



# Azure

*Exploring greater inclusion of people with dementia  
in museums and galleries in Ireland*

## Pilot Evaluation 2012

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## Foreword

Greater participation in the arts by people of all ages is a question of citizenship and of enabling people to fulfil their potential. It plays a particularly important role in the development of a positive self-image and identity for older people and it can build connections and promote social capital.

We at Age & Opportunity are committed to increasing the participation of older people in the arts as artists, participants, audience and organisers. We are proud of the contribution that our programmes make towards this aim. For example, by working collaboratively with a growing number of partner organisations in promoting and coordinating the Bealtaine festival every May, we reach tens of thousands of people.

The contributions of each of the organizations that have partnered with us in the pilot phase of Azure are critical to the programme. Each has contributed in a very committed and positive way. Also, following the experience of the pilot, each is convinced that the approach has great potential in an Irish context, as evidenced by this evaluation. The partners in Azure are: Age & Opportunity, The Alzheimer Society of Ireland, Butler Gallery, and the Irish Museum of Modern Art.

We recognize that there is an ongoing challenge to ensure that harder-to-reach older groups are involved in the country's arts and cultural life. We and our partners have been pleased to collaborate on Azure as it has enabled us to explore ways of involving more people with dementia and of addressing some of the barriers that hinder participation.

The arts can play an important role in the lives of people with dementia in a number of ways, contributing to changes in awareness and to developing thinking about issues like dementia. The arts can also enhance the quality of life of individuals affected. This is because of its capacity to engage emotions and facilitate communication (including non-verbal communication). They can also

foster greater involvement in communities by people affected by the condition. Through the arts a space can be created for interaction and sharing between people with dementia and those close to them in a non-medicalised environment.

The latest projections for the incidence of dementia in Ireland suggest that over 140,000 people may be living with dementia by 2041. This requires a range of responses from different sectors of Irish society as we seek to create communities that are inclusive of people affected by dementia and their carers. We are hoping that this evaluation of the pilot phase of Azure will enable other statutory bodies and organisations to contribute with us to taking this work forward.

*Catherine Rose*

*CEO*

*Age & Opportunity*

## Acknowledgements

Age & Opportunity would like to acknowledge and thank a number of people who contributed to this evaluation and to the pilot of the Azure programme. The Butler Gallery organised the delivery of pilot, which was funded by the Community Foundation of Ireland. This evaluation and the round-table meeting have been funded by the Ireland Funds and the HSE National Lottery fund, 2012.

Sheila Grace coordinated the compilation of the evaluation. Each of the members of the Steering Group and the organisations they represent contributed in a range of ways to both the pilot programme and to its evaluation. They are: Avril Dooley, Alzheimer Society of Ireland, Ann Leahy, Age & Opportunity (Chairperson of the group), Bairbre Ann Harkin, Butler Gallery, Helen O'Donoghue, Irish Museum of Modern Art, Rebecca McLaughlin, Age & Opportunity, and Caroline Orr, Irish Museum of Modern Art.

# Introduction

## General Background

The Azure project was initiated in 2012, arising from the work of Age & Opportunity in the arts, through the Bealtaine festival, celebrating creativity as we age, and as part of a strategy of ensuring that the programme extend its reach to people not currently participating in creative activities. These harder-to-reach groups include those living with dementia. The project was structured in a way that would build on a number of existing partnerships involving key organisations who share Age & Opportunity's interest in working in the arts with people with dementia (see below); it would involve a practical pilot during Bealtaine 2012 with a view to exploring its expansion thereafter.

As well as building on existing working relationships with a range of Irish organisations, the pilot was informed by links made over a number of years by Bealtaine festival staff and the Museum of Modern Art, New York (MoMA). MoMA developed the Meet Me at MoMA project in order to involve people with dementia and their family or close friends in responding to the works exhibited at the museum; it has been positively evaluated<sup>1</sup> and is being adapted and replicated by a range of other cultural bodies in different parts of the world.

Meet Me at MOMA provides a responsive and welcoming space for people with dementia to participate in facilitated discussions about exhibited artworks, and thus to remain, or to develop, as active participants in the life of the museum.

## Demographics and Public Policy

The ageing of the Irish and indeed the world population is an important backdrop to the work of Age & Opportunity and of those who partner with us in our work.

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<sup>1</sup>Mittelman, M. & Epstein, C. (2008), Evaluation of Meet Me at MoMA project: Making Art Accessible to People with Dementia.

## Pilot Evaluation

The following are some facts about the current population (from the 2011 census results):

- Over half a million people are over 65, representing nearly 12% of the population
- Those over 65 increased by 14.4% between 2006 and 2011
- A bigger increase (22%) occurred amongst those aged 85+ (Source: 'This is Ireland': Highlights from Census 2011, Part 1)

By 2041:

- Number of people aged over 65 is expected to reach 1.3million (a 180% increase)
- Number of people aged over 85 is expected to increase from 47,800 (in 2006) to 248,200 people (that is, a growth of over 400%) (From Cahill, S., O'Shea, E., & Pierce, M., 2012. *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*. Department of Health<sup>2</sup>)

Latest estimates suggest that some 41,700 people in Ireland are living with dementia. (This includes both people over 65 and those under 65). Research anticipates that numbers of people living with dementia in Ireland will reach between 140,000 and 147,000 people by 2041.<sup>3</sup>

The ageing of the population and the growing numbers amongst the oldest-old has many implications for all sectors of society, for all communities and of course for the incidence of dementia. A national positive ageing strategy has been in development for several years now – its publication before end of 2012 has recently been flagged. Government now proposes to introduce a national

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<sup>2</sup>Based on the CSO M0F2 assumption, which forecasts the lowest growth in the population.

<sup>3</sup>Cahill, S., O'Shea, E. & Pierce, M. (2012), *Creating Excellence in Dementia Care: A Research Review for Ireland's National Dementia Strategy*, Department of Health.



strategy on dementia by 2013, and, during 2012, the Department of Health invited submissions from the public on the subject. Obviously there should be areas of synergy between the two strategies.

In its submission to the National Dementia Strategy, the Alzheimer Society of Ireland referenced the need to 'reclaim dementia' through the emergence of a new social and community model that focuses on abilities, possibilities and personhood and one where dementia is viewed as a social issue, owned by our community and requiring a community response. This view also informed the submission made by Age & Opportunity to the strategy, which recommended that the strategy should seek to normalise the involvement of people with dementia and their carers in the everyday life of communities so that communities become dementia-friendly.

The Azure programme is conceived of as an attempt to do just that in the area of arts and culture. The piloting of this work in 2012 is considered to be very appropriate given the simultaneous developments in the area of public policy.

### **Azure Pilot Programme**

The partners who joined with Age & Opportunity in the steering group for the pilot were the Irish Museum of Modern Art (IMMA), the Butler Gallery and The Alzheimer Society of Ireland.

IMMA has a national remit and a long track-record of involving the local community in the work of the museum, of partnering with Age & Opportunity on their older people's programme, and they also have links to MoMA. The Butler Gallery, which is a long-standing participant in the Bealtaine festival, has a staff member who had worked as an intern at MoMA, and who had already delivered a similar programme entitled *Discovering Dublin Contemporary* at the Dublin Contemporary exhibition (Sept-Oct 2011), which was inspired by the Meet Me at MoMA programme. The Alzheimer Society of Ireland brings experience of working with people with dementia and their carers, and of contributing to the development of policy and practice in this area.

### **Pilot Evaluation**

During the first half of 2012, a steering group with members from each of the four partner organisations, and chaired by Age & Opportunity's Assistant CEO, planned an event to take place during the Bealtaine Festival, May 2012, and a second stage involving investigating how to take the work forward in a sustainable way, requiring a reinterpretation of the Meet Me at MoMA programme within an Irish cultural context.

A round-table meeting at IMMA is proposed for autumn 2012 in order to explore this second stage. The name 'Azure' was chosen for the pilot because, being a colour pigment used by artists, it would associate the programme with the visual arts, and because it can be considered the colour of a clear blue sky, which was considered appropriate for a project that involved new, innovative thinking.

Coming from different sectors and with different overall remits, the partners in Azure shared a common interest in working in the arts with people with dementia, something that was consistent with the individual strategies of each. For Age & Opportunity this centred on continuing strategies to make their work in arts and culture more inclusive of hard-to-reach groups, including those with dementia. For IMMA, the project offered an opportunity to extend its programming for older people and to become involved in a research and development opportunity. For the Butler Gallery, it was an opportunity to facilitate greater access to the Gallery by older people, and in particular by people with dementia, consistent with their own strategy and their contribution to Kilkenny's Age Friendly County programme. For the Alzheimer Society, the main motivation was to develop opportunities for people with dementia and their carers to remain visible in their communities in a project that involves people with dementia as partners. All partners were interested in exploring the Meet me at MOMA model and both contributing to and learning from the partnership while working toward encouraging more accessible art/cultural programming generally for people with dementia.

In late May 2012, the Butler Gallery delivered three facilitated sessions, using the 'Meet Me at MoMA' toolkit to provide a framework, to which people with

dementia along with their carers were invited. Steering group meetings provided guidance and advice prior to the event, and some members provided practical support, including by helping with recruitment, providing advance training, and acting as observers at sessions, and contributing to this evaluation of the project. Funding was obtained by the Butler Gallery from Community Foundation of Ireland for the May programme<sup>4</sup>, which involved three facilitated sessions in which people with dementia and their carers (some professional carers, some family members or friends) participated in facilitated discussions about artworks. This document outlines the evaluation of the pilot programme.

## Evaluation Framework

Documenting the pilot and evaluating its strengths and weaknesses was considered important to taking the work forward. The following aims and objectives were set by the steering group for the evaluation of the Azure pilot.

### *Aims*

- ▣ To document the first Azure programme at the Butler Gallery from the perspectives of those involved
  
- ▣ To assess what elements worked well, what ones did not (from the various perspectives)
  
- ▣ To outline the kinds of issues which have to be considered in organizing a project of this kind with a view to informing the future development of the programme

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<sup>4</sup>In this document, the term 'programme' will be used to describe the overall programme of events at Butler Gallery, which consisted of three individual facilitated sessions that involved people in discussion of artworks.

*Objectives*

1. The organization of the Butler Gallery sessions, documenting how participants were recruited and facilitated to participate, how the artworks were chosen, what worked in this regard and what did not
2. Profile the participants (were they regular attendees of arts events or new to this type of event?)
3. Observe the impact of the sessions on participants
4. Seek feedback on the experience for the participants (both the people with dementia and their friends/family)
5. Document the experience of the organizers, facilitator and observers

## Evaluation Methodology

The aim of the Butler Gallery programme was to pilot and evaluate how the facilitated sessions, based on the Meet Me at MoMA model, would work in an Irish context. Three sessions were organised over two days, with each session scheduled for sixty to ninety minutes. Two observers were assigned to each of the three sessions tasked with observing the participants, in order to assess their level and mode of engagement in the session.

The sessions were facilitated by Bairbre Ann Harkin, Education Curator of the Butler Gallery. Steering Group members Avril Dooley (AD), The Alzheimer Society of Ireland, Caroline Orr (CO) IMMA, Ann Leahy (AL), Age & Opportunity, acted as observers for the sessions and Sheila Grace (SG), Age & Opportunity, also acted as an observer and provided continuity by attending all three sessions and by coordinating the observers' feedback afterwards. Three separate forms were designed to gather information at different stages of the project. They are included as appendices to this report and are as follows:

### 1. *Advance Information (obtained verbally)*

The questions on this form were devised to ascertain where the participant heard about the programme, what were their expectations in advance; and if they had previously visited a gallery. The information was collected verbally and informally at the booking stage.

### 2. *Facilitated Session Evaluation - Guidelines for Observers*

In order to make an informed evaluation of each of the sessions, guidelines were drawn up for the observers. These guidelines comprised indicators designed to capture the level of engagement and enjoyment, or otherwise, of the participants; (e.g. did they smile or frown, show interest or anxiety, etc) and to evaluate their experience of the sessions. No notes were taken during the sessions, as this could have been off-putting for the participants, but forms were completed immediately after the sessions.

### 3. *Facilitated Sessions – Feedback after the event*

This form was devised for the facilitator and observers in order that there was consistency in terms of the questions put to members of each group to determine how they felt about the sessions and whether or not they would be interested in coming again. This feedback was largely obtained informally after sessions and was written down immediately afterwards.

Pseudonyms are used throughout this evaluation for the participants in sessions.

## Organisation

In this section the organisation of the programme, its promotion and delivery are reviewed.

### **Art Works & Exhibition Space**

Consideration was given to the most suitable venues available for the programme. IMMA was undergoing renovations and would have no available hanging space until June. The Butler Gallery is located within the basement of Kilkenny Castle and as such, is not accessible to wheelchair users; it can also pose difficulties for visitors with mobility problems. In addition, the exhibition scheduled to take place in the gallery during the Bealtaine Festival was a contemporary installation over four galleries, including two film projections, which was not considered ideal.

Taking all of these factors into consideration, it was felt that the exhibition should take place in another venue and Butler House, Kilkenny, was chosen. A temporary exhibition of paintings drawn from the Butler Gallery permanent collection was thought to be a more suitable test-ground for these pilot sessions. This allowed the facilitator to choose works according to MoMA's Meet Me 'Guide for Museums,' choosing work according to a selected theme and with a particular sequence in mind. Using works from the Butler Gallery collection was of additional value, as it was thought that some participants might be familiar with elements of the collection, for example scenes of Kilkenny, or work of artists well known in the Kilkenny area. The exhibition was titled, Exploring Place – An Exhibition of Gems from the Butler Gallery Collection.

All of this involved additional set-up costs and planning time.

When curating the exhibition every effort was made to choose a diverse selection of modern and contemporary work from the beginning of the 20th century to the

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present; including figurative and abstract paintings. Taking a non-prescriptive approach to which style of work the participants might respond to, the diverse selection of work enabled the facilitator to examine how participants respond in different ways to figurative and abstract work during the pilot programme.

### **Recruitment, Promotion and Publicity**

The programme was promoted in the following ways:

#### *The Alzheimer Society of Ireland*

Contact was made with the South Midland and South East Regional Manager from The Alzheimer Society of Ireland, who brought on board the Day Care Centre Manager and Home Care Coordinator who undertook to promote the programme through their clients' families. Some initial concerns were expressed regarding the safety of the participants and the sensitivity with which they would need to be treated within the programme. However, these concerns abated following a meeting at which the facilitator detailed her experiences with MoMA, Dublin Contemporary, and the relationship-focused nature of the programme. A request was made from the Day Care Centre manager that clients of the centre attend as a group, and it was suggested that they be accompanied by staff from The Alzheimer Society of Ireland.

The Day Care Centre Manager disseminated information about the programme at the Alzheimer Society of Ireland Carers Support Group meeting a month before the event. Families were notified through the Home Care visits. The week of the event there was further mention of the sessions at the monthly Carers Support Group meeting and information leaflets were distributed.

#### *Bealtaine Publicity Material*

Azure was featured in the national programme for Bealtaine and was also included in the Kilkenny Bealtaine Festival Highlights press release, released countywide in the first week of May.



### *Radio*

KCLR radio covered Azure in a general interview with the Butler Gallery facilitator.

### *GP Surgeries*

Phone-calls were made to all GP surgeries in the county two weeks before the event, followed by information by email, where possible.

### *Pharmacies*

All pharmacies in Kilkenny City centre were visited to publicise the programme and posters were distributed.

### *Age Friendly County Forum*

Kilkenny's Age Friendly County coordinator publicised the programme throughout the Age Friendly County network, including Active Retirement Groups and the Age Friendly County forum.

### *Public Health Nurses*

Public Health Nurses throughout the county were contacted by phone.

### *Local Hospital*

Contact was made with the Department of Old Age Psychiatry in a local hospital to inform them of the programme.

### *Residential Home*

Contact was made with the activities coordinator of a local residential care facility.

### *Consultant Geriatrician*

A Consultant Geriatrician was contacted in the local hospital.

### *Carers Association*

The Carers Association was contacted, but, due to time constraints, this happened only a week before the programme

**Training for all Staff**

Butler Gallery staff and two of the observers took part in the advance dementia awareness training, conducted by Kate Brennan (The Alzheimer Society of Ireland) and Bairbe Ann Harkin (Butler Gallery).

The training included briefings on the following:

- ▣ Different types of dementia and how the disease manifests itself
  
- ▣ Dementia in Ireland
  
- ▣ The Alzheimer Society of Ireland – mission, ethos and overview of services
  
- ▣ Language – do's and don'ts when speaking about dementia
  
- ▣ The Azure Project – background and information on programme
  
- ▣ Meet Me at MoMA (a video) looking at a similar programme in action

**Bookings**

Three separate sessions were offered:

- ▣ Wednesday afternoon (an open session)
  
- ▣ Thursday morning (attended by clients of the Alzheimer Society of Ireland's Day Care Centre)
  
- ▣ Thursday afternoon (an open session)

Thus, two were open to the public and were attended by people with dementia accompanied by family or friends, and one session (Thursday morning) was a group from a Day Care Centre accompanied by professional carers. Bookings for the two afternoon sessions, which were open to the general public, were made by phone directly with the facilitator. This allowed for an explanation of the format

of the session to participants and for an informal assessment as to whether they had any concerns relating to the programme. It was also possible to inquire about additional needs they, or the person they were accompanying, might have, in order to maximise enjoyment of the experience.

As recommended in the Meet Me at MoMA guidelines, participants were informed that words "Alzheimer's," and "dementia" would not be used during the sessions, or on any relating signage.

As bookings were made, it was ascertained where people heard about the programme and whether they were typical attendees of galleries. Three participants who booked for the first session (Wednesday afternoon) heard about the programme through the Day Care Centre and one through the Nursing Home that had been contacted. In relation to the second session open to the general public (Thursday afternoon), one person booking heard of it through the Day Care Centre, one through Bealtaine publicity, and one through The Alzheimer Society of Ireland.

This initial contact also provided the opportunity to determine whether the participants were regular gallery visitors or had any prior knowledge of, or interest in, the arts.

Most of the relatives said they would have an interest in the arts, but this was not the case for all. One person wished to support an Alzheimer Society event; and one said the main attraction was that this was one of the very few events that they felt welcome to take their relative with dementia.

### **Set Up**

As already mentioned, an exhibition specially chosen from the Butler Gallery permanent collection was mounted in Butler House for the sessions. Clear signage indicating the Azure Project led participants from the car park and the main entrance to the exhibition space. Each participant was greeted and

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registered upon arrival, receiving a name tag similar to the name tags worn by the facilitator and the observers.

Small, lightweight folding stools were offered to participants to allow them to sit at each painting discussed during the session. At the first session many of the participants requested chairs with better support, to allow for hip replacements and mobility difficulties. As a result, a number of these chairs were brought into the room for subsequent sessions.

After completion of the gallery visit, participants, the facilitator and observers all moved outside of the room to a reception area with two large sofas and comfortable seating. Tea, coffee, biscuits and cake were served. Due to the schedule of participants on Thursday morning (the Day Care Centre group), they were unable to stay for tea.

## Facilitated Sessions

This section includes a report of each of the three facilitated sessions that took place – two open to the public, where individuals living with dementia attended with family members or friends (the first and third sessions), and one session for a group of clients from The Alzheimer Society of Ireland Day Care Centre (second session). This group was accompanied by carers from the Day Care Centre. As it was a pre-existing group accompanied by professional carers rather than family or friends, it deviated from the Meet Me at MoMA model. However it had been decided to test this approach when requested by the Day Centre Manager.

### **Session 1: Wednesday-2pm. 30-5-2012**

The first of three sessions took place on Wednesday afternoon. There were seven participants and two observers. The participants comprised a couple, a mother and daughter, and a mother with two daughters. The couple arrived about twenty minutes early and the facilitator engaged them in discussion about the memories that a particular painting evoked for the person with dementia.

Participants were then invited to sit in a semi-circle in front of the first painting. The group engaged right from the start with eyes on the artwork or on the facilitator. People relaxed more as the group moved from painting to painting and developed a warm sense of togetherness especially between carers and people with dementia. This was evidenced by spontaneous touching and physical closeness. The people with dementia encouraged each other, allowing others time to speak and backing up their comments. There were a number of one-to-one conversations taking place accompanied by smiling and tactile gestures.

It was noted by the observers that even when a person was not speaking there was communication happening at a level not easily identified. This was illustrated in the case of Margaret when the facilitator asked a direct question about the material used for the artwork. She spotted Margaret trying to read the label and

remarked to her that she “had it sussed”. Margaret laughed and was clearly delighted at this spontaneous exchange and the way her actions had been noticed. One woman very aptly used the word “falling” to describe the Tony O’Malley painting and though perhaps mildly embarrassed when the facilitator complimented her on this description she was visibly pleased.

It was noted that people found abstract questions more difficult (e.g. “what is a UFO” or “what do people use TV for?”). They were very interested and engaged with discussions that took place around colours used in the paintings. Remarks made during the session included: “very good painter”, “lovely” “the best” and “I love that picture.”

Following the session, there was a cup of tea for the group; this was an enjoyable social interval where participants and carers spoke openly about what the experience meant to them. One carer remarked that she felt like picking up her brushes to start painting again and that she had felt drawn into some of the paintings during the programme. Margaret’s daughters pointed out that they could rarely take their mother to public places due to concerns about how her behaviour might be experienced. They commented that the session had provided a lovely space to spend a relaxing afternoon with their mother and to engage with her in something she clearly enjoyed so much. When they were asked, each of the participants said they would be happy to come back again.

### *Challenges: Session 1*

When invited to look closely at the work, one participant was inclined to repeatedly touch the paintings. The facilitator overcame this by ensuring she stood between the participant and the work, verbally reinforcing that the paintings cannot be touched as this can damage them. Whilst at the same time she gently touched the participant on the arm and guided her back towards her seat to rejoin the group.

## Session 2: Thursday-11.30am. 31-5-2012

This group was from The Alzheimer Society of Ireland's Day Centre and came with the manager. There were sixteen people including two people, a man and a woman, with visual impairments, one of whom was both blind and hard of hearing. There was only one hour's advance notice that these two people were part of the group and the facilitator had to make a special effort to make them feel included. Some people seemed more withdrawn than others, and one woman, Christine, was reluctant to join the group initially. Each client was accompanied by a professional carer.

Once the discussion started, participants displayed high levels of interest and engagement, most people having their eyes on the paintings or the facilitator for the duration. This was also true of one of the visually impaired people, who had peripheral vision. He contributed a lot and was very engaged. The second visually impaired person who was also hard of hearing did not contribute.

The facilitator gave everyone an opportunity to contribute and most did so. Sometimes they contributed without prompting but mostly when asked a question directly. They listened to what others had to say and occasionally expressed contrary opinions such as one woman disagreeing that a painting was "depressing" as viewed by some of the other participants. Comments made about the paintings included "it's nice", "it's colourful", "I like it", "I don't think it's depressed", "It's as if something is preventing it coming out", "it's like a dream". When asked what words occurred to them on viewing one abstract painting, the responses included "red", "a butterfly", "an iron", "I don't know how I feel about it...I feel all mixed up."

The staff members present were observed to be reluctant to contribute at first, but this changed as the session continued and they joined in with the people they were caring for. The observers felt that this showed a sense of engaging together in the session rather than staying in a 'caring' role.

The dynamic was quite different from the session the previous day - more spontaneous discussion between the participants, less physical closeness, but again real engagement. There were two participants who seemed anxious, one in particular, Christine, looked cross and did not take part in the discussion. A second participant, Noel, was quite anxious, keeping his eyes down and looking at his watch, but he seemed to relax as the session went on and contributed when asked for his opinion. Christine contributed nothing when asked questions twice by the facilitator.

However, towards the end of the session, when work by artist Tony O'Malley was being discussed, Christine volunteered how she knew the artist and his sister. Following that engagement with the facilitator, her whole demeanour changed, she turned around and smiled at the room. Participants, including Christine and Noel, who were asked when leaving, if they had enjoyed it and would be interested in coming again, said they had and they would.

### *Challenges: Session 2*

The group arrived a half hour late. However, as the facilitator had allowed extra time between the two sessions on that day, this did not become an issue.

Shortly before the session, the facilitator received a phone call from the Manager of the Day Care Centre, to say that two of the participants of that session were severely visually impaired, and that a small number of the participants had hearing difficulties. The facilitator requested that these participants be identified on their arrival. At the beginning of the session the facilitator asked carers accompanying people with hearing and sight difficulties to ensure that they placed their chairs towards the front. There was initially some reluctance to do this. However, when the carers witnessed the increasing participation of these people as the session progressed they made a point of moving them to the front.

The facilitator explained to the partially sighted participants that she would be asking the group questions about what they saw in the paintings being viewed. She undertook to make a point of describing the works at intervals throughout



the session so as to enable them to take part in the discussion. One of the people concerned participated to quite an extent whilst the other, who also had a hearing difficulty, did not contribute.

### **Session 3 Thursday 2pm. 31-5-2012**

Unfortunately, there were a number of cancellations by prospective attendees at the last minute. This meant that there was only one woman with memory loss - Nuala, who attends a Health Service Executive day-care facility - who came with an artist who had been working in that centre. There were two observers. All joined in the discussion because of the small numbers.

Nuala and the person accompanying her appeared quite at ease with each other. The fact that the person who accompanied her was an artist and was quite comfortable in her surroundings may have helped to gel the small group. Nuala did exhibit some signs of what appeared to be anxiety at the beginning of the session, such as hand-wringing and moving from one foot to the other; however the intensity of these gestures reduced as the session continued. She showed pleasure on a number of occasions throughout the session, notably when looking at a street scene with houses, and when prompted by her carer, remembered houses she used to paint herself. Questions about colour and questions based on the personal preferences tended to elicit a more enthusiastic response than factual questions about the artwork.

Nuala gave more involved and developed responses when considering the abstract works by Tony and Jane O'Malley. When viewing an abstract work of a fish in a pond by Jane O'Malley she voiced quite confidently, that what she saw was cornfields, a bird and a flowering bush.

The facilitator was mindful of the focus being primarily on one person and, having asked Nuala directly if she had had enough, ended the session early and invited all to a cup of tea to which Nuala responded positively. This was a very relaxed occasion at which Nuala evidently enjoyed directly engaging with the artist who

accompanied her as they made plans to go and study the view from Nuala's window.

### *Challenges: Session 3*

Due to bad weather on the day, two couples cancelled as they were nervous of the possibility of slipping on the way to the venue, on account of the rain. Two people expected from a HSE day-care facility cancelled due to illness. This meant there was only one person with dementia, Nuala, and her friend/carer (a professional artist), who attended this session. Nuala asked would there be more people coming. The facilitator helped to lessen the entire focus being on Nuala by occasionally inviting the participation of the observers, thereby orchestrating a more natural group dynamic. The session time was shortened by the facilitator when Nuala assented that she would like a cup of tea.

## Analysis

Overall the programme was considered a very positive experience from the various perspectives of those who participated in the pilot programme. The analysis was approached under the following headings:

### **Recruitment**

A comprehensive approach to the publicising of this programme was undertaken. Some aspects worked better than others. Due, at that particular time, to the heavy workload of two of the services of The Alzheimer Society of Ireland involved, there was an unavoidable delay in starting the promotion of the programme with them. However, direct contact and one-to-one meetings were held with local service providers including, the Alzheimer Society of Ireland, The Carers Association and a local residential care facility.

It was found that these were the most productive contacts, in other words - those whose function involves providing support for people with dementia. Most of the participants heard of the programme through these sources, which underlines how people with dementia can be very difficult to reach unless they are already availing of services. The groups were comprised of participants experiencing significantly different levels of memory loss as well as considerable physical disabilities in some cases.

### **Choice of Venue & Artwork**

A lot of thought went in to choosing the most appropriate available venue and, given that it was not a traditional gallery context, it worked exceptionally well. There was wheelchair access which is essential. The large bright airy room was easily navigable and was adjacent to a very pleasant comfortable reception area where the participants gathered afterwards for a cup of tea.

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Careful choice of artworks was equally important as it allowed for a range of discussions and interactions on different topics, from simple straightforward comments to more complex exchanges.

### **Training for all Staff**

The training provided by The Alzheimer Society of Ireland and the Butler Gallery for the observers and the Butler Gallery staff was focused and comprehensive. It was pivotal to equipping personnel involved with an awareness of the disability and how to sensitively communicate with people who live with dementia.

### **Set-Up & Social Aspect**

The sessions were managed well in terms of the practicalities, such as access, signage and seating. The choice of stools or chairs offered, acknowledged the different needs of the participants and in the case of the stools, facilitated ease of movement around the exhibition. Clear signage and similar name tags for everyone enabled registration to take place in a relaxed fashion. This in turn helped to generate an air of cohesion and equality within the groups, enhancing the whole social aspect of the event. The much enjoyed 'cup of tea' which followed the sessions, when time allowed, further promoted this social dimension.

### **Bookings & Participant Information**

The facilitator took bookings by phone for the two sessions that were open to the public. This gave her the chance to acquire background information on those attending as well as to inform them what to expect from the programme. The facilitator was also able to establish herself as a reassuring point of contact.

### **Facilitated Sessions**

The observers' comments and all the feedback suggests the sessions worked on a number of levels and the participants enjoyed them. This was confirmed by Ruth

O’Gorman, Manager of the Day Care Centre who subsequently emailed the facilitator and The Alzheimer Society of Ireland to this effect, saying that some of the clients “really seemed to be on a high” after the session and that one client who would not be considered very sociable “spoke at length about it afterwards.”

Unfortunately, there were a number of cancellations at the last minute due to participants being unwell or unable to attend due to bad weather.

### **Facilitation Skills**

It was apparent that the skills of the facilitator were fundamental to the success of the programme. Her intuitive communication with the participants encouraged their progressive relaxation and enabled an atmosphere whereby they could really engage with the artwork and take the time to give considered responses. Her strong intuitive sense with regard to how and when to focus on specific individuals in order to draw them out, helped people who were reluctant to be part of the discussion to be part of the group. This enabled the balance to be maintained between being welcoming, friendly and caring without tipping over into condescension or patronisation.

The multiple disabilities which affected some of the participants (for example, hearing and sight impairments) increased the need for skilled facilitation and careful planning, and also points to the desirability of obtaining these kinds of details well in advance. Sufficient notice was not, however, available in respect of some participants in one session (Thursday morning), which was unfortunate. Despite this, skilled facilitation ensured that the workshop was as inclusive as possible in the circumstances.

### **Day Centre Group**

The Meet Me at MOMA model focuses on people with dementia and their family/friends, but one session deviated from that model, in having a pre-existing group with professional carers from a Day Care centre (the difference being that

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they did not make contact individually, and they were not accompanied by family or friends). This session still worked well in the opinions of the observers, the facilitator, and the Manager of the Day Care Centre. It included both clients and carers in the discussion. A key element of success was the strong buy-in by the centre Manager, who ensured that each client was accompanied by a carer (providing both security and a sense of occasion.)

### **Steering Group**

All steering group members actively contributed to the programme at different levels, with different but complementary input. All of the four partners have a different remit but the programme facilitated working to a common objective. There was a high level of buy-in and sustained motivation. It also meant that the project was planned, delivered and evaluated within a time-frame of approximately four months.

## Recommendations

The following are the recommendations to be considered in any future roll out of the programme:

### **Recruitment**

A sufficiently long lead-in time needs to be allowed for a comprehensive awareness drive to impact on the target audience and, if a media campaign is included (something that would need careful consideration), to raise awareness in the greater community.

Face to face contact is crucial with potential stakeholders in order to explore opportunities and source champions at local level. Service providers are an important resource in promoting the programme within their client base. They can also help (and should be asked) to identify any physical and sensory disabilities that require consideration and indicate the stage of dementia being experienced by the different participants.

It can be challenging for people at the earlier stages of dementia and for their relatives, to engage with others at a more advanced stage. Therefore, it is recommended, where possible, that grouping people together who are at a similar stage of dementia is desirable (as per the MoMA model).

### **Choice of Venue & Artwork**

Whereas ideally, the event should take place in a gallery setting, it is possible, with careful consideration of all the requirements to find other suitable venues that can be easily accessed. The space needs to be appropriate for the exhibition of artworks. When curating the exhibition every effort should be made to choose a diverse selection, both abstract and figurative, that might have a resonance for the group. This gives the facilitator the opportunity to engage with the participants on a number of different levels. A theme for the exhibition enables a

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particular line of enquiry to be followed and gives the facilitator the scope to expand on this with the group.

### **Training of all Staff**

Training in dementia awareness is essential for all personnel involved in the delivery of the programme. It will give staff insight into the nature of dementia, how it affects those who live with the condition and their families. Such training will enable all concerned to feel more comfortable interacting with people with dementia. This in turn will contribute to the overall delivery of the programme in an informed and sensitive manner.

### **Set-Up & Social Aspect**

Rigorous attention to the practical details of setting up the venue for the facilitated sessions and for registration is important in achieving the correct balance in terms of acknowledging the independence, as well as the differing needs of the participants. Offering choice where possible to the participants anticipates some small effort and decision-making on their part. This helps promote the facilitation of the participants and their carers in meeting on an equal footing. The significance of 'a cup of tea' at the end of each session should not be underestimated in terms of providing a social context for both the people with dementia and their carers to socialise in a secure, relaxing environment.

### **Bookings & Participant Information**

A well informed approach to this initial contact is advised in order to establish a reassuring point of contact and to determine the necessary background information on the participants. This initial engagement should be recognised as the vital first step in establishing a relationship with the participants that can influence their perception of the programme.



## **Facilitated Sessions**

Given the nature of the target group, a flexible approach needs to be adopted in order to accommodate participants with a wide variety of needs. Last minute cancellations or changes can also affect the anticipated dynamic of a group and these are factors which a facilitator needs to be able to work around in order to maximise the potential of the programme.

## **Facilitation Skills**

Comprehensive training in communication and facilitation skills is required for delivering a programme such as Azure as well as innate characteristics like empathy and openness. Specialised skills such as the ability to communicate with individual participants, including those experiencing multiple disabilities, according to their need and ability, are also paramount.

## **Day Care Centres**

Pre-existing groups of clients from Day Care Centres had not originally been considered as the main target for this project. However, this experience highlights the fact that this can work well with the support of management and staff. Opportunities for including family members should also be explored in the future.

## **Steering Group**

In order to progress the roll out of the project, a range of partners will need to be part of a national steering group. These partners should represent people working in the area of ageing, the arts, and dementia, regionally and nationally. Once these links are established it will be possible to build and expand on these in terms of how and in what contexts the programme might be delivered.

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## Conclusion

The Azure programme represents the piloting of a new way of including people with dementia and their family members and carers in the normal life of museums and galleries. Innovative in an Irish context, the programme relied on the Toolkit published in relation to the Meet Me at MOMA programme at MOMA in New York. A number of challenges were overcome to deliver the pilot, and a lot has been learned in the process. Aspects of the MOMA model were adapted for the particular context, and these were judged to have worked very successfully.

Overall, the pilot is considered by the partners who collaborated to make it happen to have demonstrated tremendous potential. They are keen to find ways of making the possibilities of dementia-friendly arts provision better known, and of taking the work forward to include more arts venues and to reach more people living with dementia. Many thousands of people in Ireland are already living with dementia, and it is estimated that over 140,000 people will be living with the condition by 2041. Given this context, arts organisations that aspire to inclusivity must plan to find ways of including them and their carers in their mainstream provision. We hope that the Azure programme can start to inform the new awareness and planning that will be required for this to happen.

# Appendices

## Appendix 1 - Advance Information Form

### *Introduction*

The Azure Project is for people with Alzheimer’s and their care givers. It is an arts initiative being developed by the Butler Gallery in partnership with Age & Opportunity, the Irish Museum of Modern Art and the Alzheimer Society of Ireland. The aim of the project is to give people with Alzheimer’s and a family member or friend, a stimulating enjoyable, social experience. It would help us with the future planning of the programme to have your response to the following questions in advance of the session.

Name \_\_\_\_\_

**1.** How did you hear about the project?

\_\_\_\_\_  
\_\_\_\_\_

**2.** What are your expectations of this event?

\_\_\_\_\_  
\_\_\_\_\_

**3.** Do you tend to participate in arts events or have you visited the Gallery before?

\_\_\_\_\_  
\_\_\_\_\_

*Thank you*

### Appendix 2: Observer Evaluation Form & Guidelines

Observers should be as discreet as possible in how they go about observing individuals and refrain from taking notes during the event. Straight after the event they should make note of their observations in relation to the following headings.

Interest - eg. Eyes following educator; Responding verbally without prompting:

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Pleasure - eg. Smiling or laughing; Reaching warmly to others:

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Sadness - eg. Frowning; Eyes/Head down:

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Anxiety - eg. Repetitive calling out; Leg jiggling/hand rubbing/tapping:

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Anger - eg. Making distancing gestures; Shaking fist:

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Memories / Past Knowledge:

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Group Dynamics - Please comment on the group's liveliness, responsiveness (to the programme, to each other, certain works, mood, agitation and anything that helps characterize this group:

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Miscellaneous:

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### Appendix 3: Verbal Feedback Form for after Event

#### *Introduction*

We hope you have found the Azure Programme at the Butler Gallery stimulating and enjoyable. The programme has been developed in partnership with Age & Opportunity, the Irish Museum of Modern Art and the Alzheimer Society of Ireland. Your feedback will help to develop additional programmes and services.

#### *Questions*

1. Did you enjoy the experience?
2. Was it what you expected?
3. How was it different from what you expected?
4. What was the best thing about your visit?
5. How could we make the experience better for you?
6. Would you like to attend the Butler Gallery again?
7. Would you like to have the opportunity to do other arts activities because of your Gallery experience?





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