Slaying the Dementia Dragon: Alzheimer and Related Organisations Responding to Stigma and Social Exclusion

Gráinne McGettrick
• The issue............

• The challenge...........

• The solution.............
Dementia and Stigma

Dementia (demens) = ‘without a mind’
Dementia Reconsidered
“How you relate to us has a big impact ..........You restore our personhood, and give us a sense of being needed and valued. Give us reassurance, hugs, support, a meaning in life. Value us for what we can still do and be, and make sure we retain social networks. We're still here, in emotion and spirit, if only you could find us.”

Christine Bryden
• Why the Dementia Dragon?
Slaying the Dementia Dragon – the Challenge

New Social Group

Life lesser lived

Public ignorance negativity

Not health care priority

Stigma by Proxy
Slaying the Dragon: The Solution

Active Citizenship

Public perceptions

healthcare system

dementia workforce

People with dementia and their carers

Alzheimer Orgs
Alzheimer and Related Organisations

Innovators of Change
What People with Dementia are Saying about Us

“Why do I play this exhausting game of hide and seek in relation to others? Is this my problem alone or is it also yours?”
(Marcel Brasey speaking at conference in Paris 2009)

“For better or for worse the world depends on the people seated in this room to make it right for people living with dementia”
(Richard Taylor, ADI 2009)

“We look for leadership from our leaders, from our Alzheimer societies to do more than raise money for research. We look to you to provide more than information, group experiences, places to store us for a day. Why don’t you do first things first: directly support people with the dementia in whose name you raise money?”
(ditto)
Fellow Travellers?

“Solidarity, comfort and reassurance are not ‘nothing’”
What is your dragon?

Do we really believe in the power of the person with dementia?
Valuing People with Dementia

“

We do not bite, We may sometimes need an explanation; we may need to be told several times, we may get confused in ways you are not. But does that mean we should not be full partners with you in our crusade?….Let us in! Affirm our worth by partnering with us”

Richard Taylor (ADI 2009)

Only those living with dementia know what it is really like............cease to be a sideshow and instead are full participants in the work”.

Knauss and Moyer (2006)
Checklist for Organisations
From the inside out
Where to from here?
Taking Action Irish Style
Dublin to Perth ?
Dementia Manifesto 2007-2009

Making Dementia a National Health Priority

The time for action is now

Currently there are 38,000 people with dementia in Ireland; in 2026 there will be 70,115; in 2036 there will be 103,998

There are 50,000 carers of people with dementia in Ireland

Right now, there are 100,000 people in Ireland whose lives are directly affected by dementia; this figure increases three or four-fold when you consider the effect on the wider family

The 2006 baseline cost of dementia in Ireland is estimated at €400m

A reluctance to commit additional resources is at the heart of the problem in relation to the implementation of the national Action Plan for Dementia

Demographic trends, health and social care cost and disease burden mean that dementia must become a national health priority issue.

Positive Solutions

The Alzheimer Society of Ireland calls on the Government to recognise and designate dementia as a national health priority. One of the key ways to achieve this begins with the full and accelerated Implementation of An Action Plan for Dementia (APD). The Alzheimer Society’s Dementia Manifesto is a further refinement of the priorities set out in the three-year APD, based on consultation and research with a key range of stakeholders. In practical terms, The Alzheimer Society of Ireland wants the Government to support positive solutions to improve the quality of life for people with dementia and their carers. It seeks an investment in three main areas over the next three years:

1. Enhanced and flexible community based services - €63m
2. Early diagnosis, intervention, awareness and education - €12m
3. Medical and Social Research - €30m

The total financial investment required to achieve the implementation of this Manifesto is €35m per annum for the next three years; €21m for service provision; €4m for awareness raising and €10m for research.
Election 2011 Manifesto Voter Prompt Card

Action on Dementia

As part of our election campaign we are asking all the public representatives if elected, to pledge their support for the following:

- A commitment to developing a National Dementia Strategy by 2013 to be included in the next Programme for Government and ensuring that there is a Minister/or Minister of State appointed with overall political responsibility for its delivery, with dedicated funding and an implementation plan.
- The provision of quality driven, dementia specific services in the community to keep people living at home.

When the election candidates call canvassing, as a carer/ person with dementia, tell them what you want them to do:

1. Ask for a clear answer about what are they doing/propose to do to support the provision of community services (day care, home care, respite care) for the people living with dementia and the carers in your constituency?
2. Ask them directly what they will do to protect and support the further development of dementia-specific community services in your constituency?
3. Ask them have they supported the development of a National Dementia Strategy by 2013 by signing up to the petition online at www.alzheimer.ie
4. Tell them your story of the reality of living with dementia.

There are 44,000 people with dementia in Ireland and 50,000 people caring for them in the community. Dementia is an umbrella term of conditions that cause brain cells to die with life changing impacts. It has significant social, medical and economic implications.

Please support our campaign to make dementia a national health priority at www.alzheimer.ie

Alzheimer National Helpline 1800 341 341
Perceptions of Stigma in Dementia: An Exploratory Study

by The School of Nursing and Midwifery, Trinity College Dublin
Finding Solutions

“talk openly about dementia because if we are to kill the demon then first we have to say its name”

Terry Pratchett
Thank you

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www.alzheimer.ie