

Impact case study (REF3)

Institution: University of Central Lancashire		
Unit of Assessment: 34 – Communication, Cultural and Media Studies, Library and Information Management		
Title of case study: A Life More Ordinary – Supporting and Empowering People Living with Dementia		
Period when the underpinning research was undertaken: 3/10/2016-31/12/2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Ian Beesley	Role(s) (e.g. job title): Reader Practitioner in Visual Representation	Period(s) employed by submitting HEI: 3/10/2016-31/12/2019
Period when the claimed impact occurred: 3/10/2016-31/12/2020		
Is this case study continued from a case study submitted in 2014? N		
<p>1. Summary of the impact (indicative maximum 100 words) Through a series of collaborations with dementia and Alzheimer's support groups Beesley has co-created a series of trade union style banners to promote the experiences, challenges and activism of these groups. The banners have helped to invigorate social campaigns that have led to policy changes for the benefit of people living with dementia, including improved access to public transport. The process of co-production and exhibiting, bringing together banners from groups from across the country, has had a profoundly transformative impact on support group members, relatives, carers and the public who have experienced the challenges faced by loved ones living with dementia. Support group members have been empowered to overcome the societal challenges of a dementia diagnosis and feel that they remain valued members of society.</p>		
<p>2. Underpinning research (indicative maximum 500 words) Ian Beesley, honorary fellow of The Royal Photographic Society, is an award winning, socially engaged documentary photographer. His novel approach to practitioner engagement with social groups, immersing himself in the communities and cultures he documents, enhances their lives through artistic co-creation. His candidly captured realities of the lived experience of his subjects, showcases their desire for normality and their struggles for an improved quality of life. A unique feature of Beesley's work has been his ability to co-create new cultural artefacts that also become tools for their subjects and co-creators to use in their activism.</p> <p>The origins of the project began in 2015 with Beesley documenting the final days of Kellingley Colliery, once the largest coal mine in Europe and the last remaining coal mine in the UK. In recognition of the industry's historic links with trade unions, Beesley was commissioned to produce a trade-union banner to commemorate the mining heritage of Kellingley. He also produced a series of unique photographs, taken with a 19th Century Hunter Penrose camera twice the size of a fridge. It was originally used for wallpaper prints and, thanks to Arts Council England funding, Beesley restored it to working order after years in storage in Gallery Oldham. The photographs formed part of the <i>Big, Big Camera in a Van</i> exhibition at Gallery Oldham in February 2017 and the National Coal Mining Museum in February 2018 [5].</p> <p>This experience informed Beesley's practices, working with collaborators, poet and broadcaster Ian McMillan and cartoonist Tony Husband. Beesley began working with dementia groups in the <i>A Life More Ordinary</i> project in 2016, a sub-project of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) programme, led by the University of Exeter. Receiving a diagnosis of dementia is an emotional and difficult experience. While dementia is a life limiting condition those diagnosed can still live fulfilling lives. For many concerned they yearn to live a life more ordinary rather than being seen as an immediate burden on their families and communities. According to the Alzheimer's Society 850,000 people in the UK are currently suffering from dementia or an associated condition and that figure is expected to almost double within 20 years.</p>		

Beesley and his collaborators conducted thematically led workshops with people with dementia and their carers. The project's aim was to illustrate the everyday experience of coping with dementia through the production of a series of chapbooks. Chapbooks are small publications, normally A5 in size and they feature illustrations and photographs, narrative text and poems.

The chapbooks *The Allotment of Time* [1], *A Grand Day Out* [2] and exhibition *From the Negative to the Positive* [3] were produced with dementia groups in Exeter, Yorkshire and Oldham respectively. The chapbooks and exhibition brought together the photographs, poetry and cartoons that were inspired and informed by the experiences, hopes and memories of the group members. Each illustrated the everyday experience of coping with dementia; the challenges of simple non-routine tasks like travelling and the loneliness, fear and struggle to maintain the relationships they used to have with themselves, their family and friends. The projects delivered a positive and realistic portrayal not only of these challenges but also their thoughts and hopes.

A powerful element of Beesley's research praxis has become the production of trade-union style banners, beginning with the Kellingley banner. This inspired the dementia groups he worked with to co-create their own banners, beginning with the Yorkshire DEEP [DEFINE]. This theme was taken up by members of DEEP networks across the country, leading to *The Unfurlings* project which collaboratively designed a further 16 banners. The groups included 'Hamari Yaadain', a dementia cafe for South Asian people in Leeds and the 'Cottingley Crew', part of the Young Dementia Leeds service supporting dementia sufferers under 65 years of age.

The banners produced by these groups were exhibited initially at Exeter Library October 2019 [4], before beginning a national tour with further exhibitions in Poole, Preston, Leeds and London. As highly symbolic cultural artefacts they became rallying points for these invisible communities allowing them to re-engage with contemporary challenges and re-invigorate contemporary activism through their personal histories and experiences.

3. References to the research (indicative maximum of six references)

1. Beesley, I. (2017) *The allotment of time* by Ian Beesley, Tony Husband & Ian McMillan. The Darkroom Press, Exeter. ISBN 978-0-9957712-2-2
2. Beesley, I. (2018) *A grand day out* by Yorkshire Deep with Ian Beesley, Tony Husband and Ian McMillan. The Darkroom Press, York. ISBN 978-0-9957712-5-3
3. Beesley, I., McMillan, I. and Husband, T. (2018) *From the negative to the positive*. [Show/Exhibition], Gallery Oldham, 8th January-2nd February 2018
4. Beesley, I., McMillan, I. and Husband, T. (2019) *The Unfurlings* [Show/Exhibition], Exeter Library, Exeter, 16th October 2019-31st March 2020
5. Beesley, I. (2017) *The Big, Big Camera in a Van* [Show/Exhibition], Gallery Oldham, Oldham

4. Details of the impact (indicative maximum 750 words)

Working with dementia groups to achieve a life more ordinary.

Trade-union style banners hold a significant cultural position in many working-class communities. They represent strength in unity for communities and social groups tackling common challenges. Social solidarity through art is highly valuable for invisible disabilities like dementia.

The project aimed to give people diagnosed with dementia and their families tools and strategies to help them cope with living with the condition in a pragmatic and positive way. By collaborating with the respective dementia support groups, the *A Life More Ordinary* project gave a voice to their hopes, worries and frustrations. The project has now developed banners with 16 dementia groups to help them promote campaigns and highlight their experiences. The groups from across the country represent a variety of different backgrounds and objectives including the 'Cottingley Crew', a group for under-65s in Leeds,

'The New Seaside' a recently established group in Kent, and 'Hamari Yaadain', a dementia café focussed on BME dementia sufferers in Leeds.

These interventions are important in improving the quality of life for people who are suffering from, or living with someone with, a life limiting condition. Kathleen Storton, Services Manager for the Alzheimer's Society, Central & West Lancashire, commented that **"...when you have a diagnosis you can sometimes feel that you are a bit useless and you're not needed anymore and how am I going to contribute to society? Doing something like this [the banners] has helped people feel valued."** [G] The participation in the projects gave the group members an opportunity to feel in control of an aspect of their life at a time when their diagnosis may have left them experiencing a lack of control. The physical outputs they co-created, the exhibitions, chapbooks and banners, provided a tangible reminder of the activity with a condition that may have otherwise robbed them of this memory [J1-3].

Terry, a founding member of the Ragamuffins group in Oldham, found the sessions with Beesley, McMillan and Husband provided significant therapeutic benefit. **"There is also the collective benefit to the group as a whole of memories being rejuvenated on times and issues perhaps long forgotten! Such recollections are both therapeutic and stimulating and it is interesting to see the frequent change in demeanour that often manifests itself among so many of those attending within a short period of time."** [C]

Campaigning with dementia groups for "the right to a grand day out"

The Yorkshire DEEP consisted of three groups who were all campaigning on different aspects of the challenges of using public transport. 'Minds and Voices' (York) had focussed on improving journeys by train, 'DEEP Vibes' (Scarborough) had been campaigning for North Yorkshire Council to make blue badges available to people with dementia and 'Face it Together' (Bradford) had focussed on improving journeys by bus.

The banner produced by the Yorkshire DEEP helped to kick start a campaign to make York Railway Station more dementia friendly. The groups had been campaigning for some time but had not captured public attention, leading to the groups becoming demoralised [B]. One participant wrote on their personal blog **"...we've worked hard to get change but disheartened at the fact no one is listening to us."** [H2] Beesley's work with the Yorkshire DEEP [2] had highlighted both the positive and negative sides of travel for people with dementia, identifying problems with timetables, platform layouts and station announcements. The banners were unveiled by group members, with the help of a local brass band, in front of members of the press and rush-hour commuters in York Station in May 2018 [A, B]. The ceremony attracted interest and support from the watching public, press and local businesses, helping to raise the profile of the issue.

The event helped to raise awareness and understanding of the issues with the station management. Following the event Northern Rail have engaged with Minds and Voices to provide advice on redesigning timetables to make them more dementia friendly. The involvement of people with dementia is a key tenet of the *A Life More Ordinary* project. One participant summarised the importance of the project and these activist interventions: **"Travel is so important to me, yet is so stressful. Yet small changes can make it possible. I'm so glad I changed my plan today because all our words of the past 18 months, today became an ACTION of our own"** [H4]

Prior to Beesley's involvement the three groups that made up the Yorkshire DEEP network were campaigning individually on different aspects of transport challenges. The project brought together these groups in 2017 [H1] and provided a forum to coordinate their approach and generate a louder voice for change. The groups worked in collaboration with Innovations in Dementia, an organisation that supports and campaigns for the rights of dementia patients, to contribute to two major policy submissions. Firstly, their alternative

report to the UN Convention on the Rights of Persons with Disabilities and second was their response to the Government consultation on extending the Blue Badge scheme to people with 'hidden' disabilities such as dementia [D, E]. As a result of Beesley's development of the campaign the groups issues were recognised as the **“County Council [North Yorkshire] agreed that people with dementia or their carers could now apply for a Blue Badge over the phone – and answer ‘cognitive questions’ such as ‘How will a Blue Badge help you?’, ‘Do you want to give up and go home if things go wrong when you are out?’”** [D]. Nationally, change was also brought about as the government approved the calls for blue badges to be made available for people with 'hidden' disabilities. [F]

Engaging dementia communities around the UK to achieve “art for all.”

The success of the York banners prompted other similar groups to explore their challenges and hopes through the use of banners [G]. Beesley and his colleagues worked closely to co-produce a series of banners, each distinctly personal to the groups. Each banner took inspiration from an existing trade-union banner and conveyed a message through the images and symbolism.

Polly Kaiser, Consultant Clinical Psychologist at Pennine Care Oldham, commented: **“They [The Ragamuffins dementia group] have gathered to re-collect their memories, to laugh and to create and in doing so relationships and connections have been built. Profound issues and themes have been addressed with a lightness of touch.”** [C]

The banners were reflective of the group members interests, cultures and experiences. All the ideas included in the banners came from the group participants, which were then brought to life by Beesley and his colleagues through the production of the physical banner. In conversation, Liz Menacer, the group facilitator with Young Dementia Leeds, commented that Ian had included their clients and facilitated their needs to make a statement about their dementia experience while celebrating their individuality and personal history [J1]. As one group facilitator observed **“After a dementia diagnosis people feel cast aside, they don't feel valued as there is no treatment.”** [J2] The project provided users with a feeling of recognition, allowing them the opportunity to feel **“...in some degree of control...”** along with friendship and fun [J2]. When asked about their involvement in the project one participant with dementia said: **“Really enjoyed [the project], nice to be involved and to know people take notice of what you say.”** [J3]

A common theme highlighted by facilitators from different groups was the contribution the project made towards the peer support networks between both the users and their family members. In some cases, these peer support networks have continued after loved ones have passed away, supporting family members in bereavement [J2].

Although the disruption brought about by COVID-19 limited the opportunity for the banners to be displayed, the book and website produced to go along with the exhibitions proved a useful alternative for the groups, acting as a tangible reminder of their participation in the project [J3, K]. The nature of the condition has meant that many participants no longer have clear memories of their participation in the various project elements. The simple act of producing tangible outputs, such as chapbooks, aided participants memory of involvement.

The Unfurlings exhibition at the Harris Museum, Preston, launched 6th March 2020 and was designed to be a welcoming environment for people living with dementia. The space was designed in collaboration with the Museum and the local dementia group to provide a homely, welcoming environment with comfortable seating centrally in the room. This allowed anyone with mobility issues to enjoy the banners in comfort [J4]. Following the lockdown, The Harris digitally captured *The Unfurlings* exhibition and linked in recordings of Ian McMillan's poetry to allow visitors to experience the exhibition safely from home [I].

5. Sources to corroborate the impact (indicative maximum of 10 references)

- A. Campaigning for better public transport services for people living with dementia, *Telegraph & Argus*, 7th August 2018
<https://www.thetelegraphandargus.co.uk/news/16404160.campaigning-for-better-public-transport-services-for-people-living-with-dementia/> (Retrieved 11th February 2020)
- B. Dementia friends make political banners to show they want 'a life more ordinary', *Homecare*, 28th May 2019
<https://www.homecare.co.uk/news/article.cfm/id/1610213/dementia-friends-make-political-banners-to-show-they-want-a-life-more-ordinary> (Retrieved 11th February 2020)
- C. From the Negative to the Positive (2018) Beesley, I., McMillan, I. & Husband, T., *University of Exeter*
- D. How can we really make the Blue Badge work for people with dementia? *Innovations in Dementia*, 17th June 2019 <http://www.innovationsindementia.org.uk/2019/06/how-can-we-really-make-the-blue-badge-work-for-people-with-dementia/> (retrieved 11th February 2020)
- E. Our Lived Experience: Current Evidence on Dementia Rights in the UK (2017) *Innovations in Dementia*
- F. Blue Badge consultation: summary of responses and government response, *Department for Transport*, 29th July 2018 <https://www.gov.uk/government/publications/blue-badge-disabled-parking-scheme-eligibility-consultation-summary-of-responses-and-outcome/blue-badge-consultation-summary-of-responses-and-government-response#part-3-response-to-questions> (Retrieved 11th February 2020) See Part 2, para 14.
- G. The Unfurlings: Banners for Hope and Change,
<https://www.youtube.com/watch?v=jAPu7wCQwsQ>
- H. Which me am I today? Blog
1. *Minds and Voices head to the seaside.....* 4th September 2017
<https://whichmeamitoday.wordpress.com/2017/09/04/minds-and-voices-head-to-the-seaside/> (Retrieved 10th September 2020)
 2. *Transport, Blue Badge and dementia....* 22nd February 2018
<https://whichmeamitoday.wordpress.com/2018/02/22/transport-blue-badge-and-dementia/> (Retrieved 29th June 2020)
 3. *Our Right to get Out and About...* 19th April 2018
<https://whichmeamitoday.wordpress.com/2018/04/19/our-right-to-get-out-and-about/> (Retrieved 29th June 2020)
 4. *Unfurling of the Great Yorkshire Banners...* 24th May 2018
<https://whichmeamitoday.wordpress.com/2018/05/24/unfurling-of-the-great-yorkshire-banners/> (Retrieved 29th June 2020)
 5. *A Lovely Trundle to York...* 8th February 2019
<https://whichmeamitoday.wordpress.com/2019/02/28/a-trundle-to-york-2/> (Retrieved 29th June 2020)
- I. The Unfurlings: Banners for Hope & Change at The Harris, Preston– virtual walkthrough
<https://www.theharris.org.uk/product/the-unfurlings-banners-for-hope-change/> (Retrieved 10th September 2020)
- J. Corroborating contacts and emails from project groups and venues:
1. Liz Menacer – Service Manager, Young Dementia Leeds – CONTACT & EMAIL
 2. Terry Ann Shaw – Dementia Strategic Partnership Manager, Kirklees Council – CONTACT
 3. Judith Baron – Dementia Support Worker, Alzheimer’s Society, Bradford – CONTACT & EMAIL
 4. Caroline Alexander – Curator, The Harris Museum & Art Gallery, Preston – CONTACT
- K. The Unfurlings: Banners for Hope & Change,
1. Website: <https://theunfurlings.org.uk/> (Retrieved 10th September 2020)
 2. Exhibition Book: Beesley, I., Hall, M., McMillan, I. & Husband, T. (2020) *The Unfurlings*. The Darkroom Press, York. ISBN 978-0-9957712-6-0