

Overview of dementia issues in intellectual disability

Aging represents the success of the resilience of people with intellectual disabilities (ID), advances in medical care and treatment, advocacy and self-advocacy, and the development by providers of quality living environments and opportunities for enriching lives for the clients served. Equally the dedication of family carers, principally parents and increasingly siblings has supported the ageing of many more people with ID.

However, the dramatic shift in the age profile of persons with ID in Ireland and elsewhere from a younger to an older population has also resulted in a growing awareness of new and emerging challenges. Because people with ID are living longer, greater numbers of individuals are surviving into the age where they are at risk of developing dementia. This is particularly true for older people with Down Syndrome (DS) who are uniquely at risk of developing Alzheimer's Disease (AD) and who account for about one-third of all people with ID who have dementia. Over the next 20 years, the biggest proportional increase in numbers of people with ID will be in the over-55 age group, the age group at increased risk of dementia (McCarron and Lawlor 2003). It is generally agreed that dementia in persons with DS exceeds that of the generic population and it is estimated that 15 to 45% of people with DS over the age of 40 years have dementia (Prasher and Krishnan 1993). A recent Irish study involving 285 subjects with DS reported an age-specific prevalence of dementia at 5.7% in persons aged 40-50 years, 30.4% in persons aged 50-60 years, 41.7% in persons aged 60-70 years, and 50% in persons over the age of 70 years (Tyrrell *et al.* 2001).

These rates are considerably higher than the prevalence of dementia reported in the general population of between 4.3% to 10% in persons aged 65 years and over (Hofman *et al.* 1991). There is also evidence that people with DS experience an early and more abrupt decline in memory, behaviour and day-to-day functioning and work skills. The prevalence of dementia in adults with ID other than DS has been reported to be from 15.6% in persons aged 65-75 years, to 23.5% in persons aged 75-84 years, and 70% in persons aged 85-94 years (Cooper 1997). However, others (e.g., Janicki and Dalton 2000) report prevalence rates similar to the general population.

The increase in the numbers of people with ID and dementia is posing new challenges for those caring for and developing services for people with ID, and policy and service provision for this population is lacking. Many services are poorly prepared to meet and respond to the diagnostic and care needs of people with ID who are risk or have dementia. The potential impact for staffing, the current residential and service structures, and the financing of services is enormous.

The implications of increasing level of AD are best illustrated using statistics drawn from one Irish service provider. In 1993, at the Daughters of Charity Service, in preparation for a longitudinal study, 80 women with DS were identified who at that time were over age 35 years. They were then periodically assessed and followed for a 10-year period. In 1993, (7) 9% of the women were assessed as having symptoms of dementia; by 2003, notwithstanding deaths over time in the sample, (59) 74% were diagnosed

with dementia. Currently within the Dublin region of the Daughters of Charity Service there are 48 women with DS and AD, and 13 out the 31 community group homes are supporting at least one person with dementia, with five homes supporting two to three people with dementia. Given the increasing aging demographics of the population served by the Daughters of Charity Service and using age-specific prevalence rates for dementia in persons with DS, the above figures suggest that in five years there will be 30 more clients with this diagnosis, and 51 more in 10 years. As a result, 23 of the current 31 community group homes (many of which are two-storey) are likely to be supporting persons with dementia (McCarron 2005). Growing longevity means that a majority of the three groups will still be alive in 10 years, radically changing the make-up of this provider's population. Our work indicates that the same picture is being repeated in services throughout Ireland and the US.

In Ireland and the US, the financing of services has been based upon assumptions of fixed needs. Responding to the changing needs of persons with dementia—in terms of new requirements for 24-hour staffing, increased medical costs, and capital support for environmental modifications—presents new challenges that have not been planned for. In addition, staffing numbers and patterns, and the training of staff, have been focused upon client groups who are young and middle adult. Staff training focuses on supporting and promoting the independence of those who are working and engaging in community participation. Very different issues present when the client group has AD and these issues are challenging such staffing approaches and philosophies.

Impact for care and service provision

Despite these pressing concerns, to date responses to AD issues have tended to be reactive rather than proactive and the ID services system is just beginning to address these concerns. The impact on family carers is at an even earlier stage of response (McCallion *et al.* 2005). In fairness to providers, staff and families, these are new care situations and there is a need for an evidence-based model for services if resolution is to be realised, institutionalisation and re-institutionalisation avoided, quality of life maintained and costs contained. Help is also needed with day-to-day care issues when dementia is present.

The ID services system has traditionally been focused upon serving and maintaining persons with ID in the community for as long as possible and it has been driven by a service philosophy which emphasises positive approaches, skill acquisition and increasing independence. The inevitable decline associated with AD challenges this programming philosophy and there has been a danger within ID services that with changing needs providers seek transfer to other, often more expensive, institutional alternatives when dementia presents. This does not need to happen. Instead there are also opportunities in efforts to support aging in place and a growing interest in understanding the role of specialised units for people with ID and AD (Janicki *et al.* 2002). There have been some important developments in Ireland—for example, the development at St Michael's House of our first specialist dementia unit for persons with ID and AD, the redesign of a residential unit to support persons with dementia at Peamount Intellectual Disability

The ID services system has traditionally been focused upon serving and maintaining persons with ID in the community for as long as possible and it has been driven by a service philosophy which emphasises positive approaches, skill acquisition and increasing independence.

Services and the more recent development of a Memory Clinic and palliative care unit at the Daughters of Charity Services. Other important developments include the development and delivery of the first higher diploma in specialist nursing at Trinity College Dublin designed to prepare clinical nurse specialists in ID and AD. There is also research underway investigating the characteristics of models of service to maintain persons with ID and AD in the community (see, for example, Janicki *et al.* 2002; McCallion, Nickle and McCarron 2005; McCarron *et al.* 2003). These efforts are being advanced with support from the Health Research Board in Ireland and the Administration on Aging in the US. Cost and quality issues associated with such models are now being investigated. At a more basic level, work is also underway to find appropriate assessment instruments, to develop models for delivery of such screenings in a systematic manner and to develop an evidence-based approach to individual care and support.

A particular concern is to address end-of-life care issues for persons with ID and advanced AD. The Health Research Board and the Irish Hospice Foundation in Ireland, and the New York State Developmental Disabilities Council in the US, are supporting efforts to develop training programmes for ID services and palliative care provider staff. Increasingly, ID services providers attending to end-of-life care situations are confronting complex nutrition and hydration issues.

While it must be remembered that each person is unique and each individual will experience dementia differently, the experience to date at the Daughters of Charity Services and elsewhere suggests that clients and the services they need tend to fall into three groupings.

- Group 1: Some people may experience a relatively slow progression of dementia over approximately 5 to 8 years. While these individuals will require increasing supports, particularly in terms of staffing and some relatively low cost environmental modifications to their living spaces, they can often be maintained within their 'family unit', i.e. the home they have lived in throughout their decline. Aging in place and thereby retaining contact with familiar environments, family and friends is the optimal approach to service delivery for this group.
- Group 2: For some people, while decline may not necessarily be compressed, they present, particularly at mid-stage dementia, with behavioural and psychotic features such as nighttime wakening, wandering, agitation, screaming, and visual and auditory hallucinations. Some behavioural issues may be addressed in existing settings with improved communication approaches and attention to programming and environmental concerns. For other clients, dementia-specific environments with specialist-trained staff will be required to address their additional care needs.
- Group 3: For some people decline may be compressed and the person may progress to a stage of advanced dementia within a relatively short period of time, i.e. 1-2 years. This group will require specialist nursing and palliative care.

Meeting the needs of all three groups is the challenge for services providers. There are already specific recommendations emerging from the research to date to be considered by providers, staff, and families in the areas of assessment, communication and psychosocial strategies, environmental modification, day programme development, responses to challenging behaviours and end of life care. Also, ideas are emerging on effective ways to restructure person-centred plan development and monitoring to support programming and maintenance of quality of life at this life stage. Yet the issues are sufficiently complex that further research needs to be based upon a genuine collaboration between persons with ID, their families, the services community and academic researchers. A systematic and long-term effort is needed to accumulate an evidence base to guide care, policy and service redesign. Only when we understand what works best and in what situations it works will we have a rational basis for making important decisions, choices and resource allocations and re-allocations.

When it comes to dementia and ID, the future is now. Nothing will have a greater impact on the care of persons with ID and dementia than combining research evidence with clinical experience to redesign the services and care we offer to improve and maintain quality of life. This *Frontline* special issue will explore some of these issues and suggest relatively small changes likely to have a big impact on the experience of dementia for persons with ID, their families and carers.

**Dr Philip McCallion,
Dr Mary McCarron,
Dr Martin McLoughlin,
Clinical Director,
The Daughters of Charity Services,
Dublin.**

References

- Cooper, S.A. 1997 High prevalence of dementia among people with learning disabilities not attributable to Down's syndrome. *Psychological Medicine* 27, 609–16.
- Hoffman, A., Rocca, W.A., Brayne, C., Breteler, M.M.B., Clarke, M., Cooper, B., *et al.* 1991 The Prevalence of dementia in Europe: A collaborative study of 1890-1990 findings. *International Journal of Epidemiology* 20, 736–448.
- Janicki, M.P., McCallion, P. and Dalton, A.J. 2002 Dementia-related care decision-making in group homes for persons with intellectual disabilities. *JGSW* 38 (1/2), 179–96.
- Janicki, M.P., Dalton, A.J. 2000 Prevalence of dementia and impact on intellectual disability services. *Mental Retardation* 38 (3), 276–88.
- McCallion, P. and Nickle, T. 2005 *The Alzheimer's Disease Coordinated Care Project: Final report*. Albany, NY: Center for Excellence in Aging Services and New York State Office for the Aging.
- McCarron, M. and Lawlor, B.A. 2003 Responding to the challenges of ageing and dementia in intellectual disability in Ireland. *Ageing and Mental Health* 7 (6), 413–17.
- McCarron, M. 2005 A strategic plan for dementia at the Daughters of Charity Service (Unpublished).
- Prasher, V. P. and Krishnan, V.H.R. 1993 Age of onset and duration of dementia in people with Down's Syndrome. *International Journal of Geriatric Psychiatry* 8, 923–27.
- Tyrrell, J., Cosgrave, M., McCarron, M., McPherson, J., Calvert, Kelly, A., McLaughlin, M, Gill, M. and Lawlor, B.A. 2001 Dementia in people with Down's Syndrome. *International Journal of Geriatric Psychiatry* 16, 1168–74.