Chapter 9

Future prospects

Older adults with ID form a minority group of the general population, but because of their complex and special needs they require an intensive and integrated specialist service. Over the next two decades the population of elderly adults with ID will grow rapidly. These individuals are susceptible to a range of psychiatric disorders, in particular dementia in Alzheimer's disease (DAD). With the recent closure of long-stay hospitals and resettlement of older adults into the community, the primary health service requires ongoing support from the specialist services to provide optimum care.

There is still limited information on how people with ID actually 'age'. Do people with Down syndrome (DS) suffer from premature ageing? Is the ageing process the same irrespective of the underlying cause of the ID, or is ageing only affected by, for example, chromosomal syndromes? Certainly an association between DS and AD has now been established, but limited research data are available about the possible association between ID generally and dementia. The effects of age-associated functional decline (normal ageing) and its relationship to dementia remain an area for further investigation.

The development of pharmacological agents to treat DAD in adults with ID has been one of the most significant developments of recent times. Undoubtedly over the next decade further research will be made available regarding the efficacy of these drugs, clinical differences between the available drug types, and their roles in disease prevention and in modifying the underlying disease process. Temporary clinical relief has been demonstrated in adults with DS who develop DAD, but long-term studies are needed to determine the effects on quality of life and the cost-effectiveness of treatment.

The accurate diagnosis of DAD in adults with ID is still an area of concern, but future developments in the identification of biological markers may help to resolve this issue. Macrocytosis, free radical changes, plasma amyloid load and neuroimaging abnormalities are areas of ongoing and future interest. Biological aspects of DAD in adults with DS will be the focus of future research.

With the molecular mapping of chromosome 21, the genetic association between DS and AD will advance considerably from the present position, namely that adults with DS have triplication of the amyloid precursor protein (APP) gene. Identification of polymorphisms of the APP gene, and isolation of promoter and other regulatory genes in the critical region of DS will enhance our understanding of the aetiology of AD in the DS population. Associated stem-cell research remains an exciting area of future development.

Service and clinical developments are ongoing. In 2001, a number of international researchers and clinicians met and developed a working group on dementia care practices (Wilkinson and Janicki 2002). They produced the *Edinburgh principles*, which can be summarised as follows.

1 Adopt an operational philosophy that promotes the utmost quality of life of people with ID affected by dementia, and whenever possible base services and support practices on a person-centred approach.
2 Affirm that individual strengths, capabilities, skills and wishes should be the overriding consideration in any decision making for or by people with ID affected by dementia.
3 Involve the individual, his or her family, and other close supports in all phases of assessment and services planning and provision for the person with an ID-affected dementia.
4 Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs and support the healthy ageing of people with ID affected by dementia.
5 Plan and provide support and services that optimise remaining in the chosen home and community of adults with ID affected by dementia.
6 Ensure that people with ID affected by dementia have the same access to appropriate services and support as is afforded to other people in the general population affected by dementia.
7 Ensure that generic, co-operative and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future needs of adults with ID affected by dementia.

The universal implementation of these principles would go a long way towards ensuring that older adults with ID receive the care they deserve and age healthily. This includes the right to a healthy lifestyle, a healthy living environment, a positive mental attitude towards ageing, a positive support network, and safety, security and stability.

Now that we have entered the twenty-first century, researchers and clinicians have an opportunity to considerably change the outlook for older adults with ID. Determination of the causes of AD, and effective treatment and prevention of DAD are aspirations which can almost be achieved. Indeed the greatest task faced by the international community will be the satisfactory implementation of future developments worldwide to ensure that all older people with ID benefit from them.