

‘CREATIVE AGEING’
A Practical Exploration of the Arts
in the Healthcare of Older People



Report for the Changing Ageing Partnership (CAP)
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1. INTRODUCTION

1.1 Overview

This project involved creative artists working with older people with dementia and staff from two Belfast Health and Social Care Trust supported housing centres, Sydenham Court and Mullan Mews. The six week project allowed the tenants and staff of the housing centres to engage with a mixed programme of dance (with Jenny Elliott), painting (with artist Helen Shields), music (with composer Elaine Agnew) and drama (with David Grant and Meriel Grant) which culminated in an open workshop with relatives and friends of the tenants. Using this wide range of art-forms created exciting connections and challenges, with one tenant playing music for the dance and another reciting her own poetry at the climax of the event. According to one the tenants of Mullan Mews, the project served to “awaken - or reawaken - folk with dementia to the endless vista of possibility already in their lives if they will only look for it.”

1.2 Research Questions

How can arts-based activities be deployed to complement traditional programmes of healthcare to improve the well being of older people with dementia and clarify the function of arts activities within a healthcare context? What practical strategies can be developed to facilitate this?

1.3 Key findings

- The programme of arts activities stimulated extensive discussion, skill-building and improvisation and encouraged high levels of concentration and acting with purpose in the tenant-participants
- The programme of arts activities awakened participants’ memory of, and ability to engage with, the different art-forms
- Carer participants were enabled to see their tenants “in a new light”, challenging assumptions and offering new insights into their interests and personalities
- The programme of arts activities enabled the development of respectful and creative relationships between tenants, carers and artists
- The different art-forms complemented and reinforced one another and the artists’ use of stimuli such as props and repetition assisted memory re-call
- A sense of well being, absence of distress and evidence of social engagement were evident during all sessions
- Sensitively filmed video recording proved to be an effective means of collecting phenomenological data relating to the impact of the project

2. RESEARCH CONTEXT

2.1 Background

2.1.1 Neuro-degenerative diseases such as dementia in older populations are becoming an ever-increasing public health problem (Brookmeyer et al. 1998). A strong body of research exists relating to the levels of disability experienced by dementia sufferers and the impact on daily functioning, ranging from lack of social interaction to lack of cognitive ability and motor functioning. There is a growing awareness within older people's healthcare services to address and meet such challenges of ageing with appropriate responses such as the integration of arts-based activities to enhance quality of life within day care facilities (Larson 1998).



2.1.2 The current study links directly to three major government documents produced since 1999 investigating the role of creativity within a Northern Ireland context (DCAL 2000, 2001, 2004). Since the inception of the government's *Unlocking Creativity* initiative (DCAL 2000 and 2001), the concept of creativity has been given a central role in Northern Ireland's response to the challenges raised by the changing global economy. By creating a vision of a developing a cultural landscape that embraces both community and educational concepts of the arts, this study complements the direction of these documents in promoting the rights of older individuals to access quality programmes of arts within a

healthcare context as part of a wider community experience. The government's policy documents focus on developing a creative dialogue between emerging partnerships through which a sense of community may be re-invigorated and re-invented and therefore embrace the concepts and practice of the current study. DCAL's (2004) strategic aim with regard to promoting a full and co-ordinated provision of creative and cultural development in the curricula of formal and informal lifelong learning further supports the location of this study within a cultural educational context.

2.1.3 Staricoff (2004) and Murphy's (2002) reports on Arts-in-Health, commissioned by the Arts Council of Northern Ireland, acknowledged that there is no easy answer in terms of assessing the impact of the arts on individuals within a healthcare context. The Arts Council however, on launching their new five-year development strategy for the arts in Northern Ireland 2007-2012 cited the positive findings of Arts Care's research study at the Mater Hospital, Belfast (Arts Care 2006). In stating the case for integration of cultural arts programmes in health, the Arts Council related statistics from the Arts Care study indicating that 88% of people surveyed at the Mater Hospital stated that arts benefited their health (Arts Council Northern Ireland 2007, Arts Care 2006). The community artist, in this context, is understood to be located within healthcare environments to provide an opportunity for the general public to access and participate in cultural programmes of art whilst in hospital or accessing other healthcare services. The aim is not to provide art services on a medical prescriptive basis but to develop quality arts programmes within healthcare settings, facilitated by professional artists and ultimately impacting positively on the lives of service users, staff and visitors (Arts Care 2003).

2.1.4 Most published Arts-in-Health research favours a rigid scientific approach in an attempt to create a hard evidence base (Staricoff & Loppert 2003). Hastings (2005) highlights the limitations of this approach in terms of extracting and structuring meaning and truth from the participants' profound personal creative experience. Attempts to produce hard scientific evidence in Arts-in-Health programmes have resulted in the delivery of a predominantly clinically-based body of research that has omitted any personal engagement with the creative process from the researcher's perspective (what Bannon (2004) describes as "the capturing of the deep human dimension of experience"). This omission by researchers to embrace their creativity as part of the traditional scientific inquiry has resulted in a failure to capture the full significance of the creative experience of participants engaged in arts-based activities within healthcare settings. Hastings also notes that the use of experimental and control groups runs counter to the patient-centred choice-oriented ethos of Arts-in-Health activities and raises ethical questions regarding exclusion issues through denial of creative engagement for the participants of those groups. Staricoff's (2006) most recent work recognises the benefit of qualitative constructs implemented within evaluation methodology in more recent Arts-in-Health research programmes such as the *Dreams Project* (Arts Care 2006).

2.1.5 Gilroy (2006) identifies the challenge in documenting and disseminating the value of art in health settings in the context of evidence-based practice (EBP) and articulates the importance of qualitative research in this field. “Outcomes are particularly problematic when the treatment being evaluated cannot be broken down into measurable component parts because it involves human interaction.” (2006: 10). Gilroy reviews Schmiedebach’s classification (2002) of three kinds of evidence in the history of mental health care: a focus on the social, cultural and political context; scientifically oriented methods concerned with both understanding and treating mental health problems; a focus on treatment alone ignoring both the nature and context of the problem. She concludes that EBP requires the third kind of evidence alone, and that:

“The examination of evidence from the range of research methodologies, including that from firsthand witnesses... would make for a far more egalitarian, less biased and methodologically robust system” (2006: 24)

2.1.6 Lepp et al. (2003) provide a valuable example for qualitative research involving drama and story-telling. Adopting a phenomenographical approach (Marton, 1986), the study aims to describe the experience of caregivers in a drama programme for patients with dementia and their caregivers. Twelve strategically selected patients with moderate and severe dementia and their seven caregivers participated in weekly ninety minute session for two months, with a focus group interview being conducted with the caregivers one month later.

“Two categories, ‘interaction’ and ‘professional growth’, and five subcategories emerged from the analysis. In these, the caregivers described how fellowship developed between participants and how they shared joy and sorrow. The patients communicated with each other and the leaders, and the programme seemed to help patients to remember and make associations with situations experienced earlier in their lives. The patients also showed knowledge and ability in things about which the caregivers were [previously] unaware.” (873).

Marton (1981) distinguishes a phenomenographical approach from a phenomenological one in relation to first- and second-order experience. By investigating people’s experience of an arts project involving people with dementia, the phenomenologist would aim at learning about dementia; the phenomenographer aims at learning about people’s experience of the arts project. The categorization of that experience is therefore central to a phenomenographical methodology.

2.2 Arts-based Research

2.2.1 This study is underpinned by an embodied “live” creative practice-based research approach (Elliott 2008, Simons and McCormack 2006 and Rye 2004). It also draws on emerging work of Performative Sciences and Ethnography (Ellis 2004, Jones 2006) and emerging research approaches in Educational Drama (Taylor 1996, Ackroyd 2006) and Applied Theatre (Thompson, 2009). Candlin (2000), in debating the academic unease encountered in validating the production of alternative creative-based texts as utilised in the emerging knowledge of performative sciences, highlights the need for re-definition of institutional boundaries within the context of research methodology. Information now emerging in literature particularly since mid 1990s reflects positively on the contribution of the Arts-in-Health (Senior & Croall 1993), but confusion in defining the role and value of the participatory arts in healthcare often arises from blurring the line that differentiates art therapy practice from cultural art practice within healthcare settings.

2.2.2 Knill, Levine & Levine (2002) provide a philosophical basis for understanding the value of such arts activities, tracking the emergence of a phenomenological analysis in preference to a Cartesian one. “The significance of the phenomenological attitude is that it opens up the world of experience as a legitimate field of philosophical enquiry.” (2002: 21-22) Epistemologically, engagement with the arts is identified with Aristotle’s idea of *poiesis* (knowing by making), as distinct from knowing by observing (*theoria*) and knowing by doing (*praxis*). This is reflected in the emphasis within the current project on participant observation within a reflective process. Cohen and Manion (1980) identify four key advantages of ‘participant observation’ over more structured data gathering methods: it allows for the collection of non-verbal as well as verbal data; it allows the investigator to make appropriate notes about on-going behaviour as it emerges; it enables the researcher to develop a more intimate and informal relationship with those being observed; it is flexible and less reactive to more structured methods where unnoticed bias can remain unaddressed through the very rigidity of the research design. Cronin and Werblowsky (1979) define process as:

“the entire sequence of events from the moment a patient begins a drawing until the conclusion of the session. Process includes the patient’s behaviour and affect; the patient’s comments or associations; the evolution of the drawing itself; the patient’s use of materials; the carryover from drawing to drawing.” (1979: 104)

2.2.3 Neelands (2006) invokes Schön (1987) in describing the role of artist-facilitators in terms of ‘reflection-in-action’. In the current project, where the facilitating artists were fully integrated within the process and has strong parallels with James Thompson’s recent emphasis (2009) on *affect* as an important corollary to *effect* in the assessment of applied arts work. Thompson quotes Gumbrecht:

“Our desire for presence as a reaction to an everyday environment that has become so overly Cartesian during the past centuries, it makes sense to hope that aesthetic experience may help us recuperate the spatial and the bodily dimension of our existence; it makes sense to hope that aesthetic experience may give us back a feeling of our being-in-the world, in a sense of being part of the physical world of things.” (2006, 116)

Thompson goes on to reflect on the experience of the artist-researcher:

“A method of research based on being next to the work ensures that we are only ever collaborators, co-inquirers, experiencing the work in an entirely valid but never superior way... We can make no claims to know the effect of the moment on others... but we will always feel the affect that propels people’s engagement with the artistic process and will in turn ripple through our body.” (2009: 134)

The current project can be seen to have taken this a step further, placing the artist-researchers not “next to” but “within” the work itself. The filmmaker was also located “within” the process, making the video record an exceptionally successful record of the effect and affect of the process. The artist-researchers have sought to use artistic forms of documentation in recording their response to the project and this will form part of the dissemination of findings through a documentary film. This reflects current thinking in educational research as exemplified by Taylor (2006) and Eisner (2002):

“How does one measure an artistic experience via rubrics? ... By embracing the artistic medium as a way of re-envisioning the data, researchers acknowledge that qualitative research is a human-situated act, and that there is no one grand narrative that should hold priority. In heightening the reader or audience member’s ability to construct their own interpretation of the data, there is promotion of the individual’s capacity for freedom”. (2006, 11-12)

“Form influences meaning and much of what needs to be understood and conveyed needs a narrative more than it needs a number... Narratives, films, video, theatre, even poems and collages can be used to deepen one’s understanding... Hence, the use of forms of representation that previously had little or no place in research have been recognized as providing new meanings, something needed if understanding is to be enlarged.” (2002: 210-11)

According to Aldridge (2000):

“The process of living is performative... we are polyrhythmic, symphonic beings improvised in the moment. That is to emphasize ‘I perform therefore I am’, rather than the Cartesian ‘I think therefore I am’... We are performers performing our roles

together in the mutual dances of relationship, songs of comradeship and anthems of solidarity... What is central to these performances is that they occur now.” (2000:11)

This connects well with the necessity for many people with dementia to live “in the moment”.

Denzin (1989) illuminates this problem in relation to establishing creative experience-based discourse within social science research methodology. He refers to the extraction of different truth elements within the research paradigm that embraces methodological constructs that relate to what he describes as the facts about the life lived and experienced. Denzin refers to fiction as a narrative account that deals with real or imagined facts. By examining the different elements of truth such as the subjective, historical, fictional and aesthetic and by paying heed ultimately to remaining faithful to the fact even within fiction narrative, Denzin argues that valuable, qualitative-based research texts can be produced.

2.2.4 Simons and McCormack (2006) argue that using the creative arts in the process of evaluation evokes different ways of “knowing and understanding the values of a programme.” The authors reflect on the insights to be gained from utilising this unique addition to evaluation stating that it not only broadens perspectives in research but also offers opportunities for participants to be part of the process of valuing. Both these authors admitted however to the present challenges of representing this artistic knowing, focusing on establishing validity and methodological rigour whilst protecting research integrity. Their work in creative evaluation is back-dropped against early forms of qualitative evaluation such as case study (MacDonald & Walker 1975) and portrayal (Stake 1972) recognising also the work of Richardson (1997) who utilised poetic and dramatic form to best represent experience. The use of dance as an instrument to disseminate findings by Cancienne and Snowber (2003) is also afforded recognition within Simons and McCormack’s (2006) study. The evolving creative research knowledge in nursing is awarded recognition in Elliott’s study (2008). In her work Elliott attempts to advance the usefulness of her artist’s craft, contemporary dance, in evaluating the impact of a contemporary dance programme on a group of men with severe enduring brain injury and the nurses who care for them. She constructed a methodology that was practice and creative-based both in the manner through which the data was collected and the subsequent analysis using live process and performance (Elliott 2008, Kontos and Naglie 2006, Jones 2006). The aim of Elliott’s research was to evaluate the impact of an arts-in-health project on well-being not from an external perspective but from an internal, intimate practice-based core of a community dance based project where she as the dancer was the chief research instrument. This study draws on her exploratory journey with regard to inviting considerations of new possibilities of evaluating and recording research findings for artists in health.

2.2.5 Nicholson (2005: 149-151) addresses the relationship between applied drama (and by association other participatory arts activities) and Human Rights, arguing that “individuals inhabit

dialogical spaces in which they continually negotiate and renegotiate a sense of who they are and who they might become, in narrative and through conversation.” (149) She argues that this approach “brings together the ethics of human rights... with the aesthetics of self-construction”, and cites Homi Bhabha’s statement of the “right to narrate”:

By the ‘right to narrate’, I mean to suggest all those forms of creative behaviour that allow us to represent the lives we lead... and dare to entertain the most audacious hopes and fears for the future... Suddenly in painting, dance or cinema you discover your senses, and in that process you discover something profound about yourself, your historical moment, and what gives value to a life in a particular town, a particular time, in particular social and political conditions. (149-150)

2.3 Personhood and the Arts

2.3.1 Although this was not an art therapy, health-based intervention but an arts-based project, some of the growing body of material about art therapy, however, can help inform the context of the work. Killick and Allan (2001) explore in depth the issue of communication with people living with dementia and, following Kitwood’s emphasis (1997) on personhood, identify, among other key issues, two that have had special relevance to the current study – individuality/group membership and agency/autonomy. “Although we tend to see our individuality as something deriving from within us, a sense of individuality can be real only when it is acknowledged and supported by others”. (2001:25) “A corollary of the idea of self is that of having the capacity to take action – agency, and having control over what one does – autonomy... Closely related to the matter of autonomy is that of opportunities to express preferences and make choices”. (2001: 32) “Respecting someone and upholding their dignity involves honouring... the individual’s uniqueness and complexity, their preferences and choices, their need for control over aspects of their lives” (2001: 34) The video record of the current project demonstrates how it provided opportunities for group involvement and individual agency.

2.3.2 Killick and Allan also attest to the importance of people with dementia remaining active: “Creativity can be regarded as one form of activity where the qualities of inventiveness and novelty are uppermost, and the special human capacity we call imagination is engaged”. As Boal has observed “Memory and imagination form part of the same psychic process: one does not exist without the other. I could not imagine if I did not have a memory. I cannot recall something without imagination, since memory itself forms part of the process of imagination.” (2005:21) But, “along with others, [Killick and Allan] challenge the view that an intact memory, at least in the sense of being able to remember facts and hold a conventional framework of time, is basic to the idea of personhood.” (2001: 35). “Part of what constitutes an imbalance of power in a relationship relates to who is able to

give and who is positioned as being the person who receives... Thinking about reciprocity in relationships takes us to the heart of questions about personhood” (2001: 40). The current project positioned participants as ‘givers’, both when working together within their own group and in the work they shared with family and friends. Killick and Allan also cite research into the experience of people with pre-existing experience of the arts (Miller, Boone and Cumming, 2000), concluding that “there is increasing evidence to believe that those who are proficient in a specific art form before the onset of dementia may be able to continue to practise it”.

2.3.3 Innes and Hatfield (2001) provide a detailed mapping of visual arts, dance/movement and music therapies with people with dementia against Kitwood (1997)’s twelve positive interactions that comprise positive person work:

- *Recognition* – the person with dementia is acknowledged as a unique and individual person, known by name and revered for who they are;
- *Negotiation* – in this type of interaction, the person with dementia is consulted about their preferences, desires and needs rather than having the carer make assumptions about the same;
- *Collaboration* – involves a kind of ‘working together’ to accomplish a shared task; often the shared task is that of giving care whereby the person cared for offers their own abilities and initiative to the care process.
- *Play* – involves the kind of spontaneous activity that has no other particular goal than self-expression and enjoyment.
- *Timulation* – involves a type of interaction in which the senses are the main focus for engagement rather than interactions which involve an intellectual or emotional component (e.g. aromatherapy, massage etc.).
- *Celebration* – involves acknowledging and holding up moments that are intrinsically joyful and participating in them to the fullest capacity.
- *Relaxation* – involves a letting go of bodily tension and a sense of comfort in sharing that tension-free slow pace with others in the common group.
- *Validation* – involves accepting the ‘subjective truth’ of the person with dementia, attempting to understand the person’s frame of reference, accepting the reality of their emotions and feelings and responding on a feeling rather than a solely intellectual, reality-based level.
- *Holding* – means providing a safe psychological space into which the person with dementia can bring any feeling or emotion and know that all will be accepted.
- *Facilitation* – enables a person to ‘do what otherwise he or she would not be able to do, by providing those parts of the action – and only those – that are missing’ (p.91).
- *Creation* – the person with dementia takes the lead and spontaneously offers the group something from his or her own ability and/or social skill (e.g. reading a favorite poem to the group).
- *Giving* – the person with dementia, because of their own sensitivity, expresses concern, affection, a desire to help or a sense of gratitude.” (2001: 13-15)

2.3.4 Shustik and Thompson's chapter on Dance/Movement Therapy quotes Kitwood's emphasis on "the language of the body: expression, gesture, posture, proximity, and so on. This conveys emotion and feeling with great authenticity, and here we are coming close to cross-cultural universals". (Kitwood 1997: 71) and argue that "dance/movement therapy techniques may be likened to such a language. It is this 'language' of the body that dance/movement therapists utilize in the creation of movement dialogue/communication and the meeting of the core psychological needs of persons with dementia, which include love, identity, comfort, attachment, inclusion and occupation" (2001: 52). The use of the stretch cloth (used in the current project) is presented as an embodiment of attachment. "In introducing movement with a stretch cloth, each member of the group grasps hold of the material. As movement emerges in a matching or clashing manner, the cloth reveals a representation of group dynamic and/or attachment/detachment." (2001: 59)

2.3.5 Hatfield and McClune (2001) in their chapter on music therapy comment on participants with pre-existing musical expertise:

"It is with surprising frequency that we meet people in our facility for whom performing music has been a significant part of life. The support and interventions needed are unique for these musicians (as, of course, they are for all persons), as the method of intervention is also the area of accomplishment. In working with these individuals, issues of identity and occupation are of utmost relevance. These are highly significant because persons who have been extremely active in music may often define themselves by it, and the loss of the ability and/or opportunity to successfully engage in active musical experiences can result in feelings of 'lost' identity." (2001:96)

They also note the importance in music work of repetition:

"Repetition is very important. Too often, caregivers ask for or present a song and then only allow the opportunity for participants to sing through it one time. Given the presence of cognitive impairment, going through a song once usually isn't enough time for an individual to identify what is being presented and then to formulate and expand his or her responses to it. A suggestion is to repeat your songs between three and four times to allow for maximum participation." (2001: 109)

2.3.6 Violets (2000), writing about dance therapy with people with dementia observes that she is "frequently amazed and inspired by the intrinsic genius of people who have to survive and find a way to communicate when there are no longer terms of reference in common, especially verbally. Movement, music, song, dance and play offer another possibility of expressing the imaginative self and a whole wealth of information about a person, if we can only enter into this frame of reference."

(2000:212-3) She notes the importance of working in a circle: “The connection between the group, where everyone had an equally seen and felt place, was a fundamental part of this unity, The form developed as a tangible and also flexible structure. There was a container for members of the group to share and develop their own movements.” (200:214)

2.3.7 Rentz (2002) documents a systematic analysis of the response of “individuals with dementing illnesses” who participated in the *Memories in the Making* art programme in Cincinnati in relation to precisely observed physical responses. The goals of the programme, which used visual arts, were for participants: “to experience:

- An opportunity for sensory stimulation
- The pleasure of being involved in the creative process
- A sense of well-being, only if momentarily
- An increased self-esteem with having created something of value to self and others” (176)

There was extensive anecdotal evidence to suggest these outcomes, but the study also sought to support these with more objective measurements based on detailed descriptors of verbal and non-verbal behaviour indicating engagement, expression of pleasure, self-esteem and the expression of emotions and feelings. Sustained attention for a period of 30-45 minutes was another key measure. Notwithstanding this systematic approach to analysis, there is an implicit frustration in the report of the limitations of the measurement regime and the findings are supported with telling, qualitative details relating specific comments by participants and carers. Noting the importance of early diagnosis, the study concludes that those “developing innovative programs must begin to look outside traditional models and build programs that support the individual during all stages of the illness and in consideration of their abilities”. (181)

2.3.8 Purshouse (2009) provides a range of references relating to the effectiveness of dance therapy with people with dementia, noting that social dance has been shown to “develop procedural learning (long term memory initiated by past experience) and concentration because dancing is a dynamic rather than a repetitive physical activity” (Rosler et al., 2002); a woman with Alzheimer’s was noted to remember Scottish country dancing steps, despite her limited cognitive ability (Lamont, 2008); and in another project, “participants who danced in a circle felt they had been accepted into and belonged to a group” (Jerome, 1999). A project allowing a freer and less structured approach to creativity has been shown to have similar benefits, awakening memories outside the dance session, and “challenging stereotypes of ageing and disease”. (Kindall, 2003) Other research has indicated that music can improve autobiographical memory and reduce agitation. (Cunningham et al., 2006; Vink et al., 2003)

2.3.9 Sandel (1992) provides a useful overall assessment of multi-disciplinary arts therapy (music, dance/movement and art therapy used together). Outcomes include but are not limited to:

- *“Increasing orientation and activation:* The creative arts therapies provide a structured interpersonal environment in which organized sensory stimulation, interpersonal interaction and physical action facilitate orientation, attention and arousal.
- *Facilitating reminiscence and remembering:* By providing concrete physical and imaginative cues through sound, touch, movement and visual forms, the creative arts therapies enhance the processes of reminiscence and remembering by facilitating access to deeper memories, as well as the subsequent sharing of these memories with others in a group context.
- *Developing meaningful interpersonal relationships:* The creative arts therapist provides a means of structured communication among people. Intimacy is created through the mutual expression of aspects of their inner lives. Because of the nonverbal nature of the arts media, people with cognitive or language deficits can participate equally. The atmosphere of play, fun and spontaneity contributes to the bonding among members of the group.
- *Building communal spirit:* Communal artistic events such as murals, songs, performances, celebrations or workshops have the power to link people of divergent backgrounds, cultures, ages or conditions and to articulate their common bond.” (quoted in Innes and Hatfield, 2001: 11)

2.4 Life-long Learning

Baines (2007) provides a useful survey of current research in relation to the creative potential of older people and cites Cohen whose “research has led to the finding that brain plasticity is greater in older individuals (as a result of control hemisphere asymmetry reduction) and that this greater connectedness between the left and right hemispheres is thought to promote creativity”. Baines notes that: “the findings of the longitudinal study of human development carried out at Harvard University over six decades, led Dr. George Valiant to the conclusion that in retirement... creativity, like play, should be a primary goal.” (2002: 224) Baines also cites Simonton that “usually creators in their sixties and even seventies are at least as productive as they are in their twenties. An octogenarian can still hope to make an important contribution albeit at a slower rate.” (Quoted in Valiant 2002: 239). Baines further observes: “Creative acts connect us to our unconscious and allow us to draw on resources and strengths which a person may not believe that she or he has at her or his disposal”. (2007: 9) The idea that older people have the capacity and a human right to participate in creativity activities underpins the current project. The issue of dementia provides a more challenging context for this work, but one in which artistic and aesthetic experience has an enhanced significance. Baines (19) cites Dr Bruce Miller in this regard: “As people lose the ability to name, to conceptualise what things are, they are forced into much more visual ways of thinking about the world”.



3. METHODOLOGY

3.1 Structure of the Arts-based Activities

The conceptual basis of the programme was as a six-week, one-session a week, community multi-disciplinary project (Maldoom 2004). This was an arts-based project that involved dance, music, drama and visual art (in different combinations on different days) and took place in a supported housing centre for older people with dementia located within the Belfast Health and Social Care Trust. The programme was service user led with the artists involved in facilitating, through their specific media practice, the creative voice of the older participants and their professional carers.

3.2 Ethical Approval

The project was approved by the Office for Research Ethics Committee Northern Ireland (ORECNI) on the basis of a comprehensive portfolio of ethical protocols for service users, staff and artists. These can be found in *Appendix 1*.

3.3 Participants

Participants included equal numbers of tenants from the host centre and from another neighbouring centre. The participating tenants and their staff were integrally involved in the development and shaping of the programme. A representative group of staff and tenants from both supported housing units advised initially on the following:

- The identification of the participants within the study
- The structuring of the study information sheets/consent forms for tenant-participants
- Location of the study arts project

The level of dementia illness identified within the tenant group ranged from moderate to severe.

The choice of a small mixed sample of numbers adopted for the study, nine tenants and three staff participants provided an opportunity for detailed exploration of specific features and characteristics of individual and group experience that according to Ritchie and Lewis (2003) supports the case for an in-depth small scale study. The residents and healthcare staff representatives of Mullan Mews and Sydenham Court met pre-study to discuss how they would like to be identified throughout the study text. The group of residents requested that they would be known as “tenants” and not as “service users” or “residents.” The professional care staff requested that they would be identified as “staff.”

3.4 Methods and analysis

3.4.1 The study is presented as a small scale investigation in terms of service users' population size. However the methodological approach adopted to secure sensitive research material resulted in the retrieval of a large amount of film recording data that captured the project process, product and the personal reflections of the service users, healthcare staff, facilitating artists and family and friends of the tenants. The study focused on the film recordings as the primary data source. Significant data was also secured and analysed from the artists' personal reflections presented through their art form and accompanying reflective notes. The evaluation of the study experience was undertaken from the following collective and individual perspectives:

- Tenants
- Staff
- Artists
- Family/friends of the tenants

3.4.2 Data were collected through film recording of process, performance and personal reflection. A film-maker was engaged to collect data under the direction of the research team. Film data were then analysed by the research team. An initial review of all film data was carried out by one researcher (JE) to identify broad, recurrent themes and confirmed by a second independent researcher (DG). The film data was subsequently coded according to the emerging themes and followed by a series of film cropping processes that reduced the 18 hours of film data to a 45-minute documentary film text (Elliott 2008). The 45-minute film was viewed and analysed by the research team (JE, DG and SM) who confirmed the emergent key themes. The thematic analysis of the film data accompanied by a specific film cropping procedure was adopted and applied from Elliott's analytical film framework (Elliott 2008).

3.5 Implementation of Process Consent

A process consent procedure was implemented at the beginning of each session. This ensured that all the tenant-participants understood all the elements of participation involved in the project and individual sessions. Tenants were reminded of the function of the study and how the findings would be utilised within an educational context. They were invited to give their verbal consent to participation in each session followed by a confirmation of consent to use the findings of the study within the educational context.

3.6 Content of the Sessions

3.6.1 A community arts-based model of facilitation (Maldoom 2004) was employed by all four artists implementing the following framework for each of the sessions:

- Warm-up
- Creative theme development and skill-building
- Cool down

3.6.2 The content of the six sessions was as follows:

1. Session 1 – Music
2. Session 2 – Dance and Drama
3. Session 3 – Art
4. Session 4 – Dance/Drama
5. Session 5 – Art/Drama
6. Session 6 – Sharing with family and friends

3.7 Abbreviations

The tenant-participants and staff are individually referred to throughout the text by the first initial of their Christian name. This is to safeguard the individual's confidentiality. The following abbreviations identify the tenant-participants: A., H., I., Ja., Ju., O., P., V., W.

4. DISCURSIVE ANALYSIS OF THE SIX ARTS-BASED SESSIONS

4.1 Introduction

Critical exploration of the film and reflective data was the key activity of the analysis procedure. The articulation of the tenant experience is presented sequentially through the weekly individual sessions. The following in-depth analysis of the six art-based sessions is included as an integral part of the research text to explore the personal journeys of the tenant/ staff-participants and artists and highlight the lived experience of all participants during the project. The data analysis across all four different art-form experiences reveals the willingness of the tenant-participants and staff to engage with all aspects of the music, art, dance and drama sessions.

4.2 Environmental Considerations

4.2.1 Sydenham Court Supported Housing Unit

Consideration of design and safety-of-living environments is paramount to best accommodate people in residential care with dementia-related illness (Calkins 1988). Sydenham Court is a purpose built supported housing unit that encourages older people with dementia to live independent lives with intensive professional care support. It is built on a square with full glass walls that permit a great deal of natural light to enter the building. The corridors surround the central garden which can be viewed from every angle. The architectural design supports maximum independence and safety with a focus on enhancing the tenants' well-being through environment (Knudstrup & Hovgesen 2007). No specific area within the unit has been assigned for creative activity.

4.2.3 Suitability of the environment for creative activity

Whilst the communal living space initially advised by staff for use in Session 1 was restful and very comfortable it did not lend easily to facilitating a creative activity. The film data evidences the musician facilitating Session 1 assessing and overcoming the static communal living area by inviting the participants to stand to play their musical instruments. According to the musician, the acceptance of this invitation by all the participants encouraged a sense of intention removing the potential problems of using the sedentary space. As a result of this it was agreed that the activity should be transferred to the communal eating area which proved a more functional and mobile space for dance, drama and visual art. The chairs were more upright and movable, accommodating the ability to change group arrangements during the activity, which in turn contributed to levels of increased

integration and social interaction. The more functional space encouraged an increased level of awareness of others in the group with participants appearing more energised and animated.

4.2.4 Developing a creative space within a residential setting

As the project progressed the participants began to identify the space as somewhere where the weekly art activities took place. The film data suggests that the fact that the art sessions took place within the same space every week gave the communal eating area a creative identity. Some of the participants however came fresh to the space every week as they were unable to remember that they had been there the week before due to their limited ability to re-call events. The evidence presented through the film data underlines the challenges encountered by artists in terms of finding a suitable work space that is functional, comfortable, safe and creative within residential communities (Elliott 2008).

4.4. Tenant-participant/staff engagement with the art forms

4.4.1. Session 1 – Music

From the outset of Session 1, the film data demonstrates willingness to participate in all elements of the music activity of the tenant-participants and staff, who not only take part but appear highly engaged in the series of developmental hand exercises during the warm-up. The data reveals how the facilitating musician develops music skills by building slowly through the following series of creative tasks:

- Tapping one hand with three fingers of opposite hand to encourage co-ordination
- A rubbing and clapping task
- Introduction of a rhythmic sound combining hands and use of voice.
- Development of rhythm and voice into a simple poem-song

After several repetitions to learn the words of the poem, the musician attaches a movement pattern for the group to follow. Everyone within the group is able to focus, follow the movement instructions and combine them with the poem song. Even the less able in the group show an ability to concentrate and act on the musician's instructions clearly demonstrating a willingness to participate and learn. The poem-song is further developed into a familiar old song accompanied by a movement pattern. It is evident from the film data that everyone within the group was keen to participate and attempted to fulfil the tasks.

The tenants and staff enjoy theme-development, learning and applying new music skills. All of the hand, leg and voice exercises in the warm-up link to the development of the skill-building section of

the session with each participant being given a chime bar and asked to play a note on it. This task goes right around the circle. The group becomes quite animated and responds well. All the participants including staff and tenants continue to create soundscapes under the musician's direction.

Summary of Session 1

This was an individual and collective activity where the participants learnt a series of musical skills. Under the musician's direction the tenants joined together working as a team creating an "orchestra" with the chime bars. The film data demonstrates that all of the tenants were happy to involve themselves in the activity and none of them opted out or were unable to fulfil the tasks. On occasions throughout the music session the tenant-participants can be seen assisting and supporting each other in learning how to play the chime bars. Throughout the music activity there was evidence of laughter and background conversations indicating a high level of social interaction and creative engagement within the group. The high level of interaction present amongst the tenant participants during the session served to reduce isolation thus enhancing well-being (Holmen 2000).

4.4.2 Session 2 – Dance and Drama

Dance

The group are initially introduced at the beginning of the class to the theme of growth. The theme evolves from an introductory discussion amongst the artists in the planning stages of the project with regard to what getting older means. The idea that, whilst reminiscence was important for older people, the importance of living in the present and looking towards a future held meaning and value in terms of promoting well-being, is discussed.

Tenants and staff demonstrate a willingness to engage with Dance

The dance session begins with a warm-up. The tenant-participants are invited to repeat the rubbing and hand clapping action used in the previous music warm-up. It is explained by the dance facilitator that the aim of re-visiting certain movements from the first session is to try and stimulate cerebral and muscle memory re-call. The intention is to encourage dance memory pathways to embed in the body potentially stimulating cognitive activity. This is a technique that the dance facilitator has developed in working with populations with dementia (Elliott 2008).

The film text demonstrates all the tenants willingly participating in the movement tasks. The group are invited to explore the surfaces of their bodies. This is to encourage a connection, awakening and an awareness of their physical body connecting to their sense of personhood and individualism. The task of throwing the arms forward into the circle from the shoulders prepares the group for moving



towards each other and builds towards a physical connection with others across the circle. The tenants and staff can be seen responding positively to the invitation to hold hands across the circle and connect. The facilitator follows this task with a request to look for spaces made through the connection such as under arms and travel through them. This task generates a high level of communication amongst the group and the participants can be seen as very animated and responsive in the film text. One of the tenants (W.) stated in the middle of the discussion during the warm-up:

“I don’t know what I am doing here... but I’ll go with it anyway... I say I’ll go with it!”

This simple statement, repeated in Sessions 1 and 2, is significant in that it confirms W.’s willingness to be part of the music activity despite not fully grasping why he was there because of his short-term memory problems.

In the creative skill-building section of the dance session the participants are invited to offer their thoughts on “growth and change”. Colourful images of gardens and flowers are shown to the participants as a stimulus to generate conversation around the process of growing. Some of the tenants (e.g. O.) share with the group that they have been keen gardeners. The existing knowledge of gardening within the group generates a discussion around how flowers and plants grow and germinate relating the topic to personal growth. The dance facilitator later reflects that she has been able to use

the tenants' comprehensive knowledge of gardening to steer the development of the group creativity and choreography:

"I enjoyed so much learning about certain aspects of gardening from the tenants. Their knowledge really informed how I shaped not just the creative theme development but also the choreography of the session. Every time I work with older people with dementia I learn something valuable about skills sometimes now lost due to modern lifestyles." (*Dance Facilitator*)

The tenant-participants report that they enjoy sharing their knowledge with each other, the artists and staff and it is shown in the film data how having the space to share their existing knowledge about specific subjects gives the tenants a sense of being valued.

Ja. brings a large striped blue box containing his accordion into Session 2. He informs the group that he played his accordion in a band for eighteen years as a young man but that he has since not played for forty years. One of the more recent reasons for not playing was that he has Parkinson's Disease and his hands are too "shakey" to hold the keys down. He admits that he has a fear that because of his condition he will be unable to play the accordion anymore. The group re-assures him he will be fully supported by them if he attempts to play it. An invitation is extended to the group to share what they imagine to be in the blue box. The following extract from the film data demonstrates the level of group response and interaction:

I.r.: I would like my husband to be in that box and we would be able to go back to where we were years ago...together and happy. I miss him.

P.: I would like to find my memories in that box and keep them in tact.

(Several others within the group agreed with this suggestion relating to memories)

B.: I would love to find a wee animal to care for in that box...cuddly and warm.

(B. cups her hands together as if cradling a young animal)

H.: I would love to find a squirrel in there!

Dance Facil.: Why?

H.: Because I just love the way they scurry across and move very fast.

H. laughs at her own suggestion. She then goes on to imitate the movement of the squirrel. H. appears very animated and has a real sense of mischievousness about her. Her suggestion brings lots of laughter to the group. At this point we are informed by the staff that H. often runs at top speed like a squirrel on her walking aid.

“You know, I was very mischievous when I was younger. My mother never knew what to do with me. I was always in trouble. You know, I haven’t changed very much. I still get into trouble!” (*H. reflecting on her past and present behaviour*)

H.’s personal professional carer’s post-session reflection records a positive shift in H’s behaviour pattern due to her participation in the art project. The carer reveals that at times H. presents with behaviour that is challenging for staff. This occurs especially in the morning when she takes a long time to decide what she wants to wear and has to have everything co-ordinated:

“She can be very stubborn and at times difficult. However I see a very different side to H. since she has been participating in the art project. On a Tuesday morning when she is reminded that it is the art day, H. decides very quickly what she wants to wear and gets dressed without any problem. She is always in good form those mornings and can’t wait to get down and take part in the group. It makes such a difference to me as her carer. It also means she begins her day in good form. H. and I get on much better on those mornings.”

The reflection of H.’s personal carer provides valuable example of the impact of participation in arts activities in terms of enhancing well-being, perceived mood improvement, improved care relationship and an increase in motivation to take part in a collective activity (Stickley 2008).

Following the discussion of the blue box Ja lifts his accordion out and hesitantly places the heavy black strap of the instrument over his right shoulder. Despite his bent shaking fingers he begins to caress the accordion buttons and it is visible from the expression on his face that he is processing information. There is a silence around the circle. One small, weak voice begins to sing, “Abide with me, fast fall the evening tide...” Others join in – artists, staff, tenants, all one voice supporting Ja. His confidence builds, his shoulders become more upright and his focus is now on his playing and the group. Further requests come from the group:

“Ja., play *The Old Rugged Cross*.”

Ja. obliges. The cohesion of the group is clearly defined through this very personal shared experience. Ja. volunteers to interpret the subsequent movement tasks through music. He freely improvises with notes and confidently plays his accordion despite the presence of a strong shake in both hands. At the end of this part of the session, Ja. takes a moment to express to the group how meaningful it is for him to play his accordion after so long and how significant this session has been to him in terms of encouragement and in enabling him to return to a much-loved activity of his youth. This moment ties Ja.’s past and present to his declared future intention that:

“I’ll definitely be playing my accordion from now on. In fact I’d like to play carols for the Christmas Concert at our place [Mullan Mews Supported Housing Unit] this year.”

Evidence presented in the data indicates the significance of this event for Ja. in relation to his sense of personhood and individuality.

“It is just great to see Ja take up his accordion and play in front of everybody. This will have done so much for his confidence. He struggles desperately at times and has no sense of who he is or what he can do. His past history doesn’t really help. This has been great for him and you can tell that it gives him so much pleasure. We will make sure that he plays the accordion for our Christmas concert.” (*Staff Member Mullan Mews*)

The statement by the staff participant that they would follow through and support Ja’s request to play at the Christmas Concert suggests that participating in the activity with the tenants they care for impacts positively on the care relationship.

Recurrent elements of the film data demonstrate how the development of the dance activity offers opportunities for positive relationship development between staff, tenant and artist. For example, O., one of the tenants and two members of staff explore and experiment with the different moves they had created in the session, bringing new and more confident shapes to create together a short dance motif. O. places herself central to the movement piece with her strong walking stick supporting her moves. Both staff form a shape around O. and bring it to stillness. O. is depicted in the film data in a very senior and supportive role. The dynamics in the shift of roles and support for the purpose of the dance presents O. with the opportunity to become the core strength holding the group together. The recognition of O’s role as the supporter rather than the supported by the staff members and the group appear in the film text to contribute to an increase in her self-confidence and value. Perceptions of the traditional care relationship are presented and challenged at different stages of the film text particularly through participation in the drama and the dance activities. Experience of the short dance motif is described by the dance facilitator as a democratic presentation of the tenant/staff relationship facilitated within the creative activity.

Drama

Warm-up

The drama section of Session 2 begins with the drama facilitator introducing an exercise with four chairs. The group is invited to suggest which chair is the most important. This generates a creative

discussion amongst the tenants. This task is about individual and collective response and decision-making within the group activity. The participants are assured that there is no right or wrong way of answering the query. The beginning of this exercise changes the dynamics of personal engagement with the art activity. Whilst the dance engaged primarily with the participants' own physicality, the drama engages the group with a focused discussion around an idea. The pace of this part of the session is much slower and balances the physical demands of the previous dance section. The group responds well to the change of pace.

Skill-building and creating

The exercise focus shifts from a discussion of the importance of the chairs to the purpose of the chairs. The drama facilitator encourages the group to think creatively, building a picture of a real life experience that may happen around a group of chairs. The suggestion from the group is that a family scene would happen around the chairs. I., who has advanced dementia, suggests that the family scene would be about the family and the children going out to school and work in the morning. The drama facilitator directs the scene, continually drawing ideas from the group through which to develop the drama. Surprisingly, I. contributes the most to the process of creative development. She presents within the group initially as being very withdrawn and isolated. However staff report being surprised at her increasing level of engagement as the project progresses. Her suggestions, creative processing of her ideas and coherent answers are apparent in the film data and indicate that she understands the concepts of developing the drama.

The participants take up the different roles within the family willingly, acting out a scene in accordance with the group's suggestions. The drama facilitator counts down ("3, 2, 1 give me a picture"). Ja. gets into character immediately and holds a strong freeze. His pose is very theatrical, demonstrating that he too fully understands the meaning of the role play and has the ability to follow instructions from the facilitator. The film data confirms the high level of interaction and fun experienced by all the participants in this part of the session. I. remains very much engaged throughout the activity and even though her facial expression in the film text at times appears vague, she releases from time to time a definite smile in response to what she has seen or heard. This appears significant for I. in terms of the drama activity drawing her back into a social engagement thus reducing her tendency for isolation. This suggests that programming a structured creative discussion activity through drama can be of value in increasing levels of social interaction amongst the tenants and reducing the potential for older people with dementia to withdraw and isolate themselves within residential care settings. This recalls Thompson's observation that "an intense awareness of presence, an aesthetic experience... can pull a person into a critical engagement with his or her surroundings" (2009: 127).

Summary of Session 2

The overall observation of the dance and drama experience focused on the tenants' willingness to engage with both these performing art activities. There was no resistance to taking part in either the dance or drama tasks. P. who had just arrived into full-time supported housing care two weeks prior to the project was more hesitant to engage with the dance activity initially and appeared more at ease with the drama. The tenants and staff appeared to enjoy contributing to the discussion and creative processing elements of both the dance and drama.

Ja.'s courage to play the accordion after forty years coupled with the group's support of him by breaking into hymn singing demonstrated the strength of cohesion and enabling within the group.

“I was deeply moved by Ja.'s tears after he played his accordion. Emotions often enter into arts-activities and at times can present difficulties for the artist. It can be a challenge to know how to best manage such situations but in general emotions expressed allow for celebration and acknowledgement of the individual as it was in Ja.'s situation. Emotions can often be neglected in medicine and lost somewhere in the application of medication. This for me presents the risk of losing the essence of the individual and full healing.”
(Dance Facilitator's personal reflections)

4.4.3 Session 3 – Art

All the tenants attend the art session except Ju. and Ja. from Mullan Mews who are unwell. The title for the workshop is 'Forever Growing'. This title is adopted by the participants for the overall project. The session begins with a brief discussion on the theme of growing as introduced in Session 2. The different elements of Session 1 and 2 are re-visited to assist the tenants with their re-call of the experience. B. and O. are not able to remember attending Sessions 1 and 2 but the majority of the tenants have some recollection of having attended the previous sessions. W. on this occasion does not make his usual statement (“Don't know what this is all about?”). He is able to contribute some of the thoughts and memories he holds from participating in the previous drama and dance workshop. This would suggest that regular participation in an identified creative space with the assistance of props and use of repetitive movement/drama exercises may assist in aiding memory re-call in individuals and groups with dementia. Two incidences of collective and individual memory re-collection that re-occurred from one session to the next were:

1. Ja. playing his accordion accompanied by the group singing
2. H. wanting to find a squirrel in Ja.'s accordion box.

The smiles, laughter and nodding of heads in the group indicate that most of the tenants are able to recall significant parts of their previous experience. Staff report an enhanced sense of well-being amongst all the participants as a result of participating in the different art activities.

The Warm-up

The visual artist brings the group of tenants and staff to sit together around two long tables. She introduces the group to the concept of plants and leaves growing. This fits well with the autumnal changes that are so obviously occurring outside in the centre's garden. The well maintained garden can be accessed and viewed from every aspect of the unit. The group are therefore able to look out through the windows of the workshop space and link the theme of the discussion with what they are able to see in the outside garden.

The visual artist introduces a large bag full of autumn leaves of different colours and shapes. The participants are invited to examine each of the leaves and to choose one that they would like to draw. She asks the group to look carefully at all aspects of the leaves examining the spines and the threads of nutrients that branched out along the surfaces of the leaves. The idea of nurture and nutrients opens a brief discussion around the work of the plant and how from a tiny seed it has to invest a great deal of life force to maintaining its health. This leads on to a discussion about the importance of nurturing and looking after ourselves no matter what our age.

Each individual within the group is then given a pencil and sheet of paper. The visual artist invites them to draw the leaves they have chosen either by tracing around them or drawing them free hand. There are signs of reluctance within the group and most of them including the staff say they can't draw or never drew since they were at school. Most of the group perceive themselves to be terrible at drawing mentioning that it was something they would never do. None of the group perceives themselves as artists.

But O. and B. share with the group that they had both been teachers. O. in particular comments that she welcomes the opportunity to be able to attempt to draw again. Both B. and O. relate classroom stories of their teaching practice and how they engaged the children in their classroom to draw every week.

“I used to allow the children to do art on a Friday afternoon. That was the best time because they were too tired to do anything else. I loved teaching art to the children. We were all able to relax.” (O.)

The visual artist continues to encourage the group to try and attempt to draw the leaves. One by one and with the encouragement of the staff the tenants begin to sketch their leaves. Some of the tenants trace around the leaves and some of the images are drawn by hand. Each individual approaches the task differently giving the experience individuality.



Some of the images are spider-like and traced with gentle hand strokes. In some cases the outline is barely visible. However many of the drawings are strongly outlined. As the tenants and staff continue to examine the leaves for the purpose of fulfilling the task of sketching them, discussion continues around the tables about the life and nature of growth.

The visual artist then encourages the group to fill in the leaves paying particular attention to the spine and the nourishing veins. This task takes half an hour and each individual participant demonstrates:

- High levels of concentration
- Careful attention to fulfilling each part of the task-outlining, sketching in details and where necessary shading in areas of the drawing.

W. demonstrates an especially high level of concentration and skill. He is thoroughly absorbed in the activity and states that he has never drawn before but really enjoys the opportunity. Conversation can be seen flowing throughout the film data with individuals inquiring from time to time about different aspects of how they would sketch the leaf. The nature of the lively interaction through the art is in contrast to the poor communication responses often experienced in older people with dementia within in communal residential contexts.

Creative skill-building and creating

The visual artist introduces a large scale painting of a sunflower. This sunflower is a template for the silk painting activity that is to take place during the second part of the art session. The sunflower template is used as a stimulus for the group to discuss further the different aspects of “Forever Growing”. Sunflowers in full bloom in the centre garden are visible from the activity space.

Following the discussion the visual artist introduces a large silk sheet on which she has sketched the outline of a sunflower. She invites the group to paint on the silk with silk paints creating a large sunflower silk painting. The film data reveals the group looking anxiously at the blank silk with some commenting on the soft touch. The silk is then stretched across a wooden stretcher and placed across the two tables in front of the group. The visual artist invites the staff and the tenants to think of five pleasures in their lives at present. A moment of silence follows this invitation. She then invites the group to write the pleasures on the leaves outlined on the silk. These include:

- Family
- Friends
- Touch contact football
- Mmmmmmmmmmm (the “mmm” represented something of a secret revealed P.)

Each individual is then given a paint brush and paint with an invitation to paint in parts of the sunflower. Again, some of the individuals show a reluctance stating that they don’t want to destroy the painting as they don’t know how to paint. Participants and staff feedback that the negative comments from their teachers at school still impact on their present attempts at creative expression. This, according to the artist’s subsequent reflection, is a common problem across all age groups and establishes real barriers to self-expression.

Each individual does eventually take up the challenge to paint the area of the silk assigned to them. Some of the group need the support of the staff to hold and guide the brush across the silk. The shared experience stimulates some humorous exchanges across the tables with respect to the feelings of holding a brush and painting, some for the first time in over sixty years.

The rest of the session is taken up applying the paint and creating making the sunflower image alive on the silk.

Summary of Session 3

Observations and comments across the painting space revealed that every participant in the group enjoyed the following aspects of the experience:

- Social Interaction
- The feeling of being able to master the skill of painting
- The colours and vibrancy of the paint
- The feeling of the silk
- The sense of achievement by working as a team and completing the picture
- The fact that the group was mixed sex
- The sense that the group owned the experience

The tenants were also able to define and deem important specific elements of the social interaction experience such as sampled in O's reflection.

"I love it that we have men in this group. We don't really get chatting like this to men normally and it feels really good, normal." (*O. comments as she laughs*)

O's simple comment relating to social interaction amongst the sexes was given support by the majority of members in the group. It indicated that the participants with dementia enjoyed the dynamics of participating in mixed activities. The social interaction included evidence of good humour and laughter suggesting the significance of providing opportunities for social interaction amongst individuals with dementia. All the staff and tenants joined in the art activity and even the least able participants fed back that they really enjoyed the painting experience. There was a great deal of positive reinforcement from the staff and the visual artist which supported the tenants as they painted.

One member of staff enquired about how she could acquire paint and some silk to try out the new art skills with the other tenants from Mullan Mews who were not part of the project. This inquiry indicated the potential of participation in the project had for staff professional and personal development. Their willingness to try out a new art activity with the tenants despite their original reservations demonstrated that taking part in the project inspired and motivated them to rise to new challenges and consider developing new art activities delivered by them. This would suggest that basic creative training would be of value for healthcare staff. Elliott (2008) investigates the impact of a specific introductory contemporary dance training programme for nursing and care professionals in relation to personal and professional care development. The outcome of that study demonstrates and promotes the value of healthcare professionals undertaking basic creative training in the arts and facilitating arts-based activities for service-users within the context of their professional practice.

The workshop came to a close quite naturally with the brushes being cleaned, the paints put away and everyone admiring the silk painted sunflower that they all had contributed to creating. The smiles and

congratulatory conversations generated very positive feelings amongst the participants and visual artist. The following elements of the session experience were observed:

- A real willingness and desire by the group to learn and apply the different art skills
- High level of social engagement
- Artist's facilitation technique of visual stimulus accompanied by discussion and action led to deep engagement in the activity by the group

4.4.4 Session 4 – Dance/Drama

Dance

The stimulus for the dance in Session 4 focuses on the silk sunflower painting the group had finished the previous week. The participants are asked to re-call the content of the art class and the technique of tracing the autumn leaves followed by re-calling the shared painting of the large sunflower image on silk. With some prompting different members of the group are able to re-call certain elements of the art class. B. has no recollection of having taken part in the class or any memory of any part of the previous weeks' experience. W. and P. amongst others are able to re-call part of the previous sessions when showed the sunflower painting they created from the previous session. All of the facilitators employ the technique of re-visiting the material discussed and created by the tenants throughout the six sessions in an effort to assist memory re-call and this discussion focuses on re-calling from the previous session with the artists the five things that gave the tenants and staff pleasure at this stage of their life. A direct question and answer technique is employed.

Observation of the film data highlights the initial lack of response from the tenants to the questions. The lack of response, forward focus and vagueness of expression in some of the faces indicates the presence of dementia and the impact on ability to re-call recent experiences. It is obvious, however, that as the discussion progresses the sunflower image serves as a useful memory prop to assist the tenant participants to re-call certain elements of the previous sessions. The staff comments support this conclusion:

“I was really surprised today during the session to hear some of the tenants remember clearly parts of the previous workshops. Normally they have little or no re-call of the experiences they have had within their weekly activity programme at Mullan Mews. It's great to hear them chat things over like that. I definitely think the use of the art work they created and just revisiting stuff from previous classes really helped them remember” (*Staff Reflection*)

Warm-up

In order to try and further develop thoughts and considerations about getting older, including the sense of pleasures that older age might bring, a purple silk parachute is introduced as a stimulus during the dance warm-up. This parachute represents the heart of the sunflower and everyone seated around it represents the petals. The aim of the prop is to encourage a focused collective activity and to bring an awareness of others into the group activity. The first part of the warm-up employs a name game. The group is invited to lift the parachute up and look underneath and across to the other side. They are then instructed to call out the name of someone they can see and know. This exercise is to draw a sense of identity and community out of a shared creative activity.

Observation across all the sessions of facial expressions and engagement or disengagement of the eyes reveals at times a sense of withdrawal in the tenants with more advanced dementia during certain parts of the discussions involving re-call. The parachute is introduced as a prompt to encourage participation by all the tenants during the discussions. The film text reveals the high level of participation and social engagement experienced throughout the warm-up activity. Each individual staff and tenant participant contributes to the discussion around the parachute exercise. Space is given to individuals to consider the question offered and extended space is given where necessary for a response. Some of the comments on the experience of getting older and what brings pleasure from the group are refreshing:

- | | |
|---------------------------|--|
| <i>Drama Facilitator:</i> | Gain more confidence |
| <i>Staff Member:</i> | Try to be more positive |
| <i>Tenant:</i> | You are as young as you feel |
| <i>Tenant:</i> | I enjoy walking and reading |
| <i>Tenant:</i> | I have time to stand and stare |
| <i>Tenant:</i> | Walking through the countryside admiring the hedges, plants and trees |
| <i>Tenant:</i> | Hard to say. I really don't look at it as getting older. I enjoy how I am at the moment. It just doesn't appeal to me. I just don't think about it. I feel happy and enjoyable just being me and I feel fine |
| <i>Tenant:</i> | Singing and music |
| <i>Tenant:</i> | Going and doing something...What do you call them?...Bowls |

All the above comments confirm the importance of activity on well-being both from a singular perspective as in B.'s case reading and collective perspective as in V.'s response playing bowls. A.'s comment ("I feel happy and enjoyable just being me and I feel fine") is encouraging and confirms a strong sense of personhood.

Creative Skill-building and creating

The parachute activity is followed by re-calling the movement patterns from the previous sessions and building on them in preparation for the 'Sharing' with the invited audience in Session 6. Ja. appears happy to accompany and improvise during this part of the session with his accordion. The film text demonstrates an increased confidence in Ja.'s desire to play his accordion in public. The film data also demonstrates an increase in the staff's contribution during this part of the project revealing a growing confidence and ease in their level of participation.

Drama

Warm-up

The tenants are introduced to a drama activity linked with identifying moods. The challenge to the participants is to respond to the sound of a telephone ring as if answering the phone. The manner in which the response is delivered is a matter of participant choice. The group then have to try and interpret the mood based on the individual's response. Although some of the tenant-participants take extended time to fully comprehend the concept and instructions, the film data clearly demonstrates the tenants' eventual ability to listen and follow the facilitator's instructions. The moods in the tenant's responses include happy, seductive, inquiring and annoyed. P. in particular responds to the drama activity in a very animated way which makes the rest of the group react with laughter and a great deal of enjoyment. This activity shifts between individual and collective experience.

Skill-building and creating

The warm-up activity is then further developed into a short sketch that consists of the six following short lines:

1. "I've been coming here for years."
2. "Years and years."
1. "I was happy then."

2. “So was I”.
1. “Goodbye.”
2. “Goodbye.”

Members of the group are invited to role play the short sequence. One of the drama facilitators goes around the circle with a few of the group exploring the lines. The other drama facilitator invites Ja. and Ju. to interpret the sketch in their individual way. Ja. and Ju. add their own words when they forget their lines, improvising the role play and adding their sense of humour to the content of the sketch. The drama facilitator encourages Ja. and Ju. to inject feelings into the sketch. The suggestion of feelings weaving into the sketch prompts a discussion within the group as to why Ja. and Ju. may have met and had this conversation. Someone suggests that perhaps the couple had been sweethearts. B. suggests that the happier times may have been when they were single. The group’s ability to generate humour and meaningful social exchanges followed by laughter and comments from the group demonstrates the contribution that drama as an activity can make in encouraging discussion and decision-making processes in populations with dementia.

Summary of Session 4

Session 4 demonstrated the development of the creative theme and the threading of meaning through the sessions. The film data indicates an increase in confidence within the group with P. and Ju. becoming more engaged with the art activities as the sessions develop over the project duration. There was a sense of social cohesion in the group during this session and increased levels of social interaction amongst the participants across the four sessions. The participants responded well to the development of the theme ‘Forever Growing’ and it was apparent in this session that the tenants had grasped the concepts of using the sunflower and garden as a metaphor through which they further developed their ideas and expressions of what it was to grow older. The film data indicates that although there were moments of hesitancy when some tenants with more severe dementia appeared to struggle to understand and consider aspects of the discussion and the development of the sketch, all the participants remained highly engaged with both the dance and drama. This would indicate that arts participation contributes something of value in relation to enhancing the tenants’ quality of life across the different stages of the dementia experience.

4.4.5 Session 5 – Art/Drama

Art

Session 5’s art activity centres on the tenant-participants developing their skills of outlining, sketching and painting. The visual artist in her reflections on the previous art sessions noted the importance of

recognising and honouring individuals' need for personal space whilst involved in the art activities. She commented on the withdrawal of one of the tenant-participants during the previous session and also registered slight discomfort in one of the other male tenants during the shared painting of the large silk sunflower. The visual artist manages and respects this need for extended space during Session 5 by accommodating the painting activity on smaller tables of four instead of the two longer tables of twelve as in the previous session. The heightened sense of awareness during her facilitation of the art activity highlights the artist's expertise and sensitivity in deploying the art activity towards the participants' needs.

The tenant and staff participants outline cardboard flower patterns and then proceeded to paint them. The film data shows that this activity appears to help tenants' concentration and skill-building. The film-maker's lens focuses on close-up shots of hands and faces to provide evidence of the tenants' increasing dexterity in the use of the pencils and paintbrushes as well as the choice of colour and application of the paint. The close-up of tenant-participants' faces shows the high level of concentration employed by the tenant-participants during the art activity.

The flowers produced during this session consist of many individual shapes, colours and sizes and are highly personalised by the tenant-participants. The ability by the tenants to choose and place colours and shapes indicate how the art activity contributes to the notions of personhood and individualism explored in Section 2 (Killick & Allan 2001). The individual flowers are later laminated and used to create a "garden mobile" (*see photograph on page 15*).

Drama

The drama facilitator introduces the drama session by exploring the "movement" of words in a poem. He invites the tenant-participants to play around with movement words such as "swirling" attempting to interpret the movement of the word through the manipulation of their voice and interpretation through playing the chime bars. All of the participants join in this activity and there is a high level of interaction and response to the tasks.

Each of the tenants is given a copy of a poem and invited to focus on the following:

- Magic of the words
- Movement of the words
- Rhythm of the words
- Expression of the words

The drama facilitator invites B. to read the poem. The film data shows her delight at reading out loud. She is offered support from all the other participants as she is encouraged to read it again and make it her own. The other tenants accompany her, interpreting the movement words with their own improvised sounds on the chime bars. Ja. offers to improvise and interpret the words on his accordion. The scanning of the camera across the tenant faces captures the delight and enjoyment in this activity.

On completion of the session Ja. offers to recite and sing a humorous poem. He stands with confidence in front of the rest of the group and is supported by a few stray voices and laughter. Everyone claps him at the end and the sense of achievement is obvious from the smile on his face and from the strong upright stance of his body in comparison to Session 1 where Ja. slowly enters the music session with his focus down seemingly quite isolated.

Summary of Session 5

Comparisons of the film data from Session 1 to Session 5 demonstrate a positive shift in levels of self-confidence and social interaction amongst all the participants including staff. The individual personalities come to the fore and there is a sense of familiarity and bonding in the group at this stage of the project resulting in increased cohesion amongst the tenant and staff participants. The participants responded well to the development of the theme 'Forever Growing' and it was apparent in this session that the majority of tenants had grasped the concepts of using the sunflower and garden as a metaphor through which they further developed their ideas and expressions of what it was to grow older.

The film data confirms that although there appeared at times moments of hesitancy when some tenants with more severe dementia appeared to struggle to understand, all the participants remained highly engaged with both the dance and drama. From this can be seen the value of the arts activity in enhancing the tenants' well-being and quality of life across the different stages of dementia experience.

4.4.6 Session 6 – 'The Sharing'

It was deemed important by the participants, host-centre manager and facilitators that the material processed during the previous five sessions should be showcased to the non-participating tenants, family and friends. The tenants from Mullan Mews and Sydenham Court came together in the morning to 'rehearse' for the 'Sharing' which took place in front of the small invited audience that included tenants' family, friends and visitors from the Centre for Excellence in Interprofessional

Education. The ‘Sharing’ consisted of the tenants performing short extracts of the dance, drama and music work they had created over the previous five sessions. It also included an exhibition of the finished silk painted art work of the large sunflower, the original leaf sketches and the garden mobile.

As in previous sessions the tenants have some difficulty in remembering the material from the previous week. All the facilitators begin to recall the material with the tenants using the visual prompts as before and then set to work on pulling it all together in the form of an interactive performance. B. demonstrates great difficulty in recollecting any of the material. She is only able to deal with the material as she encounters it in the present. B.’s challenge to re-call the material could have caused her to be anxious but the rehearsal becomes an opportunity for fun when the other tenants joined in to support her. There is a lot of laughter and in some cases bemusement on behalf of the tenants as the facilitators work their way through the previous sessions’ material with them.

The ‘Sharing’ includes elements of all the art forms – dance, visual art, drama and music. The ‘Sharing’ is perceived by the participating artists as the product of the five process sessions, although an end-product is also an important part of the process that gives rise to it. It focuses on the theme of the sunflower and the ‘Forever Growing’ concept to produce live guided material for the audience to experience. The physical appearance of the silk painted sunflower image with its bright colour continues throughout the ‘Sharing’ to be a strong linking symbol. The staff have brought in fresh sunflowers which mirror the sunflowers present in the art work and dance and those visible in Sydenham Court’s garden. The tenants respond well to the live performance directions at every level from understanding the connection of the sunflower with sunlight and life to a feeling of happiness from the jolliness of the physicality of the flower and creative expression for the audience. All of the art forms reflect this theme at some level.

Facilitating and managing the live ‘Sharing’ involving staff and tenant participants

Art

The visual artist initiates the ‘Sharing’ by relating to the audience the processes she and the tenants engaged with in creating the art work and introduces an exhibition of leaf sketches, a silk painting and a “garden” mobile hanging with different flowers painted and created by the tenants. All of the art work reflects the commitment of each of the tenants to create something of beauty and value that holds personal meaning to them. The tenants are extremely proud of their art work and comment on how much they have enjoyed working on one large painting together. They describe it as a very sociable activity which made them feel more part of the group.

“I loved working on the big sunflower. We did it all together. It was great fun and I liked meeting up with the others from the other centre.” (*Sydenham Court Tenant*)

Music

Although the facilitating musician could not attend the ‘Sharing’, the drama and dance facilitators build on the music work accomplished by the tenants in Session 1. An interpretation of the music experience in Session 1 is presented with the final dance and drama work. A soundscape of wind and rain falling on the seeds is created building on the musical skills the tenants have developed with the musician using the chime bars and the sounds they created with their hands. The dance facilitator guides all the participants through an improvised sound piece using words and body gestures to direct the live music performance.

Drama 1

B., one of the tenants, follows the music interpretation with a poem about music and dance. The poem also includes the use of the chime bars led by the other tenants and staff connecting sounds with words.

Dance

After three verses of the poem all the tenants accompanied by staff share their dance piece with the audience. This short piece has been inspired by the image of the sunflower. The group sit in a circle and create the head of the sunflower, moving from the scattering of seeds to the flower bursting through the ground. The tenants then form small groups standing with the staff and begin to create images of the flower growing up and the leaves moving from side to side, rising up to the sky and out to the sides. The dance facilitator, artist and drama facilitators all dance together with the staff and tenant-participants.

The groups then work on shapes representing connection and support. These are represented through a series of still images. The dance finally concludes with a trio in the middle of the performance space. This involves and represents the working relationship of the health professional, tenant and artist, negotiated as a live text in front of the audience. O. as the central dancer in the trio again holds the core position of strength in the middle of the dance piece. The trio further develop through improvisation concepts of support and connection, with all three dancers intertwining and connecting through a series of shapes. The dance work concludes movingly with B. completing the last verse of the poem.

Drama 2

The Drama begins with a short sketch involving three of the tenants. The purpose is to engage the audience in guessing “What was in the Box”. The tenants read from their scripts and the audience offer their suggestions. What was that smelly thing in the box? ... “Gorgonzola Cheese” shouts a member of the audience. Everyone laughs! The interactive element of the drama piece is enjoyed by both audience and the participants.

Drama 3

The last drama piece is the sketch previously created on the theme of ‘family’. Several of the tenants represent characters such as the mother, father, daughter, cat, son and his girlfriend as created and rehearsed in Session 2. This short sketch has an element of comedy about it and again the audience appears totally engaged with the creative material as are the tenants. One of the drama facilitators directs the piece live with performers improvising when necessary.

H. also read out one of her poems supported by a visiting student as part of the ‘Sharing’. The film data again provides evidence of the importance of delivering a creative product for people with dementia in terms of personal achievement. The film recording of H. saying her poem and her delight in the audience response underlines the importance of creative expression in relation to well-being in older populations.

The ‘Sharing’ comes to a close with the tenants receiving a certificate of participation from the Centre for Excellence in Interprofessional Education, Queen’s University. The certificates are much appreciated by the tenants and H. comments that her son would really be surprised at her receiving a certificate from Queen’s University, illustrating the value of providing life-long learning programmes for older populations including those with advanced dementia. H. becomes quite emotional and sheds a few tears. Her sense of achievement is obviously very real and meaningful for her.

Summary of the ‘Sharing’

The film data offers the viewer an opportunity to witness the development of the project as it happens in the present tense. Certain elements of the product were presented as rehearsed elements derived from the project process. The overall experience of the ‘Sharing’ with the audience was, however, presented very much in the ‘present’ or the ‘now moment’ as the tenants produced the creative work under the live direction of the dance/drama facilitators. The dance facilitator directed and danced with the tenants and the staff in the ‘Sharing’ dance pieces and the drama unfolded under the live direction of the drama facilitator. Most of the tenants showed an ability to re-call some of the performance

material and on those occasions when they failed to remember they were closely directed live by the facilitators.

This live direction was particularly apparent in B.'s poem. Although B. had rehearsed the poem several times just before the 'Sharing', she was unable in the present moment to re-call any of that rehearsed experience. Nor did she remember that she was going to perform for the audience. This was obvious from the comment she made to an audience member as she sat amongst them waiting for something to happen:

B.: I don't know what is going on here. Do you? (*Question directed at an audience member*).

Drama Facil.: B., it is time for you to read your poem now for the audience.

B.: Who me? Oh, I didn't know I was to do that. What do you want me to do?

The drama facilitator gave B. the poem and invited her to read it to the audience as if for the first time which she was very happy to do. B. delivered her words with expression and sensitivity, following the directions of the drama facilitator. The audience clapped and B. was extremely pleased confirming the significance of the product/performance in the very present moment in terms of well-being and achievement. The film data shows B.'s sense of achievement from the smile on her face and the feedback from her family members who attended the 'Sharing'.

The film record demonstrates that the method of facilitation employed by the artists across all three art forms for the 'Sharing' was professional and supportive, enabling the tenant-participants with the assistance of the staff and artists to showcase the creative products they developed over the six sessions. The success of the 'Sharing' experience dispelled the staff's initial concern that the tenants would be unable to showcase any of the performance work because they would not remember the material and would be placed in a vulnerable and risk laden situation. The artists' live reflections bear witness to the very real consideration of all the elements and potential risks of the project including the 'Sharing' in Session 6.

4.5 The role and expertise of the artist

A key reflection to emerge from the artists' commentary was concerned with how the individual artist structured and facilitated their sessions. All the artists implemented a community/educational art-based model of engagement that focused on skill-building, creative exploration and self-expression.

An art therapy model of arts facilitation adhering to a medical model of art engagement and outcome was not employed within the study.



All of the artists commented on how they implemented similar frameworks of facilitation adapting the content where necessary to accommodate the needs of individuals within the group. The data reveals that the adaptation with this group of older people with dementia centred on an increased use of repetition to generate and support memory re-call accompanied by the use of props such as the sunflower painting and images of gardens. The consideration and ability to adapt to certain individual or group needs demonstrated the level of practice expertise amongst the artists in facilitating art-based activity with older people with dementia. The musician in her reflections highlights how she adhered to an educational model of facilitation with the study participants. She underlines that she uses the same framework with the study group as she would use with other community groups such as children and professional musicians.

“So I suppose my views of the session this morning are that they are so able, they’re just like any other group. You just tailor things to meet their needs. But definitely myself as a creative person I always use the same starting points, you know, the

warm-ups, the things with feet – so I would do that whether I was working with kids or a session with professional musicians...That group are capable of doing anything if they get the opportunity just like any centre, whether it's residential care or supported housing if they can get a group of people together.”

One of drama facilitators reflects on the importance of “creating an atmosphere that inspires confidence from the beginning of the class,” and that failure to do so by the facilitator results in an unsatisfactory experience for the facilitator and the participants.

All the artists reflected on the value of acknowledging, drawing on and utilising the older people's life experience within creative exploration and skill-building. The acknowledgement of the participants' life experience was deemed significant within the artist's facilitation process in that it placed value on the individual's lives recognizing their meaningful contribution to the art activity.

“A group like this is fabulous from my point of view. You have two ladies who were teachers. I could tell just from how they held their pencils, when they were doing their sketches...they had an ease and they had done it before. So that's quite beautiful.” (*Art Facilitator*)

Reflections relating to the contribution of the artist were also offered by members of staff and the unit manager. The staff member from Mullan Mews Supported Housing Unit reflected that working with the artists inspired her to try “something different and arty” with the tenants under her care. She related how the artist's practice offered her new ideas and skills that she was keen to utilise within her work environment. She inquired from the arts facilitator where she would be able to purchase the materials and how she could develop her creative skills further. She also commented on how participating in the project and gathering fresh ideas to use with the tenants motivated her within her workplace. The unit manager's reflections supported this experience in relation to staff's desire for professional development. She reflected that since the beginning of the study the staff reported that they were inspired by observing the artists facilitate the sessions and sought to develop their own creative skills post project so that they could enhance their activity programmes with the tenants. These reflections demonstrate the value of the artists' skills and expertise in relation to contributing to existing programmes of healthcare, professional care development of staff and the tenants' overall well-being.

5. FINDINGS

Four key themes emerged each with a number of sub-themes from analysis of the film and reflective data (*Table 1*). In addition there was evidence that the sensitively filmed video recording proved to be an effective means of collecting data relating to the phenomenological impact of the project.

Table 1: Emergent themes and sub-themes

Theme	Sub theme(s)
Life-long Learning	Collective and individual learning experiences, skill development
Relationships	Impact on participants and artists, personhood, communication,
Memory	Embodied memory, ‘in-the-moment’
Well-being	Positive feelings, absence of distress, ability and desire to engage socially, mobility

5.1 Life-long Learning

The tenant-participants who participated were observed to engage in discussion, skill-building and improvisation. This finding was supported by comments from staff participants who remarked on the tenants’ ability to pick up on conversations and contribute to discussions. Film data indicated that the programme awakened participants’ memory of, and ability to engage with, the different art forms and provided them with a new set of tools through which to express their feelings, desires and aspirations as older people with dementia. Other evidence of learning included the tenant-participants acting with purpose and concentrating on the creative tasks as illustrated in the art session. Memory re-call was prompted by the use of props to generate discussion and film data clearly demonstrated the role of props such as the silk parachute, photographs of gardens and the older people’s collaborative sunflower art work as important stimuli in shared, knowledge-building discussions.

5.2 Relationships

5.2.1 Relationships: Impact on participants and artists

The film text provided evidence of the development of a respectful creative relationship between the older people; between the older people and their carers; between the artists and all participants. There is also evidence that on completion of the programme staff had a clearer understanding of the benefits of participatory arts in relation to enhancing the quality of life for older people with dementia.

“I never really thought that taking part in an arts programme could offer something educational for the tenants or even me for that matter but I can see quite clearly now that all of us have learned something new by being part of this. It just shows you that you can still learn no matter what your age or even your ability.” (*Staff Member*)

5.2.2 *Relationships: Personhood*

The data revealed that concepts of participant individualism and autonomy were celebrated and encouraged (Killick & Allan, 2001). These concepts of personhood were facilitated through a creative learning experience that was immediate, sensory and personal. The framework of facilitation employed by the study appeared to nurture notions of individualism by reinforcing the independent creative contributions of each of the older people and carer participants during the different art sessions. The way in which the artists promoted and respected the concept of personhood was particularly evident in one art activity session where some of the older people rediscovered art skills and in the group dance activity where the musical skills of one of the older people were reawakened. During the first dance session (Ja) played his accordion for the first time in forty years despite the presence of Parkinson’s disease and moderate dementia.

5.2.3 *Communication*

The film text provided evidence of positive communication experiences in all arts activities which contributed to the development of meaningful creative relationships for tenant and carer participants. This was encouraged by the artist facilitation methods employed in the project and examples can be found in:

- The development of the “Chime Bar Orchestra (Session 1)
- Physical connection and travel through physical spaces in the dance (Session 2)
- The Family ‘Image Theatre’ exercise (Session 2)

5.3 Memory

5.3.1 *Memory: Embodied Memory*

The intensity of the arts activities contributed to recall of certain key ideas and the repetitive use of the creative tools appeared to assist memory re-call of the tenant-participants from one session to the next: *Music* – rhythm, rhyme and song; *Dance* - repetitive movement patterns; use of props such as a silk parachute; *Art* - shapes, colours, familiar images; *Drama* - word repetition, rhyme, poetry and movement.

Data indicated that sensory-based activities such as art, music, drama and dance have an important role in aiding memory re-call in older people with dementia. These performance art activities were found to induce memory re-call through sensory exploration and achievement particularly in the various developmental stages of the dance sequences.

5.3.2 Memory: In-the-moment

Positive evidence emerged throughout the data of the tenant-participants' ability to enjoy a series of in-the-moment experiences in all of the art forms. Although many of the tenant-participants who participated had severe loss of short-term memory and their sense of enjoyment and achievement registered only as momentary, both facial expressions and behaviour indicated that these in-the-moment experiences had a lasting significance.

An example of the enjoyment experienced by the tenant-participants with severe reduced cognitive ability is the moment when B. reads a poem out loud with expression. This experience provides her with a sense of personhood and achievement. However due to the severity of the loss of her short term memory the sense of personhood and achievement only happens in the moment as she is unable a few minutes later to re-call having read the poem or even attending the group activity. B.'s smiles and open facial expressions however throughout and post reading task indicate the significance and enjoyment of this in-the-moment experience in terms of her well-being. Such evidence indicates the need for artist-facilitators and tenant-participants alike to respond to such moments of experience as being of value in inducing enhanced senses of well-being amongst older people with dementia.

5.4 Well Being

5.4.1. Well-being: positive feelings

The presence of positive body language and facial expression in the film data indicated a sense of well-being experienced by the tenant-participants which was found in all of the different arts sessions and the artist-facilitators frequently referred to the presence of a positive "atmosphere." The sense of well-being extended to all the centre staff who demonstrated and reported a strong vicarious pleasure and satisfaction in the tenant-participants enjoyment of the process. The staff also reported that their own participation in the different art sessions gave them an opportunity to relax and personally enjoy learning new creative skills within their work environment. Staff perceived this participatory experience as inducing an enhanced sense of personal well-being resulting in an increased motivation in the development of their professional practice.



5.4.2. Well being: absence of distress

The film data revealed evidence of pleasure expressed by the older people in all sessions (for example laughter and smiling) and there was no evidence of distress present in the older people who participated at any stage.

5.4.3. Well-being: ability and desire to engage socially

Film data revealed how participation in the programme prompted a desire in the tenant-participants, whatever the level of dementia, to engage socially with the staff and each other. The increased ability of the tenant-participants to focus, question and respond within the group interactions indicated increased levels of ability to socially engage. The continued commitment of the older people to participate in the programme, with only an occasional withdrawal, was also a strong indicator of the high level of engagement and to the presence of well-being for the participants.

5.4.4 Well-being: mobility

Data provided evidence of increased levels of mobility in the tenant-participants. Staff noted the reduction in the use of mobility aids by two of the older people during the dance/drama sessions suggesting that the physical learning structure employed in these sessions was valuable in supporting and encouraging independent movement by individuals. The findings suggested that the contribution of the dance and drama activities increased stability and contributed to increased levels of physical fitness of the older people who participated.

Table 2 tracks samples of individual tenant-participant's experience of the Arts in Health Project from observation of the level of dementia present through the art experience to reported presence of indicators of well-being as identified by the staff/ unit manager/researchers. The table demonstrates the potential of arts participation to enhance levels of well-being amongst older people living with different levels of dementia.

Table 2: Indicative samples of significant experiences that impacted on participants’ well-being
drawn from reflections and film data

Name	Levels of dementia and observations	Elements of positive experience of art-based activities	Indicators of well-being identified in-the-moment of the experience
“B”	Advanced dementia <ul style="list-style-type: none"> Severe cognitive impairment No immediate recall ability present 	Drama-“B” read a poem out loud	<i>smiles;</i> <i>laughter;</i> <i>socially engaged</i>
“H”	Advanced dementia <ul style="list-style-type: none"> Aged over 90 years old Reluctant at times to join in on existing general activity programme 	Dance-“H” offered suggestion of the blue accordion box having a squirrel inside followed by a mime of the squirrel’s movement.	<i>laughter;</i> <i>rolling her eyes up;</i> <i>shrugging her shoulders;</i> <i>positive verbal feedback;</i> <i>socially engaged</i>
“Ir”	Advanced dementia <ul style="list-style-type: none"> Seldom socially engages Is initially withdrawn within the group Seldom makes eye contact with other 	Drama- “Ir” contributed to the family drama discussion offering coherent and meaningful suggestions	<i>smiles;</i> <i>laughter;</i> <i>socially engaged;</i> <i>made eye contact with others</i>
“Ja”	Moderate dementia <ul style="list-style-type: none"> Presence of Parkinson’s disease 	Dance-“Ja” played his accordion for the first time in forty years during the dance session despite his failing memory and the presence of Parkinson’s disease	<i>smiles;</i> <i>laughter;</i> <i>tears;</i> <i>positive verbal feedback to group of the positive impact of playing the accordion after such a long time</i>
“O”	Advanced dementia <ul style="list-style-type: none"> Presents at time with behaviour that can be challenging 	Art-“O” reported experiencing a re-awakening of existing embodied physical art skills from her former teaching career e.g. mastering the skills of holding a paint brush and of applying paint and sketching	<i>verbal expression of achievement and high level of enjoyment;</i> <i>smiles;</i> <i>laughter;</i> <i>high level of social engagement</i>

6. DISCUSSION

6.1 The body of evidence generated through this study strongly supports the case for the provision of life-long learning opportunities for older people with dementia in residential and supported care environments. An in-depth trawl of the data has provided a series of individual storylines that highlight the educational journey of each of the tenant-participants and the staff-participants who care for them. Elements of the storylines revealed throughout the analytical process offered insight into the significant impact of the arts programme on relationship, educational development and well-being, linking positively with growth and change in older age. The evidence from these storylines gained strength from the development of a documentary-style film text that has proved successful in capturing and translating the live experience of the project participants into a supportive text that goes beyond the written word. The study experience raises some important issues for further consideration and debate with regard to the use of evaluative film documentary as a valid text for publication and dissemination purposes. A series of ethical protocols relating to the film recording of participant experience and dissemination of subsequent findings specifically researched and designed for this study represent valuable additional resources.

6.2 The project offers an opportunity for changing perceptions of what Arts-in-Health engagement means for older people in residential and supported care. The employment of participation in arts activities as facilitated within this study steer away from traditional models of art/music/dance therapy where the participant is perceived as a “patient” to identify the participant as a “student” who avails of a life-long learning experience. Table 2 (above) links the individual to their personal experience of the arts-based activity and the resulting impact on their well-being.

6.3 It is anticipated that the evidence and model of arts engagement presented in this study will contribute to the evolving evidence-base of the impact of the non-therapeutic models of Arts-in-Health increasingly deployed within healthcare residential care settings. As can be seen from Section 2 of this report, there has been much discussion of arts practice within health settings from a therapeutic context, but even in these cases the intrinsic value of and “art for art’s sake” approach is often acknowledged. Rentz (2002), for instance, concludes her analysis by noting that “individuals and families... are very enthusiastic about the program because they observe and then feel the immediate effects of the artists’ creative and pleasurable experience”. Following Thompson (2009) we might also read “affects” for “effects”. The embodied ‘live’ creative, practice-based approach on which this study is founded reflects the importance of understanding the experiential nature of the work and the phenomenographic nature of the data indicates the importance to the study’s conclusions of critically assimilating the full range of participant perspectives. The findings are informed equally by the observations and comments of tenants and staff in the host supported housing centres and of

the participating artists who all acknowledge the programme's educational benefits. For these reasons, the study locates itself within the framework of lifelong learning.



6.4 The position argued by Nicholson (2005: 149), a leading proponent of applied drama, that access to creativity is a human right also chimes well with the current project. Her emphasis on *narrative* is consistent with the approach taken to the analysis of each session which includes detailed references to individual experience. While it can be seen that artists and staff also gained new insights into their working practices and new life skills, it is the careful questioning by P., the life experiences of O. and B., the courage of Ja. and the digressions of Ju., the ingenuity of Ir. and the exuberance of H. which are at the heart of the data. Some general practical principles can be extrapolated from the data, such as:

- the importance of responding flexibly to the available space to create the best environment for creativity
- the value of time limited projects as distinct from routine provision
- and the opportunity to provide basic arts training for care workers

But it is the individuality of the findings that are central to this study. Rather than seeking to generalise from these individual experiences, the very diversity of the participants' response is its most revealing aspect. The capacity of arts activities to stimulate autonomy and individual decision making within a social context are central to their effect and affect.

6.5 Individual benefits, however, are magnified when viewed in a more collective context. One of the most prominent benefits of the study experienced by both tenant and staff participants related to the contribution of arts provision to community building and cohesion within the context of supported housing. Evidence derived from the unit manager and staff reflections in particular demonstrates that the provision of arts activities may contribute through positive community development to the management of wider risks of isolation and depression as often found in populations with dementia (Hadfield 2001).

6.6 The study also acknowledges the role and value of the facilitating artists' expertise in the deployment of arts in health within the context of residential supported care. The in-depth exploration and mapping of how the artists deliver and evaluate experience through their craft within the project sessions provides valuable insight into the development of a best practice framework that maximises the educational and relationship opportunities for participants either availing of or working in healthcare services. The study findings support the value of the community model of arts employed by the individual artists in this study.

6.7 The progression traced in Section 2 from Qualitative Research to Arts-based Research to Life-long Learning provides a template for understanding the logic of the overall project. The film data provides telling phenomenological evidence of the reaction of participating tenants and staff to the programme of arts activities and this is reinforced and complemented by the facilitators' artistic response to their own experience of the programme. The film documentation offers a means of disseminating these arts-based outputs. And the film documentary itself will allow students and conference delegates to experience both the arts activities and the artists' response to them at first hand.

6.8 To conclude, the project set out to investigate the potential benefits of arts activities for older people with dementia and practical means of delivering these. The findings of the project confirm these benefits in relation to the tenants of the innovative supported housing centres from which the participants were drawn. Specific practical considerations in relation to space, timing and staff training are also recorded here. We look forward to the opportunity to widen the scope of this research to include more conventional care settings.



7. RECOMMENDATIONS

1. Resources and mechanisms should be put in place to enable the development and delivery of programmes which include a range of arts-based activities for older people with dementia in residential care.
2. Arts-based activities should be developed and delivered as a creative programme of activities so that they represent a departure from routine interventions offered within residential care facilities.
3. Tenants and their carers should be enabled to work as partners with the artists facilitating the programmes.
4. Further research using an embodied 'live' creative, practice-based (as distinct from therapeutic) approach should be undertaken with older people with dementia in a wider range of residential contexts.
5. The importance of film as a research tool should be recognised and further research undertaken to substantiate this.

8. REFERENCES:

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Appendix 1: PROTOCOLS

The Protocol outlining the role and responsibilities of the professional carers participating in the Creative Ageing Arts in Health Study for Older People with Dementia

Title of the Project: Changing Ageing Partnership: A Practical Exploration of the Arts in the Healthcare of Older People

Outline of the Role and Responsibility of the Professional Carer

The primary role of the professional carer within the study is to ensure the well-being of the service user participants with dementia as they participate in a series of arts-based sessions. The well-being of the service users will be given priority over the aims and objectives of the study.

The professional carer participating in the study will be selected by their unit managers prior to the study. The carers will then be invited to volunteer and offer their written consent to participate with the service users in the introductory session and all of the subsequent six ninety-minute art/drama/music/dance study sessions. If the carer declines to offer consent to participate in the Arts in Health study they will be assured by their manager that their professional position will in no way be compromised by their decision. A knowledge or training in delivery of arts activities in health would be appreciated but is not necessary.

The outline of the role and responsibilities of the professional carer volunteering to participate in the Creative Ageing Research Project are as follows:

Role and responsibilities prior to the study

- Must be employed by Belfast Health and Social Care Trust as a professional carer in either Mullen Mews or Sydenam Court Supported Housing Units
- Have extensive training and knowledge of Dementia Care within their role as professional carer
- Participate in existing weekly activity programmes with the service users within either of the before-mentioned supported housing units
- Must have established positive relationship with and have an in-depth knowledge of those service users consenting to participate in the Arts in Health Study
- Will attend preliminary meeting with artists, film-maker and researchers to gain understanding of each other's role and responsibilities within the study. Particular attention will be given to the role of the professional carer in gaining initial written consent and process consent from individual service users and the management of potential distress and well-being within the service user experience

Role and responsibilities during introductory and six art-based sessions

- The professional carer will attend the introductory art session and will assist Dr Elliott explain to the individual service users and their family member (if present) what participation in the Arts in Health study will involve for the service user. This will include an explanation to the service user of the consent procedure involving written and process consent (see Protocol on Process Consent).
- The professional carer will then assist Dr Elliott to gain the initial written consent from each service user through a short individual interview and signature process during this

session. The interview will also offer an appropriate explanation to the service user and their family member informing them what process consent means and will involve. This will include how process consent will be obtained before and after the six art sessions during the study (see Protocol on Process Consent)

- It is the responsibility of the professional carer to assist the researcher in ensuring process consent is fully understood and verbally obtained from the participating service users during each of the art sessions. The artists will explain the aim, content and the service user involvement to the participating group. The researcher will then seek to obtain consent with assistance of carer (see Protocol on Ensuring Process Consent).
- If service user declines consent at any time prior to or during the art sessions the professional carer will assist in escorting the service user back to a safe space or their accommodation (either in Sydenham Court or Mullan Mews) with immediate effect
- If the service user becomes distressed at any time during the workshops the professional carer will request that filming is halted and if necessary the art session with immediate effect. The artists and filmmaker will support this decision (see Protocol on Service User Distress)
- Initial assistance and re-assurance will be offered by the carer to the distressed service user within the session, with the support of the facilitating artist. However if it is deemed necessary by the carer following assessment of distress, then the service user will be escorted with immediate effect to their accommodation and the carer will remain with the service user offering continued support and re-assurance (see Protocol on Service User Distress)
- The professional carer will assure the service user that their professional care will be in no way compromised by their withdrawal from the individual art session or study.
- It is the professional carer's responsibility to report and record the service user's distress as experienced within the art session to the Unit Manager (see Protocol on Service User Distress)
- The carer will maximise service user's experience of the art workshops by offering if necessary to assist them with artist support to:
 1. Use basic musical instruments
 2. Develop creative themes
 3. Use basic art materials and develop art work
 4. Create basic dance moves
 5. Develop basic drama work

Please note: If service user offers any information which the professional carer feels requires onward reporting such as disclosure of any risk, potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on the care provision they will be obliged to pass this information on to the unit manager/ medical staff or relevant nursing staff (see Onward Reporting Protocol).

Protocol Outlining Ensuring Process Consent in Older People with Dementia agreeing to participate in the Creative Ageing Research Arts in Health Research Project

Title of the Project: Changing Ageing Partnership: A Practical Exploration of the Arts in the Healthcare of Older People

The intention of employing process consent is to seek, maintain and ensure the consent of older people with dementia as they participate in six specific art sessions within the Arts in Health study. The aim is to protect the service users' best interests whilst participating in the specific art activities (Dewing 2002).

Ensuring Process Consent

The protocol content draws on the methodology and practice of past studies that have involved and explored the issues and challenges of ensuring process consent in older people with dementia (Dewing 2002, Dewing 2007, Knight 2005). The decision to implement "verbal" process consent in relation to respecting service users' creative experience within the study is informed by a verbal process consent methodology developed specifically for a group of service users with enduring brain injury (Elliott 2008).

- The protocol ensuring process consent is based on the premise that all the service users with dementia agreeing initially to participate in the arts in health study will have the capacity with the support of their carer to understand, participate in and offer their consent to participate in the series of six specific art sessions. The ability of the service users to give consent to participate will be assessed by the respective multi-disciplinary teams at Sydenham Court and Mullen Mews.
- The process consent procedure employed by the study will place the service user with dementia at the centre of the decision-making processes with regard to their specific situational consent to participate (Dewing 2007).
- Process consent will be ensured by the implementing the following practice at the beginning and end of each art session:
 1. Facilitating and concluding the arts activity in a safe familiar space where the service users will feel comfortable and where process consent can take best place
 2. Process consent will be sought only in the presence of a professional carer who knows the service user/service users well
 3. At the beginning and end of the individual art session service users will be seated in a small circle for process consent to take place.
 4. The carers, artists and researcher will be present and placed specifically within the circle to ensure that support can be offered to individual service users during the process consent procedure
 5. All the service users offering process consent will be at all times visible and able to be heard by the researcher, artists and carers
 6. The facilitating artist at the beginning of the specific art session will talk directly to the group of service users offering a short simple explanation of what will happen and what they will be doing during the art session.

7. The service users will be informed whether or not the specific session will be video recorded. A simple explanation will be offered with regard to the recording procedure.
8. The service users will have an opportunity to ask questions or express concerns before offering their verbal consent
9. The service users will be re-assured that all information gathered during the session will be dealt with confidentially.
10. The researcher will ask the following simple direct questions to the service users:
Beg. of session-“Do you fully understand what you will be doing in this art session?”
 a) Do you agree to participate in this art session as part of the study?”
 b) Are you happy to offer your consent to take part?
End of session-“All the information that we have collected about what you have been doing during the session today will be kept and examined for the purpose of the study. Do you fully understand and are you happy to give your consent for the researchers to use this information for the study?”
11. The expectation will be that the service user will offer a simple verbal response of “yes” or “no”.
12. The expertise of the carers will be drawn on throughout the process consent procedure to ensure that consent is secured or otherwise.
13. If the service user appears not to fully understand the simple explanation or question procedure, the carers seated in the circle and known to the service users will if necessary employ a face to face encounter with them engaging in a meaningful way to observe and interpret their facial, bodily and verbal communications (Kitwood and Benson 1995, See also Protocol on Service Users Distress).
14. An assessment of the service user response to the face to face encounter will be interpreted by the carer and acted on. If necessary the carer will confirm whether or not in their opinion the service user has agreed or denied consent to participate.
15. If an uncertainty exists following the carer’s observations with regard to the service user’s ability to consent, the service user will be reassured and escorted back to their accommodation by the carer and will not participate in the specific art session. Service user will also be re-assured that non-consent will in no way compromise their standard of care.
16. If service users indicate that they fully understand and agree to participate in the specific art session then consent will be secured verbally from each of the service users with the support of their carers.
17. Where participants may not adequately understand verbal explanations or have special communication needs, the necessary assistance will be provided. Where an interpreter or assistance in communication is required, provision will be made.
18. The researcher will record the date and time process consent was obtained at the beginning and end of each art session in the study diary.

The protocol will be implemented with the intention of placing the service user with dementia in a central decision and consent making process as they participate in the study thus encouraging autonomy and independence (McCormack 2003).

Dewing, J. (2002) From Ritual to Relationship: a person-centred approach to consent in qualitative research with older people who have a dementia- *Dementia: The International Journal of Social Research and Practice* 1 (2) 156-171.

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The Protocol for dealing with service user distress during participation in the Creative Ageing Arts in Health study

Title of the Project: Changing Ageing Partnership: A Practical Exploration of the Arts in the Healthcare of Older People

The unit manager of Sydenham Court and Mullan Mews, Ms Nora Mallon has advised on devising aspects of the following protocol relating to management of distress and ill-being within the study. The following protocol will be employed to reduce and manage potential levels of distress amongst service users whilst participating in the introductory and arts-based activity sessions of the Creative Ageing Arts in Health Project.

The Research Team

- The facilitating artists and film-maker employed on the project are engaged for their experience and expertise in Arts in Health practice including their experience of facilitating and filming art-based activities with older people with dementia. They will employ their expertise in creating, facilitating and filming a safe creative experience for the participants. The artists, researchers and film-maker will respect and acknowledge the professional role, decisions and actions of the unit manager and carer relating to all aspects of managing the service users' level of well-and ill being including carer's management of service user distress within the arts-based activities of the study.
- The artist, film-maker and researchers acknowledge the well-being of the service users as a priority within the study recognising that the aims and objectives of the study as secondary.
- Members of the research team are obliged to pass on information offered to them by service users during the project which he/she feel requires onward reporting such as disclosure of any risk, potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on the care provision. This information will be passed on to the consultant physician and/or unit manager (see Onward Reporting Protocol).

Risk Assessment

- A Risk Assessment (Belfast Health and Social Care Trust) has been undertaken by the Unit Manager of Sydenham Court and Mullan Mews in collaboration with Dr Jenny Elliott prior to the study. The Risk Assessment is to evaluate the likelihood and impact of the potential risk to service users participating in the arts in health study. Outcome of the evaluation has rated the likelihood of risk as possible and the impact as moderate.
- The potential harm to service users has been identified within the risk evaluation as experiencing undue distress and feelings of ill-being during the art-based sessions
- Identification of distress and ill-being have been identified for the purpose of the study as advised and implemented by both Sydenham Court and Mullan Mews on Kitwood's definition and indicators of ill-being (Kitwood & Benson 1995) Indicators of service user distress and ill-being adopted by the study are signs of:
 - a) anxiety
 - b) discomfort
 - c) pain
 - d) anger
 - e) withdrawal

The indicators of distress and ill-being will be identified and based on the carer's observation of service user's facial, verbal and body expressions (Kitwood and Benson 1995).

Indicators of well-being identified for the purpose of the study (Elliott 2008, Kitwood & Benson 1995) are:

- a) Feel good factor
 - b) Increase in functional and expressive movement
 - c) Increase in creativity and expressiveness
 - d) Desire to be part of the wider community
- A meeting will take place prior to the study with facilitating artists, researchers, carers, filmmaker and Unit Manager to discuss the outcomes of the Risk Assessment. The Unit Manager will advise on how potential expressions of ill-being and distress amongst service users will be identified as aforementioned in protocol and managed within the art sessions by the professional carers. The meeting will also clearly define the role of the artists, carers, filmmaker, researchers and service users within the study.
 - This study will employ during the introductory and subsequent art sessions, the current preventative measures in place within Belfast Health and Social Care Trust (Kitwood 1995) including those devised specifically for the study to reduce potential distress and ill-being for the service users with dementia in supported care:
 1. Professional carers participating in the study will have in-depth knowledge and well-established relationship with the service users
 2. Professional carers will be informed by the Unit Manager of the outcome of the Belfast Health and Social Care Trust Risk Assessment of the study. Carers will be offered professional advice by the Unit Manager on how to identify and best manage levels of distress and ill-being amongst the participating service users within the art-based activities
 3. Framework of Action-The following framework of identification of distress and action will be employed within the study by professional carers to manage levels of distress and ill-being amongst service users whilst participating in the art-based activities:
 - a) Early signs of distress and ill-being (discomfort, withdrawal)-reassurance and support will be offered to the service user by carer and artist and will take place with immediate effect
 - b) Medium signs of distress and ill-being (discomfort and anxiety) –reassurance, support and assistance will be offered to the service user by the carer and will take place with immediate effect
 - c) High levels of stress and ill-being (discomfort, anxiety, pain, anger, tears, withdrawal)-reassurance, support, assistance by the carer and the escorting of service user by the carer to a safe place or to the service user's accommodation will take place with immediate effect.
 - d) The service user will be re-assured that their decision to withdraw from the study will in no way compromise their levels of care
 - e) Filming will halt with immediate effect following the request by the carer if a service user is distressed by any aspect of the filming process or any part of the arts-based activity

- f) The facilitating artists and film-maker present during the event of service user distress will support the carer fully in her professional role in supporting and taken action in the event of a service user experiencing distress
- g) The carer will report to the unit manager and record service user experience and level of distress
- h) If necessary a safe confidential space will be offered to all the service users where they can express to their carers any concerns or needs they wish to further discuss regarding content of their self expression or distress within the arts activity
- i) The carers are obliged to pass on information offered to them by service users during the project which he/she feel requires onward reporting such as disclosure of any risk, potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on the care provision. This information will be passed on to the consultant physician and/or unit manager (see Onward Reporting Protocol).

Dispensing Service User Information to reduce potential distress prior to study

- The service users will be offered a full verbal explanation at the introductory session and at the beginning and throughout each art session informing them of what participation in each part of the session will involve. This will include information about the filming process (See Protocol on Film Process). It is the responsibility of the facilitating artist and carer to ensure that the service users understand fully what participation in the session will involve thus reducing potential for distress prior to the study.
- The service user will be reassured that should they decide to withdraw from the study at any point any film recording secured during the sessions in which they are included will be destroyed at their request.

Finally, mindfulness and attentiveness in relation to the service user experience will be encouraged and employed by the artists, researchers and carers during the introductory session and all the art sessions. Mindfulness is summarised for the study by four verbs; think, feel understand and do (Langers 1989).

Elliott, J. (2008) *Dance Mirrors: Embodying, Actualising and Operationalising a Dance Experience in a Healthcare Context*, Unpublished Phd, University of Ulster, Jordanstown

Kitwood, T. & Benson, S. (1995) *The New Culture of Dementia Care*. Hawker Publications. London

Langer, E.J. (1989) Minding Matters: The Consequences of Mindlessness-Mindfulness, *Advances in Experimental Social Psychology* 22 137-173

Onward Reporting Protocol

In the event of a study participant disclosing information which requires onward reporting, the researcher will comply with the following protocol:

1. Prior to the commencement of an interview the study participant will be informed that the researcher is obliged to pass on information which he/she feel requires onward reporting such as disclosure of any risk, potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on the care provision. The researcher will then pass on the relevant information to an appropriate member of medical, nursing or academic staff. In addition, study participants will be advised by the researcher to report the information themselves to the relevant individual(s) (see below).
2. Individual participants will be assured that the forwarding on of relevant information by the researcher will be done so respecting confidentiality and within the Healthcare Trust Guidelines
3. The participant information and consent forms have been amended to reflect this protocol, so all participants are fully aware of the procedures for the onward reporting of relevant information.

Service Users/Carers

The researcher in the case of conducting interviews/conversations or disclosures through creative expression with service users/carers will forward relevant information to the Unit Manager or Director of Older People's Services (who is then responsible for initiating an investigation within the guidelines of Belfast Health and Social Care Trust). The researcher will ensure the service user/carer is fully aware of this and will advise the service user/carer to also inform their Unit Manager directly.

Artists

Similarly, when conducting interviews and facilitating service users/carers creative expression, artists will be obliged to pass on any relevant information revealed by service users/carers to the researcher. The researcher will inform the Unit Manager or Director of Older People's Services (who is then responsible for initiating an investigation within the guidelines of Belfast Health and Social Care Trust). The researcher will ensure the artist is fully aware of the procedure.

The Protocol outlining the process of film recording older people with dementia and their carers participating in the Creative Ageing Research Arts in Health Research Project

Title of the Project: Changing Ageing Partnership: A Practical Exploration of the Arts in the Healthcare of Older People

The role and use of the film recording is:

1. To gather relevant data for the analyses of the lived experience of the study participants involved in the weekly art sessions of the Creative Ageing Older People with Dementia Arts in Health research project facilitated at Sydenham Court Supported Housing Unit.
2. As a educational tool to disseminate and report study findings

The primary reference source for guidance pertaining to ethical implications for the study is drawn from The General Medical Council's Document "Making and Using Audio Visual Recordings of Patients (2002) and Elliotts' (2008) ethical framework development for use of film as an evaluative tool in Arts in Health research.

The well-being of the service user will be given priority over the recording processes of the study at all times.

Role of film-maker

- The film-maker, Matthew Adamson has been specifically selected for his expertise, experience and sound knowledge of ethical implications within the field of evaluative documentary-making and performance-based research (Adamson 2005). He has advised on the development of the film protocol.
- The film-maker and Dr Elliott will arrange a site location visit to Sydenham Court prior to the study to map the creative space and location of film equipment during the art sessions. This visit will familiarise the film-maker with the creative space and assist in minimising potential disruption on the first day of recording.
- The film-maker will discuss with the artists, carers, unit manager and researchers at the initial research team meeting how he intends to record the art session experiences (i.e. number of cameras, sound equipment, roving and static, remote and close-up camera techniques, inclusion of artist, service users and carer experience).
- The film-maker is responsible for filming four of the six weekly art sessions. The introductory session will not be filmed.
- The film-maker will capture the participants' experience of the art sessions by recording service users/carers participation in the art process, interviews and the sharing at the end of the project which may involve a short performance
- The film-maker will employ a non intrusive, low level film recording technique during the art sessions e.g. miminalising his presence by sensitive placing of film and sound equipment within space where the art sessions will take place
- The film-maker will halt recording with immediate effect on request of carer or facilitating artist if undue distress is induced in any of the service users as a direct result of the filming or their participation in the art session. Any of the service user distress captured on film will be destroyed and will not be included in the final edit of the documentary.

Informing Service Users/Professional Carers/Family

- The introductory session – during this session the researcher will explain the following to the service users, service user families and carers:
 1. Service user/carer involvement in the recording process e.g. recording service users/carers taking part in the music, dance, art and drama sessions with their consent
 2. Recording informal interviews with service users/carers
 3. Service users/professional carers will be informed of how the film-maker will record the art sessions e.g. position of camera, how camera might come close to where they are working to capture facial and body expression, the unfamiliar sounds of the camera equipment.
 4. Service users/their families/professional carers will be informed that they will be included and identifiable in the final evaluative documentary with their consent and for the service user with the knowledge of their family
 5. Service users/their families/professional carers will be informed about the film recording process through the information sheets that will be given to them and to the service users' families.
- At the introductory session service users will be given the opportunity with the support of the professional carer or a family member to ask any questions or express any concerns they might have about the recording process
- Professional carers will be given the opportunity to ask questions or express their concerns with regard to the recording process
- Initial written consent permitting service users and professional carers to be included in the recording of the study will be secured at the introductory meeting. Verbal process consent regarding permission to be included in the recording will be obtained from service users with professional carer support at the beginning and end of each art session
- Service users will also be informed and reminded of the filming procedures at the beginning and during the art sessions

Pre-Final Edit Private Film Screening

The final film edit will be produced as a short documentary.

- Service user participants with a family member, professional carers, artists, unit managers will be invited to a private pre-final edit screening of the evaluative film documentary on completion of analysis. They will be given opportunity to register their suggestions for change and approval or otherwise of the documentary content
- Process consent will then be secured again for service users at the end of the private screening. Service users and professional carers will be invited sign a consent form to ensure that all the participants fully understand and agree to the content of the film documentary and the subsequent use of the film for educational purposes within a Queen's University context including the inclusion/ management/ protection of the final evaluative documentary as part of the final study report

Issues of Confidentiality

- The film recordings will be analysed by the research team and a focus group of relevant stakeholders will be invited to view a pre-final edit to offer their confidential perspective on the film
- It will be made known to both carers and service users that they will be identifiable on the final evaluative film documentary. All participants will be informed of and will have given

written and process consent for their inclusion in the final evaluative film documentary. The minimalisation of the service user's identity will be achieved through:

1. Identifying service users by shortened versions of their forename as agreed by them
 2. Employing sensitive editing techniques within an evaluative framework (Elliott 2008)
 3. Discriminate and protected access to the final recorded evaluative documentary (Homan 2001)
- All video recording data will be safely kept in secure confidential storage in a locked environment within Queen's University post art sessions and during analyses. Only the researchers, film-maker and Director of Older People's Services will be able to access the film recordings. No data will be shared with any other agency or research team.
 - If any of the participants withdraw from the study the video recordings capturing their experience will be removed and subsequently destroyed if deemed necessary by the participant.
 - The service user participants will be assured that their professional care will not be compromised in any way by their withdrawal from the study.
 - The professional carer will be assured that their professional position will be in no way compromised by their decision to withdraw from the study
 - The original film recording data will be safely stored and destroyed within 12 months-3 years of completion of the study.

The Role of the Evaluative Film Documentary

This documentary will be used in the following ways:

1. Included in the final research report to publish the findings of the study
2. Screened at public conferences to disseminate information with regard to the role of the arts in caring for older people with dementia
3. As an educational tool within a classroom context to inform and to offer a better understanding to students at Queen's University Belfast of the role and significance of arts inclusion within healthcare programmes

Protection of the Evaluative Film documentary

The evaluative film documentary will have protected and discriminate access with regard to how it is utilised. This will be assured by:

1. Professionally encrypting the film documentary to safeguard against unlawful reproduction of the material
2. Gate-keeping the evaluative film documentary as part of the final report by ensuring that access will be granted on request and offered at the discernment of the research team (Homan 2001)
3. Storing the evaluative film documentary safely in secure confidential storage in a locked environment in Queen's University Belfast

If any service user offers information or anything of a sensitive nature is captured on the film recordings during the art sessions such as disclosure of any risk, potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on the care provision, the film-maker/artist/professional carer will be obliged to pass on the information to the researcher. The researcher will then pass on the relevant information to an appropriate member of medical,

nursing or academic staff. In addition, service users/ professional carers will be advised by the researcher to report the information themselves to the relevant individual(s).

References

Adamson, M. (2005) *International Dance and Disability Development Film*. Arts Care, Belfast

Elliott, J. (2008) *Dance Mirrors: Embodying, Actualising and Operationalising a Dance Experience in a Healthcare Context*, Unpublished Phd, University of Ulster, Jordanstown

General Medical Council (2002) *Making and Using Visual Recordings of Patients*.

Homan, R (2001) The Principle of Assumed Consent: the Ethics of Gatekeeping. *Journal of Philosophy of Education*, 35, 3, pp.329-43.

Appendix 2: Service Users (Tenants,) their families and Staff Information Sheets

Service Users and their Families Information Sheet

Note: This amended information sheet was drawn up with a specially convened service user action group Sydenham Court and Ms Nora Mallon, Unit Manager following the requests of the Ethics Committee. The service group has requested that the word “tenants” replace “service users” for the purpose of the information sheet. The group has also advised on font size and lay out.

Title of Research Project-Changing Ageing Partnership: A Practical Exploration of the Arts in the Healthcare of Older People with Dementia

This information leaflet gives details of a research project that will take place in Sydenham Court Supported Housing Unit. The research project will look at how taking part in music, dance, drama and art sessions affects older people with dementia. We would like to invite you to take part in this research and tell us about your experience of joining in on the different art activities with your carers and other tenants.

Thank you for taking the time to read this leaflet and considering taking part.

Purpose of this study

The aim of this study is to consider the potential role of art activities in:

- Promoting well-being in older people with dementia
- Improving the quality of life for older people with dementia within their programmes of care
- Improving healthcare education in relation to the use of the arts in the care of older people with dementia
- Promoting interest in the arts for older people with dementia

Research Questions

The study will ask two questions:

1. How can arts-based activities be used in healthcare to improve the well being of older people with dementia and clarify the function of arts activities within a healthcare context?
2. What practical strategies can be developed to facilitate this?

Who will be invited to take part?

The tenants of Sydenham Court and Mullan Mews Supported Housing Units and their carers will be invited to take part.

Where will it take place?

It will take place at Sydenham Court Supported Housing Unit. The tenants who live at Mullan Mews will be collected with their professional carers and left back by a Belfast Trust bus every week in order to take part in the arts sessions at Sydenham Court

The Introductory Session

Before taking part in the research project, you will be invited to attend an introductory session with your professional carers and if so requested by you, a family member. At this session you will be given all the information by the researcher about the project including what taking part will involve.

You will also with your professional carers/family, be invited at this session to take part in a short introductory art session to help you understand what will be involved if you decide to take part in the research project.

What do I have to do?

At the end of the introductory session when you have read this information sheet and fully understood what is involved you will be asked whether or not you wish to take part in the research project. If you agree to take part you will then be invited by the researcher with the support of your professional carer and/or family member to sign a consent form.

You will also be invited to give your verbal consent to take part in the art activity at the beginning and end of every weekly session. This is called “process consent”.

What will happen to me if I take part in the research project?

If you consent to take part in this research project you will be invited to participate in a series of six weekly art-based activity sessions in Sydenham Court Supported Housing Unit. You will have the opportunity with other participants to take part in art sessions that will involve drama, music, dance and art. There will be an artist, dancer, drama and dance teacher present to support you and help you enjoy the sessions. A professional carer who you will know will also be there with you to support you.

It is hoped that at the end of the six-week programme everyone who has taken part will participate in a short relaxed performance which you may or may not wish to be part of. It is your choice if you wish to take part.

How long will each session be?

Each art session will be 1 hour 30 minutes long. There will be a short break in the middle.

Do I have to take part?

It is up to you to decide whether or not you wish to take part in this research project. If you agree to take part you will be given this information sheet to keep reminding you of what is involved.

If you consent to take part in the project but wish to withdraw from the research project at any time, you are free to do so without giving a reason. Everything you say will be treated in confidence by the researcher conducting the interview.

Your decision not to take part or to withdraw from the research project will not in any way affect your standard of professional care.

Gathering Information of your experience of the art sessions

The information collected for the research project is known as data. The data when examined by the research team will tell us about your experience of taking part in the six art sessions. The data will be collected in the following ways:

- Video recording
- Interviews/discussions

Film Video Recording

Four of the weekly art sessions will be recorded on video. If you take part in this creative project, you along with the professional carers will be recorded on video during four of the sessions. The filming process will be low key. The film-maker will let you know at every art session how he will record your experience e.g. he may place the camera, sound equipment filming close to where you will be working etc.

The video camera and equipment will be placed in the room so that it does not disturb anyone participating in the art session. If at any time you are uncomfortable with this procedure we will stop recording immediately.

Will I appear on the Film Video?

It is more than likely that you will appear on all the video recordings and on the short final edited film for the purpose of the research. You will be recognizable on the film. However the film-maker is an expert in the field of filming art sessions in healthcare settings. He will do his utmost to ensure that you are happy with the work he has produced.

How can you reassure me that I will be happy with what you have filmed?

You with a family member and professional carer will be invited to view the final film video at a special private screening in Sydenham Court. You will have the opportunity with your family member to ask questions or express concerns about the final film or your role in it. If you are not happy with any part of the film that includes you then the film-maker will remove it at your request.

Interview/discussions

During the six art sessions you may also be invited to participate in short interviews and discussions as part of the project experience. This is to find out what you thought about participating in the study. These interviews will also be recorded on film with your consent.

Confidentiality of Data

All the information collected during the project including the film recordings will be strictly confidential. They will be stored securely, in a locked cabinet within a locked office. The information will not be shared with any other research team.

Your personal or hospital details will not be identifiable throughout this process. Only members of the research team will have access to this data.

If you withdraw from the research project you can request that the film recordings that include you will be destroyed.

The consented recordings will be retained for up to 3 years and then destroyed in accordance with Queen's University Belfast Data Disposal Policy.

How and when will the final film video be used?

The video recordings will be made into a short film. This film will be used in the following ways:

4. Included in the final research report to publish the findings of the study
5. Will be shown at public presentations and conferences to show to the people who attend how arts can be used in caring for older people with dementia
6. Shown during specific art in health lectures at Queen's University so that the students will understand that when older people take part in dance/music/art classes it may help them in different ways.

The short film will be protected at all times. It will only be used in the above circumstances. The research team will protect the film by storing it at all times in a safe confidential place, in a locked cupboard in Queen's University Belfast.

Complaints Process

If during your participation in the research project you wish to make a complaint about any part of your experience please inform any of the following:

- Unit Manager
- Professional carer
- Family member
- The artists

All complaints will be reported and dealt with immediately by the Unit Manager. Everything you say will be recorded and acted on in the strictest of confidence in accordance with the Service User and Staff Complaints Policy of the Belfast Health and Social Care Trust.

If you wish to tell something that upsets you during the art sessions such as disclosing you are at risk please tell your professional carer and unit manager. This risk may be from potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on your care provision. If you pass on a complaint to a researcher they will be obliged to tell an appropriate member of medical, nursing or academic staff. The professional carer will also be advised by the researcher to report such information to the Unit Manager/Medical or relevant Nursing Staff. Registering a complaint will in no way effect your professional position.

All complaints will be reported immediately to the unit manager, dealt with and acted on in the strictest of confidence in accordance with the Service User Complaints Policy of the Belfast Health and Social Care Trust.

What will happen to the results of the research project?

The results of the research project will be used to:

- Promote the development and inclusion of art education programmes for older people with dementia.
- Let health professionals and artists know how art activities may help older people with dementia

Who is organising and funding the research?

This research project has been funded by the Changing Ageing Partnership and the Centre for Excellence in Interprofessional Education at Queen's University Belfast.

Thank you for your giving this study your consideration. It is greatly appreciated.
For further information, please contact:

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Centre for Excellence in Interprofessional Education
Queen's University Belfast
Grosvenor Road
Belfast
BT12 6BP*

Tel: 028 9063 5313

www.qub.ac.uk/ceipe

Professional Care Staff Information Sheet for Research Study

The Professional Carer Information Sheet has been amended as requested by the Ethics Committee. Dr Elliott convened a meeting with the professional carers Unit Manager, Ms Norah Mallon to consider and seek advice on implementing the requests of the Ethics Committee. The information sheet has therefore been substantially revised and as a result the changes have not been underlined. The role and use of the film data recordings and the evaluative film documentary as part of the final report are also reflected and accordingly amended within this document

Professional Care Staff Information Sheet for Research Study:

Title of Study -Changing Ageing Partnership: A Practical Exploration of the Arts in the Healthcare of Older People with Dementia

This information leaflet gives details of a research project that will take place in Sydenham Court Supported Housing Unit. The research project will look at how participation in music, dance, drama and art sessions affects older people with dementia. We would like to invite you to take part in this research and tell us about your experience of joining in on the different art activities with the service users you care for.

Thank you for taking the time to read this leaflet and considering taking part.

Purpose of this study

The aim of this study is to consider the potential role of art activities in:

- Promoting well-being in older people with dementia
- Improving the quality of life for older people with dementia within their programmes of care
- Improving healthcare education in relation to the use of the arts in the care of older people with dementia
- Promoting interest in the arts for older people with dementia

Research Questions

1. How can arts-based activities be deployed to complement traditional programmes of healthcare to improve the well being of older people and clarify the function of arts activities within a healthcare context?
2. What practical strategies can be developed to facilitate this?

Who will be invited to take part?

The carers and the service users (tenants) of Sydenham Court and Mullan Mews Supported Housing Units will be invited to take part.

Where will it take place?

It will take place at Sydenham Court Supported Housing Unit. The service users with their carers who live and work at Mullan Mews will be collected and left back by a Belfast Trust bus every week in order to take part in the arts sessions at Sydenham Court.

Preliminary Research Team Meeting

You will be invited to a pre-study meeting with the art facilitators, researchers, Unit Managers and film-maker to gain an in-depth understanding of your role within the study. A particular focus will be given to your role in assisting the researcher to obtain the initial written consent from the service users at the Introductory meeting prior to the study. You will also be informed of your role in assisting to obtain process consent at beginning and end of each individual art session. You will be issued with a Care Staff Protocol outlining other aspects of your role such as how to deal with service user distress during the art sessions.

The Introductory Session

Before taking part in the research project, you will also be invited to attend an introductory session with the service users and some of their family members. You will be given all the information by the researcher about the project including underlining your role.

You will also with the service users and their family members, be invited at this session to participate in a short introductory art activity to help you better understand what will be involved if you decide to take part in the research project.

What do I have to do?

At the end of the introductory session when you have read this information sheet and fully understood what is involved you will be asked whether or not you wish to take part in the research project. If you agree to take part you will then be invited by the researcher to sign a consent form.

What does participating in the research study involve?

If you consent to participate in this research project you will be invited to participate in a series of six weekly art-based activity sessions in Sydenham Court Supported Housing Unit. You will have the opportunity to take part and support and assist the service users where necessary in the art sessions. These sessions will involve drama, music, dance and art. There will be an artist, dancer, drama and dance facilitator present to support you as you assist the service users.

It is hoped that at the end of the six-week programme the service users will share the movement, drama, art and music pieces with friends and family in an appropriate space if they are happy to do so. This may involve a short informal performance. Part of your role as professional carer within the study will be to take part in the short performance to support the service users.

How long will each session be?

Each art session will be 1 hour 30 minutes long. There will be a short break in the middle.

Do I have to take part?

It is up to you to decide whether or not you wish to take part in this research study. If you decide to take part you will be given this information sheet to remind you of what is involved.

If you consent to participate in the study but wish to withdraw from the project at any time, you are free to do so without giving a reason. Everything you say will be treated in confidence by the researcher conducting the interview.

Your decision not to take part or to withdraw from the research project will not in any way compromise your professional position.

Gathering Information on the experience of the art sessions

The information collected for the research project is known as data. The data will primarily be examined to inform us of the service user experience. It will also be examined to inform us of your experience as a carer in the art activities. The data will be collected in the following ways:

- Video recording
- Interviews/discussions

Film Video Recording

Four of the weekly art sessions will be recorded on video. If you participate in this creative project, you along with the service users and the artists will be recorded on video during four of the sessions. The filming process will be low key. The film-maker will inform you at every art session how he will record the experience e.g. positioning of camera, sound equipment filming close to where you will be working etc.

The video camera and equipment will be positioned in the room so that it does not disturb anyone participating in the art session. If at any time you or any of the service users are uncomfortable with this procedure we will stop recording immediately at your request.

Will I appear on the Film Video?

It is more than likely that you will appear on all the video recordings and on the short final edited film for the purpose of the research. You will be recognizable on the film. However the film-maker is an expert in the field of filming art sessions in healthcare settings. He will do his utmost to ensure that you are happy with the work he has produced and that your dignity and that of the service users will in no way be compromised.

How can you reassure me that I will be happy with what you have filmed?

You will be invited with the participating service users and their family members to view the pre-final edited version of film video at a special private screening in Sydenham Court. You will have the opportunity to ask questions or to express concerns about the final film or your role in it. You may be requested by the service users and their family members to also ask questions and express concerns about the service users' role in the film. If you or the service users are not happy with any part of the film in which you or they are included then the film-maker and researcher will remove it at your request.

You will be invited at the end of the private screening to offer your written consent stating that you are in agreement with the final editing decisions and the use and role of the evaluative film documentary after the study is finished.

Interview/discussions

During the six art sessions you may also be invited to participate in short interviews and discussions as part of the project experience. This is to find out what you thought about participating in the study. These interviews will also be recorded on film with your consent.

Confidentiality of Data

All the data collected during the project including the film recordings will be strictly confidential. They will be stored securely, in a locked cabinet within a locked office at Queen's University Belfast. Data will not be shared with any other research team.

Your personal or professional details will not be identifiable throughout this process. Only members of the research team will have access to this data.

If you withdraw from the research project you can request that the film recordings that include you will be destroyed with immediate effect.

The consented recordings will be retained for up to 3 years and then destroyed in accordance with Queen's University Belfast Data Disposal Policy.

How and when will the final film video be used?

The final film video will be produced as a short documentary. This documentary will be used in the following ways:

7. Included in the final research report to publish the findings of the study
8. Screened at public conferences and presentations to inform the audiences of the role of the arts in caring for older people with dementia
9. Shown during specific art in health lectures at Queen's University to offer a better understanding to students about the role of the arts within healthcare programmes

The documentary will be protected at all times. It will only be used in the above circumstances at the discretion of and with the support of the research team. It cannot be copied and will be stored at all times in secure confidential storage in a locked environment in Queen's University Belfast.

Complaints Process

If during your participation in the research project you wish to make a complaint about any part of your experience or the service user experience please register and record the complaint with the Unit Manager Ms Nora Mallon, in compliance with the Complaints Procedure, Belfast Health and Social Care Trust.

All complaints will be dealt with immediately by the Unit Manager and dealt with and acted on in the strictest of confidence in accordance with the Service User and Staff Complaints Policy of the Belfast Health and Social Care Trust.

If service user offers information of a sensitive nature during the art sessions such as disclosure of any risk, potential criminal behaviour that involves sexual/other forms of abuse, or anything that impacts on the care provision, you as the professional carer will be obliged to pass on the information to the researcher. The researcher will then pass on the relevant information to an appropriate member of medical, nursing or academic staff. The professional carer will be advised by the researcher to report the information themselves to the Unit Manager/Medical or relevant Nursing Staff. Registering a complaint will in no way effect your professional position.

What is the research hoping to achieve?

It is hoping that the research evidence will show that an arts-based activity programme may contribute to an enhanced quality of life for older people with dementia availing of Day Care Activities within a healthcare context.

What will happen to the results of the research project?

The results of the research project will be used to:

- Promote the development and inclusion of art education programmes for older people with dementia.
- To offer a better understanding amongst health professionals and professional artists of the role and outcome of art-based activities in healthcare settings

Who is organising and funding the research?

This research project has been funded by the Changing Ageing Partnership and the Centre for Excellence in Inter-professional Education at Queen's University Belfast.

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This study has been funded by the Changing Ageing Partnership and the Centre for Excellence in Inter-professional Education at Queen's University Belfast.

Who has reviewed the study?

The project has been reviewed by expert researchers in this area as part of the application for funding and has obtained full ethical approval from the Office of Research Ethics Committee for Northern Ireland (www.orecni.org.uk).

Thank you for your giving this study your consideration. It is greatly appreciated.

Appendix 3: TRANSCRIPT OF THE VIDEO REFLECTIONS

Week 1 (Music)

Elaine: It was a great idea to have tea at the beginning... There was no disruption whatsoever and no-one needed to leave.

David: I thought it [music] was a good session to start with because it involved collective activity – listening to one another.

Elaine: I think in this kind of work no one should ever be left behind. You as a facilitator have to work around all that so that everyone's going with you. Some people in that group are very able. I wanted my session today in terms of music to incorporate as much listening as actually doing, and to always stress that as a musician it does involve your eyes as much as your ears. By the end of the session when we were playing in the circle, especially when we stood up, they were really following and everyone was playing one after each other, and even some of them who didn't have as good physical mobility as others were there – bang on time.

David: Did you notice the way they were helping one another? That was good, that sort of interdependence.

Elaine: As a group they have a great dynamic. You've some quiet ones and some who seem content to sit and listen, who are taking it all in, and then you've got real characters in amongst that... So I suppose my views of the session this morning are that they so able, they're just like any other group. You just tailor things to meet their needs. But definitely myself as a creative person I always use the same starting points, you know, the warm-ups, the things with feet – so I would do that whether I was working with kids or a session with professional musicians... That group are capable of doing anything if they get the opportunity just like any centre, whether it's residential care or supported housing, if you can get a group of people together... This morning really shows that they got so much out of it, because they really took part, they really listened, they watched, they helped each other.

David: I think something that would be good to cultivate is a sense of leadership within the group.

Meriel: I think the atmosphere that was creating at the start was tremendously important. That must be a very delicate time. Because if you don't create that atmosphere that inspires

confidence right at the beginning it could fall through... It's marvellous to think that there's all those good years to be lived where people can do creative things.

Elaine: And the creative approach and the creative arts can have a very profound impact on them, even at this stage of their lives as it does with very young children.

WEEK 2 (Dance and Drama)

David: It seems to me you come away with fragments like pictures at an exhibition... And just that sense of sharing and atmosphere was powerful... And actually you come out of these sessions uplifted, enhanced, transported in a very special way... One of the difficulties, for instance when we were going through the ethical process, was having to say what it was that you do. And the simple fact is that it doesn't work if you come in knowing what you're going to do... And there was that [collective] sense of reclaiming stuff that you thought maybe you'd had to give up.

Jenny: There was just that whole contemporary sense of an artist, a dancer, working with a musician and Ja. was the musician who was able to interpret what our bodies were doing.

David: So in a sense you do become a community of artists.

Jenny: H! There is something of a knowledge there which almost steers the creativity of the group. Because she takes us off the wall... One of the things we're looking for is that whenever we repeat this activity and the intensity of this activity do we have a greater memory recall. There's that embodiment thing. [O.] was very strong in the centre of that [image]. The strength of that was coming from the knowledge base, the life of this older woman and the stick was actually reaffirming, she calls it her third leg, but it was really reaffirming as the elder within the group.

David: Of course they live with the imminence of death all the time. And I think that that's actually one of the liberating things about working in this environment... I need to challenge my own kind of discomfort at that.

Jenny: Elaine... was saying that it was this kind of acceptance that life was moving on and that there is a reality that one might not be there the next week, but that's ok... It's in the moment now and if the group changes then we regroup and we celebrate that life and we move on. So their approach is very different to our cautiousness and

sensitivity. We very right to be sensitive, but I think I'm learning a lot in terms of living in the moment... This is not about us and them. This is not about us teaching skill-building. This is about life skills.

Jenny: Today if I was to think of a word to sum up the session, it's "courage"; the courage particularly of Ja. to lift up his accordion and admit that he was playing it for the first time in 40 years, which actually was very deeply moving in that he has Parkinson's Disease so he struggles with the shake in his hand. And he courageously played and the group completely supported him and began to sing as he played a hymn. And there was just this, for me, this wealth of support, understanding, age, experience in the moment, people together, human-ness, relationship, teamwork – just everything in that moment in time seemed to come together and epitomised for me what arts and health and the contribution of arts and health really within environments like this, with people with dementia. The challenging thing for me is just to remember that we are living in the moment with people who have very short-term memories on this project, not remembering what the material was the week before. Sometimes not even remembering that we were here. But certainly throughout the session remembering certain aspects of the session, being able to recall certain parts of the choreography, certain parts of the drama, just seeing the brain work in a different way through different artforms... The sense of control within the drama and the dance. And the value within their contribution. And also their contemporary thinking... And how they can offer something very contemporary at this stage of their lives and within this stage of the disease that they are actually experiencing.

WEEK 3 (Painting)

Participant Vox Pop (questions are not transcribed)

I enjoy it. I like the company and all the rest of it.

I thought it was very unusual working on one piece of art with seven or eight people, all working on one thing. I never did that before.

Staff Member from Mullan Mews

The tenants taking part, I mean, last week, the creativity of them, taking part and standing up. Even them seeing conversation in a different light. When David was doing his project I was enjoying seeing the tenants enjoying it. It's well-being. If they didn't enjoy it they would be showing signs of it.

Jenny: Whenever you talk about ill-being and well-being, how would you as a member of staff assess what your clients are experiencing? What would you look for?

Their facial expression, and if they didn't enjoy it they would be wanting to go somewhere. They'd get up and wouldn't want to be taking part and that hasn't been seen at all through the three sessions that we've been there. They've all enjoyed it. And their different input. Words they've expressed and through the art, how they've taken their time to do it. So they are showing enjoyment. And the teamwork as well, interacting with different people who they haven't met before. And picking up on different conversations with each other, which is nice to see.

Jenny: And how does this impact on you?

It's enjoyable. It's nice to see a different experience, something not of the normal day to day routine that I would be doing.

Jenny: Is it different from your normal relationship with the clients?

The relationship in the art or the music or the drama, I do see it in a different kind of a way. You obviously get to know your tenants and know their likes and dislikes. Now seeing them perform and doing something with a purpose and their concentration, it's certainly very fulfilling for myself, to know that the tenants would want to take part of it.

Helen: A group like this is fabulous from my point of view because you've all the life experience. You've two ladies who were teachers. I could tell just from how they held their pencils when they were doing their sketches they had an ease and they'd done it before. So that's quite beautiful. Also seeing W. concentrating and just taking an extra time when he was concentrating, shading beautifully and making lots of decisions. Just in that moment he was very engaged in it and I just find those moments really special. With it being a group of probably twelve people the practicalities meant that I had to choose quite a long shape so that lots of people could take part. We had some problems with that in that there were two quite long stretch

tables but the group negotiated that really well, and with great respect for each other... The wee thing we did early about having wee touches of reflection about something that gives them pleasure gives a nice extra dimension to this. So we're just getting a touch of the personalities... I think it's important to just have a look at something and with drawing to give people a chance to look really carefully at something and spend five or ten minutes really concentrating on something that's just quite ordinary and normal but just taking the time to choose to look at it really carefully.

Staff Member at Sydenham Court

Each week they've enjoyed it but today especially there's the creative aspect to it. There is a final product that they can see themselves. Ir. in particular really enjoyed it. I was surprised how much she has interacted with whatever was happening. She likes [to be with just] a very few people, one to one or maybe a couple, a small group and she's not really used to working with such big groups, but she has enjoyed it now. The music, especially, she really enjoyed, and there's no history of music there at all. She owned that musical instrument. Where I don't think that side of things because of her form of dementia it can be, she would find it hard to focus from one place to the other, proportions of things. But she managed fine... They won't necessarily remember that it's every Tuesday that they're going to be taking part, maybe not even from the day before, but they would remember what took place if I say: "Do you remember the music session we had?" or the instrument, they would remember the activity itself.

Jenny: What struck me was the ability to recall a lot of the material that they did last week. Even H. and her squirrel, so for me it was back to that interaction and connections. And that within that intense activity they just seemed to be remembering some of the stuff. And when they're busy doing things like that it can just get people talking, which is great – even about memories, things which aren't related at all. And H. in particular doesn't like art but when she gets down to it she really enjoys it.

Jenny: This week was a different art-form. It was visual art and probably an art-form that the tenants would be more used to and would have participated in before. Helen the artist had thought through very carefully the theme of change and growing and the most beautiful image of a sunflower was for me indicative of what happened in the group today. You could see that there was a lot of growth even from last week in the sense of interaction, the coming together. The reflection from the group very much focussed on the importance coming together and socialising with others. Also a

mixed group, although we were joking about it, more men being in the group, or just that interaction that's just a very normal life interaction and sometimes that not always experience by older people with dementia.

I think for me it was the ability to concentrate, to apply the skills that Helen had taught them, to really spend quite a long time concentrating and also just remembering the theme from last week that we'd been working on and then to develop that theme further. So from the questions that I have been asking as a researcher over this last couple of weeks the impact of arts activity on older people with dementia I think for me the biggest impact has been a reduction of isolation, an increase in socialisation and the enjoyment of just being with other people. Even those within the group who were identified as less sociable within the art today and in the particular teamwork of creating this fabulous art-work you could see that everyone was very, very comfortable, including the staff.

WEEK 4 (Dance and Drama)

David: I think it's good to be linking in from one week to the other and I thought it was nice to bring back the chime bars at the end because, as you were saying, Jenny, at the start, we can't be sure how the recollection operates – it may not be a surface memory thing, but certainly the whole relationship between the purple fabric and the art-work, the sunflower, was lovely.

Jenny: I think that the big thing for me as a facilitator is to try to engage their thoughts and feelings of their life at that moment. Primarily that's just my curiosity as a younger person. But I think it's just that thing of knowing that when you getting older, a lot of older people I know have a lovely vitality about them, they have aims and objectives. And I wanted to find out if people within residential care with dementia have expectations, have aims and objectives, and I have to say they were all very positive.

Jenny: It's a good thing to identify your moods, because sometimes you can't verbalise the mood that you're in feel it and if you can actually verbalise it or act it through or feel it then that's another way of knowing you're alive.

David: One of the first things they said to us here and first visited Sydenham Court was about the theoretical notions of well-being and ill-being, concepts that don't require long-term recollection. It's the being in the moment that you [Jenny] always talk about. And in a process like this there are going to be times when people feel at ease and time when they aren't. And what's important is that the environment is flexible enough to accommodate that.

Jenny: And there's a challenge to remember. And that's maybe where people sometimes struggle. [to Meriel] But what you're doing is brilliant. There's a nice democracy in it. We're giving you these lines. There's an expectation. Like Ja. said to me this morning: "Don't you be having high expectations of me playing today". I said: "Ja., excuse me, we will have totally high expectations of you. You have to deliver here!" There's a lovely struggle. I love the struggle because it's not that sedentary culture of living in an older peoples' home.

Jenny: The session today, session 4, was drama and dance... There were many recalls and memories from last week. They needed prompted as to what their favourite pleasures were but it certainly brought the group together very quickly and there was definitely memories of the session. Some people did forget and then when prompted by the image itself that brought the memories back clearly. My overall impression of the session today: I think that the drama was quite demanding. Now, that's neither good nor bad really. It's good for people, to have to concentrate their thoughts and their cognitive patterns to really remember words. But I could see that at times people were really struggling with concentration level although they did very well. One lady left. Another lady was going in and out of the kitchen. But Ju. finds it difficult to focus normally, but she returned to the space again. The other lady didn't return. Apparently she had a sore back. And it's just the flexibility with which you have to facilitate a session like that. And as a facilitator it can be unnerving and I know that Meriel found it slightly unnerving but I think that the challenge is not to patronise and to offer something that's authentic and real in your facilitation and that people have a choice either to stay with it or to go.

WEEK 5 (Art and Drama)

Meriel: I think the art-work was a wonderful idea because it settled everybody down and calmed the atmosphere. We didn't have to go straight from the outside world. I know that drama workouts and other methods can work, but I thought that was particularly effective and then it built to that climax and it was very clever the way we fitted one bit in while the paintings were drying.

David: What struck me about the painting was it adapts very readily to the individual.

Helen: And it starts off with a very simple idea. Within the simplicity of a flower and "make your own flower up", as you say, every individual can put their stamp on it.

Meriel: Absolutely – all their personality.

David: But in terms of just drawing general principles about this kind of work, something that works from the individual to the collective is good in principle because the fact they'd all established their, if you like, their artistic credentials, I think it made it easier then to get them all to take part in that final section.

Helen: The previous week when I'd done the silk painting there'd been a few people who found the group was too physically close for them. There was a man I think who was a wee bit uncomfortable in the group situation so this just gave a bit more space around people, but you only know that by doing it. O. needed a bit more time to herself. You recognised that she needed a bit more space and she came and went.

David: It is about listening and being responsive to the group. I feel it was lovely that Ja. came over at the start today and said: "I've got something that I want to do". Because obviously he's been thinking about it between times. And [a staff member] was saying that he's the kind of sort of person in Mullan Mews who keeps himself to himself. And it's because he's a performer. He's at his happiest when he's up there holding the floor.

Helen: Matthew [the cameraman] has a different eye and the camera has come and caught things... You stayed with O. quite a long time, I recognise, just because I had to give her a bit of space. She didn't want to paint and she talked about an olive colour and I

mixed an olive colour and then it was: “Well, a petal isn’t ever olive. That’s the foliage”. And then she thought she just needed to go back to her room, so I just quietly mixed up a couple of colours and just left them there and that was her, she was deciding, But I saw you [Matthew] just resting with the camera near her... I suppose from my experience if someone... as long as I feel things have been gently explained then the person has a complete right to say this is not for me. And in my experience people will often choose to stay... It’s not about words, but as you say, you’re moving around and you’re quietly speaking to people. And I love when the focus is on a piece of art-work you can gel.

Vox Pop

Tenant 1: It was just a reflection that I had with myself, that I experienced this notion that I didn’t have to be shy from now on. And a sense of not so much the shyness going away, but it’s just gone out of the room for a while.

It’s interesting to be among people again, and also people some of whom I haven’t met before and doing different kind of things. I have problem. I forget a lot.

Jenny: But you enjoy it in the moment.

Tenant 1: Oh, Heavens yes! In the moment. It also takes you out of yourself and out of where you usually are from morning to night.

I also live here. I like myself. I’m me all the time. [on being a teacher] I have to put a rein on myself and say let somebody else do something sometimes.

New Tenant: I’m enjoying it because I’m a bit self-conscious at times and I enjoy the company. And I really enjoyed the music and all the wee chime things. When you’re only moved in you’re a bit shy.

Tenant 2: [To Jenny] Are you the lady that does the dancing?

Tenant 3: I would like a pasta dish one night and maybe a rice dish another, but with the rest of them it’s potatoes, potatoes, potatoes...

Tenant 4: When I came here at the start I was in a pretty low ebb, so I was. Since I’ve been there [Mullan Mews] and they’re looking after me, it’s worked miracles with me, so it has. The people in Mullan Mews, they’re great. I wouldn’t have known about this place if it wasn’t for Mullan Mews. I can go wherever I want. I’ve a pass for the

buses. I can go wherever I want. I've no special time for coming in. So they're very good to me, so they are. I had to go through a sort of a test for to walk. And they sent out for to give me the examination. And they walked me round the roads, so she did. She said, no problem with you.

Tenant 5: I would know three of the people in there, including myself, *[laughs]* and none of the rest of them I would have known at all. And to lose shyness in that kind of condition is truly remarkable. I'm not shy by nature, but I am reticent. I would prefer to have an opportunity to think before I would speak, more calculated, if you like. But it loses the whole point of the excitement of life, to not react to the moment. I was a landscape architect. I left architecture because I discovered the magic of landscape architecture. It may seem like it's a similar kind of thing and it is in some ways but the emotions that drive landscape architecture are different from the emotions that drive architecture. There's no special connection with the art project, but from an overall life study of "me the guy" it was extremely important... It certainly opened up my brain to other possibilities.

WEEK 6 (SHARING)

Relative: Creative aging is, I think, a very apt name for the project. I looked at the participants. They were all taken with it. I looked at the audience. We were all taken with it. Time went like a flash. Quite wonderful, every part of it: the drawing, the dancing, the music, quite wonderful... Participation, activity, it's much better than sitting in the chair.

Student 1: What we have learnt about is patience and taking time. And what I've learnt today personally from these people is taking time to spend with people and so much will come. People with Alzheimer's and dementia are so often dismissed as being stupid or silly. I know this. Both of us have relatives with dementia which is another reason why we wanted to come today. And I just think spending that time, those memories are there. People are capable of doing a lot.

Student 2: I think the real thing that I learnt today is that the ability to be patient with the people and using creative tools brings out creativity in people. I think we've seen that today definitely with H. and her poem and Ja. and his song. Maybe the use of a single note or the use of text brought that into their memory and then they were able to bring those things forward. So that people that have been very creative in their day, like H.

wrote that poem, and Ja. was telling me he was a tenor – maybe just the trigger of those creative things brought those skills back in to their memory.

Student 1: For a pilot scheme it's clearly been very successful... The sense of community is just so great, I mean, everyone's sitting in there now talking away and these aren't just rooms. People, they do like to mix and interact and it's something that needs to be rolled out across Northern Ireland.

Student 2: Yes, and today the thing they were saying they got out of it most was that they were a community and that they got together communally to create something together. And I think it gave them all a sense of purpose. They were all saying about how fun it was to be with other people. It gave them a purpose-driven goal together as a group.

Staff Member: The feedback has been extremely positive, Jenny. The tenants that took part in the project for six weeks have thoroughly enjoyed it. The measure for me is quite a lot of the folk wouldn't remember a wee while after what had happened, but the sense of achievement, the sense of well-being remains. And it was just lovely to see that. And also the discussion among the staff group that were involved with it – I think everybody got an awful lot out of it. It's been a truly worthwhile project. The other thing for me, Jenny, is that it demonstrates to anybody that's interested that living with dementia you can achieve, you can have a quality of life and quite often dementia can be viewed in a very negative way, that if somebody's got dementia well there's incapacity but I think that this proves that that's not the case. People living with dementia can achieve and enjoy a quality of life and actually be creative which I just think's wonderful and I think that this project has demonstrated that without a shadow of a doubt.

Jenny: Can you reflect on anything in terms of the impact on staff?

The staff have all marvelled at just how much enjoyment the tenants got out of it and even as facilitators in reminding the tenants the day that it was and what was happening, they have thoroughly enjoyed the experience and have learned a lot from it, and I think the biggest learning curve and the most powerful message is that people with dementia are like you and me and there is a creative side that can be tapped into. The project and each of the six sessions created a sense of well-being within each of the participants that was absolutely marvellous to see. And whilst the memory was lost of the actual event that feeling of well-being that is created is sustained for quite a while afterwards.

David: For me, there was an interesting thing happened in terms of memory. Ja. sang perfectly well last week, and just couldn't find it when he recited it but once he started to sing the kind of song memory was there and that's another example of how memory operates – in different layers, because undoubtedly the singing of it helped him.

Jenny: Well, I think that that in many ways can inform health as well. Creativity can actually inform health about how memory works. And rather than just a total clinical perspective that there are other ways of generating memory and bringing it up through the layers. And we've talked a lot about embodiment and now even in terms of the music that's there, how it generates memory as well, so I think there are new ways, maybe, of looking from a clinical perspective at memory. Although, we're not here from a clinical perspective.

David: Another thing that we were taking to B.'s relatives about was just how an environment like this takes away the fear of aging... the fact that you can have such a positive experience in this sort of supported housing environment I think speaks volumes. And as you say, we learn so much from doing it as well.

Jenny: Absolutely, and I've just loved the sharing and how this morning we worked on it and then B. forgot that we were working on the poem with her this morning. When I said to her: "Are you ready to say your poem", and she said: "Well, what poem?". But she delivered her poem and as her brother said, in the moment, he could really see that that was really contributing something really valuable to her and her ability to share that with a wider group.

David: I think for me one of the most interesting parts of it as well was seeing the full person. I mean, somebody like B....teaching in Africa, and all sorts of wider experience came through; you know, O.'s enormous history of teaching. It's very interesting that two of the biggest contributors were teachers.



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