

## Learning Disability Specialist Library

### Evidence Bulletin 013 – April 2008

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

This study looked at what people with learning disabilities affected by dementia, either diagnosed with dementia, or living with somebody with that diagnosis, thought about arrangements for care and support. The study drew on data from three-year study of an English organisation providing residential and day services, using information from the Service User Advisory Forum, individual interviews with eight people with a learning disability and dementia, and ethnographic work in the workplace/homes of eight people with dementia.

Close reading of the transcripts of the interviews revealed seven main themes:

1. Confusion.
2. Forgetfulness.
3. Wandering.
4. Health and safety.
5. Impact of dementia on staff time
6. 'Special privileges' as interpreted by others
7. Organisational level communication about dementia, and the impact of major changes to the physical environment.

Findings from the interviews suggest that the eight people with dementia had a restricted understanding of the condition. The study also found that wider systems of support were often not adequately considered when working directly with service users with dementia. The authors point out that the condition impacts on practical, relational and organizational levels in a service. Communication about changes in the environment and the way in which symptoms impinge were given insufficient attention.

Service users with dementia did not appear to have had their diagnosis shared with them, suggesting a lack of prior discussion/education about other aspects of ageing. Other residents living with people with dementia had not had dementia explained to them, and the authors recommend the provision of some basic education about the conditions of older age for all service users. There were also concerns about the way in which little explanation was offered to people when friends and/or housemates were moved out of the home as a result of their dementia. The authors suggest a need for further research into the relationship between knowledge of dementia and preferences for accommodation.

*Where should people with dementia live? Using the views of service users to inform models of care, Forbat L, Wilkinson H in British Journal of Learning Disabilities 36 (1) , 6 -12*

#### **LDSL Summary**

<http://www.library.nhs.uk/learningdisabilities/viewResource.aspx?resid=283002&code=ba556f822820c7989c53e13f6262e412>

- **Are there inequalities in weight problems between the adult population with intellectual disabilities and the general adult population?**

This large scale population based prevalence study aimed to look at inequalities in weight problems between adults with Intellectual Disabilities and the general adult population. Using the Leicester Learning Disability Register information was gathered from all adults on the register about ethnicity, level of understanding, physical disabilities, epilepsy, relevant skills deficits, eating problems, other behavioural problems, autism, participation in sports, smoking status and medication.

Body Mass Index (BMI) was calculated for each individual, and men and women were categorised separately as underweight, normal weight, or overweight and obese. The study population was relatively young, with 74% being under 50. Half the group had difficulty preparing simple foods independently. 25% had Down syndrome and almost half the sample were taking medication of some kind.

With regards to range of weight - 18.6% of study population were underweight, 32.7% normal weight, 28% overweight, 20.7% obese. Obesity was almost twice as prevalent in women as in men, and underweight more prevalent in men than in women. There were no significant sex differences in proportions of men and women who were normal weight or overweight.

In both the ID and general population aged 25 and over, a higher proportion of women are obese than men. 19% of men with ID were underweight however, compared to only 2% in the general population.

The prevalence rate of 21% obesity reported in the study is lower than in previous studies. The finding that adults with intellectual disabilities living independently or with family were more likely to be obese than those in residential care is however consistent with earlier and small-scale studies.

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Underweight was associated in this study with relatively profound intellectual disabilities, and this is consistent with previous studies. People with Down syndrome were more likely to be obese than others in this study.

The authors suggest that the evidence based on managing obesity through diet etc. relates to the general population, and needs to be tested in the intellectual disabilities population. Recommendations also included more training on intellectual disabilities for all medical staff, annual health checks for people with intellectual disabilities and improved access to and support within mainstream services.

*Body mass index in adults with intellectual disability: distribution, associations and service implications: a population-based prevalence study, Bhaumik S Watson JM Thorp CF Tyrer F, McGrother CW in Journal of Intellectual Disability Research 52 (4) , 287–298*

### **LDSL Summary**

<http://www.library.nhs.uk/learningdisabilities/viewResource.aspx?resid=283003&code=fc8133b6d96e40f7b54fa5940f49ae95>

- **What behavioural characteristics of people with Down Syndrome and dementia lead to supporters referring them for specialist clinical assessment?**

This study set out to compare the behavioural and cognitive profiles of people referred to specialist clinical assessment for dementia with those of people not referred, to try to understand what behavioural characteristics that carers and supporters might see as warranting specialist assessment.

The study divided forty-six adults with Down syndrome into two groups, depending on how they entered the study. In the first group, the referred group was for participants who entered the study after having been referred to specialist psychology services. The second, the comparison group, was for participants volunteered into the project after receiving information on dementia sent out to day centres and residential care homes.

Statistical comparisons indicated that the groups did not differ significantly on age, gender, sensory impairments, diagnosed hyperthyroidism, living or day place arrangements. No participants in the study had significant psychiatric history.

Those in the referred group were found to have scores that indicated cognitive decline on also showed more behavioural excesses, although not behavioural deficits, and lower socialisation and coping skills than those in the comparison group.

Carers of those in the group referred for a dementia assessment reported greater impact of the reported behavioural excesses on staff than in the comparison group.

Those referred for dementia assessment showed more behavioural deficits along with decreased socialisation and coping skills. The authors suggest that there are

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potentially two factors involved in instigating a referral for a dementia assessment: first, the behavioural presentation of the individual, and second, the reaction or interpretation or effect of that behaviour upon carers or support staff. The authors suggest that the results of their study provide further support for the presence of behavioural changes in the course of cognitive decline in adults with Down syndrome. As with the general population, when behavioural or cognitive changes are significant, carers tend to seek help.

The authors suggest their findings demonstrate the importance of providing a specialist service for older adults with intellectual disabilities and Down syndrome, as appropriate referrals are being made for clinical assessment.

*Behavioural characteristics associated with dementia assessment referrals in adults with Down syndrome, Adams, C. Oliver, S. Kalsy, S. Peters, M. Broquard, T. Basra, E. Konstandinidi, S. McQuillan in Journal of Intellectual Disability Research 52 (4) , 358–368*

### **LDSL Summary**

<http://www.library.nhs.uk/learningdisabilities/viewResource.aspx?resid=283001&code=be6d625c59c51b765a584cc85cd10a5e>

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### **What else is new?**

A decade on: What have we learnt about supporting women with intellectual disabilities through the menopause?

Willis D.S. in Journal of Intellectual Disabilities, Vol. 12, No. 1, 9-23 (2008)

This article looks at the state of research into the menopause in women with intellectual disabilities 10 years after early work of Hollins et al. Studies have suggested the age of onset of the menopause is earlier for this group, but there are few studies helping us to understand how women with intellectual disabilities understand and experience the menopause. This study worked with 15 women with mild to moderate intellectual disabilities using a semi-structured interview to ask about their knowledge and understanding of the menopause. There was limited accessible information about the menopause and a paucity in the women's knowledge and understanding about it. The authors suggest a need for more accessible information in order to increase understanding and awareness of the menopause for women with intellectual disabilities.

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