



Innovations
in Dementia



THE ALZHEIMER
SOCIETY *of* IRELAND

Report on Creating Dementia Friendly Communities

March 2012

Overview

In November 2011 and February 2012, The Alzheimer Society of Ireland (ASI) invited staff and volunteers from across the organisation to come together to discuss the idea of Dementia Friendly Communities (DFC), how learning from elsewhere could be integrated into an Irish context and what the benefits of a “dementia capable community” approach would be for people with dementia, their families, carers and the wider community.

The main objectives of the workshops were to:

- Explore what is meant by Dementia Friendly Communities
- Learn from innovative approaches, focusing in particular on the experience of Innovations in Dementia
- Identify ways in which The Alzheimer Society of Ireland can work with the community, voluntary, health and statutory sectors to create Dementia Friendly Communities
- Identify some of the key steps that need to be taken in order to achieve this shared vision of Dementia Friendly Communities.

This report presents the issues discussed during these workshops and makes recommendations for action.

Structure of this report:

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| Section 1: | Begins with some background to the notion of Dementia Friendly Communities (DFC) |
| Section 2: | Looks at the experience of Innovations in Dementia a Community Interest Company (CIC) based in the UK who have explored the meaning of DFC from the perspective of people with dementia in the UK |
| Section 3 | Explores the issues arising from the workshops, and the views and experiences of participants about the meaning of DFC in Ireland |
| Section 4 | Identifies some of the actions and initiatives that were instigated by the ASI as a result of the first workshop |
| Section 5 | Makes recommendations for action to take the work forward within the ASI |

Section 1 Background

What is a Dementia Friendly Community?

“An integrated society where people with dementia live in “normal” home like situations throughout their lives with support to continue to engage in everyday community activities” - (Person with dementia imagining a Dementia Friendly Community, in Innovations in Dementia, 2011)

People with dementia are among the most marginalised, socially excluded and highly stigmatised groups in society. It has been identified that exclusion from communities is all too frequently a consequence of dementia because the person often experiences reduced ability to follow the normal rules of social engagement.

In order to address this exclusion of people living with dementia, a new initiative has emerged in the form of Dementia Friendly Communities (DFC). Essentially, this initiative is about transforming our villages, towns, cities and counties into better places to live for people with dementia. It is about facilitating local communities to enable people living with dementia to live in their own community and retain their traditional networks. It is *not* about setting up ‘new’ services, but instead it is about supporting the existing community to become dementia friendly and inclusive (Goodchild, 2011).

The overall vision is to *reconfigure* the communities that we live in and *mainstream dementia* into the everyday life of that community. The shared vision of those who advocate this approach is to involve all stakeholders and members of the community to be dementia friendly. One of the core values of this model is placing the person with dementia at the centre of care provision and planning. It aims to give them a meaningful voice in determining the place they wish to occupy in their community. In many cases, people with dementia are still identified as passive recipients of care and it is now recognised that the power dynamics between them, the professionals and the service providers needs to be re-balanced.

DFC values *rights and empowerment, community action, community empowerment, social solidarity and shifting power dynamics*. It also places the concept of *inclusion* of the person at the heart of the initiative. The initiative is not about replacing existing social and health care responses to dementia but instead aims to complement and support them.

Section 2 Perspectives of people with dementia in the UK

“somewhere you can see life going on and be part of it” (Person with dementia from a rural area)

In early 2011, Innovations in Dementia a Community Interest Company based in the UK was commissioned by the Department of Health in the UK to seek the views of people with dementia and their supporters about the notion of DFC. At the workshops in Dublin, Steve Milton, one of the directors at Innovations in Dementia discussed with delegates the findings of their work.

The full report is available at:

http://www.innovationsindementia.org.uk/DementiaCapableCommunities_fullreportFeb2011.pdf

What follows is an account of this session, which includes issues and comments raised by delegates. Innovations in Dementia were asked to seek the views of people with dementia and their supporters on what constitutes a dementia friendly environment. They wanted to find out:

- What did the idea of a dementia capable community mean to people with dementia and their supporters?
- What are the things that make for a good community for people with dementia?
- How can things be improved in their community?

What is important to people with dementia?

Innovations in Dementia report to the Department of Health highlighted the five aspects of “community” life that people with dementia identified as important to them:

1. The physical environment (signage, orientation, streetscapes)
2. Local facilities (shops, pub, post office, library, sporting and activity groups)
3. Support services (community based services, day care, home care, community based healthcare professionals)
4. Social networks (family, friends, other members of the community)
5. Local groups (dementia led initiatives such as Social Clubs or support groups for people with dementia)

The Physical Environment

People told us that a physical environment in which they can find their way around and which makes them feel safe is a huge advantage, and an ideal means of staying engaged with their communities.

The importance of the physical environment is underlined by the fact that many people felt that walking provided them with an important connection to their community.

Those who are involved in designing environments, or buildings, from scratch, have an ideal opportunity to think about designing them with dementia-friendliness in mind. At the other end of the scale, we must think about how we can make changes to our existing environments to make them easier for people with dementia.

Clear signage is one way in which significant improvements can be made at relatively little cost. For example, a training event was recently run where people thought they had to walk downstairs to use the toilet. They were unaware that at the back of the training room was a fully equipped wheelchair-accessible toilet. It had everything, except for a sign on the door indicating that it was a toilet.

Aside from the lack of signage - what would have been ideal for people with dementia would have been a picture of a toilet, preferably one with a high-level cistern as some people with dementia may not recognise the meaning of the words WC or recognise the commonly-used stick-figure on the door.

Signage is important, but there are other aspects of design which can support people with dementia to engage with, feel safe in, and enjoy using the environments which make up their communities.

Keypoint:

Clear signage plays a really big part and is one way in which significant improvements can be made with relatively little cost.

Local Facilities

Many people told Innovations in Dementia that it was the “stuff of life” that was important – being able to use buses, the local shops, banks, post office, pubs, libraries, leisure centres – the same things they had always used and which “connected” them to their communities.

Shops, the church, the pub, and the gym were the most commonly cited local facilities that people with dementia used. Shops were the most commonly mentioned. Local facilities were very strongly cited for both urban and rural communities, with the pub and post office being particularly relevant for those in more isolated areas.

Keypoint:

For most people, what determined the dementia-friendliness of local facilities, over and above the physical features of the service, was **the attitude of the people with whom they came in to contact.**

Social Networks

Many people with dementia report a shrinking of their social networks following diagnosis, and it is clear that social isolation is a problem for many people with dementia, and for their carers. Anyone working with people with dementia and their carers will have heard reports of family and friends “drifting away” following diagnosis.

People identified the important role that family and friends play in their lives and the importance of telling friends and family about your diagnosis. The experience of one individual - a strong advocate for the Alzheimer Society in the UK – was discussed. This person, called Chris, who has been diagnosed with dementia, and has said that one thing that really helped him was telling people about his diagnosis in the community. Chris also said

that people are very kind and understanding when you tell them that you have dementia. He felt that people essentially have good communication skills even if they do not have an understanding of dementia.

However, one other person present at the workshop had a different experience. When she has discussed with friends that her husband is undergoing tests to determine if he has dementia, she found that people brush the issue aside and are reluctant to speak to her about it.

The challenges of daily life for someone diagnosed with dementia were also discussed. In this case, a man, when struggling with his money in a shop, mentioned his condition to the assistant. The assistant joked in response – the point was made that people do not joke about other life-limiting, progressive, conditions the way they do about dementia. This further underlines the importance of awareness-raising and stigma reduction.

Keypoint:

Not only do social networks in themselves constitute an important element of “community”, but also serve as a conduit for wider engagement.

Local Groups

Being part of a support or social group gives people with dementia confidence to be part of their wider community. Not only can these groups, in themselves, create both social networks and opportunities for engagement, but many see them as an important “stepping stone” to the wider community. The example of one Memory Café, where the men initially went along with their wives but now usually “nip out for a pint” and then rejoin their wives at the Café, was highlighted as one such example.

“The local groups for people with dementia – Singing for the Brain and the Memory Cafés are very important – it helps me to stay connected and gives me a safe haven giving me the confidence from which to venture further” (Person with dementia from a rural area).

Support Services

People in the earlier stages of dementia understandably focus on the more mainstream aspects of community engagement, it is important not to overlook the role of more specific support services as dementia progresses. However, whilst relying totally on the community to support someone with dementia is not realistic for many, it is important to consider the numerous ways in which services can enhance broader access to the community for people with higher levels of need.

How can Communities be more Dementia Friendly?

We asked people what could be done to make their communities more dementia-friendly. However, before we can make our communities more dementia-friendly we need to recognise and understand what is going on for people with dementia in terms of their fears and what is stopping them from engaging with their community.

The following issues were highlighted:

- People worry about their ability to cope
- People are afraid that others will not understand
- People with dementia often blame themselves for the impact the disease has on them rather than the shortcomings of their environment and their community. This leads to people having very low expectations of themselves, in general as they get older but which is often compounded by a diagnosis of dementia.

Participants identified what would make the biggest difference to them and the following issues were highlighted:

- There needs to be **an increased awareness and understanding about dementia**, both within mainstream services and more broadly within the community. Continued media awareness and public awareness campaigns are vital. Awareness-raising work should be delivered to people in the wider public along with a positive message about dementia. People also need information about what they can do to support someone who might be experiencing difficulties.
- **Dementia should be “normalised”**. The more visible people with dementia become in our communities, the more dementia will be “normalised”....and to this end we can:
 - Ensure that mainstream services are made more accessible for people with dementia
 - Make use of local mainstream facilities – for example a Memory Café could take place in a local café or hotel, rather than in a day centre
 - Build on the potential for people with dementia to advise others on access issues, awareness training and campaigning.
- **Support local social groups for people with dementia, and for their carers**. People told us that although there are carers’ groups in many areas, there are fewer social groups available, particularly for people with dementia. People with dementia and their supporters who were consulted with by Innovations in Dementia felt it was important to incorporate time and space for people with dementia and their carers away from each other so that they have a space to discuss their own experience and get the specific, personal, support they need without the risk of offending and hurting the other person.
- The majority of people said that an **informal one-to-one support like a “buddying” or “befriending” scheme** would support them to venture into their communities and would make a huge difference in their lives. This could mean help to get to the doctor, or more usually, to enjoy “the stuff of life” like going out socially, going to the shops, or to the library. Having stressed what a difference this could make, people with dementia and their supporters said that there was simply no provision for this kind of service in their areas. Given the loss of social networks that often seems to follow a diagnosis, this kind of support could play a crucial role in keeping people connected with their communities.

Section 3 Issues arising from the workshops

In this section we look at what participants at the workshops told us about the meaning of Dementia Friendly Communities in their specific areas.

Participants were asked to think about ways in which people with dementia connected with their communities.

- As in the UK, mainstream facilities like banks, shops and post offices were frequently cited as being key places which should be dementia-friendly. The church was seen as an important touch-point for many people with dementia. Participants talked about specific events like funerals (especially for older people) but also about attendance at regular church services. It was noted that as well as being an avenue for community engagement, the importance of people with dementia *being seen* to attend cannot be overstated.
- The importance of social networks, including family, friends and more community-based groups was stressed. As in the UK, people talked of social networks both as forms of community engagement in themselves, but also as doorways to wider engagement.
- Specialist services were also seen as an important link to the community for the person with dementia – health services in the form of public health nurses, occupational therapists, other specialists and social care services such as day care and home care.
- Simply walking, either alone, or with the dog was mentioned by many participants as an important way of both interacting with the community and of “being seen”.

The issue of “being seen” emerged frequently pointing to the importance of people with dementia being visible in their communities and supported to remain so after diagnosis and throughout their pathway of care.

Participants were asked to think about those aspects of their communities which were currently dementia-friendly

Several participants cited individual specialist services which support people with dementia, for example the Home from Home initiative in Co. Leitrim. This is a pilot initiative run by The Alzheimer Society of Ireland that offers the person with dementia an alternative to traditional day care by providing it through a normal, homelike environment in another person’s home in the local area.

Participants were asked to think about those aspects of their communities which were currently NOT dementia-friendly

By far the most discussion took place around perceived problems with specialist services. There was a lot of discussion about problems with **diagnosis**, including:

- Consultants, GPs, health professionals and families often report that they do not know how to tell the person they have dementia or they worry about the impact this will have on the person.
- The person with dementia not being informed of their diagnosis either by the GP, consultant or by carers (who have been told).
- GPs in some cases do not pursue a diagnosis even though the person and/or their family have raised issues about the memory problems they may be experiencing.

The connection with DFC might not seem obvious – but an understanding of one’s own condition is for many people a very important step in taking control of the situation, and of staying connected both to one’s community and their own life choices and direction.

In fact, the importance of early diagnosis cannot be understated. The earlier someone is aware of their condition, the sooner they are able to make decisions about their future, plan for their own care and determine

what supports and services would make the greatest impact on their lives. This is also an area of linkage to supported decision making to ensure that the person with dementia is able to plan for their own future and care provision to ensure it meets their individual preferences and needs.

Hospitals were also cited as places which were not dementia-friendly:

- Accident and Emergency (A&E) units can be challenging environments for a person with dementia. For example, the length of waiting time that people can experience, the layout of A&E, the number of people often present, and the nature of the emergency medical care may not be appropriate for people with dementia.
- Length of waiting time in hospitals is problematic. Although a person may have an appointment they may still have to wait a significant length of time to be seen by a doctor and this can be disruptive and disorientating for the person with dementia.
- Current systems of waiting or calling for services - for example, the use of tannoys or numbering systems can cause problems for the person with dementia.

Aside from specialist services, participants also cited:

Structural barriers

- Health and safety legislation can often be a barrier to participation for the person with dementia. Specifically, a person with dementia may be unable to take part in cooking or preparing food in day care centres due to health and safety constraints.
- Insurance can be very problematic for organisations because of the perceived risks that services can present.
- Accessing Garda Síochána vetting for staff and volunteers can often result in the delay of services for people with dementia. This is an essential issue however for the appropriate protection of all clients however; the significant delays posed by the process can delay service provision.

The attitudes of others

- People with dementia can often be afraid to engage and connect with their community as their confidence is low and they do not want to feel stupid about their inability to manage.
- Those not affected by dementia and those who may not understand it may not be fully aware of what the person could be experiencing.
- It is important that frontline staff and service providers in particular take the time to consider the needs of the person with dementia and be aware of how they can support them in the way that best meets their needs.

Ideas to make our communities better for people with dementia

Participants were asked to think about ways in which their communities could be made more dementia- friendly. A large number of ideas were generated which fell broadly into five main areas:

- Engagement of people with dementia
- Ideas for health provision
- Ideas for mainstream provision
- Ideas for social care/voluntary sector provision
- Raising awareness within the local community.

Engagement of people with dementia

This picked up on the previous theme of people with dementia not being aware of their diagnosis, and the impact this can have on the person's ability to engage with their own condition, their own community and their own life.

- There was a discussion around the central importance of the person with dementia being made aware of their diagnosis, and the implication this can have on their lives and the lives of those around them. Some stressed the need for the person to be given support in understanding that it was possible to live well with a diagnosis of dementia.
- It was asserted that in order for a dialogue around DFC to progress, it was important that ideas were developed with people with dementia themselves, as well as their carers and those representing them.

Ideas for health provision

Ideas and discussion were focused exclusively upon the issue of diagnosis:

- GPs could be asked to commit to passing on ASI contact details when they encounter a person with a diagnosis of dementia. A point was raised in a further workshop that GPs are often reluctant to share information about the ASI services due to the word "Alzheimer's" being used in the material.
- The importance of disclosure of diagnosis to people with dementia, as well as to their carers, was again reiterated notwithstanding issues of consent and confidentiality.

Ideas for mainstream provision

There were a number of suggestions for ways to make shopping easier for people with dementia:

- Shops and businesses could **display a symbol** which indicates that they are "dementia-friendly" or another suggestion was "dementia aware". There was recognition that there needs to be a shared understanding of what this type of symbol would mean. For example, it may mean delivery of a specific training programme for staff to enable them to understand dementia and how they can respond or it may be an excellence in customer service. There should be clear objectives set out so that a person with dementia will know what they can expect from a service that is dementia-friendly or aware.
- Have a **Dementia Friendly Community award** – to reward the most dementia friendly service of the year
- It was suggested that **supermarkets would have a designated person** to provide help to people who may need it. These designated people should be easily identifiable and readily available. Others suggested that generally raising awareness about dementia might be more effective.
- Mobile telephone companies could be invited to develop a **dementia friendly phone** (it was noted that there are already phones on the market that are more accessible for people with dementia).

Ideas for social care/voluntary sector provision

There were a range of ideas for actions from the social care or voluntary sector. Some focused on specific group activity for people with dementia:

- Start a dog-walking group - there was a lot of interest in further developing this idea among many of the participants at the workshop. Further information about a similar project in Scotland is provided in the extra resources section at the end of this report.
- If it is not possible for people with dementia to get to their local library, bring the library to them e.g. read aloud reading group.

Others focused on one-to-one support:

- Train and support volunteers to roll out a buddy system.
- A befriending service that provides people with a daily friendly phone call to check in and make sure they are doing well.

Others focused on organisational structure:

- Specific individuals in organisations are identified and are committed to the person with dementia and that understands and recognises the individual and not their dementia.

Raising awareness within the local community

As one participant put it *“People need and want genuine empathy (not sympathy) and therefore people’s attitudes are very important”*.

As people with dementia who talked to Innovations in Dementia stressed, the attitude of those with whom they come in to contact has more of an impact than the physical attributes of the environment, service, or facility concerned.

Raising awareness of dementia and how to support those who may be having difficulties is of primary importance. Participants outlined a range of individuals and services within the community that could be targeted for awareness-raising:

- **Neighbours** – Make it known to them that the person has dementia (if this is agreeable to the person with dementia) and outline how they can support them.
- **Professionals** – such as **An Garda Síochána** display an understanding of the common issues facing people with dementia.
- Engage with **Small Business Association, Chambers Ireland, ISME, dentists, accountants, solicitors** to talk about how dementia-friendly businesses are good for income generation.
- Link in with people who would encounter people with dementia on a frequent basis for example, **taxi drivers, bus drivers, Community Gardaí** etc – make them more dementia aware and encourage them to discuss their interactions with people with dementia.
- **Personnel in banks, post offices and other vital community services** should be trained about dementia and how to respond.
- Engage with the Genio Dementia Project and try to encourage as many **schools, local authorities and hotels** to get involved to ensure that as many services in the community are involved in making their community dementia-friendly.
- **Solicitors** need training – put those who are trained onto a register (note - LAWNET and Solicitors for the Elderly in the UK and Ireland hold registers of dementia-aware legal professionals).
- **Dentists and other allied healthcare professionals** in the community need awareness training.
- Influence future **planning** and community buildings – especially with regard to the design elements
- Engage with **local development companies** who are already active within communities.
- Develop linkages with **existing community services** and activities to increase awareness and inclusion particularly the community e.g. gardening community, arts groups and men sheds projects.
- Drivers on **rural transport schemes** should be trained.

The role of The Alzheimer Society of Ireland in developing and delivering on these ideas

Looking specifically at what The Alzheimer Society of Ireland could do to support the development of DFC, both nationally, and at a local level, participants outlined a range of ideas for action.

Action at national level

Discussion centred on the need to develop new ways of responding to the needs of people at an earlier stage of dementia. Suggestions included:

- The need to raise awareness about the capacity of a person with dementia to deal with the changes if they are informed of their diagnosis at an early stage – allowing them the opportunity to make a personal choice whether to discuss it or not.
- The need to continue dementia awareness and understanding of the rights of the person with dementia within our own staff.
- The need for organisations involved in dementia care to focus directly on the needs of people with dementia and include them directly as partners in their work.
- The Alzheimer Society of Ireland's Helpline should encourage more people with dementia to contact them directly and facilitate them to speak to other people who have been diagnosed with dementia.
- Develop the concept of a dementia advisor who help families inform their loved one, sit down with people to explain what is happening, let them know about services available to them, offer immediate support post diagnosis and help to assure them that there is a life after diagnosis.
- Identify a town and work from the bottom up to develop a DFC model using a grassroots approach.

There were also specific suggestions for ways to take the concept of DFC forward at a national level throughout the business community:

- Make a good business argument to companies to encourage them to come on board
- Develop "champions" within businesses to be the "face" and "voice" of DFC
- Put together a DFC package for businesses and service providers
- Give staff training on dementia awareness in places that would host services for example, hotels
- Lobbying and working at the corporate level with large businesses at a national level to bring about changes

Action at local level

Suggestions for responses at local level focused on two areas – support/social groups for people with dementia (and their supporters) and one-to-one support.

- Develop **support groups** specifically for people with dementia
- Develop more **social clubs** in welcoming environments and look at the possibility of moving existing ones to more hospitable locations e.g. a café environment or a local hotel
- Explore **alternatives to formal care services** being provided by formal carers (for example, a social club could be facilitated by volunteers and give those in attendance a shared responsibility)
- **Recruit and train volunteers for the buddy system**
- **Befriending services** that provides people with a daily friendly phone call to check in and make sure people are doing well
- **Key people are appointed** in each area to champion the development of early intervention responses for people with dementia.

Section 4 Direct community-led interventions for people with dementia

This section outlines some of the actions and initiatives that were led out by staff within the ASI as a result of the previous workshop in November. Some of the initiatives are underway whilst others are works in progress or ideas that people would like to see developed.

General community support

Mayo - A successful grant application has resulted in significant funding from Genio for the development of a community based dementia project in Mayo. As part of this broad project, there are significant plans to put in place a training programme for staff working in the community in places like banks, post offices, libraries and supermarkets to name but a few in County Mayo. The aim of this training will be to increase their understanding of dementia and how they can respond more effectively to people's needs.

Donegal – A motion has been put forward to the local town Council in Letterkenny where it is being asked to contribute directly and indirectly to make Letterkenny one of the first “dementia-friendly” towns in Ireland. Some of the suggestions highlighted above in Section 3 were put to the local town council. They were encouraged to think about how they use local tourist attractions for the benefit of the person with dementia, for instance they are hoping that the local heritage walking tours will host a tour for people with dementia and their carers.

Blackrock/Stillorgan – a shopping day is being organised each week in the local shopping centre where school students will be made available to assist the person with dementia with their shopping.

Wexford – although the consortium was unsuccessful in their funding application to Genio there were many positive aspects that have since developed from the work. There is a very real interest and willingness from people to be involved in improving services for people with dementia when they are asked. It is hoped that work in this area will be progressed through a number of different initiatives.

Waterman's Lodge – one of the key objectives of this service is to anchor it more centrally in the community. On one particular day they have a small group of people with dementia who visit local services in the community to do normal every day activities such as paying bills at the post office, having a cup of tea in the local café or going on a walk around the beautiful area in Killaloe. People are more familiar now when they see the clients and the person with dementia feels more engaged with their community.

Sports officer – one of the participants highlighted that there is a Sports Officer in every County that could be availed of to start a walking group for people with dementia.

Intergenerational work

Kildare – a project is being delivered in partnership with a local school for a particular group of men that attend a local day centre. There was recognition that many of the men who attended the day centre were particularly bored as many of the activities were seen as female orientated. As a result, transition year students are now invited in to discuss general farming issues with the men. They have also brought in baby lambs and hunt puppies for the men to see and there are plans to extend the project to organising outings to local farms in the community.

Development of one-to-one support

A number of people highlighted cases where the ASI services were unable to directly support the person with dementia that had just been diagnosed but instead had put them in touch with other services. For example, a person with dementia was connected up to a volunteer service as he is very good at maintenance jobs and was willing to volunteer his skills and time to help them out with some odd jobs.

Section 5 Conclusions and Recommendations

The starting point for the work of Innovations in Dementia in the field of DFC in the UK is the voice of people with dementia themselves – it should be the start and the heart of developing communities which enable people with dementia to live well.

This was reinforced by many of the comments and suggestions made at the workshops, although the challenges that this presents for many existing services were acknowledged. However, despite this there are numerous opportunities already in existence or in development to advance this work and some of the examples were cited during the workshops. People did emphasise that for the DFC projects to be successful we must give the person with dementia “*ownership of their future*” particularly for those in the earlier stages of dementia.

It was recognised that traditionally, services were focused primarily on carers, and that most of the people with dementia served by ASI were in the later stages of dementia with high degrees of dependency. This has been an important factor in shaping our services both nationally and locally. However, with the increasing **emphasis on early diagnosis**, the demographic is shifting rapidly. There is a need to **focus on the needs of people with dementia as well as those of carers**. As one participant said “*we need to offer the person with dementia a wider door to walk through*”.

There was a recognition that there needs to be a shift in thinking at many levels to **develop the capacity of services to respond to people with dementia at an earlier stage**. Given that there is an emphasis on increasing the numbers of those who are receiving an earlier diagnosis and who will need a different kind of support to that which is available in many areas. Numerous opportunities for the ASI to develop this work were discussed.

As there was so much discussion around the **disclosure of diagnosis** and the problems that this can present for many of the cohorts of people it was acknowledged that DFC must also incorporate people with dementia who are unaware of their diagnosis.

There was also **recognition that what is developed and works in one local area may not be appropriate for another**. However, the importance of the ASI incorporating and sharing the learning from these projects was emphasised for the overall growth and development of DFC in the organisation. The ASI must ensure that there are **guiding principles in place for the development of DFC** so that best practice is put in place through local solutions. We must look at ways of evaluating their effectiveness and how they can be replicated.

Throughout the two workshops the opportunity to discuss **the role of consultation with people with dementia** was explored. There were a number of examples of consultation being undertaken with clients of day centres and also at a national level through the National Dementia Summit where people with dementia and their carers had an opportunity to present their issues and lobby politicians. The importance of consulting with the person with dementia cannot be underestimated particularly in the earlier stages where people have the opportunity to input and shape how they wish their future to be.

Many of those that participated in the workshops highlighted that it “*opened their eyes*” to the **opportunities we can avail of in our local communities** to support people with dementia to be more involved. It also highlighted the willingness of others to be involved when they are asked even though they may not be “experts” in dementia care.

We should not lose sight of the importance that **the attitude of people in services** can play in creating DFC. We have a role to play in educating staff to remove some of the fear they may have around their own understanding of dementia, raising awareness about people living with dementia in local communities and lifting the stigma that can often surround it. Throughout the workshops we heard numerous stories of positive interactions people with dementia have with service providers in their communities, this must be capitalised and built upon.

We need to **use more public awareness tools** such as social media to promote and develop the concept of DFC locally and nationally. It was suggested that the ASI should continue to work in partnership with other

organisations to promote and develop this concept and grow the awareness about how communities can be more “dementia aware”.

The importance of building **upon the opportunities for people with dementia and their loved ones to engage** was emphasised. For instance, social clubs can often be the ideal mechanism for those who have just received a diagnosis to interact and begin to adjust their diagnosis through the support of others going through the same experiences. One of the major things that was highlighted through the workshops is that people who have been diagnosed benefit from being around people who are at a similar stage as them. It is for this reason that a person who has been newly-diagnosed can often be put off by the thought of a day centre where people are more dependent. People want to experience their journey together and this serves to emphasise the importance of bringing people together at the earliest possible stage.

Finally, the importance of **putting the fun back into people’s lives** was also highlighted. The Social Clubs endeavour to create an environment where people can have fun together and create a circle of support for each other despite the difficult circumstances they may find themselves in. The only image that we often see of the person with dementia is of decline and despair, it is important to convey more positive images of people with dementia.

In summary:

- It was recognised that nationally, work to refocus activity on people with dementia as well as carers should be continued.
- At a local level – it was felt that the development of support/social groups for people with dementia and their supporters be continued.
- It was also felt that the development of one-to-one support in the form of “buddying” or befriending schemes should be supported and encouraged.

Recommendations

1. The development of local support groups and one-to-one support would represent a high-impact intervention on behalf of The Alzheimer Society of Ireland, at a relatively low cost. We must enable our local services to have something to offer to people with dementia, especially those at earlier stages.
2. The importance of The Alzheimer Society of Ireland incorporating and sharing the learning from these Dementia Friendly Communities projects. Continue to grow and develop the learning and sharing opportunities for staff in the organisation and beyond through the development of regional forums and newsletters.
3. Develop a toolkit of guidelines on how to develop Dementia Friendly Communities which can be used for wider circulation and development
4. Design activities that serve to connect, or re-connect people with dementia to their communities in a way which is supportive to the individual needs of people with dementia, and which would raise the visibility of people with dementia within their communities.

Key Resources

Other resources of interest in relation to developing Dementia Friendly Communities

The **Dementia Services Development Centre at Stirling University** has developed a wealth of resources on dementia-friendly design. More information can be found here http://dementia.stir.ac.uk/design_welcome

The **Wellbeing in Sustainable Environments Research Unit** of the Oxford Institute for Sustainable Development has also published guidelines for designers on making the physical environment more dementia friendly. More information can be found here: http://www.idgo.ac.uk/about_idgo/docs/NfL-FL.pdf

The **Oxford Institute for Sustainable Development**, Department of Architecture, School of the Built Environment has produced this checklist of criteria that should be considered in developing dementia-friendly urban areas. It is called – “Designing dementia-friendly outdoor environments - Checklist of characteristics of dementia-friendly neighbourhoods”. The checklist can be found here: http://www.idgo.ac.uk/about_idgo/docs/NfL-FL.pdf

Alzheimer Australia have produced this document - Building Dementia and Age-Friendly Neighbourhoods and it can be found at this link: <http://www.fightdementia.org.au/research-publications/alzheimers-australia-numbered-publications.aspx>

Historypin is a way for millions of people to come together, from across different generations, cultures and places, to share small glimpses of the past and to build up the huge story of human history www.historypin.com

Dementia Dog is a project that is trying to build a service for people with dementia that brings dogs back into their lives or supports them to continue their relationship with dogs. This could be through a full assistance dog program, through a network of visiting dogs or through supporting families to find the best pet dog for them and their particular dementia needs. <http://www.dementiadog.org/dementiadog.org/Home.html>

The European Foundations’ Initiative on Dementia (EFID) European Awards 2012: “Living well with Dementia in the Community” is an awards scheme designed to improve perceptions of dementia and to stimulate solidarity at the local level. By rewarding the best local initiatives that promote social inclusion, through a Europe-wide awards scheme, EFID aims to encourage context-relevant projects in the field of awareness building about dementia. 10 projects were selected by an independent jury to receive an award of up to € 10,000 each. http://www.nef-europe.org/sites/default/files/EFID%20Awards_Info%20pack_officialcomm1701.pdf