Dementia Friendly
Ireland
Sounding Board Event Overview
June 13th 2016
Attendance

- 132 people attended
- Broad range including individuals, carers, PWD, organisations.
- Organisations represented across sectors- HSE, health and care professionals, voluntary/comm, research/academic, retail, advocacy
Attendance

Breakdown of attendees

- HSE: 29.9%
- Voluntary/comm/Charity: 22.2%
- Other: 13.7%
- Hospital/Health Centres: 9.4%
- Private care providers: 8.55%
- Retail/Banking: 6.84%
- Research/Academic: 5.13%
- Professional bodies: 1.71%
- Statutory/State Ag: 1.71%
- County Council: 0.855%
Attendees

- The breakdown of attendees shows a dominance of vol/community sector, health and HSE attendees
- Stakeholder outreach should be considered for business and industry
- In addition County and City Councils should be targetted
- Professional bodies including those in the medical and health sectors
- Research community- some key academic figures need to be included
Speakers

▷ Brian Lawlor, Chair of Steering Group - Campaign overview to date

▷ Zuilmah Wallis, Kick Communications - Qualitative Research Review

▷ Joan Fitzpatrick, Living Well with Dementia - Overview of Stillorgan Project
Speakers

▷ Ronan Glynn, HSE - Overview Quantitative Research & Literature Review

▷ Ronan Smith, Irish Dementia Working Group - Personal Perspective

▷ Louise O’Mahony, Banking and Payments Federation - Service/Business Perspective
Speakers

Dr Leandro Herrero

Explored the principals of social change and how a campaign might maximise its impact.
Participation
Ideas for Change

Attendees asked to discuss and suggest ideas for change
Ideas for change

- Attendees asked to discuss their ideas in relation to 3 key areas
  - Me & Mine
  - Community
  - Organisations
824 Ideas for Change

- Me & Mine
  - 340 Post its

- Community
  - 193 Post its

- Organisations
  - 291 Post its
Me & Mine

Access to services/supports
Information
Talking/listening/sharing
Awareness
Education/Training
Voice of PWD
Social Incl/Comm

No. of responses

Services & Support
Information
Awareness
Talking & Listening
Education & Training
Respect & Dignity
Themes
Voice of PWD
Social Inclusion
Intellectual Disability
Independence
Carers
Diagnosis
Other
"Real experiences, authentic voices need to be heard"
"Sometimes it seems that there is a lot of talk - what about action! Real people are suffering daily..."
“Denial can prevent people flourishing”
“When I got my diagnosis, I wanted to meet someone else who had dementia and I wanted education”
Community

Access Services/Support
AWARENESS
Voice of PWD
Environment
Volunteering/
Befriending
Information
Intergenerational
Training

Themes

No. of responses

Awareness
Voice of PWD
Environment
Training
Social Inclusion
Build existing projects
Services/Supports
Volunteering
Intergenerational
Information
Other
"Giving people with dementia an opportunity to contribute"
“We need to talk positively about dementia with all”
"Do with rather than for"
“Need personal assistants for PwD to help them integrate in community"
“Public health nurses need dementia specific training to identify needs in community"
“Under 65s need more community supports and services"
"Creating a community where PWD feel comfortable"
“Public perceptions of dementia need to be change...life after diagnosis"
Organisations

Access
Services/Support
Practical actions businesses can take
Environment
Awareness
Information
Training
Voice of PWD
Social Inclusion
"Ask people what they need themselves"
"Dementia friendly champions at national and local levels"
"Creating a sensory environment that is dementia friendly"
“More dementia friendly training needed for shops and services”
“Businesses need to recognise their customers living with dementia may have particular needs”
“Treat people with respect and give them more time e.g. slow lane checkout"
“Don’t make assumptions. Take time and listen”
Frequently mentioned words
Key areas identified in feedback

**Access to support/services**
- Need for centralised info/signposting
- Better co-ordination of services
- Lack of knowledge about what is available
- Need for pathways to diagnosis and post-diagnosis to be identified and communicated

**Voice of PWD**
- The voice of the individual needs to be heard and listened to
- Emphasis on seeing the person not the disease
- Right to express preferences
- Dignity & Respect
- Personhood

**Supports for carers**
- Role of carer recognised/respected
- Care and support for carer
- Peer-Peer support
- Respite services

**Awareness**
- Need for greater public awareness
- Intergenerational awareness
- Personal experiences to be communicated
- Challenging language

**Transport**
- Transport emerged as a barrier to accessing services and supports
- But also a barrier to social inclusion and community involvement for PWD

**Building on existing projects/networks**
- Need to build on local and national pilots and existing projects
- Need for better communication and collaboration between groups and projects
Key areas identified in feedback

**Information**
- Need for a centralised trusted source for information
- Info on signs and symptoms
- Info on coping
- Info on types of dementia
- Info re under 65s dementia
- Info re preventative approaches

**Community**
- Strong feeling that a lot of support can be built among sports, clubs, associations at community level
- Need to engage with orgs that have national/local spread e.g. GAA, IFA etc

**Supermarkets and local shops**
- Identified as key locations where awareness can be built and steps can be taken to make DMF Post Offices and pharmacies also ident.

**Cohesion and Coordination**
- Need for umbrella organisation frequently mentioned to co-ordinate efforts

**Financial Issues**
- Issues around finance/fraud/abuse frequently raised
- Better info on consent/legal issues
- Engagement financ. orgs

**Balancing positive/negative**
- Significant mention of need to balance the realities of living with dementia/ and caring with positives e.g. Focus on abilities
Some outlying themes

Fear
Anxiety
Confusion
Anger
Grief

Helplessness
Caution
Fear
Misunderstanding
Willingness to help

Caution
Consent
Resourcing
Legal implic.
Research
Next steps

- Finalising campaign plan and beginning creative development
- Linking with existing organisations and providers to enable sharing of information and resources
- Developing resources as agreed including printed materials, website etc
- Following up with organisations and partners to discuss involvement in campaign
- Working towards Phase 1 launch September
Towards a Dementia Friendly Ireland

Nearly 50,000 people in Ireland are living with dementia, and every year another 4,000 are diagnosed. 11 new people every day. There are also more than 50,000 people in Ireland who are caring for someone with dementia - and a great multiple of that when counting all of their wider family and social networks. By 2026, the number of people living with dementia will have increased to over 100,000.

Health Services, in partnership with Atlantic Philanthropies, the Alzheimer’s Society of Ireland, academics and dementia experts, the wider health, pharmacy, community, and potentially the retail and banking sectors, wish to develop and implement a nationwide support movement for people with dementia and their carers. This campaign is one of the key programmes underway.

www.hse.ie/dementiafriendly