



Working Resources List on Dementia Care Management and Intellectual Disability

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

v.10d5

PCAD Project
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Alzheimer's Association

Guidelines for Dignity: Goals of Specialized Alzheimer/Dementia Care in Residential Settings

Chicago: The Alzheimer's Association [919 North Michigan Avenue, Suite 1000, Chicago, IL 60611-1676] (1992)

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 Disease International

Planning and Design Guide for Community Based Day Care Centres

London: Alzheimer's Disease International [45/46 Lower Marsh, London SE1 7RG, United Kingdom (www.alz.co.uk)] (1999)

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)

London: Alzheimer's Disease Society [Gordon House, 10 Greencoat Place, London SW1P 1PH, United Kingdom] (1994)

30 pp.

Abstract: A 30 page booklet designed for the carer who is concerned about an older person with early to mid-stage dementia who may be living on their own. The booklet examines risks that the older adult may encounter and suggests how they could be minimized. The intent of the booklet is to aid the older person remain functional at home, with as minimal risk, for as long as possible. Covers personal care, finances, wandering, security, medication, utilities, and household safety. Whilst information is generic, resource information is geared toward the UK.

Antonangeli, J.M.

Of Two Minds: A Guide to the Care of People with the Dual Diagnosis of Alzheimer's Disease and Mental Retardation.

167 pp.

Malden, Mass.: Cooperative for Human Services [110 Pleasant Street, Malden, MA 02148] (1995)

Abstract: Written in training manual format, this text covers a range of topics related to dementia among persons with intellectual disabilities, including the notions behind dementia, structuring physical environments, safety and control issues, communication strategies, assessing and aiding with activities of daily living, behavior management strategies, medical concerns, and aiding carers. Much of the text is drawn from general practice in the Alzheimer's field with reference to application for settings with persons with intellectual disabilities.

Antonangeli, J.M.

The Alzheimer project: formulating a model of care for persons with Alzheimer's disease and mental retardation

The American Journal of Alzheimer's Disease, 1995, 10(4), 13-16.

Abstract: Article speaks to a pilot project conducted in Massachusetts to increase staffing, education and Alzheimer case management supports. Special supports were designed and offered to a number of adults with Down syndrome affected by dementia, including specialize assessments, team care planning meetings, home adaptations and behavior loss supports.

Aylward, E., Burt, D., Thorpe, L., Lai, & Dalton, A.J.

Diagnosis of dementia in individuals with intellectual disability: report of the task force for development of criteria for diagnosis of dementia in individuals with

mental retardation

Journal of Intellectual Disability Research, 1997, 41, 152-164

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

Ball, S.L., Holland, A.J., Hon, J., Huppert, F.A., Treppner, P., & Watson, P.C.

Personality and behaviour changes mark the early stages of Alzheimer's disease in adults with Down's syndrome: findings from a prospective population-based study.

International Journal of Geriatric Psychiatry, 2006, [Jun 26]

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

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both measures, with a significantly greater degree of decline in memory. Older participants without informant reported changes showed a more generalized pattern of decline. These findings confirm that the early presentation of AD in DS is characterized by prominent personality and behavior changes, associated with executive dysfunction, providing support for the notion that the functions of the frontal lobes may be compromised early in the course of the disease in this population. This has important implications for the diagnosis, treatment and management of dementia in people with DS.

Ball, S.L., Holland, A.J., Treppner, P., Watson, P.C., & Huppert, F.A.

Executive dysfunction and its association with personality and behaviour changes in the development of Alzheimer's disease in adults with Down syndrome and mild to moderate learning disabilities.

British Journal of Clinical Psychology, 2008, 47(Pt 1), 1-29.

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

Bauer, A.M., & Shea, T.M.

Alzheimer's disease and Down syndrome: A review and implications for adult services

Education and Training of the Mentally Retarded, 1986, 21, 144-150

Abstract: In this article, the diagnosis of Alzheimer's disease and its progressive behavioral impact on persons with Down syndrome is discussed. Several implications and suggestions for care and service provision for adults with Down syndrome are presented, including that Alzheimer's disease in an adult with Down syndrome has an impact on the carer, adjusting communication strategies to correspond to the stage of dementia, aiding families to seek assistance from social agencies, stressing the remaining abilities and skills, aiding families and carers to develop realistic methods of providing care, and adapting the persons care and environment to help them cope with losses stemming from dementia. The authors also suggest proactive strategies for anticipating decline among adults with Down syndrome associated with dementia.

Bittles, A.H., & Glasson, E.J.

Clinical, social, and ethical implications of changing life expectancy in Down syndrome

Developmental Medicine & Child Neurology, 2004, 46, 282-286.

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

 **Brawley, E.C.**

Designing for Alzheimer's Disease - Strategies for Creating Better Care

Environments.

313 pp.

New York: Wiley (1997)

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

Burt, D.B., & Aylward, E.

Assessment Methods of Diagnosis of Dementia

In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, Aging, and Intellectual Disabilities*. pp. 141-156

Philadelphia: Brunner-Mazel (1999)

Abstract: Standardized diagnostic criteria and procedures are proposed to further progress in the understanding and treatment of dementia in adults with intellectual disabilities. This book chapter is a revised summary of previous reports prepared by participants of an international working group, which was conducted under the auspices of the International Association on Intellectual Disability and the American Association on Mental Retardation. Similarities in diagnostic issues between adults with intellectual disability and those in the general population are discussed, followed by a summary of issues unique to adults with intellectual disability. A brief overview of the application of ICD-10 diagnostic criteria to adults with intellectual disability is presented, including a description of procedures for determining whether criteria are met in individual cases. Finally, clinical and research recommendations are made.

 **Cairns, D., Kerr, D., Chapman, A.**

Difference Realities: a Training Guide for People with Down's Syndrome and Alzheimer's Disease

pp. 54

University of Stirling (Dementia Services Development Centre), Stirling, Scotland FK9 4LA

A working guide for staff who are working with people with intellectual disabilities affected by Alzheimer's disease. Topical sections cover the definitions of dementia and deal with diagnostic suggestions, as well as dealing with communication, helping maintenance of skills, dealing with challenging behaviors, structuring activities, and overall management of dementia. Written in an easy style, this guide is a very useful addition to any materials given to staff to help them understand and related to people affected by dementia.

Chaput, J.L.

Housing people with Alzheimer disease as a result of Down syndrome: a quality of life comparison between group homes and special care units in long term care facilities.

Master's thesis, Department of City Planning, University of Manitoba (1998)

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

Chaput, J.L. & Udell, L.

Housing people with Alzheimer disease as a result of Down syndrome: a quality of life comparison between group homes and special care units in long term care facilities.

Journal of Intellectual Disability Research, 2000, 44, 236 (abstract No. 186) [Paper presented at the 11th World Congress of the International Association for the Scientific Study of Intellectual Disabilities, Seattle, Washington (USA), August 1-6, 2000]

Abstract: The purpose of the study was to determine which form of housing, i.e., group homes or special care units (SCUs), provided a better quality of life for individuals with Alzheimer disease (AD) as a result of Down syndrome (DS). The study also provided Winnserv Inc. (a non-profit housing organization that houses

people with mental disabilities) with important information. Using the study results, Winnserv Inc. was able to determine that their group homes were suitable to maintain individuals with DS and AD and that their group homes were more cost-effective than SCUs in terms of caregiving. Twenty caregivers from both group homes and SCUs were selected to participate in this study. Ten long term care (LTC) facilities with SCUs for people with AD were selected in the Winnipeg area and ten group homes for people with Down syndrome and AD were chosen in Winnipeg and across Canada. The results indicated that the group homes seemed to provide the best quality of life for people with AD as a result of Down syndrome because they provided a home-like environment and they operated according to a therapeutic philosophy of care. In addition, costs for caregiving seemed to be more economical in group homes than in SCUs because group homes utilized lower staff wages and medical costs. Based on the results, it was recommended that Winnserv Inc. continue to house people with DS and AD.

Chaput, J.L.

Adults with Down syndrome and Alzheimer's disease: Comparisons of services received in group homes and in special care units

Journal of Gerontological Social Work, 2002, 38, 197-211

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

Cohen, U., & Wiesman, G.D.

Holding on to Home: Designing Environments for People with Dementia.

181 pp.

Baltimore: Johns Hopkins University Press (1991)

Abstract: General text on adapting homes and living environments for persons with dementia; applicable to home and other residential situations for adults with intellectual disabilities and dementia.

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

Determinants of aggression, and adaptive and maladaptive behaviour in older people with Down's syndrome with and without dementia.

Journal of Intellectual Disability Research, 1999, 43(5), 393-399.

Abstract: In a cross-sectional study of aggression, and adaptive and maladaptive behavior in 128 subjects with Down's syndrome (DS), 29 of whom had dementia, the current authors found that the presence of dementia was not predictive of aggression or maladaptive behavior. However, the level of adaptive behavior was shown to be lower in subjects with dementia, and in those with lower levels of cognitive functioning, as measured on a rating instrument, the Test for Severe Impairment. Although the presence of aggressive behaviors is not higher in subjects with dementia and DS on cross-sectional review, it remains to be seen whether aggression will increase in individual cases with the onset or progression of dementia. The decline in adaptive behavior shown in the present study confirms the findings of previous studies and indicates a direction for service development for persons with the dual diagnosis of dementia and DS.

Cox, S.

Home Solutions: Housing & Support for People with Dementia

London: The Housing Associations Charitable Trust [78 Quaker Street, London, England E1 6SW; e/m: hact@hact.org.uk] (1998)

112 pp.

Abstract: Publication details some 10 case studies of housing options and accommodations for persons affected by dementia (and applicable to adults with intellectual disabilities). Models covered include: support in a person's own home, support in a shared home, specialist dementia support with communal facilities, and different types and levels of support on one site. Sections also deal with housing and support solutions for people with dementia from ethnic minority communities and the repair, remodeling, adaptation and renovation of ordinary housing. Case models contain full descriptions of settings and accommodations.

Davis, D.R.

A Parent's Perspective

In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, Aging, and Intellectual Disabilities*. pp. 42-50

Philadelphia: Brunner-Mazel (1999)

Abstract: Book chapter that provides an account of the experiences of a family with an adult son with Down syndrome who eventually succumbs to dementia of the Alzheimer's type. Includes a discussion of the difficult early years of the son's life and the challenges the family faced as he aged. It also examines the family's problems in recognizing that their son was experiencing the onset of dementia and his gradual decline until his death at age 46.

Day, K., Carreon, D., & Stump, C.

The therapeutic design of environments for people with dementia: A review of the empirical research

The Gerontologist, 2000, 40, 397-416

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

Davies, M., McGillade, A., & Bickerstaff, D.

A needs assessment of people in the Eastern Health and Social Services Board (Northern Ireland) with intellectual disability and dementia

Journal of Learning Disabilities, 2002, 6, 23-33.

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

Deb, S., Hare, M.A., Prior, L., & Bhaumik, S.

Dementia screening questionnaire for individuals with intellectual disabilities.

British Journal of Psychiatry, 2007, 190, 440-444.

Abstract: Many adults with Down syndrome develop Alzheimer's dementia relatively early in their lives, but accurate clinical diagnosis remains difficult. The authors set out to develop a user-friendly observer-rated dementia screening questionnaire with strong psychometric properties for adults with intellectual disabilities. They used qualitative methods to gather information from carers of people with Down syndrome about the symptoms of dementia. This provided the items for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) which was then tested for its psychometric properties. The DSQIID was administered to carers of 193 adults with Down syndrome, 117 of whom were examined by clinicians who confirmed a diagnosis of dementia for 49 according to modified ICD-10 criteria. They established that a total score of 20 provides maximum sensitivity (0.92) and optimum specificity (0.97) for screening. The DSQIID has sound internal consistency ($\alpha=0.91$) 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 construct validity that the DSQIID is valid, reliable and user-friendly observer-rated questionnaire for screening for dementia among adults with Down syndrome.

Deb, S., Hare, M. & Prior, L.

Symptoms of dementia among adults with Down's syndrome: a qualitative study.

Journal of Intellectual Disability Research, 51, 726-739.

Abstract: Dementia is common among adults with Down's syndrome (DS); yet the diagnosis of dementia, particularly in its early stage, can be difficult in this population. One possible reason for this may be the different clinical manifestation of dementia among people with intellectual disabilities. The aim of this study was to map out the carers' perspective of symptoms of dementia among adults with DS in order to inform the development of an informant-rated screening questionnaire.

Unconstrained information from carers of people with DS and dementia regarding the symptoms, particularly the early symptoms of dementia, was gathered using a qualitative methodology. Carers of 24 adults with DS and dementia were interviewed. The interviews were recorded and fully transcribed. The transcripts were then analysed using qualitative software. There appeared to be many similarities in the clinical presentation of dementia in adults with DS and the non-intellectually disabled general population. Like in the non-intellectually disabled general population, forgetfulness especially, impairment of recent memory combined with a relatively intact distant memory and confusion were common, and presented early in dementia among adults with DS. However, many 'frontal lobe'-related symptoms that are usually manifested later in the process of dementia among the general population were common at an early stage of dementia among adults with DS. A general slowness including slowness in activities and speech, other language problems, loss of interest in activities, social withdrawal, balance problems, sleep problems, loss of pre-existing skills along with the emergence of emotional and 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.

Devenny, D.A., Krinsky-McHale, S.J., Sersen, G., & Silverman, W.P.

Sequence of cognitive decline in dementia in adults with Down's syndrome. *Journal of Intellectual Disability Research* 2000, 44, 654-665.

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

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.

Alzheimer's Disease & Down Syndrome: A Practical Guide for Caregivers.
36 pp.

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

ENIDA

Face to Face: Respectful Coping with Dementia in Older People with Intellectual Disability
52 minutes

Working Group on Coping with Dementia in Older People with Intellectual Disability, European Network on Intellectual Disability and Ageing [ENIDA - c/o Patricia Noonan Walsh, Ph.D., Director, Centre for the Study of Developmental Disabilities, University College Dublin, Belfield, Dublin 4, IRELAND -- e-mail: patricia.walsh@ucd.ie] (2000)

Abstract: A 52-minute video with an accompanying information booklet, which uses a number of case vignettes from France, Belgium and the Netherlands to illustrate the various symptoms and stages of dementia among older people with intellectual disability. Examples of practices to promote "respectful coping" with dementia, death and dying on the part of direct support professionals and clinicians are presented. Devised for staff training and development, Face to Face may be viewed in short segments. A version with English subtitles and English booklet is available in formats suitable for Europe and for North America. Developed with funding and support from: ENIDA, Fondation de France, the European Union, and University College Dublin, Ireland.

Forbat, L., & Wilkinson, H.

Where should people with dementia live? Using the views of service users to inform models of care.

British Journal of Learning Disabilities, 36(1), 6-12.

Abstract: The authors report on study examining how people with intellectual disabilities understand dementia and posit some implications for developing appropriate models of care. The data in this paper came from a 3-year study of an organization in England that provides residential and day services to people with intellectual disabilities. A combination of focus groups, ethnography, and individual interviews were used to gather data at with eight sites across England. Participants were people with an ID who had dementia, and those who have lived with someone with dementia. From those who lived with people with dementia, the authors found that vocal persons with ID were able to reflect on what were the experiences of living with others with dementia, since they all had personal experience with it. Seven main issues were apparent: confusion, forgetfulness, wandering, health and safety, the impact of dementia on staff time with the person with dementia and other service users, 'special privileges' that may be misunderstood or misinterpreted, and organizational-level communication about, and the impact of major changes to, the physical environment. When querying adults diagnosed or suspected of dementia the clarity of understanding was less evident - there was little reflection or understanding of the individual's changing condition. The authors surmise that the difference may be a function of several factors of the people with dementia, for example, a defense mechanism employed to avoid internalizing awareness of the condition, the impact of the dementia on cognitive processes which prevent this self-awareness, and fear of staff to have prolonged discussion with these service users about the meaning and cause of memory loss and confusion. It is clear that these respondents had a very restricted understanding of the condition, even when they had a formal diagnosis and sufficient capacity to consent to participate in research. The conclusions drawn from this study is that there is much work to be done on raising awareness and understanding of people with intellectual disabilities about aging generally and about dementia in particular.

Foundation for People with Learning Disabilities

Down's Syndrome and Dementia - Briefing for Commissioners

London: The Foundation for People with Learning Disabilities [c/o Mental Health Foundation, 20/21 Cornwall Terrace, London, England NW1 4QL; e/m mhf@mhf.org.uk; www.learningdisabilities.org.uk] (February 2001)
8 pp.

Abstract: Background document, written for funders of services in the United Kingdom, outlines the epidemiology of dementia and Down's syndrome and identifies key support services necessary as part of a package of local services to be established for persons affected by dementia and intellectual disabilities (ID). While titled for dementia and Down's syndrome applicable for all persons with ID. Written in brief style, covers main issues and funding considerations and serves as an excellent planning tool for establishing services. Also covers basic clinical diagnostic information and basis for care management decision making. Routes the reader to associated organizations for further information

 **Fray, M.T.**


Caring for Kathleen: A Sister's Story about Down's Syndrome and Dementia. Kidderminster, United Kingdom: British Institute of Learning Disabilities [BILD, Wolverhampton Road, Kidderminster, Worcestershire, UK DY10 3PP -- www.bild.demon.co.uk] (2000)
44 pp.

Abstract: Biographical monograph on the aging and eventual decline and death of a woman with Down syndrome as told by her sister. Provides many insights in service barriers and successes, while also providing a vivid case example of how Alzheimer's disease affects a family carer of a person with an intellectual disability.

Gitlin, L.N., and Corcoran, M.

Making homes safer: environmental adaptations for people with dementia
Alzheimer's Care Quarterly, 2000, 1(1), 50-58

Abstract: Evaluating the safety of the home environment is an important component of clinical care for persons with dementia. This article discusses safety concerns for persons with dementia living at home alone or with family members, specific modifications to the physical environment to address these issues, and guiding principles for implementing environmental changes. A wide range of environmental strategies can be introduced to maximize home safety. Different adaptations may need to be implemented with progressive memory loss thus necessitating periodic reevaluation of the home.

 **Hammond, B., & Beneditti, P.**

Perspectives of a Care Provider
In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, Aging, and Intellectual Disabilities*.
pp. 32-41

Philadelphia: Brunner-Mazel (1999)
Abstract: Book chapter that provides a descriptive chronology of a middle-aged woman with Down syndrome who, once diagnosed with Alzheimer disease, follows a classic course of decline and eventual debilitation and death. Staff of her residence chronicled the progression of her dementia and provide some insights into the care management practices used in providing for her care. The authors place the course of her disease in perspective and offer comments on the stresses and strains on agency resources. Suggestions are offered for agencies facing similar challenge in providing day to day care for adults with dementia.

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.

 **Hellen, C.R.**

Alzheimer's Disease - Activity-Focused Care (2nd ed.)
Boston: Butterworth-Heinemann (1998)

436 pp.
Abstract: A 13-chapter text that provide voluminous information on developing and provision of activities for persons affected by Alzheimer's disease and

related dementias - with application to persons with intellectual disabilities. Written from a practitioner viewpoint, it is designed to promote an individual's cognitive, physical and psychosocial well-being. It includes forms and profiles for use by program personnel, presents a holistic intervention program, features content on refocusing activities for physically combative or violent situations. Contains chapters on communication, daily living care activities, aiding at mealtimes, facilitating physical wellness (mobility and exercise), addressing dementia induced behaviors, creating meaningful activities for daily life, and aiding in terminal care, among others.

 **Holland, A.J.**

Ageing and its consequences for people with Down's syndrome
Fact Sheet Series - Learning about intellectual disabilities and health
Accessed 24 August 2004 at

http://www.intellectualdisability.info/lifestages/ds_ageing.htm
Down Syndrome Association (UK) and the Department of Mental Health & Learning Disability at St. George's Hospital Medical School, University of London.
9 pp.

Abstract: Fact sheet outlines the evidence which suggests that ageing and 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

Oxford: Oxford University Press (1993)

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

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.
British Journal of Learning Disabilities, 2005, 33(4), 188-193.

Abstract: This study investigated the frequency and severity of challenging behavior in adults with Down's syndrome with and without signs of dementia. Care staff were interviewed using the Aberrant Behaviour Checklist-Community version (M.G. Aman & N.N. Singh, Slosson, East Aurora, NY, 1994), to investigate the frequency and severity of challenging behavior. Individuals' 'dementia status' was assessed by using the Dementia Scale for Down's syndrome (Gedye Research and Consulting, Vancouver, 1995). The results showed that the dementia group displayed more frequent and severe forms of challenging 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.

Janicki, M.P., Dalton, A.J., McCallion, P., Davies Baxley, D., & Zendell, A.

Group home care for 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 in Developmental Disabilities
In N. Bouras (Ed.), *Psychiatric and Behavioral Disorders in Developmental Disabilities and Mental Retardation* (1999)
pp. 121-153

Cambridge: Cambridge University Press
Abstract: This book chapter provides a brief overview of the current status of knowledge about dementia and its relationship to intellectual disability, touching on current developments in the evaluation of possible comorbid psychiatric, medical and age-associated conditions. The clinical presentation of dementia is examined as well as relevant contemporary issues related to diagnosis, assessment, and care management. Lastly, questions of dementia policy and suggestions for training programs on dementia and intellectual disability are addressed.

Janicki, M.P., & Dalton, A.J.

Dementia and Public Policy Considerations
In M.P. Janicki & A.J. Dalton (eds.), *Dementia, Aging, and Intellectual Disabilities* (1999)
pp. 388-414
Philadelphia: Brunner-Mazel

Abstract: This book chapter examines a number of the major public policy considerations related to the aging of adults with intellectual disabilities who evidence change due to dementia. Specifically addressed is the changing structure of at-risk adult populations with intellectual disabilities in service systems, the programmatic and policy issues raised by providers attempting to cope with these changes, needs for further training, education and dissemination of information on aging, and lastly, the challenges and policy imperatives to be confronted with the new millennium.

Janicki, M.P., & Dalton, A.J.

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

Janicki, M.P., & Dalton, A.J.

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

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

The effectiveness of dementia care mapping in intellectual disability residential services: A follow-up study.

Journal of Intellectual Disabilities, 2006, 10(4), 365-375.

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

Jervis, N., & Prinsloo, L.

How we developed a multidisciplinary screening project for people with Down's syndrome given the increased prevalence of early onset dementia

British Journal of Learning Disabilities, 2008, 36(1), 13-21.

Abstract:

The authors report of the process used by a multidisciplinary working group based within the Manchester Learning Disability Partnership (MLDP) to explore service/clinical issues in relation to the premorbid screening and assessment of people with Down syndrome (DS) suspected or at risk of dementia. Following the recommendations of the AAMR/IASSID Study Group, the report details the manner in which screenings and periodic assessments are undertaken, the instrumentation used, and how the findings are integrated into the service plans for each affected individual. The authors note that the screening project has been viewed as a positive example of multidisciplinary and multi-agency working within Manchester and has ensured that people with DS receive the necessary health screening detailed in the literature and has therefore helped to reduce discrimination around access to health services for this group. It has helped to identify people with DS with concerns known to MLDP and has led to these concerns being addressed by referrals to other professionals (e.g. dementia, health, social needs, etc.). Although this process has taken around 1 year of an assistant psychologist's time it is believed that this has been a valuable use of time given the issues that have been identified and given that the assessment process for people with DS in the future should be a faster process given that a baseline has already been established.

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.

Effects of donepezil on cognitive functioning in Down syndrome

American Journal on Mental Retardation, 2003, 108(6), 367-372

Abstract: This study to determined whether donepezil, an acetylcholinesterase inhibitor, would improve cognitive functioning in 19 subjects with Down syndrome and no dementia. They were assigned to either a donepezil or placebo group. Cognitive functioning and caregiver ratings were measured at baseline, 4 weeks, and 12 weeks. With the exception of one area (language), no improvement was noted in any of the cognitive subtests, behavioral scores, or caregiver ratings. Subjects in the donepezil group showed an improvement in language scores compared to subjects in the placebo group. The results suggest that donepezil may improve language performance in subjects with Down syndrome and no dementia, but further studies need to be done on a larger group to confirm this result.

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

Manual for the "Assessment for Adults with Developmental Disabilities" (A.A.D.S.) Questionnaire

School of Psychology, University of Birmingham, Edgbaston, Birmingham B15 2TT (2000).

Scales designed to assess behaviors associated with dementia and levels of caregiving. American version is available for download from www.uic.edu/orgs/rrtcamr/dementia.

Kalsy, S., Heath, R., Adams, D., & Oliver, C.

Effects of Training on controllability attributions of behavioural excesses and deficits shown by adults with Down syndrome and dementia.

Journal of Applied Research in Intellectual Disabilities, 2007, 20(1), 64 -68.

Abstract: Whereas there is a knowledge base on staff attributions of challenging behavior, there has been little research on the effects of training, type of behavior and biological context on staff attributions of controllability in the context of people with intellectual disabilities and dementia. A mixed design was used to investigate the effects of three factors on care staff attributions of the controllability of challenging behavior. Pre- and post-training measures were administered to participants (n = 97) attending training on ageing, dementia and people with intellectual disabilities. Authors found no significant effects of diagnosis or type of behavior on attributions were found. There was a significant increase in knowledge after training (P < 0.001) and training was found to significantly decrease the attribution of controllability (P < 0.001). Conclusion was that the results suggest that training that focuses on aspects of change relevant to behavior can favorably influence care staff's knowledge and attributions of controllability within the context of people with Down syndrome and dementia.

 **Kerr, D.**

Down's Syndrome and Dementia

76 pp.

Birmingham, UK: Venture Press (1997)

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

Kirk, L.J., Hick, R., & Laraway, A.

Assessing dementia in people with learning disabilities: The relationship between two screening measures.

Journal of Intellectual Disabilities, 2006, 10(4), 357-364.

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

 **Koenig, B.R.**

Age and Dementia Care Issues for People with an Intellectual Disability: Best Practices (vol. 2).

80 pp.

Brighton, South Australia: MINDA, Inc. (1995)

Abstract: Text covering a range of useful topics related to service provision for dementia among persons with intellectual disabilities. Highly detailed chapters cover health issues, physical decline, behavioral changes, and social aspects. Specific remedial information is provided on communication issues and adapting the environment. A chapter also addresses counseling strategies, examining a diverse range of approaches.

Krinsky-McHale SJ, Devenny DA, Kittler P, & Silverman W.

Selective attention deficits associated with mild cognitive impairment and early

stage Alzheimer's disease in adults with down syndrome. *American Journal of Mental Retardation*, 2008, 113(5), 369-386.
Abstract: Adults with Down syndrome and early stage Alzheimer's disease showed decline in their ability to selectively attend to stimuli in a multitrial cancellation task. They also showed variability in their performance over the test trials, whereas healthy participants showed stability. These changes in performance were observed approximately 2 years prior to a physician's diagnosis of possible Alzheimer's disease, which was made when they were exhibiting declines in episodic memory suggestive of mild cognitive impairment. Performance on this task varied with the evolution of dementia, showed modestly good sensitivity and specificity, and was relatively easy to administer. Given these qualities this task could be a valuable addition to a neuropsychological battery intended for the assessment of mild cognitive impairment and Alzheimer's disease in adults with Down syndrome.

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.

Lynggard, H., & Alexander, N.

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

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

Fifteen-year follow-up of 92 hospitalized adults with Down's syndrome: incidence of cognitive decline, its relationship to age and neuropathology
Journal of Intellectual Disability Research, 2007, 51, 463-477.
Abstract: The clinical and neuropathological features associated with dementia in Down's syndrome (DS) are not well established. To examine clinico-pathological correlations and the incidence of cognitive decline in a cohort of adults with DS. A total of 92 hospitalized persons with DS were followed up from 1985 to December 2000. At outset, 87 participants were dementia-free, with a median age of 38 years. Assessments included the Prudhoe Cognitive Function Test (PCFT) and the Adaptive Behavior Scale (ABS), to measure cognitive and behavioral deterioration. Dementia was diagnosed from case records and caregivers' reports. Eighteen (21%) patients developed dementia during follow-up, with a median age of onset 55.5 years (range 45-74). The PCFT demonstrated cognitive decline among those with a less severe intellectual disability (mild and moderate) but not among the profoundly disabled people (severe and profound). Clinical dementia was associated with neuropathological features of Alzheimer's disease, and correlated with neocortical neurofibrillary tangle densities. At the age of 60 years and above, a little more than 50% of patients still alive had clinical evidence of

dementia. Authors concluded that clinical dementia associated with measurable cognitive and functional decline is frequent in people with DS after middle age, and can be readily diagnosed among less severely intellectually disabled persons using measures of cognitive function such as the PCFT and behavioral scales such as the ABS. In the more profoundly disabled people, the diagnosis of dementia is facilitated by the use of behavioral and neurological criteria. In this study, the largest prospective DS series including neuropathology on deceased patients, the density of neurofibrillary tangles related more closely to the dementia of DS than senile plaques. In people with DS surviving to middle and old age, the development of dementia of Alzheimer type is frequent but not inevitable, and some people with DS reach old age without clinical features of dementia.

Marler, R., & Cunningham, C.

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

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

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

McBrien, J., Whitwham, S., Olverman, K., & Masters, S.

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

McCallion, P.

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

McCallion, P., & Janicki, M.P.

Intellectual Disabilities and Dementia (Computer-based Course)
2 CD-Rom set
Center for Excellence in Aging Services, School of Social Welfare, Richardson 208, University at Albany, Albany, New York 12222 (2002)
Abstract: 2 disk set - usable on Windows 9.X/2000 on 233 MHz Pentium or faster

with audio/video playback. Instructional course on aging, intellectual disabilities and dementia. Contains digital video version of "Dementia and People with Intellectual Disabilities—What Can We Do?"

McCarron, M.

Some issues in caring for people with the dual disability of Down's syndrome and Alzheimer's dementia

Journal of Learning Disabilities for Nursing, Health and Social Care, 1999, 3(3), 123-129

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

McCarron, M., Gill, M., Lawlor, B., & Begley, C.

Time spent caregiving for persons with the dual disability of Down's syndrome and Alzheimer's dementia: Preliminary findings

Journal of Learning Disabilities, 2002, 6(3), 263-279

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

McCarron, M., Gill, M., McCallion, P, & Begley, C.

Alzheimer's dementia in persons with Down's syndrome: Predicting time spent on day-to-day caregiving

Dementia, 2005, 4, 521-538.

Abstract: The aim of this study was to investigate the amount of time formal carers 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., 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.

Dementia, 2005, 4(4), 521-538.

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

McKenzie, K., Harte, C., Patrick, S., Matheson, E., & Murray, G.C.

The assessment of behavioural decline in adults with Down's syndrome

Journal of Learning Disabilities, 2002, 6, 175-184

Abstract: Article reports study that 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.

Millichap, D., Oliver, C., McQuillan, S., Kalsy, S., Lloyd, V., & Hall, S.

Descriptive functional analysis of behavioral excesses shown by adults with Down syndrome and dementia.

International Journal of Geriatric Psychiatry, 2003, 18, 844-854.

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

engagement and staff.

▣ **Moss, S., Lambe, L., & Hogg, J.**

Physical and Mental Health

Ageing Matters - Pathways for Older People with Learning Disabilities: Manager's Reader.

pp. 41-60

Kidderminster: British Institute of Learning Disabilities [Wolverhampton Road, Kidderminster, Worcestershire DY10 3PP United Kingdom] (1998)

Abstract: This unit, one of six that is used for training staff, covers briefly some of the key issues related to physical and mental health, and touches on dementia. Although not specifically developed for care management of adults with dementia, the text, in total, can be a useful resource for staff working in care settings when one or more of the adults in the setting are affected by dementia.

▣ **McQuillan, S., Kalsy, S., Oyebode, J., Millichap, D., Oliver, C., & Hall, S.**

Adults with Down's syndrome and Alzheimer's disease

Tizard Learning Review, 2003, 8(4), 4-13

Abstract: Adults with Down's syndrome are at risk of developing Alzheimer's disease in later life. This paper gives an overview of the current research in the area and discusses the implications it raises for individuals, carers, and service providers. Information on the link between Down's syndrome and Alzheimer's disease and prevalence rates are given. The clinical symptoms of Alzheimer'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 which include maintaining skills, adapting a person-centered approach, implementing psychosocial interventions, and multi-disciplinary care management. Recommendations for the future include increasing education and awareness, implementing screening services, improving assessment methods, and developing appropriate services.

▣ **NAMHI**

Alzheimer's Dementia in Persons with Intellectual Disabilities: Some Common Questions and Concerns

NAMHI, 5 Fitzwilliam Place, Dublin 2, Ireland

Abstract: 28 page booklet with 18 sections/question areas outlining basic information about Alzheimer's disease and people with ID, diagnostic resources, and service to help cope with the course of the disease. Developed by Dr. Mary McCarron of Trinity College Dublin.

▣ **Nelson L.D., Orme, D., Osann, K., & Lott, I.T.**

Neurological changes and emotional functioning in adults with Down Syndrome. *Journal of Intellectual Disability Research*, 2001, 45, 450-456.

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

▣ **New York State Developmental Disabilities Planning Council**

When People with Developmental Disabilities Age

18 minutes

New York State Developmental Disabilities Planning Council [155 Washington Avenue, Albany, New York 12222] (1992).

Abstract: A 18-minute video outlining the major physical and social change issues affecting adults with intellectual and developmental disabilities as they age, including a brief mention of Alzheimer's disease and Down syndrome. Available in video format from the address shown above. Also available as CD-ROM from Mary Mercer, Community Staff Training Director, North Dakota Center for Persons with Disabilities, Minot State University, Box 131, Minot, ND 58703 as well as the New York State Developmental Disabilities Planning Council [155 Washington Avenue, Albany, New York 12222].

▣ **New York State Developmental Disabilities Planning Council**

Dementia and People with Intellectual Disabilities – What Can We Do?

23 minutes

New York State Developmental Disabilities Planning Council [155 Washington Avenue, Albany, New York 12222] (2001).

Abstract: An instructional video which covers the basics of how dementia affects adults with intellectual disabilities, and provides information on diagnostics and suggestions on providing supports and services in community care settings. Produced by the University at Albany, this video can serve as primer on dementia and intellectual disabilities and provides information on basic design and service issues. Available in VHS and CD-Rom format.

▣ **Newroth, S., & Newroth, A.**

Coping with Alzheimer Disease: a Growing Concern.

28 pp.

Downview: Ontario: National Institute on Mental Retardation (Kinsmen NIMR Building, York University Campus, 4700 Keele Street, Ontario, Canada, M3J 1P3) (1981)

Abstract: Monograph describing one residential program's experience in caring for persons with Down syndrome who developed Alzheimer's disease; includes a chart of observations and guidelines for care. The guidelines are reproduced as an appendix in Janicki & Dalton (1999).

▣ **Noelker, E.A. & Somple, L.C.**

Adults with Down Syndrome and Alzheimer's

In K.A. Roberto (Ed.), *The Elderly Caregiver: Caring for Adults with Developmental Disabilities*.

pp. 81-92

Newbury Park: SAGE Publications (1993)

Abstract: Book chapter providing a brief summary of significant assessment and care issues affecting adults with Down syndrome who have Alzheimer's disease. Noted are the needs for education of carers and families, as well as specialty care provision and community services.

▣ **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.

▣ **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

Journal of Learning Disabilities, 2001, 5(4), 345-352

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

Prasher, V.P.

Review of donepezil, rivastigmine, galantamine and memantine for the treatment of dementia in Alzheimer's disease in adults with Down syndrome: implications for the intellectual disability population

International Journal of Geriatric Psychiatry, 2004, 19, 509 - 515

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

Prasher, V.P., & Filer, A.

Behavioural disturbance in people with Down's syndrome and dementia.

Journal of Intellectual Disabilities Research, 1995, 39(5), 432-436.

Abstract: Behavioral disturbance associated with dementia in people with Down

syndrome has not been fully researched. This study investigated such problems in subjects with Down syndrome and dementia and controls with Down syndrome but free of dementia. Changes in mood, difficulty with communication, gait deterioration, loss of self-care skills, sleep disturbance, day-time wandering and urinary incontinence were found to be associated with dementia. Problems giving the greatest cause for concern to carers were restlessness, loss of communication skills, urinary incontinence and wandering. Care provision specifically focused on management of behavioral disturbance in individuals who develop dementia is recommended.

Prasher, V.P., Sajith, S.G., Rees, S.D., Patel, A., Tewari, S., Schupf, N., & Zigman, W.B.

Significant effect of APOE epsilon 4 genotype on the risk of dementia in Alzheimer's disease and mortality in persons with Down Syndrome.

International Journal of Geriatric Psychiatry. 2008 May 8 [Epub ahead of print]

Abstract: Virtually all adults with Down syndrome (DS) have neuropathological manifestations of Dementia in Alzheimer's disease (DAD) but not all develop clinical psychopathology. The effect of allelic variants of Apolipoprotein (APOE) gene in development and progression of DAD and mortality in persons with DS is examined. Recruited participants with DS underwent two to 14 sequential assessments over a follow up period of 6 years on average and their APOE genotype determined. Dementia status was confirmed as recommended by the Working Group for the Establishment of Criteria for the Diagnosis of Dementia in Individuals with Intellectual Disability. APOE genotype results were available for 252 individuals. Participants with APOE epsilon4 allele had significantly higher risk of developing DAD (HR = 1.8, 95% CI: 1.12-2.79), had an earlier onset of DAD (55.0 vs 57.0 years; $p = 0.0027$) and a more rapid progression to death compared with participants with epsilon3 allele (4.2 years vs. 5.4 years, respectively, $p = 0.048$). In non-demented persons with DS, epsilon4 allele was associated with earlier death by 17 years (mean survival age, 55.7 vs. 72.7 years; HR = 5.9, 95% CI: 1.7-21.3). This study highlights the relationship of APOE genotype to morbidity and mortality in persons with DS which has important clinical implications. Authors recommend screening for APOE genotype in persons with DS to identify those at risk of DAD and premature death and note that further research is required to investigate the underlying reasons for the early mortality in non-demented DS persons with an epsilon4 allele.

 **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.

Rosewame, M.

Learning disabilities and dementia: a pilot therapy group.

Journal of Dementia Care, 2001, 9(4), 18-20.

Abstract: Author describes a project where she established a day activity program (the "pilot therapy group") at a dementia services center for persons with ID and dementia. The primary aims for the project were (a) to improve each individual's quality of life through improved emotional well-being, and (b) to enhance and maintain each individual's level of functioning. Setting used structured activities, such as matching sounds heard to pictures, lotto using everyday signs and symbols, quizzes and other cognitive exercise games. Events were used to stimulate memory, attention, communication and learning, as well as maintaining social functioning and building confidence through activities, movement, discussion, and planned social time. Author concludes that 'psychotherapeutic' approaches useful with persons with dementia in general can be effectively modified to be applicable to people with ID and dementia.

Shultz JM, Aman MG, Rojahn J.

Psychometric evaluation of a measure of cognitive decline in elderly people with mental retardation.

Research in Developmental Disabilities, 1998, 19, 63-71.

Abstract: Forty elderly persons with mental retardation were assessed by their care providers on a modified version of the Short Informant Questionnaire on Cognitive

Decline in The Elderly (IQCODE) an instrument designed to quantify cognitive decline in elderly people in the general population. They were also assessed for IQ, aberrant behavior, and current mental status; test-retest and interrater reliability were evaluated as well. Internal consistency, as assessed by coefficient alpha, was moderately high ($\alpha = .86$). Test-retest reliability was mediocre and interrater reliability levels did not reach statistical significance. The Short IQCODE was not correlated with a variety of demographic features or with behavior ratings, showing evidence of divergent validity. However, the Short IQCODE was only weakly (nonsignificantly) correlated with a measure of current mental status, which challenges its concurrent validity. The Short IQCODE probably needs to be modified further for satisfactory psychometric performance in people with mental retardation. However, some features of this study may have resulted in suboptimal estimates of the Short IQCODE's psychometric characteristics.

📖 **Scottish Down's Syndrome Association**

What Is Dementia? - A Booklet about Dementia for Adults Who Have a Learning Disability.

14pp

Edinburgh: Scottish Down's Syndrome Association [158-160 Balgreen Road, Edinburgh, Scotland EH11 3AU; e/m: info@sdsa.org.uk; www.sdsa.org.uk] [n.d.] [also available on www.uic.edu/orgs/rrtcamr/dementia]

Abstract: Written for the Scottish Down's Syndrome Association by Diana Kerr and Mo Innes this A4 size booklet is designed to explain dementia and its nuances to persons with intellectual disabilities (termed "learning disabilities in Scotland). Using drawings and easy language this booklet covers many of the symptoms and behaviors classically associated with Alzheimer's disease.

Service, K.P.

Considerations in care for individuals with intellectual disability with advanced dementia

Journal of Gerontological Social Work, 2002, 38, 213-224.

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

📖 **Service, K.P., Lavoie, D. Herlihy, J.E.**

Coping with Losses, Death and Grieving

In M.P. Janicki & A.J. Dalton (eds.), *Dementia, Aging, and Intellectual Disabilities*.

pp. 330-351

Philadelphia: Brunner-Mazel (1999)

Abstract: This book chapter uses a composite case to demonstrate strategies to address the issues related to losses and death for people with mental retardation 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.

Strydom, A., & Hassiotis, A.

Diagnostic instruments for dementia in older people with intellectual disability in clinical practice

Aging & Mental Health, 2003, 7(6), 431-437

Abstract: There is a need for simple and reliable screening instruments for dementia in the intellectual disability (ID) population that can also be used to

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

Strydom, A., & Hassiotis, A., Livingston, G., & King, M.

Prevalence of dementia in older adults with intellectual disability without Down syndrome

Journal of Applied Research in Intellectual Disabilities, 2006, 19, 253.

Abstract: The aim of this study was to determine the prevalence of dementia in older adults with intellectual disability (ID) without Down syndrome. The authors identified the total population of adults with ID aged 60+ in the five London boroughs served through local social services registers, ID teams and residential services providers and then screened the Ss with a simple object memory task, information about functional status, and the Dementia Questionnaire for Persons with Mental Retardation (DMR). Screen positives on the DMR, or those with unexplained functional decline or memory deficits underwent detailed examination. Full assessment of cognitive and physical function was undertaken and additional information was collected from informants and medical records. All information was summarized to determine dementia status with 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.

A. Strydom, G. Livingston, M. King, A. Hassiotis

Prevalence of dementia in intellectual disability using different diagnostic criteria. *British Journal of Psychiatry*, 2007, 191: 150-157.

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

Strydom A, Hassiotis A, King M, Livingston G.

The relationship of dementia prevalence in older adults with intellectual disability (ID) to age and severity of ID.

Psychological Medicine, 2008, 15, 1-9.

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

groups. Age was a strong risk factor and was not influenced by sex or ID severity. As predicted, SMRs were higher for younger age groups compared to older age groups, indicating a relative shift in age-associated risk. Criteria-defined dementia is 2-3 times more common in the ID population, with a shift in risk to younger age groups compared to the general population.

Temple, V., & Konstantareas, M.M.

A comparison of the behavioural and emotional characteristics of Alzheimer's dementia in individuals with and without Down syndrome.

Canadian Journal of Aging, 2005, 24(2), 179-190

Abstract: The behavioral and emotional changes associated with Alzheimer's disease (AD) are compared for individuals with Down syndrome and AD and individuals with AD from the general population (AD-only). The primary caregivers of 30 people with Down syndrome and AD and 30 people with AD-only completed the BEHAVE-AD and the Apathy subscale of the CERAD. As well, behavioral observations at adult day programs were undertaken with selected participants (n=26). The Down syndrome group experienced fewer delusions and had lower total scores on the BEHAVE-AD, indicating fewer problem behaviors overall. Day program observations suggested that the AD-only group were more likely to be sedentary and observe the activities of others, while the Down syndrome group were more physically active. Improving our understanding of the similarities and differences between these two groups may help facilitate the integration of individuals with Down syndrome into adult day programs for the general population.

Temple, V., Jozsvai, E., Konstantareas, M.M., & Hewitt, T.A.

Alzheimer dementia in Down's syndrome: the relevance of cognitive ability. *Journal of Intellectual Disability Research*, 2001, 45, 47-55.

Abstract: More years of education have been found to be associated with a lower rate of Alzheimer disease (AD) in individuals without intellectual disability. It has been proposed that education reflects greater 'synaptic reserve' and that greater synaptic reserve may defer the development of AD. The present study compared individuals with Down's syndrome (DS) who were found to have symptoms of dementia with those who remained symptom-free to determine if the two groups differed in their level of education, employment, recreational activities, years in an institution or overall level of cognitive functioning. Thirty-five adults with DS aged between 29 and 67 years were assessed. The participants were recruited from a community health facility and included individuals with a wide range of ability levels. Neuropsychological testing, caregiver report and the Dementia Scale for Down Syndrome (Gedye 1995) were used to identify decline in participants over periods of 6 months to 3 years. After the effect of age was statistically removed, multiple regression analyses revealed that level of cognitive functioning was significantly associated with decline such that a higher level of cognitive functioning predicted less decline. None of the environmental variables (i.e. educational level, years in an institution and employment) were directly associated with decline; however, a post hoc regression using level of cognitive functioning as the outcome variable revealed that level of cognitive functioning itself was associated with these environmental variables. A higher level of cognitive functioning was associated with fewer cases of dementia in individuals with DS, and level of cognitive functioning appears to be associated with environmental factors such as level of education, years in an institution and employment. The present findings suggest that environmental interventions aimed at improving level of cognitive functioning may also be useful in deferring the onset of dementia.

The Arc

Developmental Disabilities and Alzheimer Disease: What You Should Know. 43 pp.

Silver Spring, Maryland: The Arc of the United States [1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910 -- www.TheArc.org] (1995)

Abstract: A booklet covering some of the fundamentals concerning adults with intellectual disabilities and Alzheimer's disease including what is Alzheimer's disease, its course and outcome, diagnostic suggestions, care considerations, and how to obtain assistance. Contains resource list and glossary.

Thompson, D.J., Ryrie, I., & Wright, S.

People with intellectual disabilities living in generic residential services for older people in the UK

Journal of Applied Research in Intellectual Disabilities, 2004, 17, 101-108

Abstract: As part of a UK program of work focusing on older people with ID, the circumstances of those who reside in generic services for older people were investigated. Some 215 people with ID were identified living in 150 homes. They were significantly younger than other residents and were placed in these homes more because of organizational change or the aging/death of family carers, rather than due to their own needs. Of the residents, 24 adults had

Down syndrome, 8 of whom were noted to have dementia. Of the 215, 45 had dementia. Average age of people with DS upon entry was 60 and those remaining at the homes was about 65.

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.

Udell, L.

Supports in Small Group Home Settings

In M.P. Janicki & A.J. Dalton (Eds.), *Dementia, Aging, and Intellectual Disabilities*. pp. 316-329

Philadelphia: Brunner-Mazel (1999)

Abstract: This book chapter covers what organizations that provide residential supports to adults with an intellectual disability need to consider in terms of planning and implementing program changes. Covered are areas that examine the nature of dementia and its possible impact on service provision. Its particular focus is on how agencies that decide to support people with dementia in small group home settings can accommodate their organizational and operational structure and offers insight on the perspectives and questions that agencies need to consider. Suggestions are offered on how to address some of the difficulties that organizations will encounter.

University of Maryland School of Medicine

Hi Buddy... The Developmentally Delayed Individual with Alzheimer Disease 19 minutes

VideoPress, the University of Maryland School of Medicine [100 North Greene Street, Suite 300, Baltimore, Maryland USA (1 800 328 7450; fax: 1 410 706 8471; www.videopress.org)]

Abstract: Video on the subject of Alzheimer's disease and adults with developmental disabilities.

University of Stirling

Building Networks - Conference on Learning Disabilities and Dementia 58 pp.

Dementia Services Development Centre, Department of Applied Social Science, Faculty of Human Sciences, University of Stirling, Stirling, Scotland FH9 4LA (2000).

Abstract: Proceedings of conference on community dementia care and people with intellectual disabilities held in Dunblane, Scotland (November 11, 1999). The report summarizes the main points made by the numerous speakers at the conference. The conference highlighted the need for wider awareness among managers and service personnel of the need for (and for resources and developing expertise on) training staff in residential and home support services on responding to the needs of people with intellectual disabilities who have dementia. The 16 papers range from the theoretical to the practical.

Visoosak, 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.

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.

Whitehouse, R., Chamberlain, P., & Tunna, K.

Dementia in people with learning disability: a preliminary study into care staff knowledge and attributions

British Journal of Learning Disabilities, 2000, 28(4) 148- 153

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

Whittick, J.E.

Dementia and mental handicap: attitudes, emotional distress and caregiving

British Journal of Medical Psychology, 1989, 62, 181-189

Abstract: Against the current climate of hospital closure programs and community care, attitudes to caregiving were examined in three groups of carers, namely mothers caring for a mentally handicapped child, mothers caring for a mentally handicapped adult and daughters caring for a parent with dementia. An 'attitude questionnaire' was developed by the author and administered, postally, to the three groups. Daughters were found to be more likely than the mothers to see their caring role in a negative way and were more inclined to favor institutional care. Possible reasons for this are discussed. The relationship between attitudes and emotional distress (as measured by the

GHQ-30) were also examined for the sample as a whole. Negative and pro-institutional attitudes towards the caregiving situation were associated with elevated levels of emotional distress. Implications at both a local and a national level for all those involved with carers are discussed in the light of these findings.

Wilkinson, H., & Watchman, K.

Growing older with a learning disability and dementia

CRFR Research Briefing 17, The University of Edinburgh, 23 Buccleuch Place, Edinburgh, EH8 9LN, Scotland (www.cfr.ac.uk), June 2004.

Abstract: A research brief compiling information from several studies that reports on the importance of families and relationships in the lives of people with intellectual disabilities who are growing older and experiencing dementia. Contains two components: (1) Home for good: The experience of people with a learning disability and dementia in residential care, and (2) Sisters' caring: Experiences of the long term care of siblings with Down syndrome.

Wilkinson, H., Janicki, M.P., & Edinburgh Working Group on Dementia Care Practices (EWGDCP).

The Edinburgh Principles with accompanying guidelines and recommendations.

Journal of Intellectual Disability Research, 2002, 46, 279-284.

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

Wilkinson, H., Kerr, D., & Rae, C.

People with a learning disability: their concerns about dementia

Journal of Dementia Care, 2003, 11(1), 27-29.

Abstract: With people with a learning disability live longer, more of them are developing dementia. In planning the services they need, an important first step is to ask them what they think. Author report information from surveying a group of older adults with intellectual disabilities.

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

Dementia: Issues in Early Recognition and Intervention in Primary Care.

Journal of the Royal Society of Medicine, 2003, 96, 320-324.







Abstract: Generic article about the need for quality and accurate screening and assessment of adults suspected of showing signs of Alzheimer's disease and the need for psychosocial interventions and family carer supports. Authors note need for better training of medical practitioners who may be screening for dementia, indicating that there is a need for timely detection and diagnosis that will prevent crises, facilitate adjustment and provide access to treatments and supports.

Related Articles of Interest *****

Schupf N, Winsten S, Patel B, Pang D, Ferin M, Zigman WB, Silverman W, Mayeux R. (2006). Bioavailable estradiol and age at onset of Alzheimer's disease in postmenopausal women with Down syndrome. *Neuroscience Letter* (2006 Aug 18); [Epub ahead of print]

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.

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

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sign on the "Dementia and Intellectual Disabilities" listserv at www.yahogroups.com - look for "**dementia-IDlistserv**"

Look for updated information at
www.uic.edu/orgs/rrtcamr/dementia