

Ageing & Health - People with Intellectual Disability
National Designated Expert –
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Adlin M (1993) Health Care Issues. In E. Sutton, Factor A, Hawkins B, Heller T, Seltzer G (ed) *Older Adults with Developmental Disabilities: Optimizing Choices and Change* (p. 49-60). Baltimore, MD: Paul Brookes Publishing.

Alborz A, McNally R, Swallow A et al (2003) From the Cradle to the Grave: a literature review of access to health care for people with learning disabilities across the lifespan. London: National Co-ordinating Centre for NHS Service Delivery and Organisation. http://www.sdo.lshtm.ac.uk/pdf/access_alborz_report.pdf

Anderson, D. (1997). Health status and conditions of older adults with mental retardation. Paper presented at the Eighth International Roundtable on Aging and Intellectual Disability, Chicago, April 1997.

Ashman, A. F., Suttie, J.N. and Bramley, J. (1995) Employment, retirement and elderly persons with an intellectual disability. *Journal of Intellectual Disability Research* 39 (2), 107-116.

Ball, S. L., Holland, A. J., Huppert, F. A., Treppner, P., Watson, P. & Hon, J. (2006) 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*; 21: 661-673.

Barr O., Gilgunn J., Kane T. & Moore G. (1999) Health screening for people with learning disabilities by a community learning disability service in Northern Ireland. *Journal of Advanced Nursing* 29, 1482–91.

Beange H., Lennox N. & Parmenter T. (2000) Health targets for people with an intellectual disability. *Journal of Intellectual & Developmental Disability* 24, 283–97.

Bell AJ, Bhate MS. (1992) Prevalence of overweight and obesity in Down syndrome and other mentally handicapped adults living in the community. *Journal of Intellectual Disability Research* 36, 356-364.

Bigby. C. (2002) Ageing with a life long disability: Challenges for the Aged Care and Disability Sectors. *Journal of Intellectual and Developmental Disabilities* Vol 24(4):231-421.

Bittles, A. H., Petterson, B. A., Sullivan, S. G., Hussain, R., Glasson, E. J., & Montgomery P D. (2002). The influence of intellectual disability on life expectancy. *The Journal of Gerontology. Series A, Biological Sciences and Medical Sciences* Vol. 57(7): 470-472.

Blackman, N., & Todd, S. (2005). *Caring for People with Learning Disabilities who are Dying*. London: Worth Publishing Ltd.

Brown, A. A. & Murphy, L. (1999). *Aging with developmental disabilities; Women's health issues*. Arlington, TX: The Arc of the United States and the RRTC on Aging with Mental Retardation.

Center J, Beange H & McElduff A. (1998) People with mental retardation have an increased prevalence of osteoporosis: a population study. *American Journal on Mental Retardation* 103: 11-28.

Cooper S.-A. (1999) The relationship between psychiatric and physical health in elderly people with intellectual disability. *Journal of Intellectual Disability Research* 45, 54-60.

Cooper, S-A. (1999). Psychiatric disorders in elderly people with developmental disabilities. In N. Bouras (ed.), *Psychiatric disorders in developmental disabilities* (pp. 212-225) Cambridge: Cambridge University Press.

Cosgrave M, Tyrrell J, McCarron M, Gill M, BA Lawlor. (1999) Determinants of aggression, and adaptive and maladaptive behaviour in older people with Down's syndrome with and without dementia. *Journal of Intellectual Disability Research* 43(5), 393-399.

Cosgrove, M., McCarron, M., Anderson, M., Tyrrell, J. Gill, M., Lawlor, B.(1998). Cognitive decline in Down's Syndrome: a validity/reliability study of the test for severe impairment. *American Journal on Mental Retardation*. 103, 193-197

Cosgrove, M., Tyrrell, J., McCarron, M., Gill, M., Lawlor, B.(1999). Age at onset of dementia and age of menopause in women with Down's syndrome. *Journal of Intellectual Disability Research*. 43(6), 461-465

Cosgrove, M., Tyrrell, J., McCarron, M., Gill, M., Lawlor, B.(2000). A Five Year Follow up Study of Dementia in Persons with Down's Syndrome: Early Symptoms and Patterns of Deterioration. *Irish Journal of Psychological Medicine* 17(1), 5-11.

Cumella S, Ransford N, Lyons J and Burnham H (2000) Needs for oral care among people with intellectual disability not in contact with community dental services. *Journal of Intellectual Disability Research* Vol 44 (1): 45-52.

Day, K., & Jancar, J. (1994) Mental and physical health and aging in mental handicap: a review. *Journal of Intellectual Disability Research*, 38, 241-256.

Draheim C.C., Williams D.P. & McCubbin J.A. (2002a) Prevalence of physical inactivity and recommended physical activity in community-based adults with mental retardation. *Mental Retardation* 40, 436-444.

Durvasula, S., Beange, H., & Baker, W. (2002) Mortality of people with intellectual disability in Northern Sydney. *Journal of Intellectual and Developmental Disability* 27(4), 255-264.

Elliott J, Hatton C and Emerson E (2003) The health of people with learning disabilities in the UK: evidence and implications for the NHS. *Journal of Integrated Care* Vol 11(3): 9-17.

Emerson E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disability Research* 49, 134-143.

Evenhuis H. M. (1997) Medical aspects of ageing in a population with intellectual disability: III. Mobility, internal conditions and cancer. *Journal of Intellectual Disability Research* 41, 8–18.

Evenhuis, H., Henderson, C.M., Beange, H., Lennox, N., Chicoine, B., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Physical Health Issues*. Geneva, Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.5).

Fahey-McCarthy, E., McCarron, M. Connaire, K, McCallion, P (2008). Supporting Persons with Intellectual Disability and Dementia. Fusing the Horizons of Intellectual Disability, Palliative and Person Centred Dementia Care. An Introductory Education and Training Programme. (Including Trainers Manual, CD ROMS, Student Reflective work book.

Fender A., Marsden L. & Starr J.M. (2007a) What do older adults with Down's syndrome want from their doctor? A preliminary report.

Fender A., Marsden L. & Starr J.M. (2007b) Assessing the health of older adults with intellectual disabilities: a user-led approach. *Journal of Intellectual Disabilities* 11, 223–39.

Fujiura, G. T., Fitssimmons, N., Marks, B., Chicoine, B. (1997). Predictors of BMI among adults with Down syndrome: The social context of health promotion. *Research in Developmental Disabilities*, 18, 261-274.

Hogg, J. (2007) Intellectual disability and ageing: ecological perspectives from recent research. *Journal of Intellectual Disability Research* Vol. 41 (2):136-143.

Hogg, J., Lucchino, R., Wang, K., Janicki, M.P., & Working Group (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy*. Geneva: Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.7).

Holland, A.J., Hon, J., Huppert, F.A., Stevens, F. and Watson, P. (1998) A population-based study of the prevalence and presentation of dementia in adults with Down Syndrome. *British Journal of Psychiatry*, 172: 493-498

Hollins S, Attard MT, von Fraunhofer N, McGuigan S and Sedgwick P (1998) Mortality in people with learning disability: risks, causes and death certification findings in London. *Developmental Medicine and Child Neurology* 40 (1): 50-56.

Janicki MP, Dalton AJ, Henderson CM and Davidson PW (1999) Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability and Rehabilitation* Vol 21: 284-294.

Janicki, M.P., Dalton, A.J., Henderson, C.M., & Davidson, P.W. (1999). Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation*, 21, 284-294

Janicki, M.P., Dalton, A.J., Henderson, C.M., & Davidson, P.W. (1999) Mortality and morbidity among older adults with intellectual disability: Health services considerations. *Disability and Rehabilitation* Vol. 21: 284-294

Janicki, M.P., Heller, T., Seltzer, G. & Hogg, J. (1996). 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*, 40, 374-382.

Jansen DEMC, Krol B, Groothoff JW and Post D (2004) People with intellectual disability and their health problems: a review of comparative studies. *Journal of Intellectual Disability Research* Vol. 48(2): 93-102.

Kapell D, Nightingale B, Rodriguez A, Lee JH, Zigman WB, Schupf N. (1998)Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation* 36: 269-79.

Lavin, E., McGuire, B. & Hogan, M. (2006) Age at death of people with an intellectual disability in Ireland. *Journal of Intellectual Disabilities*, 10:1-10

Lennox, N., & Kerr M P. (1997). Primary health Care and people with an intellectual disability: the evidence base. *Journal of Intellectual Disability Research* Vol 41(5), 365-372.

Lifshitz, H. & Merrick, J. (2003) Ageing and intellectual disability in Israel: A study to compare community residence with living at home. *Health and Social Care in the Community* 11(4): 364-371

Martin D. M., Roy A., Wells M. B. & Lewis J. (1997) Health gain through screening – users' and carers' perspectives of health care: developing primary health care services for people with an intellectual disability. *Journal of Intellectual & Developmental Disability* 22, 241–9.

McCallion P., & McCarron M. (2007) Perspective on Quality of Life in Dementia Care. *Intellectual and Developmental Disabilities*. 45(1) 56-59.

McCallion, P., & McCarron, M. (2004). Aging and Intellectual disabilities: A review of recent literature. *Current Opinion in Psychiatry*. 17(5), 349-352.

McCallion, P., & McCarron, M. (2004). Creating a Unified Research Agenda: Using focus groups to elicit views across disciplines, nations and experiences of intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*. 1(2), 88-94

McCallion, P., McCarron, M., & Force, L.T. (2005) A Measure of Subjective Burden for Dementia Care: The Caregiving Difficulty Scale-Intellectual Disability. *Journal of Intellectual Disability Research*. 49(5), 365-371.

McCallion, P., Nickle, T., & McCarron, M. (2005). A comparison of reports of caregiver burden between foster family care providers and staff caregivers of persons in other settings. *Dementia*, 4(3), 401-412.

McCarron M, Gill M, McCallion P and Begley C (2005) Health comorbidities in ageing persons with Down syndrome and Alzheimer's dementia. *Journal of Intellectual Disability Research* Vol 49(7): 560-566.

McCarron M, Tyrell J, Cosgrave M, et al (2000) Influence of APO-E alleles on risk for dementia in Down's syndrome. *American Journal Medical Genetics* 96(4): P178

McCarron M., Lawlor B.A. (2003) Responding to the Challenges of Ageing and Dementia in Intellectual Disability in Ireland. *Ageing and Mental Health* 7(6), 413-417

McCarron, M., & McCallion, P. (2005). A Revised Stress and Coping Framework For Staff Caregivers of Ageing Persons with Intellectual Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 2, 139-148.

McCarron, M. & McCallion, P. (2007) End of Life Care Challenges for Persons with Intellectual Disability and Dementia: Making Decisions About Tube Feeding. *Intellectual and Developmental Disabilities*.45(2) 128-131.

McCarron, M. (1999). Some Issues in Caring for persons with the dual diagnosis of Alzheimer's dementia and Down's syndrome. *Journal of Learning Disability for Nursing Health and Social Care* 3(3), 123-129

McCarron, M., Fahey-McCarthy, E., Connaire, K., & McCallion, P. (2008). *Supporting Persons with Intellectual Disability and Advanced Dementia: Fusing the Horizons of Intellectual Disability, Dementia and Palliative Care*, Report. Dublin: Trinity College Dublin.

McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). Alzheimer's Dementia in Persons with Down syndrome: Predicting Time Spent on Day-to-Day Caregiving. *Dementia*. 4(4) 521-538

McCarron, M., Gill, M., McCallion, P., & Begley, C. (2005). Health Co morbidities in Ageing Persons with Down syndrome and Alzheimer's dementia. *JIDR*, 49(7) 560-566.

Melville C.A., Cooper S.A., McGrother C.W., Thorp C.F. & Collacott R. (2005) Obesity in adults with Down syndrome: a case-control study. *Journal of Intellectual Disability Research* 49, 125-133.

Moore, K.A., McGillivray, J. & Illington, K. (2004) An investigation into the incidence of obesity and underweight among adults with an intellectual disability in an Australian sample. *Journal of Intellectual & Developmental Disability* 29(4): 306-318.

Moss, S., Patel, P. (1995) Psychiatric symptoms associated with dementia in older people with learning disability. *British Journal of Psychiatry*, 167, 663-667.

NHS Health Scotland (2004) *Health Needs Assessment Report: People with Learning Disability in Scotland*. NHS Health Scotland, Glasgow.

NHS Health Scotland. Health needs assessment report. People with learning disabilities in Scotland. Glasgow: NHS Health Scotland, 2004.

Patel, P., Goldberg, D.P., & Moss, S.C. (1993). Psychiatric morbidity in older people with moderate and severe learning disability (mental retardation). Part II: The prevalence study. *British Journal of Psychiatry*, 163, 481-491.

Patja K, Molsa P and Iivanainen M (2001a) Cause-specific mortality of people with intellectual disability in a population-based, 35-year follow-up study. *Journal of Intellectual Disability Research* Vol 45(1): 30-40.

Patja, K. Iivanainen, M., Vesala, H., Oksanen, H. & Ruoppila (2000) Life expectancy of people with intellectual disability: a 35 year follow up study. *Journal of Intellectual Disability Research* 44: 591-9.

Prasher V. & Janicki M. P. (2002) *Physical Health of Adults with Intellectual Disabilities*. Blackwell, Oxford.

Prasher, V. P., Adams, C., Holder, R. & the Down's Syndrome Research Group. (2003) Long term safety and efficacy of donepezil in the treatment of dementia in Alzheimer's disease in adults with Down syndrome: open label study. *International Journal of Geriatric Psychiatry*, 18, 549-541.

Prasher, V.P. (1995) Overweight and obesity amongst Down's syndrome adults. *Journal of Intellectual Disability Research* 39: 437-41.

Prasher, V.P. (1995). End stage dementia in adults with Down Syndrome. *International Journal of Geriatric Psychiatry* 10, 1067-1069.

Prasher, V.P. (1999) Adaptive Behavior. In M. Janicki and A. Dalton (Eds.). *Dementia, Aging and Intellectual Disabilities: A Handbook* (pp. 157-183). Philadelphia: Brunner-Mazel.

Prasher, V.P. (1999). Adaptive Behavior. In M. Janicki and A. Dalton (Eds.). *Dementia, Aging and Intellectual Disabilities: A Handbook* (pp. 157-183). Philadelphia: Brunner-Mazel.

Prasher, V.P., Chung, M.C., & Haque, M.S. (1998). Longitudinal changes in adaptive behavior in adults with Down syndrome: Interim findings from a longitudinal study. *American Journal on Mental Retardation*, 103(1), 40-46.

Regnard, C., Reynolds, J., Watson, B., Matthews, D., Gibson, L., & Clarke, C.(2006). Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DISDAT). *Journal of Intellectual Disability Research* 51 (4), 277-292.

Review of Mental Health and Learning Disability: Equal Lives: *Review of Policy and Services for People with a Learning Disability in Northern Ireland* (2005).

Rimmer, J.H., Braddock, D., & Fujiura, G. (1993) Prevalence of obesity in adults with mental retardation: Implications for health promotion and disease prevention. *Mental Retardation* 31, 105-110.

Rimmer, J.H., Braddock, D., & Marks, B. (1995). Health characteristics and behaviours of adults with mental retardation residing in three living arrangements. *Research in Developmental Disabilities* 16, 48-99.

Robertson J., Emerson E., Gregory N., Hatto C., Turner S., Kessissoglou S. & Hallam A. (2000) Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities* 21, 469-486.

Rubin, S.S., Rimmer, J.H., Chicoine, B., Braddock, D., & MCGuire, D. E. (1998) Overweight prevalence in persons with Down syndrome. *Mental-Retardation* 36(3): 175-181.

Schupf N, Zigman W, Kapell, D, Lee J, Kline J, Levin B. (1997) Early menopause in women with Down syndrome. *Journal of Intellectual Disability Research* 41, 264-267.

Seltzer, M.M., Krauss, M.W., Walsh, P., Conliffe, C., Larson, B., Birkbeck. G., Hong, J. & Choi, S.C. (1995) Crossnational comparisons of ageing mothers of adults with intellectual disabilities. *Journal of Intellectual Disability Research* 39 (5) 408-418.

Stanish HI, Temple VA and Frey GC (2006) Health-promoting physical activity of adults with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews* 12: 13-21.

Stanish, H. & Draheim, C. (2006) Walking Activity, Body Composition and Blood Pressure in Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities* 20(3): 183-190.

Thorpe, L., Davidson, P., Janicki, M.P., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioural Issues*. Geneva, Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.4).

Todd, S. (2004). Death counts: the challenge of death and dying in learning disability services. *Learning Disability Practice*, 7(10), 12-15.

Tuffrey-Wijne, I. (1997). Palliative care and learning disabilities. *Nursing Times*, 93(31), 50-51.

Tuffrey-Wijne, I. (2002). The palliative care needs of people with intellectual disabilities: A case study. *International Journal of Palliative Nursing*, 8 (5), 222-231.

Turk MA, Geremski CA, Rosenbaum PF, Weber RJ. (1997). The health status of women with cerebral palsy. *Archives of Physical Medicine and Rehabilitation* 78(12 Suppl 5); 210-217.

Tyrrell, J., Cosgrave, M., McCarron, M., McPherson, J., Calvert, J., Kelly, A., McLaughlin, M., Gill, M., Lawlor, B.A. (2001). Dementia in people with Down syndrome. *International Journal of Geriatric Psychiatry*. 16(12), 1168-74.

van Schrojenstein Lantman-de Valk H. M. J., Metsemakers J. F. M., Soomers-Turlings M. S. J. G., Haveman M. J. & Crebolder H. F. J. M. (1997) People with intellectual disability in general practice: case definition and case finding. *Journal of Intellectual Disabilities Research* 41, 373-9.

Wallace, R.A. & Schluter, P. (2008) Audit of cardiovascular disease risk factors among supported adults with intellectual disability attending an ageing clinic. *Journal of Intellectual & Developmental Disability* 33(1): 48-58.

Walsh, P.N., Heller, T., Schupf, N., van Schrojenstein Lantman-de Valk, H., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues*. Geneva, Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.6).

Wilkinson, H.A., & Janicki, M.J. (2002). The Edinburgh Principles with accompanying guidelines and recommendations. *Journal of Intellectual Disability Research*, 46, 279-284.

World Health Organization (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Summative Report*. Geneva: Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.3).

Sectoral Plans under the Disability Act 2005, December 2006

Disability Act 2005

Equality Act 2004

Equal Status Act 2000

European Convention on Human Rights Act 2003

UN Convention on the Rights of Persons with Disabilities 2008

United Nations. Convention on rights of people with disability. New York; 2007.

United Nations. Standard rules on the equalization of opportunities for persons with disabilities. New York; 1993.