

BUILDING A DEMENTIA FRIENDLY COMMUNITY IN NORTHERN IRELAND: LEARNING FROM THE DEED PROJECT IN DERRY

What's the issue?

The growing population of people living with dementia requires a community based response. We need to develop an understanding and awareness of the impacts of dementia on quality of life, and to make physical and behavioural changes that enable people living with dementia to integrate into civic society and community life.

The Old Library Trust (OLT) is a charity located in the Creggan Estate in Derry, one of the most deprived areas in the North of Ireland (NI). The DEED project (Derry Engages & Empowers Dementia) was established in 2014 to increase awareness and train and support communities and businesses to become dementia friendly. The overall aim is to create the conditions to enhance and improve the experience of people living with dementia and their carers in Derry.

Ways forward

- Awareness raising, information and guidance is valuable for businesses, community organisations and groups that play a role in the daily lives of people living with dementia.
- These groups should be supported and resourced to make small but effective behavioural and physical changes to become more dementia friendly.
- Early awareness raising through schools and community organisations should be promoted, to give children and young people more awareness of dementia and what people with dementia need.
- In line with the shift to more community based health and social services (DHSSPS, 2011a) and learning from the review of the DEED project, non-traditional methods of engaging people living with dementia should be used to enable them to prepare and plan services that best meet their needs.

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BACKGROUND

In 2011, the OLT did a small piece of consultative work with carers and older people with dementia. Feedback included a desire to have greater opportunities to participate in community activities, to be treated with respect and dignity in various public settings, and to have opportunities to mix socially. These findings were later reflected in the Alzheimer's Society report *Opportunity for Change* (Alzheimer's Society, 2014) which identified that 40 per cent of people living with dementia felt lonely, 52 per cent felt they did not get enough government support, 34 per cent did not feel part of their community and 18 per cent were not living well.

In 2014, the Joseph Rowntree Foundation (JRF) awarded grant funding to the OLT to deliver the DEED Project. This 18-month initiative adopted a community development approach, providing workshops, programmes and toolkits to support businesses, individuals and community organisations to become more dementia friendly and to challenge misconceptions about dementia. The project worked in partnership with Alzheimer's Society NI to develop the Dementia Friendly Communities programme in NI, rolling out joint awareness raising and collaborating on the physical environment toolkit.

What are Dementia Friendly Communities?

The concept of dementia friendly communities has been championed by the Alzheimer's Society, JRF and others for a number of years. In the context of the growing prevalence of dementia and the ever increasing social and economic impact, towns, cities and larger regions from across the UK have identified a need to embrace the concept of becoming dementia friendly, and to act and change to better support people with dementia.

We know that the social and economic impact of dementia in the UK is high: approximately 850,000 people in the UK are living with dementia at a cost of £26.3 billion to the UK economy. More than 94 per cent of these are aged 65 years and over. Prevalence data from the Dementia UK research suggests that 1 in 14 people aged 65 years and over are living with dementia.

Building on the recommendations published in the National Dementia Strategy (Department of Health, 2009), David Cameron set out his Prime Minister's Challenge on Dementia in March 2012 (Department of Health, 2012) which identified a target of 20 cities, towns and villages signing up to become more dementia friendly by 2015.

The JRF paper *Creating a Dementia Friendly York* (Crampton *et al.*, 2012), uses the four cornerstones model to describe the various components required to create a dementia friendly community: These are:

Place: this cornerstone relates to the physical environment within which people living with dementia find themselves, i.e. at home, in their neighbourhood, in local shops, businesses or community settings. It also considers their ability to move around and between these places.

People: the report identifies critical people as partners, families, carers, neighbours, everyday service providers (such as shopkeepers), as well as health and social care workers (and particularly GPs). This cornerstone considers how much these people know about dementia, what they should say and how they should act. This is critical to treating people living with dementia with dignity and respect.

Resources: this cornerstone considers the extent to which people living with dementia can rely on other services and resources outside the health and social care system. The report talks about the concept of people feeling that they become the 'property of the health system'. This cornerstone suggests that it is important to provide community based access to supportive interventions.

Networks: this considers the extent to which organisations and people that have a role to play in the lives of people living with dementia, interact, communicate and then act to ensure a better experience and quality of life. The ability to share resources and information and refer services is key to creating a dementia friendly community.

Northern Ireland context

It is estimated that about 21,000 people living in Northern Ireland have dementia. The Alzheimer's Society (Alzheimer's Society and Marie Curie Cancer Care, 2015) suggests that rates of diagnosis vary significantly across the UK with the Northern Ireland average of 64.8 per cent comparing relatively well with that of England, estimated to be in the region of 48 per cent.

The NI strategy for improving dementia services (DHSSPS, 2011b) reinforces dementia as a major public health and societal issue, with numbers of people with dementia rising to 23,000 by 2017 and around 60,000 by 2051. Thus, calls have been made for services to be redesigned and implemented across NI, with particular emphasis placed on improving care within the home environment and within local communities. The dementia strategy gives the five health and social care trusts the lead in developing services for people with dementia. It proposes greater awareness and acceptance in the community; better informed and supported families and carers; seamless, accessible and pro-active services and greater partnership working across sectors, as critical in enabling people living with dementia to retain their independence and value in society.

Transforming Your Care (DHSSPS, 2011a) is a roadmap for change in the provision of health and social care services in NI. This model creates new structures to make better use of resources, enhance sustainability and improve the care provided for individuals and families. In response, the Alzheimer's Society (2013a) suggests that money could be more effectively invested in workforce capacity and development of community services outside hospitals.

Northern Ireland's dementia friendly communities programme is a four-year programme (2013–2017), funded by The Atlantic Philanthropies, which will raise awareness about dementia within the voluntary, community and business sector of NI. In February 2014, the programme secured commitment from more than a third of all members of the NI assembly to support the creation of dementia friendly communities through its work. The Alzheimer's Society has developed foundation criteria for the dementia friendly communities' recognition process in Northern Ireland, based on feedback from a number of stakeholders and communities (Alzheimer's Society, 2013b). The criteria include:

- make sure you have the right local structure in place to maintain a sustainable dementia friendly community;
- identify a person or people to take responsibility for driving forward the work to support your community to become dementia friendly and ensure that individuals, organisations and businesses are meeting their stated commitments;
- have a plan to raise awareness about dementia in key organisations and businesses within the community that support people with dementia;
- develop a strong voice for people with dementia living in your communities. This will give your plan credibility and will make sure it focuses on areas people with dementia feel are most important;
- raise the profile of your work to increase reach and awareness to different groups in the community;
- focus your plans on a number of key areas that have been identified locally;
- have in place a plan or system to update the progress of your community after six months and one year.

The NI context supports a greater responsibility on community based services, alongside local health and social care trusts, to play a lead role in addressing key health concerns. The DEED project has already shown a distinct contribution to the priority areas under the NI strategy, offering beneficial training for staff, businesses and community groups to raise awareness around the issues and challenges which people living with dementia encounter, and introducing the subject in schools.

Derry and DEED

There are more than 20,000 people aged 65 years and over in the Derry City Council & Strabane District Council area. (NB The catchment area for the DEED project was Derry City Council which has since merged with Strabane). We can estimate that there are around 1,450 currently living with dementia in the area. The diagnosis rate in the Western Health and Social Care Trust area was reported as 68.75% of those suspected of living with dementia (November 2014).

The Derry City & Strabane District Council area has a strong community and voluntary sector infrastructure. In June 2003, the Department for Social Development launched a neighbourhood renewal strategy. This sought to target those communities throughout Northern Ireland which were suffering from the highest levels of deprivation. Five of the 36 designated neighbourhood renewal areas were in Derry and Strabane, with significant levels of investment to each of these areas over the past 12 years designed to deliver services against agreed community based action plans. The responsibility for urban regeneration (neighbourhood renewal falls under this) will transfer to the 11 new local authorities in April 2015, agreed as part of the recent reform of local government.

The local authority is therefore currently engaging in a process of community planning to identify the key priorities and actions to be delivered under this programme. The Derry City area is well represented in terms of health services, with the two established healthy living centres (OLT is one of those) represented on an NI-wide healthy living centre alliance comprising 12 organisations. The high level of capacity across the community and voluntary sector has historically enabled the city to leverage significant revenue and capital investment to address a range of inequalities that are largely a consequence and legacy of the NI conflict. Despite this, dementia services have received little or no attention.

The Derry City and Strabane district area is widely regarded as progressive in dealing with contentious issues such as parading, flags and emblems. High levels of partnership working and collaboration between organisations that are typically representative of differing communities have contributed to improving levels of community relations over the past number of years, demonstrating potential for significant investment in health services in this area led by the community and voluntary sector.

DEED's work also supports Derry City's regeneration initiative, the One Plan. Led by Ilex Regeneration Company and Derry City Council, this was a widely endorsed, comprehensive vision and framework within which clear objectives and priorities are set. Health and wellbeing ('health for all') is one of five overarching themes for the city. The focus is about adopting a 'proactive' approach to health and wellbeing across all ages through raised awareness and targeted preventative measures. Without specific reference to dementia, the priorities under the health for all theme include the promotion and improvement of mental and emotional health for all age groups as well as ensuring greater equality of access for all citizens and the development of a charter of rights for older people underpinning service delivery and improving access to and delivery of services.

The concept of a dementia friendly community clearly aligns with the priorities and outcomes under the health for all theme, placing DEED strategically at the heart of local policy.

The DEED approach

The DEED project, which started in 2014, focused on raising awareness and encouraging organisations and individuals to make small changes to better support people living with dementia. The DEED project aligns closely with both the four cornerstones model and the seven foundation criteria for dementia friendly communities.

Awareness raising workshops and environment toolkits

Over a period of 18 months, the DEED project delivered more than 100 awareness raising workshops to a total of 47 organisations, including 33 community and voluntary organisations/schools and 14 businesses (several hosted multiple workshops). A total of 2,736 individuals were engaged across the various workshops, which lasted for two hours and were free. The workshops enabled participants to develop a basic understanding of dementia and learn practical communication techniques, as well as providing information on how organisations can make small adjustments to make their premises more dementia friendly. The workshops were largely informed by the dementia friends sessions, with slight adjustments to ensure they were relevant and tailored to each organisation. Organisations taking part were offered the opportunity to place the DEED dementia friendly logo on their premises to let people with dementia, their families and carers know that they commit to providing them with a good service.

Following the workshop, organisations were provided with a toolkit for creating a dementia friendly environment to enable monitoring of physical changes to premises and buildings. A DEED staff member would complete a walk around the physical environment and make recommendations about physical alterations. These were aimed to be small cost-effective changes (e.g. using appropriate signage). DEED then gave the organisation a timescale within which to complete agreed changes (usually three months), at which time DEED conducted a follow-up providing practical assistance and support in making their premises dementia friendly. On completion, the DEED butterfly logo was displayed to show people that these premises are working to become dementia friendly.

The impact of these workshops is summarised in Table 1. Before and after each workshop, participants were asked to complete short surveys about changes to levels of knowledge, confidence and potential impact and changes they would embed as a result. A total of 890 survey responses were gathered.

Table 1: The impact of the dementia workshops

Q: How do you rate your current knowledge of dementia? (1 = no knowledge; 5 = very good knowledge)

Response	Pre-workshop response		Post-workshop response		Change	
	Number	%	Number	%	Number	%
1	118	13.3	6	0.7	-112	-12.9
2	323	36.3	14	1.6	-390	-34.7
3	287	32.2	60	6.7	-227	-25.5
4	105	11.8	390	43.8	+285	+32.0
5	40	4.5	391	43.9	+351	+39.4
Skipped question	17	1.9	29	3.3	+12	+1.3

Table 1 highlights a 71.4 per cent increase in the number of people who felt that their knowledge of dementia was either ‘Good (4)’ or ‘Very Good (5)’ as a result of the awareness raising workshop (16.3 per cent pre-workshop compared with 87.7 per cent post-workshop). The number of responses for those who felt they had ‘No knowledge (1)’ or ‘Some knowledge (2)’ of dementia showed a significant reduction as a result of the workshop. Pre-workshop responses grouped almost half (49.6 per cent) of respondents under these categories; while post-workshop responses showed a much lower figure of 2.3 per cent (47.3 per cent change).

The DEED workshop has also been shown to have a positive impact on those who felt their knowledge was ‘Average (3)’: the number within this category fell by 25.5 per cent after the workshops (32.2 per cent before the workshop compared with 6.7 per cent after it). Overall, 87.7 per cent of those involved (estimated at around 765 people) felt that they had either a ‘Good’ or ‘Very good’ understanding of dementia after having taken part in the programme.

Similarly, participants were asked to rate their confidence and skills to relate to, communicate with and support someone with dementia before and after the DEED workshop. Table 2 below presents the findings.

Table 2: Participants’ ratings of confidence and skills

Q: How do you now rate your current confidence and skills to enable you to relate, communicate and support someone with dementia? (1 = no confidence/skills, 5 = very good confidence/skills)

Response	Pre-workshop response		Post-workshop response		Change	
	Number	%	Number	%	Number	%
1	176	19.8	2	0.2	-174	-19.6
2	272	30.6	10	1.1	-262	-29.4
3	260	29.2	115	12.9	-145	-16.3
4	112	12.6	401	45.1	+289	+32.5
5	43	4.8	327	36.7	+284	+31.9
Skipped question	27	3.0	35	3.9	+8	+0.9

Table 2 shows significant increases in confidence and skills to enable people to relate to, communicate with and provide support to people with dementia. Before completing the workshop, 17.4 per cent of participants described their level of confidence and skills as ‘Good (4)’ or ‘Very good (5)’. Having completed the workshop, this figure increased to 64.4 per cent, an increase of 47 per cent.

The number of people who felt they had ‘No confidence /skills – 1’ or ‘Some confidence/skills – 2’ reduced significantly after the workshop from 50.4 per cent to 1.3 per cent, a change of 49.1 per cent.

For those who felt they have 'Average confidence/ skills – 3', there was also a decrease, with the percentage dropping by 16.3 per cent following the workshop (pre-workshop – 29.2 per cent compared with post-workshop 12.9 per cent).

Clearly, the workshops were able to increase knowledge, confidence and skills among participants. However participants were also asked to provide information on the extent to which this new knowledge, information and skills would create change within their organisation, both in terms of physical and behavioural change. Comments included:

- 'The information was very useful for working with clients.'
- 'Valuable advice was given about working and communicating with clients.'
- 'I've had dementia training in the past, but this had extra information as well as some good real life examples.'
- 'I am more aware of how to communicate with people with dementia more effectively.'
- 'I think this training is very beneficial for families and staff with no background or knowledge of dementia or living with dementia.'
- 'Very valuable training which will assist with our role in the community.'
- 'I found it very interesting and feel more knowledgeable about dementia and dealing with people with it.'
- 'I would try and implement changes such as non-reflective floors, or similar items within the community or workplace.'
- 'I will look around to see if I could make small changes to stop clients getting confused such as removing reflective objects.'
- 'I will try to apply the knowledge and skills I have learned today, such as removal of mirrors and usage of images which are good for dementia.'
- 'Workshops like this should be made available to the general public, through leisure centres, schools, community facilities etc.'
- 'Make all staff more aware, and give training on how we can help people with dementia.'
- 'I would encourage family members of dementia patients to learn and attend this workshop to make them more aware.'
- 'I would like to provide more knowledge on dementia through informative booklets and leaflets in my premises.'
- 'I would have more community centres send out information through leaflets to raise awareness.'
- 'I will put out flyers with more information.'

The range of comments and intended changes are reflective of the four cornerstones model mentioned earlier. Several references were made regarding the intention to change the physical environment across several premises (place), others talked about the ability to behave and communicate with people living with dementia enabling them to retain their dignity and respect (people). The reference to engagement with carers, family members, community organisations and general public is reflective of the need to establish strong (networks) to support people living with dementia. Additionally, the feedback indicates potential changes in community centres, schools and businesses, aligning to the (resources) cornerstone in that people living with dementia can rely on those outside the health and social care setting to access support.

Case study

DEED delivered a series of awareness raising workshops and completed the environmental toolkit with local community organisation The Bogside and Brandywell Health Forum. The co-ordinator described the workshops as 'really informative, it has made us more aware and more mindful of dementia'. The co-ordinator also identified that 'we are more aware of communication styles and overall feel more confident working with people living with dementia. We will also be making changes to the gym equipment'. This type of impact is consistent with feedback from the 16 organisations that completed both the awareness raising workshop and the environmental toolkit, demonstrating the potential impact of this approach.

Further engagement with people living with dementia to assess the actual, anecdotal effect of these changes would be useful for DEED.

Raising the profile of DEED

In addition to awareness raising workshops and environmental toolkits, the project sought to establish a local presence that would become the platform through which it could engage local groups and the wider public. This involved multiple meetings with key organisations and stakeholders, as well as a significant launch event hosted at Free Derry Corner in July 2014. The event attracted 80 people including the Mayor. It provided the OLT and project workers with an opportunity to outline their approach and generate awareness and interest in the project. The gable wall at Free Derry Corner was painted with the DEED project logo; this was a symbol and brand that would become synonymous with being dementia friendly.

The project also created its own Facebook and Twitter pages to interact with service users, clients, stakeholders and the wider public. The social media accounts remained extremely active throughout the project with 1,144 Facebook friends and 423 Twitter followers.

The DEED project developed and hosted a series of events to raise awareness and understanding of dementia throughout the 18 month timeframe.

- Dementia and physical activity training, hosted by the Dementia Services Development Centre (DSDC), was delivered to 10 people. It focused on building capacity to understand the benefits and impact of physical activity for people living with dementia.
- DEED hosted a tea party to coincide with Dementia Awareness Week. This was attended by around 50 people including service users, partner organisations and stakeholders. The event attracted significant media and social media coverage.
- The project hosted the DEED recognition awards to acknowledge the contribution of those organisations and individuals that contributed to the project by taking part in workshops, volunteering as a dementia champion or supporting awareness campaigns. Approximately 60 people attended the event.

In addition to organising and delivering their own events, the DEED team was also invited to attend other events. This usually involved hosting a stand and providing information on the project and the activities on offer, as well as making a valuable contribution to discussions regarding dementia. The team attended the following events:

- launch of Dementia Friendly Community Awards, Titanic Quarter, Belfast, hosted by the Alzheimer's Society;
- St Cecilia's College dementia awareness event, to provide information and advice;
- launch of the dementia awareness play at Irish Street Community Centre;
- The Alzheimer's Society celebratory event;
- DSDC's dementia achievements event at the Europa Hotel, Belfast;
- health and information day at Caw/Nelson Drive;
- dementia Innovation Lab – to contribute to ongoing policy and practice debate and discussion regarding dementia in Northern Ireland.

The level of networking and engagement achieved by the project was significant. The decision to invest time and effort in developing a strong brand for the project proved to be worthwhile. DEED was well represented at 11 events in total and displayed a strong presence at each, raising awareness about the work in Derry and its progress as a dementia friendly community.

Dementia champions

DEED sought to build the capacity of a range of volunteers and individuals who may interact with people living with dementia.

To become a dementia champion, volunteers had to complete a two-day training course delivered by the Alzheimer's Society. The purpose of becoming a dementia champion is for individuals to deliver the workshops to businesses/community organisations and to other individuals.

The DEED project recruited and trained 11 volunteers to participate in the two-day training module. These comprised:

- staff members at OLT (DEED co-ordinator and Health for Life support worker);
- former carer and volunteer for OLT;
- facilitator of a memory group;
- social work student;
- exercise facilitator.

In developing this network of people, who are adequately trained and skilled to pass on knowledge, understanding and awareness, the project has extended its potential to engage greater numbers of people. It has created a network and person based resource to help promote positive messages about how to act, behave and engage with people living with dementia. It should be noted that only 3 of the 11 have been regularly delivered workshops and this is perhaps an area to build upon for any future investment or programme.

Engaging Children and young people

Growing numbers of children and young people are cared for by their grandparents, and, as the number of people living with dementia rises, children and young people may become carers later in life. Early understanding, knowledge and experience can have long-term positive impacts on the quality of life and experiences of people living with dementia.

In response to a growing demand from schools for workshops and training on dementia for both pupils and staff, the DEED project created a partnership with author Irene Mackay, author of the children's book *Ellie the Forgetful Elephant*. The book seeks to explain the memory loss aspect of dementia in a way that young children can understand, and to suggest ways to maintain a loving relationship with a person who has dementia or other memory related illness.

A number of schools in Derry expressed a desire to participate in the workshops and activities offered by DEED. The team therefore adapted the training content and developed two awareness workshops that were suitable for children and young people aged 4 to 16, and which incorporated the book. The DEED project worked with three schools and a girl scout group. A parent from one of the schools said *'Oran was so excited to tell us all about the forgetful elephant, how inspiring that children are learning and understanding about dementia at such a young age'*.

St Cecilia's College embraced the project, hosting training for all of its 825 pupils and 93 staff. The school then created a competition for pupils to create an Ellie jingle, a song to be used by the DEED project when working in primary schools. In addition, the Year 6 pupils developed a play based on the theme of dementia; they sought advice and guidance from the DEED team on language and behaviour. The play was showcased in front of the Mayor of Derry. St Cecilia's College received an Education Initiative Award from DSDC to recognise its efforts to become a dementia friendly school. Holy Child Primary School, Ebrington Primary School and The Model Primary School introduced Ellie the Forgetful Elephant to its pupils. The book was read to children at story time, allowing for questions and interaction afterwards. The children enjoyed the activity and many could relate to the story. Typical questions such as 'Why does my granny forget my name?' or 'Will I get dementia' allowed for more discussion. The children were given homework relating to the story to open conversations at home.

The dementia friendly community workshops were also delivered to 170 students at the North West Regional College, and to 340 students at Ulster University Nursing Department.

Subsequently, the DEED project was invited to take part in the NI Innovation Lab for dementia services in June 2015. This is a forum that is established to advance the policy and practice debate relating to dementia services in Northern Ireland. Members identified a lack of work in this field, with the majority of interventions focused on those living with dementia and their direct carers. DEED's work with the younger generation was widely acknowledged as groundbreaking in NI, and there was a call to extend this approach to remove stigma and lack of knowledge associated with dementia.

Involving people with dementia

DEED was delivered by a full-time project manager supported by a steering group comprised of community voluntary representatives, private sector, statutory bodies, volunteers, residents and carers including:

- City Centre Initiative;
- Derry City Council;
- Western Health and Social Care Trust;
- Derg Valley Care;

- Alzheimer's Society;
- a volunteer dementia champion;
- a dementia carer;
- a local resident;
- Mindwise;
- University of Ulster;
- Crescent Cultural & Community Centre;
- a local pharmacist;
- Seagate;
- OLT – project director and programmes manager;
- Chamber of Commerce.

The steering group included representation from a carer as well as a range of organisations working in the topic area, ensuring strategic direction and alignment to key events and policy. The original proposal was informed by strong levels of engagement with people with dementia, who continued to act as a touchstone for the delivery of the dementia friendly community workshops and toolkit. However it is recognised that more direct involvement of people with dementia in shaping the project is desirable. The DEED project invited a number of individuals living with dementia to join the steering group. Several were identified as being in the latter stages of dementia: they felt they would not be in a position to adequately express themselves and were reluctant to be exposed to this situation. One who was newly diagnosed felt 'too angry and let down by health and social care services' and she didn't feel she could make a positive contribution. It became apparent that traditional involvement in the form of structured steering group meetings would be difficult for this target group. DEED is therefore eager to explore alternative methods of participation such as home visits, video diary or dictaphone input or Q&A sessions using dementia friendly technology.

A user led group has recently been established led by Dementia NI. Any future delivery model for DEED should seek to engage and work in partnership with this group to ensure input from service users.

Conclusion

The ever increasing concerns about the prevalence and impact of dementia, and its cost to the UK economy have resulted in growing focus on the establishment of dementia friendly communities. A number of models and criteria have been developed to define and categorise dementia friendly communities including the four cornerstone model and the seven foundation criteria for dementia friendly communities.

The DEED project, through its range of workshops, training and events, has demonstrated a strategic fit with both of these approaches. The engagement of almost 3,000 individuals across 47 organisations and more than 100 workshops has made a significant positive contribution to increased awareness, understanding, skills and confidence in supporting people living with dementia in Derry.

In addition, the project has explored a new approach through its work in schools, providing awareness raising workshops to increase understanding of dementia among future carers and key individuals. This work has been well received by a range of key stakeholders and prominent organisations in NI through the NI Innovation Lab for dementia.

The development of the DEED brand, the social media presence and the continuous marketing of events and workshops through local media outlets was an extremely effective way of raising the profile of the work and engaging organisations.

The status and reputation of OLT as one of the most prominent community organisations in the city, with a strong track record of delivering positive health outcomes, enabled it to successfully engage with a target audience and create a buy-in and commitment to the project.

The proactive and tireless work of the project co-ordinator in engaging with organisations, co-ordinating and delivering workshops and taking part in events has enabled a level of engagement that has vastly exceeded expectations. This effort has enabled participation in the NI Innovation Lab for dementia, generating significant profile for the DEED project and work funded by JRF.

The introduction of Ellie the Forgetful Elephant demonstrates a high level of innovation and strategic thinking. The concept of early intervention to increase knowledge and awareness of future carers, shop owners and health workers is positive in the context of the ever increasing prevalence of dementia.

Despite its success, the DEED project has established that involvement of people living with dementia in a traditional steering group setting can be difficult. Organisations should be creative about how they secure this participation, considering home visits and video diaries or Dictaphones, for example. Crucial to the success of any intervention of this nature is the development and maintenance of positive relationships with regional bodies (e.g. Alzheimer's Society, Dementia NI, DSDC).

Greater involvement and support from the local authority would have added to and enhanced the DEED project. Local authorities and statutory bodies should take the lead by participating and engaging in training and supporting organisations to raise awareness. In the final stages of this phase of the DEED project, the new Mayor of Derry identified the Alzheimer's Society as one of her charities of the year. In the short space of time since her inception, the DEED project has received significant recognition and engagement from the local authority, showing the importance of a prominent champion to this type of project.

The project steering group has been important in extending the reach and profile of the organisation.

There are five recommendations:

- In order to progress the wider Derry City & Strabane District Council area as a dementia friendly community, there is a need to develop an area-wide strategy and operational plan identifying the most appropriate approach as well as required resources. OLT is well placed to lead on this process in partnership with local stakeholders including both statutory and community and voluntary agencies.
- There is significant scope to increase the level of work in schools and youth based organisations through an early intervention approach, raising awareness and creating a culture of understanding and compassion. The positive feedback and experience of those taking part demonstrates significant impacts and has the potential to make a long-term positive contribution in the context of significant rises in the number of dementia diagnoses.
- Increased investment is needed to support organisations and businesses to make their services and activities more accessible for people with dementia. It would be helpful to have a budget to subsidise businesses and organisations that would like to make physical alterations to premises (e.g. signage) but who may lack the finance to do so.
- Long-term investment in further engagement, awareness raising and training is needed to achieve firm action on positive intentions.
- The evaluation process for future phases should involve people living with dementia, to enable a more accurate and reliable assessment of actual impact on conditions and quality of life.
- Non-traditional methods of engagement should be used to enable people living with dementia to help shape and inform the direction and content of any intervention.

About this paper

This paper reviews the work of the DEED project in the context of emerging definitions and criteria for dementia friendly communities. It seeks to highlight the impact of the approach adopted by the OLT and considers the potential of early intervention work in schools and youth based organisations as a sensible and worthwhile investment.

This paper has been prepared by S3 Solutions.

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FOR FURTHER INFORMATION

This *Solutions* is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF. It is available as a free download at www.jrf.org.uk

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