Working Resources List on Dementia Care Management and Intellectual Disabilities

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

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PCAD Project
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Adams, D., Oliver, C., Kalsy, S., Peters, S., Broquard, M., Basra, T., Konstandinidi, E., & McQuillan, S.
Behavioral characteristics associated with dementia assessment referrals in adults with Down syndrome.
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.
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)
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.
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)
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)
Abstract: Web-based booklet produced in the UK on the topic of intellectual disabilities and dementia. Contains background information, as well as diagnosis, identification 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.
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.

Contact: mjanicki@uic.edu
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), 681-683
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.

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.

Bittles, A.H., & Glasson, E.J.
Clinical, social, and ethical implications of changing life expectancy in Down syndrome 
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 of 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. 
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 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. Results 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: inability of residents to retire despite age and health status; 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."

Brawley, E.C.

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.

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.

Carmeli, E., Ariav, C., Bar-Yossef, T., & Levy, R.

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 Winserv Inc. (a non-profit housing organization that houses people with mental disabilities) with important information. Using the study results, Winserv 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 Winserv 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.

Cohen, U., & Wiesman, G.D.
Holding on to home: Designing environments for people with dementia. 181 pp.
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.

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.

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 9.9%, 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%.

Cosgrave, M.P., Tyrrell, J., McCarron, M., Gill, M., & Lawlor, B.A.
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.

Courtenay, K., Jokinen, N.S., & Strydom, A.
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.
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.

Davis, D.R.
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, residence and day care, special care units, group size), research on environmental attributes (non-institutional 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.


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 of findings emerged: diagnostic services were patchy; people with dementia were living in a range of residential settings; carers were not happy with the 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.


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 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 raters 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.


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 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 (κ = 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.


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 analysed using qualitative software. There appeared to be many similarities in the clinical presentation of dementia among adults in DS and the non-intellectually disabled general population. Like in the non-intellectually disabled older 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 behaviour 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.


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 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.
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.

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.

Engdahl, J.M.K.
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@ucc.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.

Esbensen, A.J.
Health conditions associated with aging and end of life of adults with Down syndrome.
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.

Foundation for People with Learning Disabilities
Down’s syndrome and dementia - Briefing for Commissioners
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.
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.

Gittin, 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
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.

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.
Abstract: Fact sheet outlines the evidence which suggests that ageing and the brain, aging and dementia, 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, providing some evidence to suggest that older people with an intellectual disability may be best served in intellectual disability homes rather than older people's homes. It was not found that participation in meaningful activity and community access when they lived in intellectual disability homes (n = 20) 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 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
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 the 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
Abstract: Book chapter that examines the implications of Alzheimer’s disease for adults with Down syndrome, including assessment and diagnosis and specialist 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 caregivers. 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 propose some general suggestions for services and adaptations.

Huxley, A., Van-Schaik, P., & Witts, P.
A comparison of challenging behaviour in an adult group with Down’s syndrome and dementia compared with an adult Down’s syndrome group without dementia.
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 Abrant Behaviour Checklist-Community version (M.G. Aman & N.N. Singh, Sloman, 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 behaviour than the nondementia group. The difference in reported levels of challenging behaviour 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.

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
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.
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 provided 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., 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(1/2), 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 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.

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 281/1000), 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., Zendell, A., & DeHaven, K.
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 care for them. They did not consider placement, but 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.

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

Johnson, N, Fahey C, Chicoine B, Chong G, Gitelman D.
Abstract: This study 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.

Kalsy, S., McQuillan, S., Oliver, C., Hall, S.
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.
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.

Abstract: Authors present the 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 (e.g., 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.

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.

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.

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.

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.

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.

Abstract: Despite the increased prevalence of dementia in individuals with Down syndrome, relatively little is known about its impact upon care provision. Caretakers 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 = 11) were compared with caregivers 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.

Lynngard, H., & Alexander, N.

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 Down syndrome. 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.
disabilities who develop dementia and their peers.

Margallo-Lana M.L., Moore, P.B., Kay, D.W., Perry, R.H., Reid, B.E., Berney, T.P., Tyrer, S.P.
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 necortical 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.
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.

May, H.L., Fletcher, C., Alvarez, N., Zuis, J., & Cavallari, S.G.

McBrien, J., Whitwham, S., Ollerman, K., & Masters, S.
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.
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) environment modification, (3) good communication, (4) memory aids, and (5) taking care of the carer.

McCallion, P., Janicki, M.P.

McCarron, M.
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.
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., & 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.
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
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, (c) 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.
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 rigorous and collaborative practice relationship based palliative care 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.
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.

McKenzie, K., Harte, C., Patrick, S., Matheson, E., & Murray, G.C.
The assessment of behavioural decline in adults with Down’s syndrome
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.


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.

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


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.

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), 4-11

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’s 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 who 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.

Nagdee, M. Dementia in intellectual disability: a review of diagnostic challenges.


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.

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., Ossan, K., & Lott, I.T. Neurological changes and emotional functioning in adults with Down Syndrome


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


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


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.


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.

Noeker, 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
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.

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.
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.

Persaud, M., & Jaycock, S.
Evaluating care delivery: the application of dementia care mapping in learning disability residential services.
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 transposed 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.

Prasher, V.P.
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.P., & Filer, A.
Behavioural disturbance in people with Down's syndrome and dementia.
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...
Considerations in care for individuals with intellectual disability with advanced dementia. K.P. Service, T., & Haque, S.


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.

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.

Shultz JM, Aman MG, Rojahn J.

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 moderately high 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.

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-mail: info@sdsa.org.uk; www.sdsa.org.uk] [n.d.] [Source: http://www.rrcadd.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.

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 are 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., Lavoie, D., Herlihy, J.E.
Coping with losses, death and grieving
pp. 330-351
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.

Simard, M., & van Reekum, R.

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 recognised dementia with Lewy bodies (DBL). Patients with DBL frequently present with changes in affect and behaviour, 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.

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.

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., & 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 (DDSS) 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
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 ICD-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
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.
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.
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-stage 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.

Dementia in older adults with intellectual disabilities—epidemiology, presentation, and diagnosis
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 to 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.

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) in individuals with Down syndrome (DS) are compared with individuals with Alzheimer’s disease (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.
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.
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
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.

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.
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.
Future research is needed, focusing on residents' characteristics, family, staff home-style features, such as kitchens, are incorporated in the buildings. Staff have integrated tasks and are part of the household, and archetypical reflected a focus on meaningful activities centered around the daily household. A domestic characteristics and care concept. 75 papers were included covering characteristics: physical setting, number of residents, residents' characteristics, identified on the internet. Concepts were analyzed according to five main PubMed, Medline, CINAHL and PsycINFO. In addition, "gray" literature was theory, planning and implementation of such dementia care settings. A international comparison of the care concepts which have adopted a homelike domestic-style care settings which emphasize normalized living. However, a systematic overview of existing types is lacking. This study provides an dementia. The 16 papers range from the theoretical to the practical. 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 setting, 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.

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.

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 Rowntree 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 is in 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.

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.

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.


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 living 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.

Woods, R.T., Moniz-Cook, E., Liliffe, S., Campion, P., Vernooij-Dassen, M., Zanetti, O., & Franco, M.
*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.

Related Articles of Interest


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.


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.


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.

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Sign on the “Dementia and Intellectual Disabilities” listserv at www.yahoogroups.com - look for "dementia-IDlistserv"

Look for updated information at http://www.rrtadd.org/TA/Dementia_Care/Resources/Info.html