



*There are rising numbers of older people being diagnosed with dementia, and this is only set to increase. With a move away from hospital and institutional care, people with dementia will be increasingly home-based. Given this trend, they stand to become increasingly isolated and their ability to socialise will be affected. An overarching question of this particular research is whether there is an opportunity for creative processes to bridge this gap. In addition, what are the opportunities for creative work and creative exploration for community arts in working with people with dementia? And how might this research contribute to policy development and advocacy work?*

# Community Arts and Dementia

An evaluative research survey  
of CAP community arts  
projects and dementia

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Community Arts Partnership

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## Acknowledgements



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## Introduction

Community Arts Partnership takes the lead in the promotion, development and delivery of community arts practice in Northern Ireland. We are an independent advocate for community arts and offer the widest possible range of assistance and opportunity to get creative and engage in community-based arts activity. *Our mission* is to take the lead in the promotion, development and delivery of community arts practice, to affect positive change. *Our vision* is to see the emergence of a just, inclusive, peaceful and creative society, where difference is welcomed and participation is valued. We have a two-fold approach to arts development: firstly, supporting access and participation by seeking to affect policy through advocacy and leadership and secondly, promoting authorship and ownership through the active engagement in projects and programmes. This report is an evaluation of community arts projects facilitated by CAP with older people with dementia carried out between 2010 and 2013. It also incorporates relevant external projects and information from professionals working in both community arts and the health profession in order to provide a wider context for the work. The evaluation was undertaken by Jen Goddard on behalf of CAP. Information for the evaluation was collected from a range of stakeholders involved with the project – artists, participants, activity officers and health professionals. This research evaluation presents the findings from these and other information and provides some recommendations for the future. It is anticipated that this evaluation will be of benefit to a number of individuals and organisations, including organisations working with people with dementia, community and community arts organisations, arts professionals, funding bodies, healthcare providers, and anyone seeking to support their work with qualitative as well as quantitative evidence in this field.

The research was funded by the Arts Council of Northern Ireland's Arts and Older People programme.

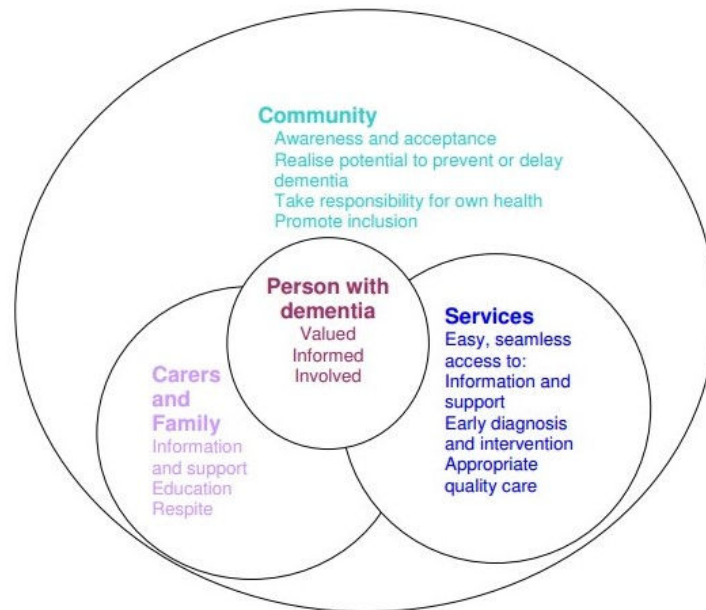
## Rationale and Context of Research Project

This report is not written to investigate the ways in which we can use the arts to change people living with dementia. We can strive to create favourable conditions for change, but those affected by dementia should be supported to make decisions about their lives as autonomously as possible. Instead, it is to investigate how as artists, meaningful activity providers and facilitators, we can change in *our* attitudes and practice in order to promote an environment of 'connectedness' which best serve to stimulate 'cognitive, physical, psychosocial and spiritual well-being' of participants (Hellen, 2000: 35).

Community arts, based on the principles of person-centred, participatory, community development, lies at the heart of this piece of research. A definition of community arts is offered below. Needless to say, there has been an overwhelming body of knowledge to emerge over the past two decades which indicates that a consistent community arts approach is good practice in working with community groups, serving to increase health and well-being (Marmot, 2011; The Angila Ruskin/UCLan Research Team, 2007; Ings, Crane, and Cameron, 2012; Brodzinski, 2010).

Best practice in community arts also embodies four out of six of the values and principles for people with dementia as laid out in the DHSSP report *Improving dementia services in Northern Ireland: A regional strategy*: dignity and respect; autonomy; justice and equality; and safe, effective, person-

centred care (2011, 4.6, pp30-31). The same report also provides a holistic model for supporting people with dementia, and the duties held by community groups, amongst others, to do this:



(DHSSPS, 2011: 5.1, p.33)

Hence, not only does community arts by its very nature adhere to the values and principles necessary for creating the right environment for people with dementia to lead meaningful lives, it also has a duty to implement these.

**The overarching question for this piece of research is therefore: given this duty, what specifically needs to be considered in addition to general ways in which community arts is facilitated in order to develop best practice when working with people with dementia?**

There are rising numbers of older people being diagnosed with dementia, and this is only set to increase. An ageing population in Northern Ireland could see the numbers of people diagnosed with dementia going from the current estimate of 19,000 to 23,000 by 2017 and around 60,000 by 2051. (DHSSPS, 2011: 13). Whilst there are higher diagnosis rates in Belfast than anywhere else in the UK, and high rates throughout Northern Ireland as a whole, growth in these figures has recently stalled:

It is disappointing to see diagnosis rates have stalled, with less than half a per cent increase from last year. Northern Ireland has been leading the way with diagnosis rates and Alzheimer's Society does not want complacency to set in.

(Bernadine McCrory, Director of Alzheimer's Society in Northern Ireland, 29<sup>th</sup> November 2013  
[http://www.alzheimers.org.uk/site/scripts/news\\_article.php?newsID=1884](http://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=1884))

Currently, reliance on care homes is much higher in Northern Ireland than the rest of the UK – almost half of all people with dementia in Northern Ireland are in care (Kings College London and LSE, 2007) and up to 25% of all inpatients in acute hospitals on any day may have dementia. (DHSSPS, 2011: 72). However, it is the government's intention to move away from hospital and institutional care, enabling people with dementia to be increasingly home-based. (Ibid: 29). Given this trend, they stand to become more and more isolated and their ability to socialize will be affected. Therefore, further

questions to be asked include: Is there an opportunity for creative processes in community arts to bridge this gap? What are the opportunities for creative work and creative exploration for community arts in working with people with dementia? And how might this research contribute to policy development and advocacy work?

Certainly, there is evidence to suggest that delaying the onset of dementia, and reducing the impact of the disease once it has taken hold, may be enabled in part by both physical and mentally challenging activity. Michael Valenzuela speaks of the neuroplasticity of the brain, and how 'regular mental activity over several weeks can help build up our store of synapses. More synapses means better cognition and, hopefully, less chance of developing cognitive dysfunction or dementia.' (2011: 179). Not only is it useful in the prevention of dementia, however, but also in arresting the development of the disease, as indicated by the 2013 report published by Arts 4 dementia *Awakening the Mind*. Participants demonstrated enhanced cognitive functioning, particularly after participating in music and dance related activities (pp6; 25). These activities incorporated best what Valenzuela terms 'The Three Keys' of physical, mental and social stimulation. (Valenzuela, 2011: 183-184)

Being, doing, and belonging, the basis for connectedness, require care receivers to be actively involved with meaningful activity. Activity, the core component of all of life, defines the person with dementia's cognitive, physical, psychosocial, and spiritual well-being. Success, when centred on the care receiver, involves the caregiver's empathic sensitivity; understanding of dementia's affect on the person receiving care; creativity, its implication for innovative approach and care strategies; ways to foster connectedness; enabling of activity participation; safety considerations; and promotion of self-satisfaction. By so honouring persons with dementia, meaningful activity upholds their heartfelt sense of connectedness. (Hellen, 2000: 35)

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#### *Rationale and Context of Research: Summary*

*Community arts in essence embodies, and in practice has a duty to embody, values of dignity and respect; autonomy; justice and equality; and safe, effective, person-centred practice - in this case as applied to working with people with dementia.*

*There is a high rate of dementia diagnosis in Northern Ireland compared to the rest of the UK, but a greater reliance on institutional care. In response to this, the legislative assembly is now committed to supporting a move towards domiciliary care, thus making activities provided within the community of greater importance than heretofore.*

*There is evidence to suggest that arts activity can slow the onset of dementia and reduce the impact of the disease once it has taken hold*

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## Definitions

### ***What is Community Arts?***

The following definition of 'community arts' has been developed by CAP, and has been offered into the Arts Council Northern Ireland's Community Arts Strategy 2013-18:

*Community art is a process of harnessing the transformative power of original artistic expression and producing a range of outcomes: social, cultural and environmental. Looked at politically, socially, culturally and/or economically, community arts aim to establish and maximise inclusive ways of working, providing an opportunity for communities and their participants to continue to find ways to develop their own skills as artists and for artists to explore ways of transferring those skills. Through this process, community arts aim to maximise the access, participation, authorship and ownership in collective arts practice.*

This definition enables arts organisations and artists to frame their practice within a local context as well as providing practitioners with models of good practice. At the centre of this definition is the principle of origination which places an emphasis on the role of participants within a project in defining both the artistic processes and end product. This provides communities wishing to explore local personal, social and environmental issues with the creative means to pursue their ambitions, and embodies the values of dignity and respect, autonomy, justice and equality and safe, effective, person-centred care as outlined above.

### ***What is Dementia?***

The word dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or communication. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Dementia can affect people of any age, but is most common in older people. One in twenty people over 65 has a form of dementia, rising to one in five people over 80. It is thought that many factors, including age, genetic background, medical history and lifestyle, can combine to lead to the onset of dementia. Dementia is a progressive condition. This means that the symptoms become more severe over time.

### ***Alzheimer's disease***

Alzheimer's disease is the most common form of dementia. Looking at Alzheimer's as a series of three stages can be a useful way of understanding the changes that occur over time. However, the way a person experiences Alzheimer's disease will depend on many factors, including their physical make-up, their emotional resilience and what support they can rely on.

### ***Early stage***

Alzheimer's disease usually begins gradually with very minor changes in the person's abilities or behaviour. Such signs are often initially mistakenly attributed to stress, bereavement or to the normal

process of ageing. Loss of memory for recent events is a common early sign. Someone with Alzheimer's may:

- forget about recent conversations or events
- repeat themselves
- become slower at grasping new ideas, or lose the thread of what is being said
- sometimes become confused
- show poor judgement, or find it harder to make decisions
- lose interest in other people or activities
- develop a readiness to blame others for taking mislaid items
- become unwilling to try out new things or adapt to change.

The person may also become anxious and agitated. They may experience distress over their failure to manage tasks, and need reassurance.

### ***Middle stage***

As Alzheimer's disease progresses, the changes become more marked. The person will need more support to help manage day-to-day living. They may need frequent reminders or help to eat, dress and for personal hygiene. They are likely to become increasingly forgetful and may repeat themselves due to a decline in their short-term memory. They may also fail to recognise people or confuse them with others. Some people at this stage become very easily upset, angry or aggressive, or they may lose their confidence and become very clingy. Other symptoms may include:

- becoming confused about where they are, or wandering off and becoming lost
- becoming muddled about time
- putting themselves or others at risk through their forgetfulness
- behaving in ways that may seem unusual, such as going outside in their nightclothes
- experiencing difficulty with perception, and in some cases hallucinations.

### ***Late stage***

At this stage, the person with Alzheimer's will gradually become totally dependent on others for nursing care. Loss of memory may become very pronounced, with the person unable to recognise familiar objects, surroundings or even those closest to them, although there may be sudden flashes of recognition. The person may also become increasingly frail, eventually becoming confined to bed or a wheelchair. Other symptoms may include:

- difficulty in eating and, sometimes, swallowing
- considerable weight loss - although some people eat too much, and put on weight
- incontinence
- gradual loss of speech

The person may become restless, sometimes seeming to be searching for someone or something. They may become distressed or aggressive - especially if they feel threatened in some way. Angry outbursts may occur, usually because the person does not understand what is happening. Although the person may seem to have little understanding of speech, and may not recognise those around



them, they may still respond to affection and to being talked to in a calm soothing voice, or they may enjoy scents, music, or stroking a pet.

Alzheimer's disease is the most common form of dementia, but there are also other types caused by different diseases of the brain. Because these diseases affect the brain in different ways, they produce different symptoms. Some of the most common forms in addition to Alzheimer's are:

### ***Vascular dementia***

In vascular dementia, which is commonly caused by a stroke or a series of small strokes, brain cells are deprived of oxygen and die. This can occur in distinct parts of the brain, leaving other areas relatively unaffected. Some people with vascular dementia find that symptoms remain steady for a time and then suddenly decline as the result of another stroke. Others experience a more gradual decline. It is sometimes difficult to determine whether people have Alzheimer's or vascular dementia. It is also possible to be affected by both.

### ***Fronto-temporal dementia (including Pick's disease)***

This type of dementia is caused by damage to the frontal and/or temporal lobes of the brain. These are the areas responsible for our behaviour, our emotional responses and our language skills. During the early stages of fronto-temporal dementia, memory for recent events may be unaffected. However, there may be other changes. For example, the disease may cause some people to appear uncharacteristically selfish and unfeeling. They may behave rudely, or may seem more easily distracted. Other symptoms may include loss of inhibition, ritualised behaviour and a liking for sweet foods. In a small number of cases, a person's first problems may be with recalling the names of objects and comprehending words (semantic dementia) or with producing fluent speech (progressive non-fluent aphasia). In later stages the symptoms are more similar to those experienced in Alzheimer's disease.

### ***Dementia with Lewy bodies***

This disease gets its name from microscopic deposits that are found in the brain after death. These cause the degeneration and eventual death of nerve cells in the brain. Half or more of those affected by dementia with Lewy bodies also develop signs and symptoms of Parkinson's disease. They may also have difficulty in judging distances, and are more prone to falls. People with this type of dementia also commonly experience visual hallucinations. One feature of this type of dementia that often puzzles those around them is that the abilities of the affected person may fluctuate from day to day, or even during the course of a single day. In the later stages, the symptoms are often very similar to those experienced in Alzheimer's disease

(Sources: Alzheimer's Society <http://www.alzheimers.org.uk/factsheet/458>; Kings College, London and LSE (2007); DHSSPS (2011); Interview with Alison McKenna, clinical psychologist)

## Dementia and the Arts

It is not difficult to deduce from the above that much of a person's experience of dementia is defined negatively. What the arts, and in particular community arts, can offer is a positive lens through which to understand the person first, by looking at what they *can* do rather than what they can't. This is vitally important as a starting point for implementing the values and principles as outlined by the DHSSPS report above (DHSSPS, 2011). But more than this, community arts offers a way to cut through the rhetoric of change to the practice of action and transformation.

[P]eople living with dementia are learning every day, incorporating names, places and many of the positive and negative experiences of their daily life and care. We tend not to see this because we focus on deficits, but *what if our focus shifted to cultivating strength through creative engagement?* (G. Allen Power's forward in Lee and Adams, 2011: xiii)

It has already been suggested above that meaningful activity can delay the onset of dementia, and that the more the mind is occupied meaningfully, the greater the chances that the dementing process can be slowed down once it has already started. Additionally, it is the sense of 'connectedness', both with good feelings experienced in the past and thus with a sense of self, and to other people, that that community arts is particularly good at promoting. For example, tapping into popular trends such as 'Strictly Come Dancing', or carefully selecting music from a recognizable era can provide an important hook on which to build this. Increasing a sense of connectedness can also help to reduce stress, leading to a decrease in behaviour that challenges. Patients are less likely, for example, to wander (try to get home). Meaningful arts activity can help to relieve boredom, distress and a sense of being in the wrong place at the wrong time. If activity involves family members, it can also lead to more engaging and meaningful relationships.

Numerous examples of good practice within community arts when working with people with dementia, and of networks in the field which are gaining an influential voice already exist. Following is a brief selection of organisations in the UK using community arts in the field of dementia.

### **Arts 4 Dementia**

Arts 4 Dementia is a London based charity founded in 2011, which helps to develop and co-ordinate high-quality intergenerational arts opportunities for people living with dementia in the community, stimulating brain activity and bringing inspirational relief from anxiety and confusion, for them, their families and carers. Their vision is of a society where people with dementia are encouraged from diagnosis to engage in creative activities, challenges and adventures to enjoy their lives to the full, in society, without stigma. Their mission is to inspire and re-energise people with dementia, to bring fulfilment to their lives and provide opportunities for quality time with their carers and loved ones through engagement with their chosen art form. Through staging conferences, organising weekly arts events, raising awareness of the benefits of the arts and providing opportunities, Arts 4 Dementia aims to establish widespread, continuing access to artistic stimulation that will enable people with dementia to live better and longer at home. (See: <http://www.arts4dementia.org.uk/about-us>)

### ***Creative Dementia Arts Network***

The Creative Dementia Arts Network, based in Oxford, and also founded in 2011, aims to promote connections and collaborations between people with dementia, their carers, commissioners, health, housing and social care providers, policy makers and practitioners, cultural institutions, artists and academics to share and exchange knowledge about the use of creative arts to improve the health and well-being of those living with dementia. promote connections and collaborations between people with dementia, their carers, commissioners, health, housing and social care providers, policy makers and practitioners, cultural institutions, artists and academics to share and exchange knowledge about the use of creative arts to improve the health and well-being of those living with dementia. (See: <http://www.creativedementia.org/about>)

### ***Doncaster Community Arts***

From 2008-2011, Doncaster Community Arts (darts) has been developing its work with people who care for a family member with dementia, offering programmes of creative activities for both the carers and the people for whom they care. The findings from this work can be found in their publication: *Report on our work in Dementia cafes in Doncaster* (Woods, 2011)

### ***Age Exchange***

Age Exchange was founded in 1983 in the context of an emerging awareness of the value of reminiscence work, especially in care settings for older people. For over 25 years they have been developing new models of work offering participants a wide range of reminiscence-based creative activities and arts products. Recently, their focus has been on those most at risk of social exclusion. They have recently also launched a three year programme entitled *Reminiscence Arts and Dementia – Impact on Quality of Life (RADIQL)*. This is a three year programme which aims to provide a model of excellence in the provision of person-centred creative care for older people, specifically those with dementia, in South London. (See: [http://www.age-exchange.org.uk/about\\_us/index.html](http://www.age-exchange.org.uk/about_us/index.html))

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#### *Reports on dementia and community arts*

*McLean, J; Woodhouse, A; Goldie, I; Chylarova, E and Williamson, T (2011) An Evidence Review of the Impact of Participatory Arts on Older People, Edinburgh, Mental Health Foundation (also available on line at <http://www.baringfoundation.org.uk/EvidenceReview.pdf>)*

*Wood, J (2011) Report on our work in Dementia cafes in Doncaster, Doncaster, darts (Doncaster Community Arts).*

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## Community Arts Partnership and Dementia

So what is CAP's interest in community arts and dementia? CAP (and previous to its formation in 2011, the New Belfast Community Arts Initiative and the Community Arts Forum) has been working in the area of social inclusion and social transformation through arts activity for over fifteen years. In this time, we have the organisation has successfully developed and provided programmes for a range of demographics, and has always included provision for older people's groups, and for people availing of day care services.

In the wake of an increasing body of evidence highlighting the value of meaningful activity and the arts for people with dementia (see DHSSPS, 2011; Marmot, 2011; The Angila Ruskin/UCLan Research Team, 2007; Ings, Crane, and Cameron, 2012; Brodzinski, 2010 etc), CAP has taken a renewed interest in evaluating the provision of community arts activity in order to determine current level of arts activity for people with dementia, what is meant by best practice, and to determine recommendations for future practice.

This report is therefore an evaluation of a selection of community arts projects with people with dementia carried out by CAP between 2010 and 2013. It is a retrospective evaluation, based on the principles of participatory action research (see methodology and scope below for a definition), which at the time of writing are complete or near completion. The evaluation seeks to do two things: a) evaluate the programme to date and b) indicate how CAP might support future work, in particular with older people with dementia.

### Critical Questions for the Evaluation

As previously stated, the overarching question for this piece of research is: **What specifically needs to be considered in addition to general ways in which community arts is facilitated in order to develop best practice when working with people with dementia?**

Bearing the above contextual research in mind, critical questions for the evaluation include:

- What are the benefits of using arts with people with dementia?
- What are the opportunities for community arts to support people with dementia living in the community? What are current gaps in arts provision for people with dementia?
- What do different stakeholders understand by community arts? What do they anticipate the arts doing? How can an emancipatory, participant-centred understanding of community arts be conveyed?
- What are the issues that arise when working with people with dementia, and can facilitation be adapted to suit these?

Findings from this report will be used to:

- support community groups in applying for funding
- provide evidence of the benefits of using arts with people with dementia
- suggest ways in which this research contribute to policy development and advocacy work?

## Project Aims and Objectives

### ***Aims***

Based on the critical questions outlined above, the overarching aim of the research project is to determine the specific ways in which community arts should be facilitated in order to develop best practice when working with people with dementia. In this case, best practice is seen as embodying the values of values of dignity and respect, autonomy, justice and equality, and safe, effective, person-centred practice.

By looking beyond the medicalised setting to consider sympathetic arts practice in a range of different settings, CAP seeks to consider practical ways in which community arts with older people, and in particular those with dementia, can be supported. A variety of stakeholders in different community settings were interviewed in order to find out a sense of what they understood by community arts, and the benefits for people with dementia in participating in such projects.

### ***Objectives***

The research recognised that there may be different objectives for the different stakeholders in taking part in the evaluation, and anticipated these including:

#### ***For CAP***

- to reflect on, and improve, community arts practice
- to contribute to strategic planning and future impact of the research on policy development
- to contribute to future project development
- to provide a resource for community organisations wishing to apply for funding for arts activities with people with dementia
- To contribute to developing a language to describe participants in non-medicalised terms
- To include as many relevant voices within the evaluation process as possible, and particularly those who are not usually heard.

#### ***For participants***

To include their voices within the evaluation where possible, so that their experiences can contribute towards how projects are shaped in the future. It is recognised, however, that as a largely retrospective report, it has not been possible to do this in all cases.

#### ***For community groups***

To determine what community groups anticipate the creative work achieving, and how they could be supported further to achieve greater success in provision of arts projects.

## Methodology and Scope

### ***Scope of project***

The project took place over a four month period, followed by analysis and write-up. The research involved using the principles of participatory action research in order to gather the opinions of a number of stakeholders involved in creating and carrying out projects with older people with dementia. These included:

- artists (semi-structured interview / post-project feedback forms)
- activity officers (semi-structured interview / post-project feedback forms)
- CAP project coordinator (questionnaire)
- participants (informal group chats / post-project feedback forms)

The research focussed in the first instance on any community arts projects which had been carried out through CAP between 2010 and 2013 with people with dementia. Six projects were selected for review. From these six projects, the following were interviewed: five artists, three activity officers, and two groups of participants. In addition, post-project feedback from the same projects was used to cross-reference information from five artists, two settings and three groups of participants, taken immediately subsequent to the projects finishing. Evaluation and monitoring reports from four of the projects, original application forms from two projects, a semi-structured interview with a clinical psychologist and a questionnaire filled in by the CAP Side-by-Side (disability) project coordinator were also taken into consideration.

### ***Principles of Participatory Action Research***

Participatory Action Research (PAR) brings together the popular knowledge located within community groups along with research rigour in order to investigate local issues for the purpose of social transformation and justice. It is committed to developing *praxis*, a practice by which researcher and research participant reflexively probe a particular issue together in order to find possible solutions. (Borda, 2006)

Within the four month framework of the research, full adherence to the principles of PAR was limited, but the project attempted to implement these by consulting artists, CAP project leaders, and a clinical psychologist in addition to carrying out semi-structured interviews based on a previously designed questionnaire (see appendix 1) and further desk research. Interview questions were subsequently written up by the interviewer in questionnaire format and sent to interviewees for their feedback, amendments and additions. The interviews and questionnaires were tailored slightly differently according to the role the interviewee took on within the projects, and this is indicated where relevant in the findings below.

## Ethical Considerations

In addition to questions of ownership and development of research materials as indicated by the principles of PAR above, the following ethical considerations were taken into account:

### ***Transparency***

Interviewees and questionnaire respondents were made aware of the reasons for the project taking place, and how the information from the research would be used. They were also made aware that there was no 'right' or 'wrong' answer to any of the questions, and that their opinion rather than factual correctness was of greater importance. All interviewees and respondents had the opportunity to state whether they were willing to be included by name, or if they would prefer to remain anonymous for the purposes of the final report.

There will be an opportunity at the end of the questionnaire to state whether or not you would be happy to have a named or anonymous quote included in the final report.

### ***Data Storage***

Participants in the research were also made aware of how the data would be stored for possible future use.

## Project outlines

Following is a brief overview of each of the six projects which were evaluated as part of the research:

### ***'My World' photography project – Alzheimer's Society***

The Alzheimer's Society in Antrim has five groups who meet regularly, and were involved in one way or another in the "My World Project". Through workshops and discussions within the five groups, views were sought from Alzheimer's groups in Antrim, Ballymena /Broughshane, Portballintrae, Cookstown and Carrickfergus. This information, giving an insight into the daily life of people with dementia with all its ups and downs, was used to create photographic images by a core group of five men, facilitated by Brian Hennessy, to explain what living with the condition means to them. The images were brought together in an exhibition launched for Dementia Awareness Week (19-25<sup>th</sup> May 2013) and currently continues as part of two N/E and S/W Alzheimer's Association touring exhibitions funded through The Atlantic Philanthropies.

### ***The Diamond Diners, Claudy, Co L'Derry***

In partnership with the Western Health & Social Care Trust, the Diamond Centre, Claudy, Co Derry-Londonderry, operates a lunch club 3 days a week for older people (not specifically with dementia) living in the surrounding rural areas. The Diamond Diners enjoy food and company three times a week, and a wide range of activities such as dance, craft, visual arts, and textiles. I visited them when they were working with an outside conservation artist to make Christmas wreaths. One of the Diamond Diners showed me around the facilities, pointing out the artworks on display in the lobby and various rooms in the centre. These included a 3D tile relief and clay model village inspired by old photos of Claudy, bunting and embroidery displayed on the walls, and collage. They are currently preparing for an exhibition of work at the Waterfront, Derry, of work facilitated by Hilary, a CAP facilitator.

### ***Craft Projects – Belfast Trust residential homes***

Four of the Belfast Trust day centres were involved in this project: Chestnut Grove, Bruce House and Ballyowen Day Centre worked with Heather Douglas (CAP facilitator) on a craft project in the creation of Christmas and Easter items with the theme of reminiscence. The project culminated at an event and workshop in February 2013, when the three groups joined a fourth at Shankhill House. The event included an exhibition of work and a flower making workshop facilitated by Heather and the project coordinator Claire Concannon.

### ***Visual Arts project – Alzheimer's Society - Down and Lisburn Activity Group***

This was run as part of CAP's Landmarks (formerly Belfast Wheel) Visual arts project. Participants in the early stages of dementia began the creative process with gentle words and visual exercises in relation to nature and themselves. They were all given a page and asked to sketch or draw (with help if needed) some of the images discussed. Using a portable printing press, they created intaglio prints. This created an individual work for them to take home. Subsequently the group worked on a communal piece for the centre by creating relief canvas landscape wall works. The project was facilitated by CAP's Clare McComish who also works with people with dementia through ArtsCare.



### ***Tree of Life textile project – Residential homes and day centres***

Sally Young and a colleague worked on a textiles project through ArtsCare with four residential homes and day centres in Belfast and Co. Down. The 'Tree of Life' textiles project [see pics] was designed as a reminiscence project. The aim was for participants to show where they came from in the roots of the tree, their life experiences within the trunk, and their achievements in the branches. In reality the process was a lot more freestyle than this. The end project was a high profile exhibition. Some of the Shankill group were very skilled in sewing, having worked in the mills earlier in life. The process involved learning different skills: felt-making, sewing and beading amongst others.

### ***Music Project – City Way Day Centre, Sandy Row, Belfast***

Tommy McMeekin facilitated two music projects at the City Way Day Centre. During the first project, the group created a song which was then recorded and produced as a CD. 26 copies were made and distributed between the participants at the City Way Day Centre and other participating groups. The song was called 'Sweet Memories' and the lyrics were written by the group about a photograph which brought back memories and reminded them of their youth, going to ballrooms, dancing and finding a partner. Tommy returned at a later date for a second project and another song was written and recorded.

## **Findings**

Many of the findings demonstrate similar concerns and observations across the multiple partners and participants involved with a project, whether they are activity officers, artists, service users or project coordinators. Therefore, responses from artists and activity officers have been collated below, unless stated otherwise, as interviews were conducted in a similar manner, with similar questions. Where responses reflected different concerns, or where additional questions were asked, this has been indicated. Responses from all other interviewees are included as supporting quotations.

### ***Themes arising from interviews with artists and activity officers:***

Interviews with artists and activity officers focussed on project design, successes and failures of projects, approach to facilitation, communication across multiple partners and the learning process involved for all participants concerned. The interviews were divided into six sections:

- 1) Aims of community arts project
- 2) Successes and Failures
- 3) Facilitation
- 4) About the participants
- 5) About the setting
- 6) Lessons for future projects

The first five sections are dealt with mainly within the *Findings* section. See subsequent section *Recommendations* for 'Lessons for future projects'.

### **Section 1: Aims of the project, and how these changed during the process.**

- Quality, enjoyment, stimulation, relaxation and providing social interaction were key aims
- it was important to give space to the downs as well as the ups
- An end product was important for many reasons - to educate other people about dementia was one of the main aims of the photography project; to showcase the quality work produced; to allow family members to view the work and see what the participants have achieved; contributes to a sense of pride for the participants; acts as a trigger for reminding them what they have done in the sessions.
- The importance of exploring themes / techniques / sharing stories / reminiscence work
- Aims are sometimes set in advance by the funding agenda [this can lead to conflict in what the funding body wants to achieve compared to the evolving arts project and the needs and wants of the group]
- original aims were modest compared to outcomes

### **Section 2: Successes and failures**

#### **What worked:**

- Having enough time to get to know the participants and establish a relationship with them; giving one-to-one attention;
- Listening to participant stories
- Having follow up projects
- Slowing things down the pace of the participants to optimise their participation
- Having a knowledgeable and engaged project officer
- Working within a group meant that participants could take inspiration from each other.
- Taking a multi-disciplinary approach
- Finding a 'hook' as a way in for the participants
- Having empathetic artists who were flexible to the group's needs
- Recognising even the smallest of progress

#### **Aims of the project**

*"The aim was to give voice to people with dementia, and allow them to show the ups and downs of living with the disease – the bad times and mood changes as well as the achievements and what people CAN do". (Brian, Dawn and John, Photography Project)*

*"We didn't originally think of recording a CD – that came 3-4 weeks later because things went so well." – (Tommy, Music Project)*

*"Using the medium of photography to give an insight into dementia by the people affected by it has been unique in Northern Ireland. John was on BBC TV as a result of the project, and attended many events – the feedback has been overwhelmingly positive. The project will now continue to tour for the next four years, and has exceeded expectations of what could be achieved." (Brian, Dawn and John, Photography Project)*

#### **What worked:**

*"Everyone was involved with the project in taking pictures. It really showed that despite dementia, people are still capable of achieving something creative. For other people, the project was a source of inspiration, especially as the topic of mental health is such a taboo." (Brian, Dawn and John, Photography project)*

*"You could deliver exactly the same project twice, and one would succeed, and one would fail. Having or finding a hook was essential in making the projects work." (Sally, Tree of Life project)*

### **What didn't:**

- Sometimes the initial approach to facilitation didn't work for the group, and had to be adapted
- Some techniques were not appropriate for people who didn't have dexterity in their hands, and had to be changed
- Timetabling, organisation and transport issues mean that sometimes not everyone gets to participate fully
- Not having enough sessions limited the outcomes
- Unsuitable transport to get to events
- Personality clashes between the artists and participants, sometimes caused by not knowing how to deal with behavioural issues.

### **Main challenges:**

- Creating genuine participation and participant-led content
- Facilitators not being sure of physical and mental needs of participants and issues to do with dementia
- Facilitators sometimes weren't sure of health and safety issues
- Limited space and resources within settings.
- Preparing for exhibitions and completing a high quality end product – both time and financial implications
- Dementia is a growing problem - due to better diagnosis and the disease being caught earlier, numbers are escalating. Much more funding is needed.
- Reliance on artist's own equipment for success of project
- Including men and women in project (women seem to be more ready to take part in projects, men need more encouragement)
- The difference between what funders want to achieve, and the needs of the group within the developing project with the group / other people's expectation.
- Participants can lose interest easily and walk out; participants numbers can change from week to week

### **What didn't:**

*"I sometimes used technical terms through habit and words that then needed to be explained, which sometimes confused people. I had to slow down in explaining what I meant sometimes." (Tommy, Music project)*

*"There were some simple things that didn't work – one idea was to work with embroidery thread, but this just didn't work." (Heather, textiles project)*

### **Main challenges:**

*"For myself and Darren, facilitating a song that was genuinely from the participants, and not putting ourselves into the project – giving it completely to them – and still getting it done in the time was challenging." (Tommy, Music project)*

*"When [participants] were experiencing the "dark side" of dementia, they could experience a lot of agitation due to a limited ability to communicate." (Brian, Dawn and John, Photography project)*

*"The temporary nature of the space curtails what can be done on a project. Some healthcare based day centres have their own designated arts space, and even their own kiln, but this is unusual" (Clare, Visual Arts project)*

*"Processing all the photographs, and putting them together for the exhibition was a vast amount of work. There were forty pictures altogether to prepare." (Brian, Dawn and John, Photography project)*

### **Section 3: Facilitation**

This section looks more closely at the experience, level of knowledge, confidence, support needs and learning of the artist facilitators, in order to determine how facilitators might adapt their practice in order to promote an environment of 'connectedness' (see *Rationale and Context* p.3).

All the artists interviewed rated themselves with an experience level of 1 or 2 out of 5 prior to the project taking place, indicating that working with people with dementia was a new experience for them. Two of the artists had personal experience of dementia through a close family member, indicating that they had a particular motivation and engagement for working with their particular groups.

Two of the artists interviewed indicated that their experience level had gone up by 2 points by the end of the project. (See Appendix 1, section 3.1 for score rating).

#### ***Level of knowledge prior to start of project***

When asked if they would like to have known more about dementia prior to starting the project, there was an even split in responses. Those with personal experience of dementia through a family member didn't want to know more, as they felt it would have limited their expectations of working with the group, and they didn't find it relevant to know more. They did indicate, however, that it wouldn't have done any harm to know more.

Those artists with little prior experience of dementia indicated a strong need for training, particularly in terms of how dementia develops, in working with people with more advanced levels of dementia, and in managing aggressive behaviour.

It was generally understood that staff members would be present to take care of any physical needs participants had, and that it would be communicated before each session if there were any particular issues relevant to individuals within the group that day.

#### ***Support needed for delivering projects for people with dementia***

- Training for artists in areas such as: effects of dementia, using resources and space to the advantage of participants, reminiscence work, knowing when participants can be challenged to develop and grow and when they need more support

#### ***Level of knowledge prior to start of project***

"I feel that from my limited experience from the medical /social perspective that the emphasis is on the sufferer's disability rather than on what they can still achieve. [It is] better to approach the project as just a group of people learning a new skill and working at their pace."  
(Brian, Photography project)

"It's difficult to know how to deal with people when this is a part of their illness – it can't be reasoned away, and you need to react with authority in those situations."  
(Sally, Tree of Life project)

- Good planning ahead of time (also helps activity officers to plan in their settings)
- Being flexible to needs of the setting and of participants
- Resourcing of high quality materials and equipment
- Further experience through: working in a variety of settings, volunteer opportunities (to determine if working in a dementia setting is compatible with personal facilitation style), and peer observation
- Excellent communication with support staff regarding needs of group prior to each session
- Artists working closely with staff to prepare them for using the arts with people with dementia as a more social rather than medical approach

***To what extent does an arts facilitator need to be aware of the abilities and functioning of people with dementia?***

- Excellent communication with support staff essential in order determine group needs and support requirements prior to each session
- A need to know health and safety issues with regard to dementia
- A basic understanding of the way in which dementia can affect older people is necessary – especially in relation to memory. Artists need to know how to interact with participants, in a level and calm way that minimises any distress they may be experiencing
- A need to know behaviour management techniques in case participants display distress, anxiety or anger (see Definitions: Dementia, p.6)

*People with dementia are very reliant on facial expressions. Negative facial expression can be seen as evidence that they are in danger, or that something is wrong. Facial expressions should be comforting, offer reassurance, and the person working with them should maintain a pleasant tone of voice. (Alison McKenna, Consultant psychologist, Northern Trust)*

***On the awareness needed of abilities and functioning of people with dementia***

*“It is incredibly important to know about health and safety. For this project, for example, cleanliness in a home setting was very important to be aware of. Scissors for each group couldn’t be recycled, for example, so as not to transfer sickness from one group to another.” (Heather, Textiles project)*

*“Time and trust, and getting to know each other without the pressure of working towards an immediate goal is really important. The group always had something to look forward to.” (Brian, Photography project)*

*“[E]ach group is unique, and the knowledge necessary is specific to the individual[s] in the groups, the setting and where the group is based, and policy and procedure (for example, health and safety) in that particular setting. Therefore the project planning stage has to carefully incorporate specialist advice as well as collaborative partners.” (Clare, Visual Arts project)*

## Adaptation of facilitation style due to dementia

Facilitators found themselves adapting their facilitation style in the following ways:

- **Time:** Slowing down some of the processes, and/or allowing participants more time
- **Materials:** Adapting equipment and materials used to better suit participants; adapting the process according to how the group responded, their experiences and what they could do.
- **Flexibility of Process:** Total flexibility, interaction and communication. Not being afraid of changing something mid-session if it's not working.
- **Preparation:** Being well planned for sessions, and well-researched in knowledge of the group
- **Sensitivity:** Being sensitive to emotional state of the participants

## On the organisation of the project, including communication, by the project coordinator

- Availability of and quality of communication with project coordinator is a key factor in helping the project run smoothly.
- The more key players involved in running a project, the greater the need for clarity
- Parameters of the project should be clearly set down in writing prior to the project taking place, particularly when multiple project partners are involved.
- Adequate time should be set aside for communication between project partners.
- Each arts provider has its own way of working, and its own budget. [The implication again is that communication, particularly at the beginning of the project, is important].

## On the organisation of the project

*"There were no problems. Claire was always on the phone to follow up on sessions. Contact was good, and there was no messing with dates." (Tommy, Music project)*

*"Coordination of the project was fine because Claire was always on hand. Having a good relationship with her helped when an extra bit of money was needed to buy higher quality resources." (Heather, Textiles project)*

## The participants

*"There is no such person as a 'typical dementia sufferer', all are individuals and must be respected and treated as such." (Brian, Photography project)*

## Section 4: The participants

### Benefits through participating in arts projects

- **Socially:**
  - Increased social confidence
  - Increased energy and alertness
- **Cognitively:**
  - memories stimulated and forgotten skill reawakened
  - recognition of artist and enjoyment of activities from week to week
  - art work produced acted as a trigger for remembering activities from previous sessions.
  - Increased engagement and excitement at the arts activities
  - Stimulus from outside their normal setting, from professional artists, helps keep their minds active
- **Personal development**
  - An aid to communication / self expression
  - Increased confidence
  - Taking inspiration from others in the group / peer support
  - Less stress / more relaxation
  - Sense of achievement
- **Changing attitudes**
  - Families could see what participants had achieved through the creation of a final product

*“The smiles on the participant’s faces were a delight to see, I noticed their sense of achievement when they wanted to keep their crafts and to give to family members. As for quality of life, I think we made a difference, for without our activities some of participants would not have had any stimulation.” (Heather, Textiles project)*

*“One challenge came from going away and forgetting what had happened each time. The group needed to see it all come together. The launch was a great day – the Mayor of Antrim attended.” (Brian, Dawn and John, Photography project)*

### **Benefits through participating in arts projects**

*“They got to know each other better, were more chatty and encouraged and supported each other a lot.” (Tommy, Music project)*

*“The launch was very emotional, and family members commented on the fact that they had never really thought about it from the perspective of the person with dementia. In this way it helped to change perspectives.” (Brian, Photography project)*

*“Through the artwork, one African lady who didn’t speak English was able to join in in a way that she hadn’t previously.” (Interview with Heather, Textiles project)*

*“Annie showed me the tiles, collages in the other room where a few of the men and Mary were playing dominoes, the bunting and the embroidery on the wall in the dining room where we are making the wreaths. She expressed a huge sense of pride about the projects she had done, particularly the clay model village of Claudy” (visit to Diamond Diner’s, Claudy)*

*“Their confidence increased as they saw what they could achieve. Acknowledging to them that they have existing skills, and that they are people who have lived through hard times is really important for this too: one man in the Shankill group was in the RUC, and really knowledgeable about politics. Others had raised kids through the troubles on very low incomes.” (Sally, Tree of Life project)*



## Section 5: About the setting

### Were there differences between the settings?

Three artists answered yes to this questions. Two artists had only worked in one setting.

- **Levels of ability** were sometimes different between the groups according to their level of dementia.
- **Workshop space** wasn't always appropriate: shared spaces were sometimes used for craft activities, making it difficult for people to concentrate.
- **Staffing:** staff make the difference in terms of safety and being able to manage the group. It wasn't always the case that there was a member of staff present in the room.
- **Resources:** Some settings had resources they didn't know how or have time to use. One staff member may have bought in something and then left, leaving resources that others didn't have use for.

### Communicating with activity officers and staff in dementia settings

Communication between artists and activity officers / staff in the individual settings was seen as key to the success of the project and to engaging the participants, with one artist stating that 'outcomes and the success of the project depends very much on how engaged the leaders of the groups are in the process. The community artist is *in partnership* with a number of different agents, so inter-personal connections are key.' (Clare, Visual arts project). This was echoed by a number of artists. In a majority of instances the experience of working with the activity officer was experienced as a positive one. Staff and activity officers were an important source of knowledge and information regarding participants. They would:

- highlight any restrictions the participants may have
- take care of participants' physical needs.
- provide information on basic health and safety and boundaries.

Where communication and working relationships with the activity officer were unclear, didn't work or failed in a small number of cases, this made the project more difficult and sometimes led to failure of the entire project.

### Communicating with activity officers and staff in dementia settings

*"It was clear that Fiona wasn't there just because it was her job to be, but really cared about the quality of life of the participants. She was very hands on, and a really good source of knowledge"* (Heather, Textiles project)

*"Sally was incredibly supportive of the arts project, and sent out emails, letters and phone calls prior to the first day to make sure that people would be there ready to participate."* (Clare, Visual Arts project)

*"ArtsCare had a really good approach – they have one coordinator for everything ... who was able to answer any questions: eg should we be left with residents and no staff? ... With dementia, the whole process has to be joined up to work."* (Sally, Tree of Life project)



**Additional Question to Service Providers: How can the arts support people with dementia?**

In addition to the categories of findings above (aims of community arts projects, successes and failures, facilitation, benefits for participants, and about the setting), a further question of how the arts can support people with dementia was posed to three service providers in Northern Ireland who work with older people with dementia, namely The Belfast Trust (residential), The Belfast Trust (day services) and The Alzheimer's Society, Antrim. Their responses, which reflect those of all participants interviewed, can be categorised as follows:

***By focussing on what people CAN do, and not on what they can't:***

This was seen as a vitally important way in which the arts can support people with dementia – by focusing on what people can do, rather than what they can't. In bringing people together and letting them talk at their own level so they are not out of their depth, whilst giving them the time to make discoveries for themselves, the arts allow people with dementia to build confidence. Even if they don't want to join in initially, just watching others can allow them to orientate themselves so they can join in later. The arts can show that age isn't a barrier to art and craft, and can demonstrate the wealth of knowledge that older people *do* have

***By using processes and outcomes which stimulate cognitive, social and personal development responses, which develop a sense of 'connectedness'***

The arts can help people with dementia to be more focused, more stimulated, more alert, and to have more energy. Without such stimulation, they might be sleeping, watching TV, or listening to the same music over and over. In a residential home, they might even withdraw from social interaction and retire to their own bedroom.

Participatory art forms promote not only cognitive stimulation, but also social interaction – of great importance to people with dementia who tend to be far more isolated than their peers without dementia. Participants not only get to interact with other members in their own setting, but there is also the

***By focussing on what people CAN do, not what they can't***

*"Finding the right artistic trigger for someone can help them to find an anchor in all the confusion they are experiencing. One time a resident who was experiencing a lot of confusion was given the opportunity to play an accordion – something he had previously done. The accordion was passed backwards and forwards between the musician and himself, and helped him to focus and become calm. (Fiona McGettigan, Belfast Trust (residential))*

***By using processes and outcomes which stimulate cognitive, social and personal development responses***

*Getting out and about as part of the project – seeing the waterfalls, and having a day out: the project was far more than learning about a new art form. Using a mixture of different art forms is really useful. People can become very agitated when they have dementia, and using music can help them to settle down more. (Interview with Dawn Beckett, Brian Hennessey and John McErline, Alzheimer's Society, Antrim)*

*There was a DVD made of a recent intergenerational project between the older people and a local primary school. Last week children from the creche came in and sang carols in the day centre. The older people love having younger ones come in and visit. The Women's Centre next door is also really supportive. (Jason McIlvenna, Belfast Trust (day services))*

opportunity to be a part of the wider community, for example through inter-generational and inter-cultural projects.

Activities must, however, be based on what participants themselves want to do – arts activities are only meaningful in this context.

***By using well facilitated community arts processes, to a high professional standard***

But the arts have to be done well, to a high standard. Exhibitions and displays of the work, develops a huge sense of pride for the participants, and allows other people (particularly families and friends) to see what they can achieve. This is largely dependent on the empathy and communication of the artist, who is key to the success of participatory arts activities.

Finally, the arts add to the range of activities on offer, and add additional stimulus, variety and expertise for the service users that the settings can't otherwise provide.

*The arts offers something for everybody. John used to play the guitar, and picking it up now and then, and listening to music helps to bring back memories. There's a picture of John and Tommy playing in one of the photos. Tommy is playing the Ukulele." (Interview with Dawn, Brian and John, Alzheimer's Society, Antrim)*

***By using well facilitated community arts processes, to a high professional standard***

*"The arts can help to overcome the challenges of the dark days: you're not just sitting down for two hours, letting your mind wander." (John McErlane, Alzheimer's Society, Antrim)*

## Summary

So what does all this mean? After collating the findings of this particular research, the question still remains: how can community arts support people with dementia? And more specifically, as artists, facilitators, project coordinators, service providers, carers and participants:

**What needs to be considered in addition to general ways in which community arts is facilitated in order to develop best practice when working with people with dementia?**

First of all, as stated in the *Rationale and Context of Research* section of this report (p. 3-5), this necessitates a change in *our* attitudes and practice towards people with dementia, in order to promote an environment of 'connectedness' which best serve to stimulate 'cognitive, physical, psychosocial and spiritual well-being' of participants (Hellen, 2000: 35). This is the foundational assumption which must be in place for any transformation of practice to happen.

Secondly, the following principles and values embodied in essence by Community arts must also be embodied in *practice* in order to move beyond mere rhetoric of change towards *action*. These are the values of dignity and respect; autonomy; justice and equality; and safe, effective, person-centred practice.

With these assumptions in place, there follows a brief summary of findings as categorised previously:

- Aims of community arts projects
- Successes and failures; Challenges
- Facilitation
- Benefits for participants
- About the setting

### **Aims of community arts projects:**

Aims of community arts projects must be both flexible, and based on the positive affirmation of what people with dementia can do, not what they can't. When people with dementia receive a diagnosis, it is based entirely on a model of deficit. In order for them to find dignity, autonomy, stimulation and a sense of well-being within this process and following, it is useful to be reminded of what they can still achieve, without minimising the struggles they face. Including a high quality final exhibition or tangible outcome for the project is therefore important, and in this way, participants of community arts projects are often able to achieve more than originally foreseen. At the same time, focus must be given predominantly to *process*, which allows for enjoyment, relaxation and social interaction in order to explore themes and share stories.

### **Successes and failures:**

Projects succeeded to the greatest extent when they were participant-centred in every aspect from conception, through the process to project outcomes and evaluation. The main considerations to be made in adjusting projects to the needs of people with dementia were:

- **time** – to establish relationships, listen to stories, slow down the pace to enable optimal participation when necessary, find a 'hook' as a way in to the project
- **empathy** – listening to participant stories; having a flexibility in all processes towards group needs; acknowledging progress
- **social interaction as a focus**
- **good communication between all parties involved for the duration of the project**
- **developing subsequent follow-up projects** – particularly using a variety of different media is useful for continued stimulation
- **transport** – from the start planning in suitable transport where this is necessary.

When the above considerations were not made, projects were not as successful. Additionally, however, there were times when things had to be adapted because they just weren't working, for no apparent reason. This is where the choice of an empathic facilitator is essential.

### **Aims of community arts projects:**

*"The aim was to give voice to people with dementia, and allow them to show the ups and downs of living with the disease – the bad times and mood changes as well as the achievements and what people CAN do". (Brian, Dawn and John, Photography Project)*

### **Successes and failures:**

*"I sometimes used technical terms through habit and words that then needed to be explained, which sometimes confused people. I had to slow down in explaining what I meant sometimes." (Tommy, Music project)*

## **Challenges**

Challenges were experienced in different ways by different project partners, and have therefore been separated here to reflect this.

### **For facilitators:**

Facilitators experienced challenges in terms of the tension between time and expectation of achievement – that is to say, creating high quality, genuine participant-led content, potentially with an exhibition or final outcome, within a limited amount of time. A second challenge which was frequently referred to was a lack of knowledge and/or confidence as to the physical and mental needs of participants, and sometimes in terms of health and safety issues.

### **Environmental and resourcing:**

Space, resources and funding were seen as significant challenges to community arts projects. Settings often have limited space and resources for the projects to be carried out. This, coupled with improved diagnosis and growing numbers of older people who will be diagnosed in the future means that greater funding is essential. Projects often rely on an artist's own equipment for success, and often inadequate preparation time and money for final displays, exhibitions and gatherings is included within initial funding allocation.

### **For participants:**

There is often a gender imbalance on community arts projects, and consideration needs to be given to the choice of project medium in order to include men. Women seem to be more ready to take part in projects, whereas men need more encouragement. Once participants have started a project, they can lose interest easily. Participant numbers can also change from week to week, making strategies for engaging participants and flexibility in project delivery essential.

### **In expectations between project partners:**

The greater the number of project partners, the more expectations need to be negotiated. There can be sometimes large discrepancies between what funders want to achieve, the needs of the group within the developing project, expectations of family members, and needs within the setting.

## **Challenges**

### **For facilitators:**

“Processing all the photographs, and putting them together for the exhibition was a vast amount of work. There were forty pictures altogether to prepare.” (Brian, Dawn and John, Photography project)

### **Environmental and resourcing:**

*“The temporary nature of the space curtails what can be done on a project. Some healthcare based day centres have their own designated arts space, and even their own kiln, but this is unusual”* (Clare, Visual Arts project)

### **For participants:**

“When [participants] were experiencing the “dark side” of dementia, they could experience a lot of agitation due to a limited ability to communicate.” (Brian, Dawn and John, Photography project)

### **Facilitation:**

As the previous 'Successes, failures and challenges' section implies, the success of a community arts project, and the ability to rise to the challenges that they bring, rests heavily on the expertise, empathy, confidence, planning, and intuition of the facilitator. It is therefore important to consider the support needed for community arts facilitators to develop and adapt their practice when working with people with dementia in some depth here.

### **Knowledge and training in dementia**

All artists interviewed gained a great deal of knowledge and experience through facilitating community arts projects with people with dementia. However, prior to the projects taking place, they had had little experience of dementia in a professional capacity. Those with personal experience of dementia were glad they didn't have further prior knowledge about the disease, as they felt that this may have limited their expectations of working with the group.

They did indicate, however, that it wouldn't have done any harm to know more, and Brian's cogently worded quote indicates that it is perhaps the *focus* and *framing* of any foreknowledge or training that is important, rather than the absence of it. This is supported by those artists with little prior experience of dementia who indicated a strong need for training, particularly in terms of how dementia develops, in its effect on memory, in working with people with more advanced levels of dementia, in managing unpredictable behaviour linked to the disease, using resources and space to the advantage of participants, reminiscence work, and knowing when participants can be challenged to develop and grow and when they need more support. This would help to reduce insecurity on the part of the artist in interacting with participants in a way which helps to minimise distress and anxiety levels related to the disease.

Although it was generally understood that staff members should be present take care of any physical needs, it was also felt that health and safety issues relating to dementia should be covered, at the least by informal training, prior to the projects taking place.

Informal ways to gain experience, and to determine whether working in a dementia setting would be of interest to an artist

### **Knowledge and training in dementia**

"I feel that from my limited experience from the medical /social perspective that the emphasis is on the sufferer's disability rather than on what they can still achieve. [It is] better to approach the project as just a group of people learning a new skill and working at their pace."  
(Brian, Photography project)

*"It's difficult to know how to deal with people when this is a part of their illness – it can't be reasoned away, and you need to react with authority in those situations."*  
(Sally, Tree of Life project)

facilitator were indicated as being desirable. Facilitation in dementia settings is demands a particular empathy, sensitivity, and ability to adapt, and it should be recognised that this isn't for everyone. Therefore there should be opportunities through volunteering and peer observation for artists to discover whether they would like to work further in this field.

### **Adapting practice**

Being flexible to the needs of participants means being able to adapt practice, both in the planning and preparation stages in conjunction with project partners, during the project itself in response to the participants, and afterwards in evaluating projects in a way that participants can contribute meaningfully towards. Those aspects particularly of importance in working with people with dementia include: Allowing adequate time to understand instructions and participate in processes; using high quality materials and equipment suited to the needs of participants; being prepared for complete flexibility of processes; and being sensitive and empathetic to the emotional state of the participants.

### **Relationship with staff**

Excellent communication and planning with support staff was seen as an essential part of the process in order determine individual and group needs and support requirements prior to each session. It was also suggested that artists work closely with staff prior to projects taking place in order to prepare them for using the arts as a social approach, rather than the more medical approach they are used to within their setting.

### ***The participants***

#### **Benefits through participating in arts projects**

In order for the 'three keys' of physical, mental and social stimulation to be met (according to Valenzuela, 2011, 183-184, as outlined in the Context and Rationale of this report, p.5), participants need to be *actively* involved in *meaningful* activity (Hellen, 2000: 35). Such active and meaningful activity results in connectedness, both to self and to others.

The findings above outline how participants benefitted from arts activities socially, cognitively and in terms of personal development. Although physical activity was not directly

### **Relationship with staff**

*"[E]ach group is unique, and the knowledge necessary is specific to the individual[s] in the groups, the setting and where the group is based, and policy and procedure (for example, health and safety) in that particular setting. Therefore the project planning stage has to carefully incorporate specialist advice as well as collaborative partners." (Clare, Visual Arts project)*

### ***The participants***

*"There is no such person as a 'typical dementia sufferer', all are individuals and must be respected and treated as such." (Brian, Photography project)*



included in the findings above, there were occasions when participants were engaged in excursions, exhibitions and social events as part of the projects which would have involved levels of physical engagement above that of their everyday activity. Fine motor skills were also necessary for all of the projects, which challenged the dexterity of participants. However, the summary here will focus on the other categories investigated.

### **Socially**

With rising numbers of older people being diagnosed with dementia, and figures of people diagnosed with the disease in Northern Ireland set to rise to approximately 60,000 by 2051 alongside a greater focus on community care, the undertaking of community arts projects is an ideal way to bring people together socially. As indicated in the findings above, the projects evaluated above benefitted participants through increased social confidence, energy and alertness. In this way, the projects fostered an environment of 'connectedness' thus stimulating the 'cognitive, physical, psychosocial and spiritual well-being' of participants (Hellen, 2000: 35).

This is more remarkable given the long list of social 'deficits' usually attributed to people during the various stages of dementia, such as: losing interest in other people or activities; forgetting about recent conversations or events; becoming slower at grasping new ideas, or losing the thread of what is being said; losing confidence in themselves; and experiencing distress over their failure to manage tasks – all of which impact on social confidence.

### **Cognitively**

As outlined in the Context and Rationale section of this report (p.5), there is mounting evidence to suggest that delaying the onset of dementia, and reducing the impact of the disease once it has taken hold, may be enabled mentally challenging activity. Regular mental activity over several weeks can be instrumental in arresting the development of the disease, most notably (though not exclusively) through music and dance. (Arts4Dementia, 2013: 6;25).

The findings in this evaluation noted cognitive stimulation through recognising the artist from week to week, and a clear enjoyment and continued engagement at participating. Creating a 'product' and using high quality 'props' as part of

### **Socially**

*"They got to know each other better, were more chatty and encouraged and supported each other a lot." (Tommy, Music project)*

### **Cognitively**

*"One challenge came from going away and forgetting what had happened each time. The group needed to see it all come together. The launch was a great day – the Mayor of Antrim attended." (Brian, Dawn and John, Photography project)*



the projects enabled further cognitive engagement by acting as a trigger by which to remember activities from previous sessions. This enabled participants to engage with activities over longer periods of time, thus increasing the level of mental stimulation. It was also noted by activity officers that having professional artists come into the settings provided a greater than usual stimulus for participants, thus helping to keep their minds more active.

Thus, community arts activity help to minimise the distress and confusion associated with dementia. By allowing for what might under normal circumstances be considered 'unusual' behaviour (such as wandering off, becoming muddled about time, being confused as to where they are) to be incorporated into the creative process, the person can feel accepted and cognitive distress reduced.

### **Personal development**

Community arts, based on the principles of person-centred, participatory, community development, can create an environment by which people with dementia can be supported to make autonomous decisions about their activities, thus respecting their dignity. The findings above indicated that taking part in the arts projects helped to increase confidence, aid communication and self-expression, reduce stress and increase participants' sense of achievement. Activity officers repeatedly referred to the need to minimise distress, anxiety and agitation that are frequently associated with dementia, and that participating in community arts activities does just that.

### **Changing attitudes**

At the core of participatory community arts practice as defined by CAP lies the principle of social transformation. This involves not only working with participating groups in order to effect change, but also working to transform external social attitudes and perceptions. In particular, projects which allowed participants to work with other groups within the community were seen as beneficial. Activities which involved families, thus allowing them to see what participants had achieved, for example through the creation of a final product, had a positive effect on their attitudes and perceptions of what people with dementia are able to achieve.

### **Personal development**

"The project gave the participants a sense of purpose. John can still talk about the project, a lot of people can't. There are more people with dementia who don't know how to or can't express themselves."  
(Brian, Photography project)

*"Their confidence increased as they saw what they could achieve. Acknowledging to them that they have existing skills, and that they are people who have lived through hard times is really important for this too: one man in the Shankill group was in the RUC, and really knowledgeable about politics. Others had raised kids through the troubles on very low incomes."* (Sally, Tree of Life project)

### **Changing attitudes**

"The launch was very emotional, and family members commented on the fact that they had never really thought about it from the perspective of the person with dementia. In this way it helped to change perspectives." (Brian, Photography project)

### **The Setting**

According to 2007 figures, almost half of people with dementia in Northern Ireland are in care (Kings College London and LSE, 2007). This means that they are not looked after at home, but in residential homes, or in hospitals. The focus of government policy, however, is to move away from non-domiciliary care, thus increasing the number of people with dementia living at home within their local communities. This will increase the need for 'joined up' thinking in terms of services, which will no longer be provided in one place, and potentially make access to the different elements of care provision much more complex.

Within the findings above, it was emphasised that communication between artists and activity officers or staff in the individual settings was key to the success of the project and thus to engaging the participants. When in isolated cases communication failed at some level, it compromised beneficial outcomes for the project. With increasing numbers of people with dementia based in a community setting, and an even greater need for social interaction to take place, effective communication will become even more vital to ensuring successful outcomes.

Information exchange between activity officers and artists was also vitally important for a projects success. Activity officers could highlight health and safety issues, individual participant needs, and could take care of participants' physical needs. Artists can demonstrate ways of working which emphasise the social rather than the medical needs of people with dementia, thus reinforcing a person-centred approach.

Those artists interviewed who had worked in various settings with people with dementia had noticed differences in levels of ability of the participants according to the severity of dementia; substantial differences in the space and resources they had access to; and the level of staffing available. All these factors need to be considered in the delivery of projects in order to maximise the resulting benefits of a community arts project.

### **The Setting**

*"It was clear that Fiona wasn't there just because it was her job to be, but really cared about the quality of life of the participants. She was very hands on, and a really good source of knowledge"*  
(Heather, Textiles project)

"With dementia, the whole process has to be joined up to work." (Sally, Tree of Life project)

## Recommendations for future practice

The findings of this review of community arts projects with people with dementia go beyond the theory as set out in the introduction and contextual section, to demonstrate how *active engagement* in participatory arts can move us from a rhetoric of change to outcomes which have a profound impact on the way that people with a diagnosis of the disease live their lives.

At the same time, it is clear that far more directed support must be offered in order to support the prevention of an impending crisis in community directed care and dramatically increasing numbers of people diagnosed with dementia in the near future. If people are to be cared for more and more from within the community, then attention must also be paid to their social well-being as much as their medical needs. This is where community arts, based on the principles of person-centred, participatory, community development, are well-placed to facilitate such change.

In order to do this, however, and in light of the above findings, investment must be made to support the development of community arts with people with dementia. The findings of this report ask that we raise expectations in ourselves, that we are far more ambitious in what community arts can achieve when working with people with dementia, and that we look beyond the external, medically defined assumption that they are no longer able, to a positive, dignified view that they have much still to offer and are able to actively participate in creative and social activity. In fact, returning to Hellen's quote (p. 5 of this report) she states:

Being, doing, and belonging, the basis for connectedness, require care receivers to be actively involved with meaningful activity. Activity, the core component of all of life, defines the person with dementia's cognitive, physical, psychosocial, and spiritual well-being. (Hellen, 2000: 35)

Of course, this is a small scale study into community arts and dementia, and there many things beyond the scope of this project. For example, collaborative and inter-agency working and communications are only touched on here. Further investigation is necessary to ascertain the mechanisms, infrastructure and networks needed in order to properly support capacity building in this area. It is therefore important that recommendations from this report are realistic and attainable in light of the above findings.

The following recommendations, therefore, follow on from the five categories highlighted within the previous findings and summary sections:

- Recommendations for aims of community arts projects with people with dementia
- Recommendations for the success, limitation of failure and overcoming of challenges in carrying out community arts projects with people with dementia
- Recommendations for facilitation when working with people with dementia
- Recommendations for meaningful participant-centred community arts processes with people with dementia
- Recommendations for creating the right environment within the setting

### **Recommendations for the aims of community arts projects with people with dementia**

1. Projects should follow best practice for community arts projects in general, according to the definition as outlined by CAP. In this way, they will adhere to the values and principles of dignity and respect; autonomy; justice and equality; and safe, effective, person-centred care as laid out in the DHSSP report *Improving dementia services in Northern Ireland: A regional strategy* (2011, 4.6, pp30-31).
2. Aims should focus on what participants **can** do, and start with the premise that people with dementia have something to offer. At the same, such person-centred ways of working demand that attention be paid to, and time invested in finding out the starting point from which the individuals with dementia are participating. That is to say, there will be ways in which they can more easily participate if, for example, their interests (past and present), dislikes and personal preferences are ascertained as 'hooks' to be incorporated into the arts projects in advance. Oliver James in *Contented Dementia* (2008) demonstrates a particular person centred method of working with someone with dementia which may be useful to explore within community arts.

### **Recommendations for the success, limitation of failure and overcoming of challenges in carrying out community arts projects with people with dementia**

3. Successful community arts projects are those which factor in the following:
  - **TIME:** Extra time should be factored in at various stages in the project process in order to establish relationships between project partners, between artists and participants and where the participant group (in full or in part) has not worked together previously. Processes may need to be slowed down, or adapted in order for people with dementia to participate meaningfully in arts activities. Extra time should also be allowed where there are any specific project outcomes expected (such as exhibitions, final displays of work and events). Extra time may also be needed in order to carry out meaningful evaluation with participants at the end of a project.

### **Definition of Community Arts as outlined by CAP**

*Community art is a process of harnessing the transformative power of original artistic expression and producing a range of outcomes: social, cultural and environmental.*

*Looked at politically, socially, culturally and/or economically, community arts aim to establish and maximise inclusive ways of working, providing an opportunity for communities and their participants to continue to find ways to develop their own skills as artists and for artists to explore ways of transferring those skills.*

*Through this process, community arts aim to maximise the access, participation, authorship and ownership in collective arts practice.*

- **FACILITATION:** This should be carried out by carefully selected facilitators, based on a sympathetic facilitator profile (see below under Recommendations for Facilitation)
- **SOCIAL INTERACTION:** Community Arts projects with people with dementia should always have a social focus as one of their aims, in order to minimise social isolation, which is likely to become an increasing issue for people with dementia in the future as their care needs are met more and more from a community base.
- **COMMUNICATION:** Good channels of communication must be made a priority when working with people with dementia, and more so given the likelihood for multiple project partners.
- **APPROPRIATENESS OF RESOURCES:** Resources should be of high quality and any equipment / transport appropriate to the needs of the group. (see below under Recommendations for Facilitation: Toolkit)

### ***Recommendations for Facilitation when working with people with dementia***

High quality, appropriate facilitation is pivotal to the success of any community arts project, and particularly so with people with dementia. The selection of an artist who is able to relate to and build a strong relationship with the participant group is essential. The facilitator has to be able to act often on intuition, be focussed on the needs of participants, possess a metaphorical 'peripheral vision', be aware of health and safety issues, be able to anticipate the emotional state of the group, and guide them towards a relaxed, interactive and participative experience.

### **Selection of Facilitators**

4. With the above in mind, it is recommended that artists be selected to work with people with dementia on the basis of a sympathetic profile which asks that they:
  - Be empathic
  - Have an interest in understanding what dementia does to people
  - Help create a personal, individualized program/activity choice for participants, that relates to their personal history
  - Know how to reduce stress

### ***Selection of Facilitators***

*"It must be evident that the artist can communicate well with an individual in a gentle and understanding manner, so as to nurture the group through the workshops rather than being focused on trying to teach individuals skills or trying to get the group to reach outcomes as final pieces of artwork." (Clare Concannon, Side by Side Coordinator)*

- Be warm and friendly
- Have good inter-personal skills
- Know the value of providing a comfortable and emotionally safe environment
- Appeal to preserved memories, not recent ones, which can help to reduce worry, anxiety and fear of the unfamiliar when people can't account for loss of memory and resulting disorientation.

(Profile suggested by Dr Alison McKenna, Consultant psychologist, Northern Trust)

### **Further recommendations on Facilitation**

Once facilitators have been chosen, the research highlights three main areas where further recommendations should be made: Knowledge and training in dementia; Adapting Practice and Relationship with other partners.

### **Knowledge and training in dementia and community arts**

5. The finding from this research suggest that in general, community artists currently working in the field of dementia have very little to no training in aspects of dementia, little opportunity to train, and where training exists, is difficult to access due to cost. (As mainly self-employed artists, funding is not readily available and is not designed with a social, participant directed community arts approach in mind). Therefore, it is recommended that provision of training is addressed on a number of levels. Artists should be given the option to take advantage of relevant training opportunities which include health and safety, behaviour management, information on dementia itself, and reminiscence work. At least some training should be made available that is tailored towards using community arts with people with dementia.
6. Currently it would seem that any training for facilitators in community arts and dementia happens 'on the job', with little or no opportunity for peer observation, or for the individual artists to trial working in such an environment. This would be of great benefit to artists who have little to no experience, but would like to see if the work suits them before making a commitment to the field, and thus to encouraging confidence in facilitation skills and potentially greater numbers of artists to work with people with

### **Knowledge and training in dementia**

*Training is a really big thing – the Reminiscence Network is useful, but cost is an issue. (Sally Young, Tree of Life project)*

dementia.

7. Opportunities for informal, in-house, setting-led training, which include Health and Safety, and information on dementia, should be discussed with service providers to be offered to artists prior to working with people with dementia. This would help to increase facilitator confidence in relevant non-artistic areas.
8. The offer of training sessions run by artists for support staff prior to the project taking place is recommended so that they can have the confidence to join in activities, and know how to support participants in arts work. This may even contribute to the continuation of arts activities beyond the project itself. Leaving behind resources for activity officers and staff members may also be of benefit.

### **Adapting Practice**

Processes need to be adapted in the planning process, as the projects are taking place, and at the evaluation stage. The following recommendations should therefore be considered:

9. As previously noted, allowing adequate time for the duration of an arts project is seen as essential by all stakeholders within a meaningful participant-centred arts process for many reasons: for trust to be established between artists and participants, and between the participants themselves; having enough time to prepare; allowing for certain processes to take longer – working at the group’s pace rather than to a tight deadline; creating a relaxing environment in order to minimise stress; allowing extra time where exhibitions and special events are part of the process. *8-10 weeks was suggested as a good length of time for a project, and ideally should be part of an ongoing series of inter-related arts activity.*
10. Quality and adequate resourcing of projects is essential for arts projects to succeed in contributing to the dignity and well-being of participants. It matters how things are presented. Paying attention to detail and introducing a range of different and unusual materials is something that artists can bring to the process. It is therefore recommended that a good materials budget is included for any arts project in order to contribute to the quality and

### **Adapting Practice**

*“Artists working with groups of people with disabilities particularly dementia should have a safe interactive plan for workshop activities which includes individual and group participation as much as possible. The artist should have previous knowledge of working, interaction with and understanding of older people; such as interests and activities they may like.” (Clare Concannon, Side by Side Coordinator)*



excellence of the process and end product. Having adequate and where possible dedicated arts spaces and resources is essential for this too.

11. Toolkits and resources kits for working with people with dementia should be made available to facilitators, in order to support high quality work.
12. Adequate transport which specifically caters to the needs of the group when outings are included in a project should also always be included in project planning.
13. Community arts processes are by nature flexible and participant focused. It is recommended that artists tailor processes according to the needs and the responses of the group, their experiences and abilities. In order to do this, initial sessions should be freeform and focus on creating a relaxed, stress free environment, so that artists can get to know the participants. There should be a recognition from all involved that doing something creative together can be more beneficial and satisfying than trying to achieve an end result in itself.
14. Collecting adequate and meaningful feedback from participants, as well as other stakeholders, during and immediately after the process, is important to determining the success of projects, and how future work should be carried out. Including a 'cool down' session using creative evaluation methods with the participants rather than a tick-box questionnaire is recommended in order to collect meaningful feedback and discussion from them. Using what they have made as a stimulus to remind them of them of the process might facilitate this.

#### **Relationship with other partners**

15. Creating arts projects with and for people with dementia works best when all stakeholders in the work are in good communication with each other at every level of the project. This involves including family members where possible, as well as service providers, support staff, participants, artists and coordinators. It is recommended that this starts at the planning stage: having a specific contact within the setting to discuss the project with from the start is of particular benefit.

*"There can be a risk that group leaders placed too much importance on the 'final work' as show pieces that the actual workshop did not offer the participants the opportunity to experience the art and enjoy the workshops as much as possible – in some projects participants could be left to watch while the able bodied people carry out the work." (Clare Concannon, Side by Side Coordinator)*

#### **Relationship with other partners**

"[Y]ou need a personal contact with someone in order for the communication to work. Initial meetings with members of staff are more successful if there is a personal contact in order to get the best out of the project... Staff need to pick the people who would get the most out of the project. It's not about bums on seats. What percentage of residents take part in meaningful activity? This should be the question. Why can't you work with just four people?" (Sally, Tree of Life Project)

*"Family is really important – developing projects which work as a family unit, eg creating memory books and boxes, and which bring the family together would be really welcome." (Fiona, Belfast Trust)*



16. Developing a working relationship between the artists and the activity officers in the setting is crucial to the success of the project, and for getting to know the needs of the group. It may also be of benefit to have an arts session with support staff prior to the project taking place, in order for them to be more involved with the process (see **Knowledge and training in dementia and the arts** above).

17. Projects which include family members, and/or intergenerational and intercultural arts work were highlighted as being of benefit, and development of such projects in the future would be recommended.

18. There is also a growing need for projects which involve younger people with dementia – this is often not recognized, and most projects are aimed at older people with dementia. This needs to be re-evaluated as the number of people being diagnosed early is increasing all the time.

19. And finally, working collaboratively with another artist, with at least one member of staff present is recommended. This ensures protection and support both for artists and for project participants.

**Recommendations for meaningful participant-centred community arts processes with people with dementia**

20. In order for arts activities to be meaningful they need to be based on the desires, wants and needs of the group. This means that artists should have adequate opportunity to get to know the group(s) they are working with prior to the activities taking place so that activities can be tailored to individuals' needs. This also allows for artists to find a 'hook' or way into the work that taps into the memories and existing interests they may have.

21. Stimulating memory, which may also take reminiscence-type work into account was seen as very useful by many of the artists and activity officers working in dementia settings. Talking about the past was something that many of the participants also enjoyed. The use of certain reminiscence techniques, props and materials as a stimulus

**Recommendations for meaningful participant-centred community arts processes with people with dementia**

*"It should be up to the participants as to what they want to do, on their terms. Activities shouldn't be childish, or there for the benefit of the medical professional's assessment. Even in terms of reminiscence work, they should be able to decide what they want to talk about – whether it's yesterday, last week or sixty years ago, all of those involve reminiscing. Participants need to be comfortable with what they're doing, and have a choice, which helps them to be settled and not restless." (Fiona, Belfast Trust)*

might be of use in tailoring activities towards the specifics of the group. It is recommended that this is investigated further.

22. Maintaining total flexibility, interaction and communication with the group helps to engage the participants more fully. Community Arts lends itself to using different forms of communication other than verbal communication, which can be problematic for someone with dementia. It is recommended that community arts should be used to exploring notions of different forms of communication, and how these can benefit participants with dementia.

***Recommendations for creating the right environment within the setting***

23. Surroundings need to be familiar in order for participants to feel comfortable and not disorientated. It is therefore recommended that the use of space, and environment, be further investigated to see how they can be maximised in working with people with dementia.

*If you have dementia, your mind is under more strain from trying not to forget things, and exhaustion. I want to get the message out – the group has taken me out of a dark hole. It gave me a focus. (John, Photography project, Alzheimer's Society, Antrim)*

“In the care home where my father was, he saw an activity nurse once a week, using soft balls and toys. He didn't want to know – possibly because he felt it was childish. It's important to realise that everyone is NOT the same, and won't want or expect the same things. Projects and activities shouldn't patronise. Participants have PRIDE and you need to get to know what people have done for a living, which really helps later on in conversations with them.”  
(Tommy, Music Project)

## References

ACNI (2013) Community Arts Strategy: A review of Community Arts in Northern Ireland and production of Dedicated Sector Strategy: 2013 to 2018 Draft Final Report v3

*Alzheimer's Factsheet: What is Dementia*

[http://www.alzheimers.org.uk/site/scripts/download\\_info.php?fileID=1754](http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1754) Alzheimer's Society (accessed 15.01.2014)

Anglia Ruskin / UCLAN research team (2007) *Mental health, social inclusion and arts: Developing the evidence base, final report* London: Department for Culture, Media and Sport/ Department of Health

Borda, OF (2006) 'Participatory (Action) Research in Social Theory: Origins and Challenges' in Peter Reason and Hilary Bradbury *The Handbook of Action Research* London, Sage Publications, pp27-37

Brodzinski, E. (2010), *Theatre in Health and Care* Basingstoke, Palgrave Macmillan

DHSSPS (2011) *Improving dementia services in Northern Ireland: A regional strategy*, Belfast, Department of Health, Social Services and Public Safety

Gould, V.F. (2013) *Awakening the Mind*, London, Arts 4 Dementia

Hellen, C.R. (2000) 'Upholding the sense of self with meaningful activities' in *Alzheimer's Care Quarterly* 1(1) pp 35-49

Ings, R., Crane, N., and Cameron, M (2012) *Be Creative Be Well: Arts, wellbeing and local communities, an evaluation* London, Arts Council England

James, O. (2009) *Contented Dementia* London, Vermilion

Kasayka, R.E. (2001) 'Introduction' in Innes, H and Hatfield K (eds) *Healing arts therapies and person-centred dementia care*, London and NY, Jessica Kingsley Publishers

Kings College, London and LSE (2007) *Dementia UK – Northern Ireland Supplement* London, London, Alzheimer's Society

Lee, H and Adams, T (2011) *Creative Approaches in Dementia Care*, Basingstoke, Palgrave MacMillan

Marmot, M (2010) *Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England post 2010*, The Marmot Review

McLean, J; Woodhouse, A; Goldie, I; Chylarova, E and Williamson, T (2011) *An Evidence Review of the Impact of Participatory Arts on Older People*, Edinburgh, Mental Health Foundation (also available on line at <http://www.baringfoundation.org.uk/EvidenceReview.pdf>)

Valenzuela, M. (2011) 'The Changing Brain' in Sykes, H (ed) *Health*, Melbourne, Future Leaders pp174-180

Wood, J (2011) *Report on our work in Dementia cafes in Doncaster*, Doncaster, darts (Doncaster Community Arts) (also available online at [http://www.thepoint.org.uk/media/uploads/article/24/4ee5eefe67578Dementia\\_cafe\\_report.pdf](http://www.thepoint.org.uk/media/uploads/article/24/4ee5eefe67578Dementia_cafe_report.pdf))

## Websites

Alzheimer's Society, Northern Ireland: <http://www.alzheimers.org.uk/northernireland/>

Dementia Centre, Northern Ireland: <http://dementiacentreni.org/dementia-northern-ireland>

Reminiscence Network, Northern Ireland: <http://www.rnni.org/>

Arts 4 Dementia: [www.arts4dementia.co.uk](http://www.arts4dementia.co.uk)

Doncaster Community Arts (darts): <http://www.thepoint.org.uk/article/arts-and-dementia>

The Creative Dementia Arts Network: [www.creativedementia.org](http://www.creativedementia.org)

Age Exchange: [www.age-exchange.org.uk](http://www.age-exchange.org.uk)

## Appendix 1: Questionnaire for artist facilitators.<sup>1</sup>



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Interview no:

Date of interview:

#### ***Details of artist***

Name of artist:

Contact details:

#### ***Details of project***

Name of project:

Partner organisation:

Date(s) of project:

Project coordinator:

No. of participants:

Had done arts projects with CAP previously? Y/N

Had done other arts projects previously? Y/N

Would like to do future projects? Y/N

Any other relevant details:

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<sup>1</sup> This questionnaire was adapted for interviews with activity officers, whereby the following sections were modified: Section 3 – About you (3.1, 3.2 and 3.4 ‘dementia’ and ‘dementia patients’ was changed to ‘arts’; 3.6 was changed to: ‘What was your experience of working with the artist’); Section 5 – About the setting (5.1 was reworded to – ‘Were there any differences in how participants in the different residential homes responded?’; 5.2 was left out)



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## community arts partnership

### ***Introduction***

Thank you for taking the time to complete the following questions for the Community Arts Partnership (CAP). Below is a series of questions which are designed to gauge what makes a successful arts project when working with people with dementia. They will be used to write an evaluation report on how community arts supports people living with dementia.

Your experience and expertise in this area will be invaluable in improving future provision for projects with older people with dementia. Your responses will also be used to provide evidence for funding bodies of how the arts can support people with dementia, and how funding can be used to bridge current gaps in this area. Therefore, please feel free to be as honest as possible in your answers, which will be treated in confidence. There are no right or wrong answers, and it is understood that the answers you provide are your expert opinion, rather than the 'correct' answer.

There will be an opportunity at the end of the questionnaire to state whether or not you would be happy to have a named or anonymous quote included in the final report.

### ***Definitions used***

The term *activity officer* is used to define the person in charge of programming activities within the host organisation where the group was based.

*Project coordinator* is used to define the person at CAP responsible for engaging you as an artist, organising and coordinating the project.



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## **community arts partnership**

### ***Section 1: Before the project happened: anticipated outcomes***

1.1 Before the project took place, what were your anticipated outcomes for the project? (Please include both personal aims and those for the group)

1.2 To what extent do you feel that these were achieved? And did any of them change during the project?

### ***Section 2: During and after the project: Successes and failures***

2.1 What worked in delivering projects? What contributed to the successes?

2.2 What didn't work in delivering projects? Why do you think this was?



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2.3 What were the main challenges in carrying out the project?

2.4 In your opinion, what makes the difference between minimal success and excellence in working with people with dementia?

**Section 3: About You**

3.1 How would you rate your current level of experience in working with dementia patients prior to the projects (P) / currently (C)? (please circle one)

Not very experienced	1	2	3	4	5	Very Experienced
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3.2 Would you have liked to have known more about dementia prior to starting the project? Y / N (please delete as necessary). If so, what would have been helpful to know?

3.3 What would support you to plan and deliver future arts projects with dementia patients?





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3.4 What have you learned from the processes of working with dementia patients?

3.5 In your opinion, to what extent does an arts facilitator need to be aware of abilities and functioning of people with dementia in order to carry out community arts practice with them?

3.6 How has working with older people with dementia affected your facilitation style?  
How do you adapt your methods to the needs of the group, if at all?

3.7 Please comment on how you found the organization of the project, including communication, by the project coordinator?



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### **Section 4: About the participants**

4.1 Did you notice any developments within the group by the end of the project? Y/N

If so, please state what these were:

4.2 What do you think participants gained from the projects (eg – skills, enjoyment, socializing with others, etc)?

4.3 Please state any artistic 'outcomes' or 'evidence' resulting from the project that could be included in the report (eg photos, drawings, paintings, poems, stories) in order to provide a contribution from participants?

### **Section 5: About the setting**

5.1 If you have worked in more than one setting, have you noticed differences between the settings? (please delete as appropriate) Y / N

If so, please state both the settings, and the differences between them, including the how they impact on project outcomes for participants



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5.2 What has been your experience of communicating/working with activity officers in dementia settings?

### ***Section 6: Future projects***

6.1 What should future projects take into consideration?

6.2 Is there anything that would have improved the project (eg for the participants / you / your setting)

***Any further comments***

Thank you for taking the time to complete the above questions – the information you have provided will be invaluable in supporting the future work of community arts involving participants with dementia.



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### How the information in this survey will be used

1. Your views will be included in a published report. Please state whether you are happy to have your name attached to these, or if you would rather remain anonymous:

*I am happy to have my name included in the final report / I would prefer to remain anonymous\**

\*please delete as appropriate

2. Where appropriate, CAP would like to include quotes within the final report to support the qualitative data. Please state below if you are happy to be quoted in the final report:

*I am happy to be quoted by name / I am happy to be quoted, but would prefer to remain anonymous / I am not happy to be quoted\**

\*please delete as appropriate

After the project, interview reports will be kept on computer file for future use – are you happy for us to use the information you have provided in future research? Y / N