

# *Psychosocial Interventions for People with Down's Syndrome and Dementia*

## **SUMMARY**

People with Down's syndrome have a very high risk of developing dementia at an early age. This project set out to develop a psychological assessment to assist the identification of dementia among this group of people. Further, it evaluated the impact of psychological and social interventions with people who were experiencing this disease. These interventions included increasing social and other activities and modifying the environment. The results confirm the value of regular screening of people with Down's syndrome over the age of 30 and of individually tailored programmes of work with those people who have developed dementia and their carers.

## **BACKGROUND**

This two-year study was based in the School of Psychology at the University of Birmingham and conducted in collaboration with Birmingham Specialist Community Health NHS Trust. It was one of the three projects in the area of Down's syndrome and dementia funded as part of the Growing Older with Learning Disabilities (GOLD) programme at the Foundation for People with Learning Disabilities.

Prevalence studies suggest that approximately 54.5 per cent of adults with Down's syndrome over the age of 50 years will present with dementia. Previous research funded by the Foundation has shown that the impact of dementia on the quality of life of a person who has Down's syndrome is significantly influenced by the difficulties experienced by the carer, in addition to the more immediate effects of dementia (Oliver et al., 2000).

A number of studies have described the sequential development of the cognitive and behavioural impairments which appear in adults who have Down's syndrome and dementia (Oliver & Holland, 1986). The sequence of acquired cognitive impairments is similar to that seen in the general population, with deficits in learning and memory preceding aphasia (problems with word finding) and apraxia (problems carrying out actions) (Oliver et al., 1998). With the onset of apparent changes for the individual in either behaviour or functional ability, a key task is to assess and identify a possible cause. It is important that the early signs of any potential decline are recognised as this helps with investigations into other possible causes such as vision and hearing impairment, hypothyroidism and depression. These changes may mimic dementia (Oliver et al., 2000). Thus, a process of differential diagnosis is vital to assess and guide interventions that may mitigate the impact of dementia on individuals and their carers (Prasher & Chung, 1996).

## THE RESEARCH

The study had two phases, assessment and intervention. The assessment phase involved identifying adults with Down's syndrome over the age of 30 and inviting them to participate in the study using a protocol for seeking informed consent. The following neuropsychological assessments and clinical interviews were carried out with the individuals and their carers.

- **Dementia:** An informant-based measure of dementia (The Dementia Questionnaire for Persons with Mental Retardation: DMR (Evenhuis et al., 1990) in conjunction with assessments of cognitive ability, using the Crayton et al. (1998) battery and clinical interviews with the individual and their caregivers and medical assessments.)
- **Adaptive behaviour:** Vineland Adaptive Behaviour Scale (Sparrow et al., 1984)
- **Receptive language:** British Picture Vocabulary Scale (Dunn et al., 1992).
- **Behavioural excesses and deficits,** including their impact on the individual and their caregiver, were assessed using the newly developed measure Assessment of Adults with Developmental Disabilities, described below.

Upon completion, the assessments were reported to the individual, their carers and to GPs.

Using the process of differential diagnosis, those individuals who were then presenting with dementia were invited to take part in the intervention phase. This phase utilised previously obtained assessment information to identify the particular personal, social and environmental needs of the individual and their carers in order, primarily, to develop appropriate strategies for psychological intervention. Secondly, to explore the impact of dementia on an individual's day-to-day functioning.

## THE FINDINGS

The aim of the psychological interventions was to help carers promote the cognitive functioning, self-esteem and general sense of well-being of the individual themselves.

- **Early identification and diagnosis:** The proactive and prospective strategy of early assessment and diagnosis has improved detection of individuals with Down's syndrome and dementia in Birmingham and Rugby.
- **Assessment of Adults with Developmental Disabilities questionnaire:** This measure was developed to explore the impact of dementia on the individual and their carer and the nature of difficulties experienced. The results showed that individuals with Down's syndrome and dementia present with more cognitive and behavioural deficits (such as forgetting what others have said to them) and excesses (such as wandering) than do individuals without dementia.
- **Observations:** Detailed direct observations of four individuals with Down's syndrome who had developed dementia revealed low levels of appropriate engagement. However, it was notable that appropriate engagement was usually preceded by staff providing active support (prompting and assisting but not 'doing for'). Additionally, some behaviours, such as talking to self, that had caused concern appeared to be functional, as they tended to occur when there were low levels of social engagement and were followed by contact with staff or other service users.

- **Carer information and training:** A more general sense of well-being can be addressed through sound, respectful communication, interaction and validation of the individual's emotional state. The carers' need for information about dementia at an early stage was evident through the provision of workshops, presentations, and weekly meetings with members of the project team.
- **Memory aids:** Memory aids were found to be a useful way of circumventing the difficulties that a poor short-term memory produces. Wall charts, portable planners and picture cues were developed to support individual recall and communication in the home and day placement.
- **Future life planning:** Future life planning, within a quality of life model, was carried out with one participant to explore and document her needs and wishes to mitigate the impact of changes to her service provision.
- **Opportunities for activities and stimulation:** Well-being can also be addressed through the provision of opportunities for activity and stimulation. Resources such as laser pictures, sensory objects and massage were provided, in liaison with occupational therapy services, and positively impacted on the individual's presentation.
- **Low-level behavioural interventions:** There was evidence that low-level behavioural interventions, such as distraction techniques, were effective in reducing specific behavioural difficulties, such as exposing oneself, shown by one individual with dementia.

## IMPLICATIONS

The study highlighted the need and importance of adopting a proactive and prospective baseline assessment strategy with individuals known to be at high risk for developing a dementia, as individual baseline assessments of cognitive and adaptive functioning enable faster and more reliable diagnosis if dementia is suspected.

Individuals with dementia require a high level of input over long periods of time and it is essential that regular monitoring and reviews occur and cases are not closed. Interventions may focus on the individual themselves, to enhance their sense of well-being and to compensate for impaired cognitive abilities, as well as supporting carers and their ability to manage difficult situations.

It is hoped that such work will raise service providers' awareness of screening methods for identifying, and techniques for meeting, the changing needs of people with Down's syndrome who develop dementia.

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- For further information about the GOLD programme contact Hazel Morgan, Head of the Foundation for People with Learning Disabilities.

**The Foundation for People with Learning Disabilities is part of the Mental Health Foundation.**

*This Update was written by Dr Sunny Kalsy and Professor Chris Oliver. For more information contact the School of Psychology, The University of Birmingham, Edgbaston, Birmingham B15 2TT. Tel 0121 414 4909/7206.*

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**The Mental Health Foundation**  
83 Victoria Street London SW1H 0HW  
Tel: 020 7802 0300 Fax: 020 7802 0301

**The Mental Health Foundation Scotland**  
5th Floor, Merchants House,  
30 George Square, Glasgow G2 1EG  
Tel: 0141 572 0125 Fax: 0141 572 0246

E-mail: [mhf@mhf.org.uk](mailto:mhf@mhf.org.uk)  
Website: [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)

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