemia early in life, and with Alzheimer's disease and a tendency toward premature aging later in life. Alzheimer's disease was once considered an inexorable result of growing old with Down syndrome, but recent data indicate that risk does not reach 100%. Although some individuals exhibit signs and symptoms of Alzheimer's disease in their 40s, other individuals have reached the age of 70 without developing dementia. This chapter presents a wealth of data from a longstanding longitudinal study with the overall objective of understanding and recounting the mechanisms responsible for these substantial individual differences.

Zigman, W.B., Schupf, N., Devenny, D., Miezejeski, C., Ryan, R., Urv, T.K., Schubert, R., & Silverman, W.
Incidence and prevalence of dementia in elderly adults with mental retardation without Down syndrome.
American Journal on Mental Retardation, 2004, 109, 126–141
Abstract: Rates of dementia in adults with mental retardation without Down syndrome were equivalent to or lower than would be expected compared to general population rates, whereas prevalence rates of other chronic health concerns varied as a function of condition. Given that individual differences in vulnerability to Alzheimer's disease have been hypothesized to be due to variation in cognitive reserve, adults with mental retardation, who have long-standing intellectual and cognitive impairments, should be at increased risk. This suggests that factors determining intelligence may have little or no direct relationship to risk for dementia and that dementia risk for individuals with mental retardation will be comparable to that of adults without mental retardation unless predisposing risk factors for dementia are also present.

- Denotes videocassette
- Denotes book or chapter in book
- Denotes CD-ROM
- Denotes report
- Denotes booklet or agency issued manual
- Denotes website

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