# National Strategy on Dementia Consultation Questions

Throughout our community we are caring for an older population with varying needs and conditions including Alzheimer’s disease and other dementias. These are progressive conditions that not only have a huge impact on the physical, psychological and emotional state of the person with dementia but also on their families and carers.

## Question A

What is your particular interest in/experience of dementia, e.g. health-care professional/ diagnosed with dementia/ caring for someone with dementia?

## Answer A

The National Disability Authority is an independent statutory body providing policy advice on disability.

## Question B

The report**, Creating Excellence in Dementia Care: A Research Review for Ireland’s National Strategy** (Cahill et al, 2012) has outlined the following elements for inclusion in the Strategy, which have been grouped below under 6 broad headings.

Of the areas outlined, what should the main priorities for the Strategy be?

## Answer B

The National Disability Authority broadly welcomes and supports the priorities as highlighted in the research documentation produced to inform the development of a national policy on dementia and detailed as follows:

### Awareness

* Primary prevention and ways of avoiding or delaying the illness
* Public awareness about dementia

### Early diagnosis and Intervention

* Early diagnosis
* Specific training in dementia for health care professionals
* Appropriate services for people with early-onset dementia, including people with Down Syndrome

### Community-based services

* Dedicated and flexible community-based services

### Long-stay residential care

* Psychosocial approaches to complement existing medical and neurological models of service delivery
* Dementia-specific residential care units

### Acute care

* Awareness, ownership and leadership of dementia in acute hospitals

### Community/Acute/Long-stay residential care

* Case management models of integrated care
* End of life care services for people with a dementia

### Research

* Information systems on the number of people with dementia, severity of disease, placement patterns and quality of life

In relation to the above, the National Disability Authority would stress that it would be important to ensure that the proposed strategy addresses as priorities:

* The issue of early diagnosis especially among people with Down Syndrome and Intellectual Disability, given the prevalence of dementia among this cohort from 30 -50 years of age
* Aligned with early diagnosis, is that systems, structures and age appropriate services need also to be put in place for this group of people
* That services for people with dementia should have skilled and competent personnel to support people with other disabilities (for example, people who have mobility, sight, hearing, mental health difficulties) who may develop dementia
* That dementia care pathways are established in line with best international practice (as highlighted in the research)
* The expansion of dedicated and flexible community-based services and family support services based on a case management system. Given the current financial constraints, some progress could be made by prioritising community care, co-ordination and integration of service provision and looking at better ways of working
* The establishment of an enhanced information exchange by:
* sharing good practice
* education and awareness among the general public about dementia and among professionals working with people with a view to stigma reduction
* gathering relevant data so there can be accurate information on prevalence of dementia and quality of life for people with dementia

**Question C**

What specific issues would you like addressed in any or all of the priorities that you have selected?

## Answer C

Specific issues that should be addressed include:

* Early diagnosis for young people who are at risk. People with Down Syndrome, for example, are a particular vulnerable group, where there are high prevalence rates for early onset Alzheimer type dementia. Good practice is to conduct baseline assessment from the age of 30 onwards and then at decreasing intervals as the person with Down Syndrome ages. A similar process should also be provided for other groups of people with disabilities under the age of 65 who have significant prevalence rates of early onset of dementia
* Education and training of key personnel working in current service provision for people with Intellectual Disability regarding dementia. Such awareness training would enable personnel recognise early signs of dementia. In addition, it would enable personnel develop techniques and make preparations for supporting those who may develop dementia. Such techniques might include learning as much about the person and their past life. This would involve developing a life story book and gathering together a box of meaningful objects. Such techniques would then help personnel make meaningful interventions with a person who has developed early dementia and is struggling with memory loss
* Development of psychosocial processes and the use of such things as music and touch to complement existing medical and neurological interventions
* Developing a partnership approach with those providing informal care such as family members in the home. Informal care from family and friends is significant. The strategy should address how best this form of care should be supported by the local community-based services on an ongoing basis and not solely as a crisis intervention approach, with a view to supporting a person with dementia to live in their own home environment as far as possible
* People with dementia are particularly sensitive to their psychosocial environment and good environmental design is now widely regarded as critical to the care of people with dementia. It is also been suggested that small-scale living makes it easier to provide good dementia care (Marshall, 1999; de Lange et al., 2011). The National Disability Authority’s Centre for Excellence in Universal Design is developing design guidance for dementia and home design for Ireland (looking at new build and retro-fit homes from a Universal Design approach), and hope to complete this work in early 2013
* Where people with dementia have to be moved in to residential settings these should be small homes that are universally designed. In this regards it would be helpful to have developed standards around such design which would encompass the basic principles for dementia where the home environment (including internal and external spaces) must be:
* Calm and stress free
* Predictable and makes sense
* Familiar
* Suitably stimulating
* Safe

The National Disability Authority’s Centre for Excellence in Universal Design would be happy to advise further in relation to the universally designed environments for a person with dementia and their family

* The national dementia strategy should be integrated across other health strategies. This would include the mental health strategy **A Vision for Change** (to address the needs of people with mental health issues in residential settings who have dementia), and the implementation plan for disability services which is to follow the recent **Value for Money and Policy Review of Disability Services in Ireland**

**Question D**

Is there anything else that should be considered for inclusion in the Strategy?

## Answer D

1. Advanced care directives - people with dementia to have a say making informed choices about planning for their care. This is now possible with early diagnosis.
2. The issue of legal capacity, in the light of forthcoming legislation on capacity and supported decision making, to give effect to Article 12 of the UN Convention on the Rights of Persons with Disabilities.
3. Taking a lifecycle approach, that reflects the full journey for the person and their family following a diagnosis of dementia, in the context of their overall health, well being and environment.