Contents

1. About The Alzheimer Society of Ireland................................................................. 2
2. Background to the multidisciplinary roundtable ................................................... 2
3. Presentation: The National Dementia Strategy - one year on.................................3
4. Facilitated Discussion ...............................................................................................4
5. Concluding note .......................................................................................................8

Appendix 1    Agenda
Appendix 2    Participant list
1. About The Alzheimer Society of Ireland

The Alzheimer Society of Ireland (ASI) is the leading dementia specific service provider in Ireland.

The ASI works across the country in the heart of local communities providing dementia specific services and supports and advocating for the rights and needs of all people living with dementia and their family carers.

Our vision is an Ireland where no one goes through dementia alone and where policies and services respond appropriately to the person with dementia and their family carers, at the times they need support.

A national non-profit organisation, the ASI is person centred, rights-based and grassroots led with the voice of the person with dementia and their family carer at its core.

The ASI also operates the Alzheimer National Helpline offering information and support to anyone affected by dementia at 1800 341 341.

Since the publication of the National Dementia Strategy (NDS), the ASI has been a member of the Irish Dementia Strategy Monitoring Group.

2. Background to the multidisciplinary roundtable

Ireland’s first National Dementia Strategy (NDS) was published in December 2014. One year after its publication, the ASI organised a facilitated roundtable discussion for multi-disciplinary clinicians. This event was a follow-up to the successful 2013 multi-disciplinary roundtable held to assist the development of the NDS.

The roundtable in December gave participants the opportunity to reflect on whether the NDS had delivered more integrated and collaborative approaches to dementia care across Ireland’s health and social care sector.

Participants at the roundtable were healthcare professionals from multidisciplinary clinical areas including occupational therapy, social work, clinical psychology, medicine, old age psychiatry, physiotherapy, speech and language therapy and nursing. Participants were invited to the roundtable discussion to share expertise and learn more about the NDS.

Participants were welcomed by Colette Kelleher, CEO of the ASI, who highlighted the role the ASI is taking to monitor the implementation of the NDS and to provide a dialogue on this. This welcome was followed by a presentation on the NDS by Dr. Emer Begley, the ASI’s Policy and Research Manager, followed by questions and a facilitated discussion session.

The facilitated roundtable discussion was structured around four key questions:

1. How does multi-disciplinary work ensure people live well with dementia?
2. Has the NDS delivered integrated and collaborative care across the dementia journey?
3. Do clinicians see leadership on dementia care since the launch of the NDS?
4. What gaps exist on the ground in turning the NDS priority action areas into practice?

3. Presentation - The National Dementia Strategy – one year on

This presentation covered the following key points:

- The aim of the NDS is “to improve dementia care so that people with dementia can live well for as long as possible, can ultimately die with comfort and dignity, and can have services and supports delivered in the best way possible” (NDS, 2014: 8).
- There are 8 strategy principles.
- There are 6 priority action areas:
  1. Better Awareness and Understanding
  2. Integrated services, supports and care
  3. Timely diagnosis and intervention
  4. Training and education
  5. Research and information systems
  6. Leadership
- There are 14 priority actions and 21 additional actions associated with these priority areas.
- Funding has been allocated to the NDS for four areas: Intensive Homecare Packages (€22.1m); Health and Well Being (€2.7m); National Dementia Implementation Office (€1.5m); and Primary Care (€1.2m).
- Under priority action area 1, a number of developments have taken place, which includes the development of a National Dementia Friendly Awareness Campaign and Education and training through the Dementia Elevator Programme, Dementia Services Information and Development Centre and HSE Dementia Education Programme.
- Under priority action area 2, progress has largely been made through the PREPARED Project, which will develop, deliver and evaluate training and education interventions for primary care clinicians.
- Under priority action area 3, the main development has been the Intensive Home Care Packages for people with dementia, which were linked initially to hospital discharge. There are 8 pilot sites: North Dublin, Dublin North City, Dublin South West, Dublin South East, Cork City, Waterford, Limerick and Galway. There are 500 packages available and in December 2015, 67 packages were in use.
- Under priority action area 4 and 5, there were no updates.
- Under priority action 6, the HSE National Dementia Strategy Implementation Office has been established. The Strategy Implementation Plan is evolving over the lifetime of the strategy; and a Senior Manager responsible for dementia is to be appointed in 2016.
- There is a monitoring group led by the Department of Health, which monitors the progress of the NDS implementation. In addition, there is a Joint Oversight Group and an Independent Advisory/Evaluation group.
4. Facilitated Discussion

Participants were divided into five discussion groups, each with a designated facilitator/note-taker. The following captures the key issues which were raised during discussions and are presented under four specific questions:

**Question 1: How does multi-disciplinary (MD) work ensure people live well with dementia?**

**Collaborative working to achieve better standards of care**

- Collaboration and communication across different clinical areas works to ensure that a person can access the right care at the right time and by the right clinician.
- MD working was referred to as “the only approach”. Without a MD approach care is general and not focused on individual’s needs.

**Challenges to this MD approach**

- Understaffing and a lack of resources can undermine the success of multi-disciplinary working.
- This approach needs to be led from the top and management buy-in is critical.
- Some gaps in MD work were noted such as a lack of knowledge among the different disciplines about who does what, why and how.
- Health professionals need more education about their roles on MD teams. This education should be started at undergraduate level.
- Training and education is also required for dementia care e.g. clinicians need to understand the diversity of needs that comes with a dementia diagnosis.

**Identified need for model of good practice**

- More scope within acute care for MD working but a model of best practice is needed.
- Most MD teams are working on the basis of interest rather than being led by a model/ framework for developing MD teams.
- There needs to be a dementia champion within teams.
- Participants had many ideas for development, such as a dementia ‘ready response’ team in hospitals, similar to the service that exists for stroke. Another suggestion was the introduction of dementia-friendly wards.

**Additional roles with the MDT**

- The GP is critical for referring the person into the MD system. However, the GP may not always be part of the MD team.
- The role of the consultant was also considered critical in the acute sector and the PHN in the community.
- Case management can be an important part of MD care as there needs to be a designated point of contact for the person with dementia and their families.
- Important to remember that care assistants and family members should be part of a MD team.
- Advocacy is critical and a MD team with a case manager could play a key role in advocacy for people with dementia within the health and social care system.
Question 2: Has the NDS delivered integrated and collaborative care across the dementia journey?

Gaps remain despite publication of the NDS

- Lack of leadership - most clinicians felt that the MD work on the ground was led by interested staff rather than strategic leadership based on the NDS.
- Stigma and diagnosis was discussed in terms of a lack of GP training and education.
- It was felt that the NDS is not on the agenda within acute care.
- There is a lack of understanding of what MD work should look like in long-term care.
- Voluntary agencies are filling-in the gaps in terms of the delivery of services.
- One area that the NDS fails to deliver is timely diagnosis. There is too much focus on GPs and not enough on the role of MD teams.
- Funding is still not balanced in terms of acute versus community care and money should follow the person not be dictated by historic arrangements where community services/supports are continuously under-resourced.

Good practice/positive approaches

- Where people have completed dementia training there is a positive impact in promoting dementia-specific approaches.
- There was a discussion around a number of innovative pieces of work that people are undertaking in their respective areas and these include Speech and Language Therapy students going into dementia specific facilities to assist people with their communication (not just swallow as was previously the case), this is a new development.
- Also there is a project being undertaken in the Mater to improve signage as part of a clinical development nurses training programme. They are looking at interventions in the environment and making it more dementia friendly.

Role identification within dementia care

- The NDS looks at social care, but does not define what this is and there is no mention of certain disciplines, for example speech and language therapy.
- It is not clear to different disciplines what their role is under the NDS and what their interventions should/could be.
- It all comes back to the need for a clear care pathway.

Vulnerable groups within the population of people with dementia

- Those in the end stages who enter respite care often do not know where to turn. There is no signposting and this has not changed under the NDS.
- People living alone with dementia were discussed as facing additional barriers to diagnosis and follow-on supports.

Poor practices

- It was noted that often care provided is still not person-centred.
Question 3: Do clinicians see leadership on dementia care since the launch of the NDS?

It was noted that leaders can have a huge influence in the HSE and are instrumental in bringing about change even if it is against the tide.

Gaps in leadership identified

- There is no structure to dictate models of best practice and there is no accountability. It is still left up to individual staff members who are visionaries.
- A dementia-friendly group was set up in one hospital in order to implement the NDS, but this did not come from top management. A group of clinicians/managers saw the need and decided that this might be a good way to go – there was no overarching leadership provided.
- Leadership could come from people with dementia and the dementia strategy office in the HSE could pull together all the available resources and involve the voice of the person with dementia.
- Dementia is a community issue so we need the Department of Education and County Councils to be involved too.
- It was suggested that a key worker is needed in each primary care team to address issues of leadership.

Services and supports are fragmented

- Gaps were noted in terms of poor or no information received from the NDS implementation office at the time of the roundtable.
- Awareness generally - there needs to be more awareness about dementia and its impact on the person and their families.

Good practices around leadership identified

- Leadership acknowledged in training (DCU and 2 day HSE course).
- One issue in a congregated setting is that different staff members may have very different skills/training on dementia.
Question 4: What gaps exist on the ground in turning the NDS priority action areas into practice?

Local responsibility
- Where MD work is taking place, there can be a gap in terms of an identified leader or designated person for people with dementia and their families.

Specialised approaches for minority groups
- Services for people aged under 65 years were identified as needing serious attention.

Better integration of services and supports
- More linkage needs to happen between clinicians and community groups and community based services like Alzheimer cafes, social clubs etc.
- There needs to be a framework for implementing the strategy and an integrated care pathway.
- The Intensive Homecare Packages need to be part of a MD approach to dementia care. Home care is not a stand-alone service nor is it the only way to ensure that a person continues to live in the community for longer.
- Need to move from a crisis response to a co-ordinated response.
- The GP needs to be integrated into MD teams and this is not happening where teams exist. It varies from area-to-area and needs to become more standardised.
- An additional gap exists given that Ireland does not have a Chronic Disease Management Strategy and yet dementia is complex and often presents with comorbidities.

Post diagnostic supports
- Gap identified in post-diagnostic supports.
- If diagnosis increases so too will demand for post-diagnostic supports; there needs to be more strategic thinking behind this development.

Funding and staffing
- The main gap is insufficient numbers of appropriately trained staff and, linked to this, funding.

Communication and awareness around the NDS
- There is a lack of communication regarding the NDS and how it is being rolled out.

Professional training
- All nursing students should be offered a module on dementia.
5. Concluding note

Participants welcomed the opportunity to share knowledge and expertise and there was an appetite for further roundtable discussions. The key messages revolved around the need for leadership for MD working; the importance of education and training; the need for communication; and the need for resources to ensure that MD work can be undertaken, with the involvement of all key stakeholders. There was a general concern that more communication on the NDS needs to take place to ensure that clinicians are aware of all related actions and developments.
Appendix 1:

**Agenda**

10.30 Registration

11.00 Welcome and overview
   Colette Kelleher, CEO, ASI

11.10 The National Dementia Strategy – one year on
   Dr Emer Begley, Policy and Research Manager, ASI

11.40 Our Hopes for the National Dementia Strategy Video, Irish Dementia Working Group

11.45 Facilitated Discussion & Feedback on
   - How does multi-disciplinary work ensure people live well with dementia?
   - Has the NDS delivered integrated and collaborative care across the dementia journey?
   - Do clinicians see leadership on dementia care since the launch of the NDS?
   - What gaps exist on the ground in turning the NDS priority action areas into practice?

12.50 Where to from here?

13.00 Lunch
## Appendix 2: List of Participants

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<tr>
<th></th>
<th>Name</th>
<th>Profession</th>
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<tbody>
<tr>
<td>1</td>
<td>John Brennan</td>
<td>Social worker</td>
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<tr>
<td>2</td>
<td>Lorraine Carmody</td>
<td>Speech and language</td>
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<td>3</td>
<td>Aofe Carolan</td>
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<td>4</td>
<td>Janet Crowley</td>
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<td>5</td>
<td>Carol de Wilde</td>
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<tr>
<td>6</td>
<td>Aisling Denihan</td>
<td>Old Age Psych.</td>
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<td>7</td>
<td>Suzanne Dooley</td>
<td>Speech and language</td>
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<td>8</td>
<td>Emer Duffy</td>
<td>Occupational therapist</td>
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<td>9</td>
<td>Karen Fahey</td>
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<td>10</td>
<td>Clare Fallon</td>
<td>Geriatrician</td>
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<td>Deirdre Fitzgerald</td>
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<td>Maria Fitzpatrick</td>
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<td>Laura Flood</td>
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<td>14</td>
<td>Matthew Gibb</td>
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<td>Christina McKenna</td>
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<td>Deirdre Moran</td>
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<td>Mareta Mullane</td>
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<td>Anne Ryan</td>
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<tr>
<td>36</td>
<td>Ruth Usher</td>
<td>Occupational therapist</td>
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Further information is available from the Advocacy and Public Affairs Team, The Alzheimer Society of Ireland
Tel: 00 353 1 207 3800 Fax: 00 353 1 210 377 www.alzheimer.ie