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The Debenham Project

A case study of a unique community-led and owned project dedicated to the support of carers of those that have symptoms of dementia and those they care for.

1. Introduction

This case study was carried out on behalf of the Joseph Rowntree Foundation for inclusion in it's "Not a One Way Street" research project. The Debenham Project was chosen as one of 6 cases across the UK and Northern Ireland which demonstrate mutuality and reciprocity.

This study involved an intensive 2 day on-site examination of the project in May 2012. A large number of those who are connected with the project – trustees, steering group members, volunteers, professional support workers, family carers, representatives of the Parish Council, County Council and the GP practice, etc were interviewed. In addition I had wide ranging discussions with the Chairman and others throughout the study period and was also able to assess the overall impact and ownership of the project throughout the community as a whole.

The study reflects the views and opinions of the many different people that I spoke to over the course of my two days in Debenham and includes observations made at the time. The focus of the case study was dictated by the terms of the wider research project and inevitably wider aspects of the project had to be omitted.

2. Overview

Debenham is a large village (or small town) in mid Suffolk with a population of about 2,400¹ and a further 4,000 in the smaller surrounding villages within a radius of 4 miles. The village has a medieval heart but there has been much new development on the outskirts of the village over the last thirty years or so as people, working for companies that have relocated from London to Suffolk, or are migrating from North London and Essex, have moved into the village.

The public transport infrastructure is relatively poor and it is difficult for people without cars to get to the surrounding towns for work, shops or services. Economic factors are driving the concentration of care facilities towards and around the major towns. This and the poor public transport system has a particular impact on people living in the village who need care, especially when they are no longer able to live safely in their own home.

*'Apart from the GP and community nurse, receiving health and social care involves distances of 7, 10, 14 miles. For carers, this creates major difficulties, excessive pressure and distress. When someone is no longer able to live safely and securely in their own home they have to give up their daily contact with family, friends, neighbours and familiar professional carers in order to move into an extra care facility which is at least several miles distant. Inevitably their relationships diminish in time and it is very difficult for them to develop new ones'.*²

The Debenham Project seeks to address this problem, with the aim of ensuring that Debenham people who have dementia should never have to leave their village to access appropriate services and care. The principle value underpinning this aim is explicit:

*'To respect and value their continued importance to their families, friends and community [of all elderly frail people, including those with dementia] and to enable them to remain active participants in the life of the village. All elderly frail persons will be able to fully participate as valued members of the community and they will be encouraged to maintain and develop their contribution to a multi-generational rural culture.'*³

The Project has taken a number of immediate and practical actions to support people with dementia and their carers who live in the village and the surrounding areas. This is often

¹ Office for National Statistics – Population Estimates Mid 2010 (adjusted)

² ['A Vision of Caring \(A rural solution\)' January 2012](#)

³ ['A Vision of Caring: Project Aspirations' January 2012](#)

referred to as the “Here and Now” thread of the project and has specifically involved setting up a comprehensive range of voluntary support services which draw in and upon the best professional services provided by the NHS, local authorities, charities, and other agencies.⁴ However, the project also has a long term vision which is of a time when no one, no matter their degree of frailty will have to leave their community to receive the care that they need. Its aim is to integrate health and social care on a local basis and provide domiciliary care, extra-care, residential care, nursing care, secure care, etc. in a single, flexible and community-led approach. Again, the vision is of *‘a range of services.....which are specified, provided and managed locally but draw in the best professional services from the County as required [and an integrated ‘bricks and mortar’] facility [to support them]...’*⁵

The Debenham Project is an example of a project building upon and designed to strengthen a mutually supportive community, involving a large number of people and both direct and indirect forms of mutual exchange. It is co-ordinated by a small group of local volunteers and has a clear vision and mandate from people in the local community.

The project is not linked to any wider movement but can be seen within the general framework of community action. Community action has a long history in this country but has come to prominence over the last few years with the Coalition Government’s promotion of localism and ‘Big Society’.

3. Project Description

a) Project History

The formal start date for the project is February 11th 2009, when a group of elders from St Mary’s Church met as a part of their joint responsibility for parochial care. One item raised was to consider the best way to respond to the challenges faced by the growing numbers of local people caring for relatives with dementia or experiencing dementia. These challenges had been increasingly highlighted in concerns that their vicar and others had been having, and were given greater weight by local and national media coverage of the difficulties faced by people with dementia.

The elders included Lynden Jackson who became the project co-ordinator. They recognised that although the church might initiate some action and had resources (buildings, people and networks) that would be useful in addressing the challenge this was a problem affecting the whole community and needed a community solution, and so they decided to hold a public meeting to increase awareness about dementia and its future impact on the

⁴ [‘Breaking the Mould’ July 2010](#)

⁵ [‘A Vision of Caring: Project Aspirations’ January 2012](#)

community and, perhaps, to explore whether there were steps that could be taken to improve the situation.

The public meeting was held on May 23rd and was attended by more than 70 local people. This meeting set the initial focus for what became The Debenham Project – family carers of those with dementia, and those they care for, should not have to travel 10 or 14 miles to access the services they need, that help and support should be available in the local community, and that “we should just get on and do something” - this despite the risk that action by the community would lead to the council doing less for local people with dementia and their families. People at the meeting also asked that the project have a longer term vision to try to provide quality day, residential, and nursing care facilities in the village so that the elderly frail would not have to leave the community when they could no longer stay in their own homes.

Lynden Jackson took on the co-ordinating role for the project and brought together a group of local people to set up some practical responses to the needs being expressed by people with dementia and their families. Ideas evolved through discussion and some rudimentary services were quickly established in time for the public launch of the project on October 26th. In parallel, they began to develop their longer term vision which has become known as “The Vision of Caring”.

The public launch of the Debenham Project was attended by a total of over 150 local people of all ages, together with the local councillors, senior health and social care and charity professionals. The co-ordinating group talked about what they were seeking to do as well as launching the first set of local services, using the public platform to check out that they were doing what people in the community wanted.

Since then the project has continued to evolve. New services have been tried and most have taken root and become established parts of The Debenham Project. Some ideas have not immediately worked and have been set aside for the time being - not forgotten. Lynden’s philosophy is that you need the *right time, right place and right circumstances* for an idea to work. *‘It is important not to become too attached to an idea, otherwise you will try and fit circumstances into an idea that isn’t right’*. Now the project has developed a comprehensive set of community-based services which are believed to represent a unique achievement throughout the UK.

Meanwhile, the longer-term vision for the project has been developed and refined. Its formal aspiration is to *provide community-led, person-centred and integrated health and social care for all elderly frail members of our community which meets their individual needs irrespective of their degree of frailty.*⁶ The building (to include extra-care housing, nursing, residential and secure care) which will provide an infrastructure for this integrated service,

⁶ [‘A Vision of Caring: Project Aspirations’ January 2012](#)

although necessary, is not seen as an end in itself. The vision is of an overarching “System for Care”⁷ for the elderly frail of a typical rural community. One which is designed to meet as much of the health and social care needs of the elderly within the community as is possible and to substantially reduce the need for hospitalisation. The people involved in the project believe that the care of older frail people should be a *‘shared responsibility between the individual, the community, the local authorities and the NHS’*⁸. They argue that as much support as possible should be provided by the individual and led by the local community, with professionals drawn in to provide specialist skills and advice and help where necessary - *‘Volunteers can’t replace the role of the professional’*.

b) Project Design

The project is co-ordinated by Lynden Jackson with support from his wife Sue. Lynden sees his role as shaping the vision and stimulating and co-ordinating activity and argues that the project activity has not been ‘designed’ but has rather grown organically. Services are identified and developed through conversations with family carers, volunteers, professionals, and ‘in the street’. There are two central principles: a) the project specifies, organises and leads the activities but seeks to draw in essential professional skills, and b) everything is done ‘in partnership’ with other local groups, eg the Church, or with the charities eg Age UK, the NHS, etc. Other professional skills are drawn upon where necessary eg: for advice and training.

Lynden believes that one of his central tasks is ‘creating a set of circumstances in which something might happen’

c) Project leadership

Each of the people who contributed to this case study emphasised the importance of the project co-ordinator Lynden Jackson to the success of the project. They variously highlighted his energy and commitment, his tenacity and his networking abilities.

‘Lynden is brilliant at making contacts with people in all sorts of areas’

‘Lynden is an arch networker and just keeps on going’

‘People know Lynden won’t go away’

⁷ [‘Putting it all Together – A Summary’ February 2012](#)

⁸ [A Vision of Caring: Project Aspirations’ January 2012](#)

Lynden himself tends to play down his importance and is keen to point to the value of the many other people involved in the project.

d) Project membership

The project has very clear focus – it is there to support people with dementia and their families who live in or within about four⁹ miles of Debenham. Project leaders have had to fight hard to maintain this focus but believe that it has been important to its success.

The project advertises widely in local shops and also makes sure that everyone in the local GP surgery is aware of the project. Initially the GP surgery sent information out about the project to everyone on their patient list who had a diagnosis of dementia. Now the surgery will automatically inform people who are newly diagnosed about the project and the services that it offers. There is now a wide knowledge of the project throughout Suffolk.

e) Project volunteers and advisers

Volunteers are drawn from throughout the community and their skills are supplemented by those of professionals when specialist help and advice is required, eg: The CPN and advisers from Age UK and the Alzheimer's Society regularly attend the Carer's Club. The librarian attends the Info Cafe to give people advice about how to access information that is useful and accurate.

Volunteers undertake a number of roles from helping with the governance of the project to direct involvement with project activities to handing out leaflets. There are 80 volunteers 'on the books'. 50 made a contribution of some kind last year and 30 have a regular involvement in the activities.

The first group of volunteers were recruited as a result of the public and launch meetings. Since the launch of the project most volunteers have been recruited by word of mouth and come in ones and twos and are of a wide range of ages. They are either known to, or informally interviewed by, Lynden and then are invited to join in at the Carer's Club and 'get to know us, and vice versa'. Where it is felt that formal training eg for the helpline, food and hygiene, memory clinic, etc. this has been arranged – but very much tailored to the specific needs. The project does not have a policy of 'blanket' induction training.

It is a feature of The Debenham Project that wherever possible it works with a number of other organisations. These often have their own requirements for volunteers in terms of registration and CRB checks, with which the project concurs eg: Age UK have specific rules

⁹ This is not a strict criterion for support - an alternative is 'within the catchment area of the GP practice'. Even then the project will try to help those who fall outside this criterion.

and requirements for volunteers involved in Food 'n' Friends lunch clubs; CAMEO (a church-based friendship group) requires certain references and checks for its volunteers. Generally however, The Debenham Project provides help, advice, and support to family carers and doesn't interact on any regular unsupervised 1:1 basis with those with dementia, and then only in the presence of their carers or relatives. This means that, as with training, CRB checks are required only 'when appropriate' rather than on a 'blanket' basis.

The majority of the volunteers are over 50. The project does not collect statistics about the volunteers and so has no detailed information about demography etc.

f) Project activities

The Debenham project runs a significant number of activities including:

- Monthly Food 'n' Friends Lunch Clubs with Age UK: Two are in volunteers' homes and specifically for carers of those with dementia and those they care for, and one at the local sheltered housing complex which is more inclusive.
- Weekly Exercise club: Chair based exercise. Not specifically dementia focused. At Dove Cottage – very popular.
- Confidential telephone helpline: Runs weekend evenings. It has not been much used, with four significant (we cannot estimate the importance to the individuals) calls over the last year, but carers value it as "just knowing that there is someone to talk to, and who understands, is a big thing – a bit like an insurance policy".
- Carers Club and Info Cafe: These run alternate fortnightly and are supported by the Alzheimer's Society and Age UK, whose workers provide support and advice. Their help is supplemented by a CPN attached to the Suffolk Mental Health Trust. The local librarian also attends to provide help to access good and accurate information.
- The Project persuaded the Suffolk Mental Health Trust to run a bi-monthly memory clinic in Debenham, initially for one year. For those that attended the clinic, this worked extremely well but the numbers using the clinic were too small to justify continuing the arrangement. The Mental Health Trust is committed to reinstating the arrangement if the numbers justify it. In the meantime the project offers trained volunteers to accompany people to diagnostic assessments at hospital clinics instead.
- Advice and information: The Project has its own simple and direct website, a wide range of straightforward leaflets written specially for carers and which are displayed in the Post Office and are also available at the local library. In addition, the local librarian attends the Carers Club and Info Café and will help people access good web-published information. Advice and information (and a 'listening ear') is also available on the 'Project Line' at any time during the week.

- CAMEO: This is a church-based group which has been transformed through its link with the Debenham Project. It meets fortnightly with activities and includes people with dementia and their families.
- Carers Co-op: Recently the project has started an activity (in partnership with 2 professional care organisations) which it is hoped will lead to a unique approach to providing professional social and specialist domiciliary care – a network of self-employed carers.
- Research: The project is conducting a funded study into how it can encourage family carers to seek help (and perhaps diagnosis) earlier and will be using the results to further enhance awareness in the community. There is substantial interest in this at County and National levels.

The project has had a noticeable impact on the wider village. There is good awareness of the project and more people in the village and surrounding area say that they feel confident and able to react usefully to someone with dementia. Lynden has also noticed that more people are happy to discuss and ask for information about dementia - “people are now prepared to talk about their concerns ‘in the street’.

g) Mutuality and reciprocity

Mutuality is at the heart of the aims of the Debenham Project – the commitment to ensure that no-one with dementia should have to leave the village for care recognises that relationships have mutual importance and that friends, neighbours and families will also lose a great deal if the person has to leave their community.

Project activities are all designed to provide the help and support people need if they are to continue to care for their relative with dementia at home. Many of them in addition provide safe and accepting spaces in which people with dementia can meet friends and continue to connect with other people in their community. The longer-term vision of course is much more radical and designed to ensure that people remain part of their community to the end.

h) Infrastructure and resources

The cost of the development of the project and the operating of the activities has been / is being met as follows:

- An initial grant from the Mid Suffolk local strategic partnership: £7.5k Further £18k to take project to the end of 2012. Part of grant has been put towards increased facilities in Dove Cottage (which belongs to the church and has been used for Cameo, the exercise club, the memory clinic and the Carers’ Club, and Info cafe).

- A grant from the County Council of £7K for office equipment and accommodation development. Money has been set aside from this grant for improved disabled facilities in Dove Cottage
- An award of £10K from the Suffolk Foundation which is being used to set up a co-operative of local care workers to provide consistent care from familiar people.
- A grant from the Norfolk and Suffolk Dementia Alliance of £22k for research into the barriers to people seeking early diagnosis and help.
- Donations towards the work of the project amounting to approximately £7K have been made by private individuals and local groups.

i) Governance arrangements

The Debenham Project is a charity. There is a small group of trustees who have legal responsibility and also a larger steering group which provides advice and ensures accountability.

The project co-ordinator is accountable to the trustees who agree the strategic direction for the charity.

j) Benefits, outcomes and other measures of effectiveness

The charity has not established measures of effectiveness and does not systematically gather data to evidence outcomes. Lynden argues that, whilst numbers are important in establishing a baseline of success (The Debenham Project has already provided some level of support to significantly more than 50% of the total estimated number of those who are caring for someone with dementia within the catchment area and is seeking to advance this to over 70%), within a community success is measured by the impact that the existence of the project has made on the quality of life for individual carers and those they care for. Evidence of benefit is therefore anecdotal and is gathered through direct contact with people with dementia and their families and people in the wider community. The trustees and the steering group have been established to ensure that the project stays on the right lines and is carrying out work that is approved by the community.

Lynden believes that The Debenham Project is neither about 'the numbers game', nor of 'meeting targets', or even of 'cataloguing testimonials' – "when trying to help those around you in your own community, you just know whether or not you are making a bit of a difference".

This case study involved interviews with 25 people directly or indirectly involved in the project, including volunteers, people with dementia and their families, trustees and steering group members, parish and county councillors and health and social care professionals. All those interviewed were positive about the project, its activities and its longer term vision.

People with dementia and their families clearly valued the support they were getting through the project, which contrasted with their experiences with the health and social services.

*'What is great is this is a group of people really trying to do something'
'They are all local people and they actually care'*

The story of one family

Jill and Chris¹⁰ are both in their 80s and live in a small hamlet just outside Debenham. They have little contact with their neighbours and are supported by their daughter who lives locally. Jill has dementia and Chris has struggled with the isolation of caring for her. He has CFS (Chronic Fatigue Syndrome) and has become very frail himself

Jill and Chris were put in touch with the project 2 years ago and say *'this is the best thing we've ever done'*. They started by going to the Carers' Club and now have joined a Food and Friends Lunch Club. They have made friends through these clubs and also enjoy seeing Lynden when he visits.

Chris' involvement with Lynden has also opened up other opportunities. Lynden discovered that Chris' hobby was making beautiful scale models of harvest equipment through the ages. Lynden persuaded his church to exhibit the models as part of its harvest festival celebrations. The exhibition was over two days and Chris came for one of the days – he enjoyed people's pleasure and interest in his work and had some good conversations.

4. Analysis and Observations

a) Why Debenham and why now?

The people interviewed as part of the case study highlighted a number of factors which they believed underpinned the success of the project:

- Debenham [and the surrounding villages] is large enough to have a number of people to call upon for help and small enough for most people to know each other. It has a defined centre with local shops and other facilities and a well-used leisure centre. There are plenty of opportunities then for people to bump into each other and the casual conversations that result have been important in identifying the issues people need addressing, in recruiting help and in checking back that people are happy with the way the project is developing.

¹⁰ Not their real names

- People in the wider community defined the problem and helped to shape the solution. The project had a wide community mandate which gave it sustainability and authenticity. *'A problem defined by a small group and with a solution imposed from outside is less likely to succeed'*
- People in Debenham had successfully tackled other projects and so had confidence that this project would succeed as well.
- The community kept control of the project, drawing on professionals as needed for help *'It was their project, theirs to make mistakes and theirs to reap success'*
- The project co-ordinator is respected and liked by people in the community, has [been able to develop] a wide network of contacts in a number of different sectors across Suffolk (locally, district council, county council, NHS etc) and is both determined (*'never gives up'*) and flexible (*'tests an idea, relinquishes it if it doesn't work and tries another way'*)
- The project had a number of influential 'project friends' (eg: the dementia lead for Suffolk County Council, senior executives in the NHS and the local authorities, the local and influential county councillor, etc).
- The project has also a number of influential supporters at national level (eg. The local member of Parliament and other MPs, members of the House of Lords, and senior executives of national organisations).

Some people felt that the demography was important – Debenham has a comparatively large number of retired professional people who have time and skills that have been useful to the project. Others argued that while this may have shaped the project it would have been entirely possible to run a successful project in a different demography.

b) Sustainability

The project is heavily dependent on the commitment and energy of a small number of people. This is a common pattern with community projects which can founder if key people end their involvement. The trustees have identified this as an issue and have thought¹¹ about what would happen if for example Lynden and Sue Jackson have to scale down their work with the project.

Funding is the other factor which has a strong impact on sustainability. Project activities are run on a limited basis but the project still needs to establish core funding to cover continuing costs in the long term. The project has had some (but very significant) time-limited support from the district and county council but grant applications take up a great of time and inevitably funding takes a significant effort away from which is a very 'lean' project management resource. In addition the bidding process and grants criteria can distort the project and its vision by seeking to achieve objectives that are not consistent with the local needs. The project co-ordinator argues that funding for community projects that are

¹¹ <http://www.the-debenham-project.org.uk/downloads/minutespolicies/policies/resilience.pdf>

established in response to local need should be eligible for core funding from the council and that there should be a simpler process of application. In addition it should be accepted that the numbers of people that are likely to benefit from a rural project are likely to be low and that project outcomes should be measured in terms of individual benefit rather than purely on numbers. Impact measurements linked to numbers will always disadvantage rural projects.

c) Scaling out and up etc

People involved in the Debenham Project believe that similar projects could flourish in other communities across Suffolk of a similar size and structure even where they have different demographics. They may well define the problem differently and come up with different solutions but the key features (a project established to address a problem defined by the community, shaped and owned by local people and benefiting community members) will be the same. Key factors for the successful establishment of a similar project in a different community will be:

- Conversations with local people (individually and in groups) to define the problem that people feel needs to be addressed.
- Identifying and motivating a strong leader who combines local rootedness with drive and good networking skills.
- A mandate from the community to develop solutions to the defined problem.
- A long term vision but one which is combined with a 'do something now' approach which will encourage involvement and commitment from local people.

This approach is painstaking and takes time. Small sparks of interest need to be nurtured and ideas tried, tested and continually reshaped. The challenge with a centrally driven approach is that there is often pressure to short cut and simplify (eg: seed funding and training) and to achieve outcomes within a comparatively short time scale.

5. Conclusion

The Debenham project is an inspiring example of what can happen when local people decide to take action themselves to tackle a problem affecting friends and neighbours in their community. I spent two days with people involved in the project and was impressed by their focus on 'big vision' and practical action, The project has already made a positive difference to many local people's lives – the 'big vision' (when it is achieved – and I know it will be) will benefit many more. Now we just need to find a way of extracting the lessons from this approach and sharing them with other communities.