Mapping dementia-friendly communities across Europe

A study commissioned by the European Foundations’ Initiative on Dementia (EFID)

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EFID’S AIM

 To promote inclusive and sustainable environments for people living with dementia and their carers in communities across Europe;
 To encourage the inclusion and participation of people living with dementia in society as active citizens;
 To change society’s perception of dementia;
 To transfer knowledge within Europe.

Who’s involved?

Fondation Médéric Alzheimer
King Baudouin Foundation
Robert Bosch Stiftung
The Atlantic Philanthropies
Joseph Rowntree Foundation
Life Changes Trust
Genio Trust

*Coordinated by: NEF – Network of European Foundations*
Started in 2011, EFID is now in its III Phase (2015-2016).

EFID I Phase (2011-2012):

1. A Europe-wide Awards Scheme “Living well with dementia in the community”
2. A learning platform:
   • Publication on frames and counter-frames
   • Workshop on messaging
EFID II Phase (2013-2014):

1. A Europe-wide Awards Scheme “Living well with dementia in the community” (II edition)

2. A learning platform:
   - Workshop on empowerment and inclusion of people with dementia in the community
   - Workshop on the specific challenges of involving people with dementia from ethnic minority groups and their families in the community
EFID III Phase (2015-2016):

1. A Capacity Strengthening Fund (CSF)

2. A learning platform:
   • Workshop « Towards a network of practitioners for dementia-friendly communities »
   • Publication « Mapping DFCs across Europe » and « Collection of DFC case studies »
   • Upcoming workshop on the exchange of practice and development of indicators to capture change (Bruges, 10-11 May 2016)
Mapping dementia-friendly communities across Europe

• A research commissioned to the Mental Health Foundation UK in 2014 and 2015.
• Information gathered through a literature review; an online survey; telephone interviews.
• Based on the research, EFID published an online collection of DFC case studies across Europe.
• Survey report and case studies will be released in May and will be available on www.efid.info
Findings

Essential factors to develop a DFC:
1. Providing training, education and awareness-raising about dementia.
2. Active inclusion and involvement of people living with dementia in the communities where they live.
3. Encouraging and supporting partnerships, networks and collaborations focused on developing dementia-friendly communities.
4. Securing and sharing resources for developing a dementia-friendly community.

Policies and strategies relating to dementia-friendly communities: most dementia-friendly community activity was taking place at regional, municipal or local level.

Some strengths and challenges were identified relating to the development of dementia-friendly communities.
A Taxonomy for Dementia-friendly Community Activity (DEM-FACT)

**‘Community support’**
Focus of DFC activity is providing community care and support to people with dementia

- Basic awareness-raising focused on community care, support services and emergency services.
- Inclusion and ‘involvement opportunities’ for people with dementia through community groups, memory cafes, etc.
- Led by a public health service, social care service, or specialist dementia NGO - small partnerships that may be time limited to complete certain tasks, or be sustained.

**‘Community involvement’**
Focus of DFC activity involves the wider community being supportive towards people with dementia

- Basic awareness-raising, challenging stigma about dementia among community organisations, public services, shops, businesses, etc. May involve ‘Dementia friends’ sessions, exhibitions, films, etc.
- Inclusion and involvement opportunities include a wide range of community activities e.g. walks, exhibitions, clubs, church services, community groups, etc. giving people with dementia a visible community ‘presence’.
- Range of organisations but probably led by dementia NGOs, and/or health and social care services - large partnerships but a minority of active members.

**‘Whole community and citizenship’**
Focus of DFC activity are community partnerships co-ordinating a comprehensive ‘whole community’ and citizenship approach with the active involvement of a range of organisations, resources, and people with dementia

- Awareness-raising across community organisations, businesses, public services, etc.; is well resourced; includes the active involvement of people with dementia; results in positive activity to change attitudes and behaviours; removes barriers and improves access; supports inclusion and participation of people with dementia in the community; and is evaluated to assess impact.
- Active participation of people with dementia and other community members in all aspects of dementia-friendly community activity, (as individuals and through groups, as equal citizens and valued members of a partnership), including awareness-raising and evaluations of impact.
- Democratic and accountable community partnerships and networks, that are co-ordinated by organisations with the ability to commit resources for community wide activity but who can also support and respect diversity, small, grassroots initiatives and the active involvement of people with dementia – most member organisations are actively involved and there are resources and commitments to sustainability.

ADI Conference, 24th April 2016
Ways forward

COLLABORATION

EVALUATION

RAISE AWARENESS

ETHNIC MINORITIES

FUNDING

NATIONAL DEMENTIA PLANS

INVESTING IN HUMAN RESOURCES
Compilation of case studies

Available online: www.efid.info

Arnsberger dementia ‘learning workshop’, Germany

• **Where:** City of Arnsberg, Germany.

• **Who is involved:** the Special Department for Future and Old Age, plus professional and civil society services supporting people with dementia. In 2014 the ‘learning workshop’ won an EFID award.

• **Nature of activity:** Arnsberg addresses the challenges of demographic change with its concept ‘Living a Long and Good life in Arnsberg’. This includes bringing services supporting people with dementia together in the ‘Arnsberger Dementia Learning Workshop’ to create a tight-knit support network for people with dementia and their environment. This involves establishing networks of professionals (medicine, nursing, etc.) and civil society partners (kindergartens, schools, cultural and economic institutions, etc.) who share the aim of improving the quality of life of people with dementia and their relatives. The main focus is on projects to connect generations, generate ideas, raise awareness, network, develop support and promote projects.

• **Website:** www.projeckt-demenz-arnsberg.de
“We don’t consider dementia as a ‘burden’ to society but rather as an opportunity to get rid of stereotypes and change society’s practices. Our society has managed to give “time to life” but now it needs to give “life to time”.” (survey respondent)

Thank you for your attention!

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