



Kent Academic Repository

Brookes, Nadia (2016) *Implementation of a community-based approach to dementia care in England: Understanding the experiences of staff*. Journal of Social Service Research, 43 (3). pp. 336-345. ISSN 0148-8376.

Downloaded from

<https://kar.kent.ac.uk/58371/> The University of Kent's Academic Repository KAR

The version of record is available from

<https://doi.org/10.1080/01488376.2016.1242448>

This document version

Author's Accepted Manuscript

DOI for this version

Licence for this version

UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our [Take Down policy](https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies) (available from <https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies>).

Author-accepted version (26 Sep 2016)

Brookes N (2016)

Journal of Social Service Research

DOI: <http://dx.doi.org/10.1080/01488376.2016.1242448> (available online 2 November 2016)

Implementation of a community-based approach to dementia care in England: Understanding the
experiences of staff

Nadia Brookes*

*Correspondence to Nadia Brookes, Personal Social Services Research Unit, University of Kent,
Canterbury, Kent, CT2 7NF, UK. E-mail: N.K.Brookes@kent.ac.uk

Acknowledgements

This article draws on independent research funded by the National Institute for Health Research (NIHR) School for Social Care Research (SSCR), England. The views expressed are those of the authors and not necessarily those of the NIHR SSCR, the Department of Health or National Health Service, England. Acknowledgement is due to the staff for supporting the research and to the other participants who took time out of their busy schedules to contribute. Lesley Cox the local fieldworker also made a valuable contribution, conducting several of the interviews. Finally, to the project advisory groups (comprising both professional and lay members) for helpful advice throughout the research process, and to colleagues Lisa Callaghan and Ann Netten.

Implementation of a community-based approach to dementia care in England: Understanding the experiences of staff

Abstract

Given the increasing numbers of people living with dementia it is imperative that new, practical solutions are found to the issues faced by this group of people and their families. This article draws on findings from a qualitative study which explored the implementation of a community-based project to support people living with dementia in one local area in England. This approach has different names, and in the United Kingdom it is known as Shared Lives or adult placement, which would be most comparable to family care in Europe, and adult foster care in the United States. Interviews were conducted with 14 staff connected to the Shared Lives project. Interview data were coded using the normalisation process theory constructs of coherence, cognitive participation and collective action. Supportive program factors identified were a dedicated staff member and resources, and the availability of specialist knowledge and skills. Detriments to program success included: a lack of understanding about the service, perceptions it was a poor fit with existing practice, and wider organizational issues that impacted negatively on the normalization of the intervention. Suggestions for future research are made that go beyond staff opinions, stressing the importance of using a wider range of stakeholders and incorporating measurement of outcomes for people using the service.

Keywords: dementia, community, implementation, qualitative study, normalisation process theory

Introduction

There are over 46.8 million people worldwide with dementia. It is predicted that this will increase to over 75 million by 2030 and over 130 million by 2050 (Prince, Wimo & Guerchet et al. 2015). By 2050, it is estimated that the numbers of people with dementia will increase by 116% in high income countries and by 227% in the rest of the world (Mesterton, Wimo & Langworth et al. 2010). There are 850,000 people living with dementia in the UK today, including over 700,000 people in England (Alzheimer's Society, 2014). By 2025 the number is expected to rise to over one million and by 2050 it is projected to exceed 2 million (Lewis, Sussex, O'Neill & Cockcroft, 2014). Given the increasing numbers of people living with dementia it is imperative that new, practical solutions are found to build connections to help these people stay in the community and support this group of people and their families.

A report published in 2007, *Dementia UK: The Full Report* (Alzheimer's Society, 2007) marked a change in awareness about dementia and highlighted the inadequacy of UK policy responses to this challenge at the time. Progress has been made since then, in particular dementia has been accorded much greater national priority through the formulation of national dementia strategies for each country of the UK (Department of Health, 2009; Department of Health, Social Services and Public Safety, 2011; The Scottish Government, 2010; Welsh Government, 2011).

The dementia strategy for England, *Living well with dementia: A National Dementia Strategy* and the supporting implementation plan was published in 2009 (Department of Health, 2009). This five-year strategy launched under the New Labour administration was endorsed by the Coalition

Government, which published a second version of the implementation guidance in 2010. The strategy was produced to enable improved care and support for people with dementia and their carers (known as caregivers in the United States). The aim of the strategy was to ensure significant improvements in dementia services across three key areas: awareness, earlier diagnosis and intervention, and high quality of care.

In March 2012 the UK Coalition Government launched the *Prime Minister's challenge on dementia: Delivering major improvements in dementia care and research by 2015* (Department of Health, 2012). The Prime Minister's challenge aimed to build on the achievements of the national dementia strategy and outlined a number of ambitions in three areas. The three identified areas for support were: improving services for this population; creating "dementia friendly" communities that know how to help this group of individuals; and basing improvements and changes as well as measuring progress through research. Linked to the Prime Minister's Challenge was the National Health Service Dementia Challenge Fund (linked to the Prime Minister's challenge), which enabled local communities to identify and implement practical solutions to the problems faced by people living with dementia. A successful application to the fund (match funded by the local authority) facilitated the setting up of the project examined here.

The dementia project was based on the Shared Lives model of community-based support and attached to an existing Shared Lives service. Shared Lives Plus (the UK network for family-based and small-scale ways of supporting adults) describes Shared Lives as 'where an individual or family is paid a modest amount to include an isolated or under-supported older or disabled person in their family and community life. In many cases that person goes to live with a Shared Lives carer and their family, although Shared Lives is also used as day support, as respite care for unpaid family carers, as home from hospital care and as a stepping stone for someone to get their own place' (NAAPS, 2010). Shared Lives carers, and the person requiring support, are carefully 'matched' to ensure compatibility by scheme staff, at present 80 per cent of schemes are run by local authorities. A key feature is that the Shared Lives carer's home is used as a resource, the service user goes to the carer's family home rather than support being provided in the person's own home or in a residential facility. The majority

of users of Shared Lives services in England are people with learning disabilities, 7,710 in 2014 followed by 820 people with mental health issues, 310 older adults and 280 with physical disabilities (Shared Lives Plus, 2014).

There is a large body of literature in the United States about adult foster care which could be considered the equivalent to this program. It is also equivalent to adult placement or family care as it is known in Europe. Whilst there are some differences between the US and the UK such as the number of people living in one home and funding arrangements, there are strong similarities in the implementation of these types of programmes. In the US a number of comparative studies (although now conducted some time ago) have shown that these programmes are as good as, or better than, more institutional options for older people, such as nursing homes, in terms of both health outcomes and levels of social activity (Bravo, Charpentier, Dubois, DeWals & Emond, 1998; Eckert, Namazi & Kahana, 1987).

There has been a limited amount of research in connection with Shared Lives in England and it is only more recently that this type of service has begun to attract attention in the literature. There is some evidence of high levels of satisfaction among people using the service (Fiedler, 2005; NAAPS & IESE, 2009) alongside cost-savings when compared to traditional services, particularly for people with learning disabilities (NAAPS & IESE, 2009; Social Finance, 2013). It has been suggested that Shared Lives out-performs alternative care and support options on some key indicators of personalisation, such as inclusion, flexibility, choice and control (NAAPS, 2010). Shared Lives has been proposed as a potential alternative to traditional respite care, with care provided in a home environment (McConkey, McConaghie, Roberts & King, 2002; Valios, 2010).

Shared Lives had been identified as having potential as an option for older people, including those with dementia (Author's own, 2013; Fox, 2011; Valios, 2010). The most recent project to focus specifically on Shared Lives and dementia was conducted by Innovations in Dementia (a consultancy and training Community Interest Company) and Shared Lives South West (a regional charity running Shared Lives services) who conducted a three-year project looking at how the service could support people with dementia and their families, what people with dementia and their families thought of

Shared Lives services, and how such services could be developed across the UK (Bell & Litherland, 2013). The project's main purpose was to gather evidence to show whether Shared Lives could be a desirable service offer from a carer or person with dementia's perspective and to support Shared Lives schemes to gain the confidence and skills they needed to be 'dementia ready'.

The project found that family carers and people with dementia responded very positively to Shared Lives services. The majority of those who used it felt it was personal, reliable and that the person with dementia enjoyed themselves. Shared Lives schemes appeared to be well placed to develop services for people with dementia and the core processes of matching, monitoring and supporting Shared Lives carers appeared to work well for this client group. It was clear that many schemes had already begun to develop dementia services on a small scale, often in response to an individual case where an existing service user with a learning disability had developed dementia or where a specific referral had been made. The experience of schemes actively developing dementia services indicated that this expansion required specific investment in knowledge and capacity within the scheme.

It was apparent from the project that Shared Lives as a concept or service model was not well known in the social and health care sectors that predominantly focus on older people or people with dementia. Recommendations from the project included the need to establish a higher profile as an option for care amongst the wide range of professionals who work with people with dementia and their family carers. Shared Lives should be seen as a core component in the local implementation of the national dementia strategy, and be fully included in the range of options commissioned for people with dementia in any area.

In 2012, the National Institute for Health Research School for Social Care Research commissioned the Personal Social Services Research Unit at the University of Kent, Canterbury, UK to examine the potential use of Shared Lives for older people. As part of this project in-depth work took place with three Shared Lives services and the project described here was one of the three research sites. Broadly the objectives of the Shared Lives dementia project were to: develop capacity in local communities; provide a person-centred alternative to traditional models of dementia care;

recruit, train and provide continued support to a bank of Shared Lives carers; and provide one-to-one support where the needs of the person with dementia match the Shared lives carer. Although the Innovations in Dementia project produced a great deal of useful information, it did not include how to implement the service for this group of people in practice. The *Outcomes, Processes and Costs of Shared Lives* project provided an opportunity to build on the previous work. To better understand the factors in implementing a service such as this, staff opinions were sought. The research questions to be explored were: how is the dementia project being implemented; what is working well; and what are the challenges?

Methodology

The overall approach adopted for the research was formative evaluation, given that the service was a new one. This meant a focus on the 'softer' side of project activities such as relationships, processes, organisational context, change processes and management. This was to encourage reflection and emphasise key lessons that could be learned for the local area and more widely.

Sample Participants

The care manager responsible for leading the dementia project provided information on potential interviewees based on their exposure to the project, either through a connection to the wider Shared Lives service or as potential referrers to the dementia project, a purposive sample. Twenty individuals were approached who either worked within the local authority that ran the Shared Lives service and dementia project, or worked for non-profit organisations covering the same geographical area. Six people declined to participate due to being unavailable during the timeframe for data gathering.

Fourteen interviews were conducted with: Shared Lives services and dementia project staff (5); Shared Lives carers (2); social care practitioners, commissioners and managers (4); and representatives from local non-profit groups working with older people and carers (3). The interviews were conducted between November 2013 and January 2014, a minimum of six months after the project had started.

Materials and Interview Guide

Normalisation process theory (NPT) was used to provide a framework for generation and analysis of data. NPT is a conceptual tool used primarily to examine the implementation of complex interventions, particularly reflecting on how changes became 'normalised' or accepted, demonstrated by changes in thinking, actions and organisation. May and Finch (2009) describe it as a theory that can be used in prospective process evaluations and to assist in directing research to the questions that are intrinsic to sustainability. It focuses attention on implementation as a social process and on the social factors that may constrain or enhance the work of implementation. NPT is concerned with understanding trust and interpersonal relationships within social networks as they impact on the introduction of something new. However, NPT can go beyond this to investigate the processes by which it may become embedded and routinized in practice. NPT uses four constructs to allow for closer examination of elements that are important in the embedding of change (see Table 1).

[Insert Table One Approximately Here]

A similar semi-structured schedule was used for all interviewees. Interview questions specific to the project were designed to reflect three of the NPT constructs as it was too early in the process of implementation to consider reflexive monitoring. There were a total of fifteen questions, two covering role and responsibilities of the interviewee, four covering each NPT construct and one closing questions (see Table 2 for example questions).

[Insert Table Two Approximately Here]

Procedure

All relevant people, groups and authorities were consulted and the necessary permissions obtained to conduct the research. Approval was obtained from the national Social Care Research Ethics Committee for the project as a whole.

Potential interviewees were emailed in the first instance by the research team and provided with a participant information sheet if they expressed an interest in taking part. Written consent was

obtained at the time of interview. Twelve of the 14 interviews were audio-recorded and transcribed (the recordings were then permanently deleted), in two cases notes were made during the interviews rather than recordings at the request of interviewees. Interviews lasted between 45 minutes and one hour and were conducted at locations within the community convenient to interviewees.

Analysis

NVivo specialist software for qualitative analysis was used to code and manage the data. The principles of thematic content analysis were followed. These categories were examined and placed under headings according to the NPT constructs plus 'other' if there were issues and topics that did not clearly fit with the theory. The procedure for assessing trustworthiness of the data analysis was through credibility or stakeholder checks with research participants and other people with a specific interest in the research. Interpretations and conclusions were also verified by on-going discussion within the research team and project advisory group.

Results

Key themes were identified and described shaped by the NPT framework, Table 3 provides a summary of the overall results organised according to the constructs of NPT. Results are described under the main NPT constructs.

[Insert Table Three Approximately Here]

Coherence

One of the main themes to emerge from the data was a lack of awareness and understanding about the dementia project, and more generally about the model being offered to support older people. There were some interviewees who knew about the Shared Lives service but only in relation to learning disabilities.

I always felt it was more learning disability rather than dementia so it was not something I ever got interested in really (practitioner)

The care manager running the project and the wider Shared Lives staff team were clear about their roles in relation to the dementia project. There was less clarity with social care professionals and staff from other organisations who were not sure what was involved in referring someone to the service, and there was a perception that this was time-consuming and complicated.

I could see why people may be uncertain about it...that the process could be lengthy and bureaucratic (voluntary sector worker)

Most interviewees could identify what the potential benefits of the dementia project were once it had been briefly described to them. They could see that it could be a viable alternative to residential care, the positive aspects of the home environment and being part of a family, and that it was person-centred. Interviewees on the whole believed the ‘idea’ of the dementia project to be a good one.

I can imagine it would be much better for somebody to feel that they have developed good relationships with people they know rather than a change of staff all the time (voluntary sector worker)

Cognitive participation

Having a key individual to drive the project forward was seen to be essential to set up systems, procedures and to engage with others. The project care manager worked closely with the manager of the Shared Lives service, and there were two or three managers out in the local authority who described themselves as ‘champions’ of the project. However, this was not always seen as enough to filter through to the care management teams to fully implement the project.

I have a role to play...we’d agreed I’d champion it wherever I can (local authority manager)

The social care professionals interviewed did not change the way they worked to accommodate the dementia project. They also identified that generally they did not discuss Shared Lives or the dementia project with colleagues because of hot-desking (multiple people using a work space during different time periods) and work pressures. Similarly, representatives of voluntary sector

organisations working primarily with carers did not have an office base and so often worked in isolation without informal contact with colleagues. As one practitioner stated:

We've missed out on lots of opportunities to discuss issues, we're just fire-fighting, so when you get a development like this we don't have the benefit of those casual conversations. We might have talked about it when we came out of the meeting but then haven't discussed it since because we're literally just in fifth and sixth gear all the time (practitioner)

On the whole it was the wider Shared Lives team who felt that they could make a valid contribution to the project through helping to approve carers and altering systems such as health and safety checklists to incorporate service users living with dementia. Shared Lives staff were also aware of the increasing number of service users part of their case load with learning disabilities who were developing dementia.

Especially as...we've almost all got one learning disability service user that have signs of dementia so we're actively supporting that anyway (Shared Lives staff member)

Collective action

The division of labour between staff members was not really affected by the project during the timeframe of the research. In terms of 'contextual integration', while there did appear to be support for the project as a concept the adoption of something new was made more difficult in the context of wider organisational change. There was the feeling that a constant process of restructuring and 'transformation' which staff were having to accommodate made taking on board new things less likely. As one commissioner stated:

There's a lot of change going on at the moment though with the whole transformation programme and people are kind of change weary and aren't able to take on new concepts (commissioner)

...huge amount of change and anxiety in the teams, the care management teams. And I think another initiative...I find you just want to say 'Oh no I don't think this is going to work' (practitioner)

Shared Lives interviewees reported some support from individual managers but that there were still difficulties in gaining help with practical issues across the local authority. There were also some difficulties caused by the service as a whole sitting within the learning disability directorate which meant that there was less commitment to the older people and dementia aspects of the work from there, but also the older people's directorate had not engaged in raising awareness of the project.

Learning disability have one agenda but that's where it's all been led...which sometimes causes a little bit of tension because we're not always going in the same direction (local authority manager)

The identification of the project as distinct from the main service was described as both a barrier and a facilitator. The provision of dedicated resources and someone with specialist knowledge and skills was identified as a positive, whilst there was a feeling amongst other interviewees that labelling it a 'project' implied it was time-limited which might have deterred people from accessing it. The appointment of a dedicated care manager was perceived by interviewees as crucial for the project. Interviewees highlighted that it was necessary to have someone who had the time to do all the necessary networking, advertising and liaison to make the project work. As one interviewee stated:

You have to talk it through because people don't get it just from reading it (Shared Lives staff member)

A factor that impacted on 'interactional workability' was the belief amongst some interviewees that the Shared Lives model of support for older people and/or people living with dementia was 'at odds' with the existing model of service delivery, which was essentially crisis-driven. Time constraints and pressures intrinsic to social work practice also meant they were less likely to use Shared Lives. As one interviewee commented:

Ninety per cent of our older people's placements are made at a time of crisis. A large percentage are made via a hospital admission, so this kind of matching and slow stream is at the moment at odds with our model of delivery (commissioner)

We try everything to keep someone at home and then we get desperate and we need it to happen today (practitioner)

Outside agencies, including those who had signed up to the original project proposal were described by local authority staff as ‘unhelpful’. Organisations working with older people, people living with dementia, their carers and families were described as acting as ‘gatekeepers’. The agencies did not want to distribute information and did not see it as their role to promote local authority services.

Not willing to disseminate our information and no local advisors, no local offices have actually agreed to a meeting...these were the people who signed up to this project in the first place (Shared Lives staff member)

The interviews highlighted that staff who were potentially the main source of referral to the project utilised well-rehearsed management strategies for older people which typically included respite or respite in a care home setting. This created a barrier to the implementation of new practices which fell outside of these normal routines. As one practitioner and potential source of referral commented:

...we tend to stick with what we know. So respite or respite at a care home is easier to organise than somebody going to somebody’s home (practitioner).

I just think that when they go back to their day jobs it’s much easier to do what they’ve always done, which is arrange a care home or arrange a care package, you know, suddenly job done. And they follow the path of least resistance (commissioner)

There was a perception from some potential referrers to the service that this was a learning disability service, was not appropriate for older people and not practical in the long-term. As one interviewee stated:

It was not really designed for dementia as it would be difficult for people to adapt to new surroundings (voluntary sector worker)

Discussion

The research findings provide useful messages for the future development of this particular service but also for the introduction of new ways of working within social services more widely. NPT did provide a useful lens through which to view implementation and this research was one of the first occasions where this has been applied to social care settings. However, there were limitations to the evidence generated, for example it would have been beneficial to collect data at more than one point in time to more fully explore how these constructs influenced the ongoing sustainability of the model within the organisation, but this was not possible within the research timeframe. Although the project involved multiple stakeholders, people using services and their families could not be included as referrals to the service did not come through during the lifetime of the research. This would have enabled analysis of implementation from a wider range of perspectives.

Several theoretical approaches could have been selected for this research, for example organisational theory, innovation studies and others that address issues of uptake and implementation of evidence. Although primarily used in health care settings, NPT did appear a good 'fit' for the project as the theory has a focus on exploring how a change of 'work' within an organisation and the complex interactions that need to be in place to ensure the embedding of change. The attention NPT gave to all stakeholders' involvement in the implementation process, collectively and individually, was a key factor here given the reliance on referrals from case managers and others outside the Shared Lives dementia project.

Coherence

Coherence or 'meaning' in practice can be difficult to achieve for several reasons including a lack of clarity and certainty about the benefits of an intervention. One of the largest implementation barriers was the variable understanding of the aims and objectives of the project from non-Shared Lives staff and a general lack of awareness about Shared Lives and/or the dementia project. Without this understanding it was unlikely that Shared Lives would be offered as an option to service users living with dementia or their families. The previous Shared Lives and dementia work (Bell & Litherland, 2013) also found this to be an issue that needed to be addressed across professional staff groups working with this client group. Once the project had been described in more detail to

interviewees the majority could see the benefits and so finding a way to communicate information effectively to staff will be key in the future.

Cognitive participation

For cognitive participation or the work to enrol individuals to engage with a new practice, having a dedicated care manager to lead the project was seen as key to getting it off the ground. However, certain hindering factors to cognitive participation were highlighted through the interviews which emphasised how essential consideration of existing working practices is when introducing something new. The perception from social care professionals was generally that this model was a poor fit with existing working practices, and this translated into a lack of ownership and engagement with the project. Apparent from the interviews was that the work of the social care professionals was often 'routinized' making it difficult to deviate from existing practices. Social care practitioners felt that their current approach to working with older adults and those living with dementia appeared to work, as this usually led to the effective management of the client. This meant that a change of practice could be perceived as unnecessary, 'risky' or more open to challenge. Brown (2010) suggests that the vulnerability of service users and carers, lack of incentives, regulatory frameworks and scarce resources all impact on innovation and risk in a social work context. There is the potential for this to be addressed in the longer-term, in this particular instance once the service can provide examples of 'success' stories from Shared Lives support for people living with dementia, this may help to convince practitioners that this is a safe and effective approach.

Peer communication was also highlighted as a factor affecting adoptive behaviour. Communication between colleagues usually serves two aims: raising awareness, often important in large organisations where dialogue between individuals may be less direct; and individual or collective evaluation of a new way of working integral to its acceptability (Sanders et. al. 2011). Staff who were potential referrers to the project acknowledged this, but felt that their current working environment, time pressures and a lack of permanent desk-space did not facilitate this kind of dialogue. The service may need to foster some 'champions' within the practitioner teams to raise awareness and to help others see acceptance of the approach amongst their peers.

Collective action

Collective action or the work to enact a new practice was seen as being supported by having a key member of staff to lead the project who had specialist knowledge and skills. Wider factors though seemed to have greater influence, such as the local authority context in which the project was being implemented, where practitioners had been and were going through various reviews, restructuring, initiatives and change processes. It was felt that this impacted negatively on their ability to adopt a new way of working with a particular client group. The perceived 'unhelpfulness' of agencies outside of the local authority in raising awareness of the project may have also been in part to do with the wider context of budgetary constraints and that they were in 'competition' to provide services. Therefore, timing should be a consideration in the introduction of new ways of working to minimise the impact of external factors.

Despite there being overall support for the concept of the project (mostly in the form of respite, short breaks or day support), the usual scenario for practitioners was dealing with people in crisis or in emergency situations and this was likely to have hindered consideration of alternative routes of care and support. This crisis management approach may also have heightened practitioner's reluctance to get involved with a model perceived as more time-consuming with the emphasis on finding a 'good match'. Addressing this issue may require a more fundamental change to practice, for example reviewing caseloads for potential referrals and linking them in to the service before crisis situations occurred.

There was a lack of buy-in from some staff based on the perception that this model of care and support was not practical in the long-term for older people and that it was not really set up to deal adequately with people living with dementia. The view held by some interviewees was that service users with learning disabilities were able to adapt to new surroundings in a way that people with dementia were not. There was no clear evidence of effectiveness for this particular group and so this, balanced against the risks to service users, may have been one of the reasons for slow adoption. However, the idea was that people with low to moderate needs would be the main target group and that there would be a move through the different types of Shared Lives provision over time. This may

need to be emphasised in any awareness raising activities, as well as the utilisation of ‘success stories’ for service users mentioned earlier once these became available.

Conclusion

Introducing new services requires investment of significant time, energy and resources and it is important particularly in times of financial constraints that these have the best chance of success. It is equally important that new ways of supporting people living with dementia and their families can be found. These findings highlighted some of the potential facilitators and barriers in trying to achieve this. Although specific to one local setting these findings can be adapted and made relevant to other situations. NPT was part of the research design and did help to explain the slow acceptance of the model for dementia care and support within the local area. In this case it would appear that despite clear support for the aims of the dementia project, adoption of a new way of working was influenced by existing working practices, the available ‘space’ staff had to take on new concepts and ideas, and communication between peers. A key recommendation for the future development of the project is consideration of the introduction of review of cases for potential referrals before a crisis point has been reached, this would then enable the timely introduction of people living with early stage dementia and their families to this type of support. There is also a need for future research to examine implementation over time, the acceptability of the service for people using it and whether it is meeting their needs and improving quality of life.

References

- Alzheimer's Society (2007). *Dementia UK: The Full Report*. London: Alzheimer's Society.
- Alzheimer's Society (2014). *Dementia 2014: Opportunity for change*. London Alzheimer's Society.
- Bell, J. & Litherland, R. (2013). *Shared Lives and Dementia*. Devon: Shared Lives South West and Innovations in Dementia.
- Bravo, G., M., Charpentier, M. F., Dubois, P., DeWals, P. & Emond, A. (1998). Profile of residents in unlicensed homes for the aged in the eastern townships of Quebec. *Canadian Medical Association Journal* 159(2), 143–148.
- Brookes, N. and Callaghan, L. (2013) What Next for Shared Lives? Family-based support as an option for older people. *Journal of Care Services Management*, 7, 87-94.
- Brown, L. (2010). Balancing risk and innovation to improve social work practice. *British Journal of Social Work*, 40, 1211-1228.
- Department of Health (2009). *Living well with dementia: A National Dementia Strategy*. London: Department of Health.
- Department of Health (2012). *Prime Minister's challenge on dementia*. London: Department of Health.
- Department of Health, Social Services and Public Safety (2011). *Improving dementia services in Northern Ireland: a regional strategy*. Belfast: Department of Health, Social Services and Public Safety.
- Eckert, J. K., Namazi, K.H., & Kahana, E. (1987). Unlicensed board and care homes: an extra-familial living arrangement for the elderly. *Journal of Cross-Cultural Gerontology* 2(4): 377 – 393.

- Fiedler, B. (2005) *Adult placement in England: a synthesis of the literature*. London: Social Care Institute of Excellence.
- Fox, A. (2011). A new model for care and support: sharing lives and taking charge. *Working With Older People*, 15, 58-63.
- Lewis, F., Schaffer, S., Sussex, J., O'Neill, P. & Cockcroft, L. (2014). *The Trajectory of Dementia in the UK – Making a Difference*. London: OHE Consulting.
- May, C. & Finch, T. (2009). Implementation, embedding and integration: an outline of normalisation process theory. *Sociology*, 43, 535-554.
- McConkey, R., McConaghie, J., Roberts, P. & King D. (2002). *Adult family placement schemes for family carers*. Ulster: University of Ulster.
- Mesterton, J., Wimo, A., By, A., Langworth, S., Winblad, B., & Jönsson, L. (2010). Cross Sectional Observational Study on the Societal Costs of Alzheimer's Disease. *Current Alzheimer Research*, 7, (4) 358-367.
- NAAPS (2010). *The Shared Life of my choice*. London: NAAPS.
- NAAPS & IESE (2009). *A business case for Shared Lives*. London: NAAPS.
- Prince, M., Wimo, A., Guerchet, M., Ali, G., Wu, Y., & Prina, M. (2015). *World Alzheimer Report 2015, The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International.
- Sanders, T., Foster, N.E. and Nia Ong, B. (2011). Perceptions of general practitioners towards the use of a new system for treating back pain: a qualitative interview study. *BMC Medicine*, 9.
- Shared Lives Plus (2014). *The state of Shared Lives in England*. Liverpool: Shared Lives Plus.
- Social Finance (2013) *Investing in Shared Lives*. London: Social Finance.

The Scottish Government (2010). *Scotland's National Dementia Strategy*.

Edinburgh: The Scottish Government.

Valios, N. (2010). *Time to Share scheme for dementia patients*. Community Care Online.

Welsh Government (2011). *National dementia vision for Wales*. Cardiff: Welsh Government.

Table 1. NPT theoretical constructs and components

Construct	Component	Meaning
<p>Coherence: the process and work of sense-making and understanding that individuals and organizations have to go through in order to promote or inhibit the routine embedding of practice</p>	Differentiation	Understanding how a set of practices and their objects are different from each other
	Communal specification	People working together to build a shared understanding of the aims, objectives, and expected benefits of a set of practices
	Individual specification	Participants in coherence work need to do things that will help them understand their specific tasks and responsibilities around a set of practices
	Internalization	Understanding the value, benefits and importance of a set of practices
<p>Cognitive participation: the process and work that individuals and organizations have to go through in order to enrol individuals to engage with the new practice</p>	Initiation	Whether or not key participants are working to drive new or modified practices forward
	Enrolment	The need to organize or reorganize themselves and others in order to collectively contribute to the work involved in new practices
	Legitimation	Work of ensuring other participants believe it is right for them to be involved, and that they can make a valid contribution to it
	Activation	Participants need to collectively define the actions and procedures needed to sustain a practice and to stay involved
<p>Collective action: the work that individuals and organizations have to do to enact the new practice</p>	Skill set workability	Allocation work that underpins the division of labour that is built up around a set of practices as they are operationalized in the real world
	Contextual integration	Managing a set of practices through the allocation of different kinds of resources and the execution of protocols, policies and procedures
	Interactional workability	Interactional work people do with each other, with artefacts and with other elements of a set of practices when they seek to operationalize them in everyday settings

	Relational integration	Knowledge work that people do to build accountability and maintain confidence in a set of practices and in each other as they use them
Reflexive monitoring: the work inherent in the informal and formal appraisal of a new practice once it is in use, in order to assess its advantages and disadvantages, and which develops users' comprehension of the effects in practice	Reconfiguration	Appraisal work by individuals or groups may lead to attempts to redefine procedures or modify practices
	Communal appraisal	Participants work together, sometimes in formal collaboration, sometimes in informal groups to evaluate the worth of a set of practices
	Individual appraisal	Participants in a new set of practices also work experientially as individuals to appraise its effects on them and the context in which they are set
	Systemization	Participants in any set of practices may seek to determine how effective and useful it is for them and for others, this involves the work of collecting information in a variety of ways

(summary produced from <http://www.normalizationprocess.org>)

Table 2. Interview questions informed by NPT

Construct	Component	Question
Coherence	Differentiation	Do staff know how the new project differs from existing services for people living with dementia and their families?
	Communal specification	Do staff know what the aims and objectives of the project are?
	Individual specification	What were the specific tasks and responsibilities of participants with regard the implementation of the project?
	Internalisation	What do staff understand the benefits of the project to be?
Cognitive participation	Initiation	Were there key participants working to drive forward the new project?
	Enrolment	Did staff organise or reorganise to be able to collectively contribute to the work involved in the project?
	Legitimation	Did staff feel they could make a valid contribution to the project?
	Activation	Were staff able to sustain the project and stay involved?
Collective action	Skill-set workability	How was the division of labour affected by the project?
	Contextual integration	How did the project relate to the organisation in which it is set?
	Interactional workability	How did the project affect interactions between people and practices?
	Relational integration	How did the project relate to existing knowledge and relationships?

Table 3. Overview of facilitators and barriers to dementia project normalisation

Construct	Component	Facilitator	Barrier
Coherence	Differentiation Communal specification		Lack of awareness; lack of understanding
	Individual specification	Clear roles for project staff	Lack of clear role for referrers; perception time-consuming and complicated to refer
	Internalization	Clear on benefits; seen as 'good idea'	
Cognitive participation	Initiation	Key dedicated staff member; close team working; some 'champions'	Lack of wider support
	Enrolment		No change in way of working; lack of peer communication
	Legitimation Activation	Project staff felt made valid contribution	
Collective action	Skill set workability Contextual integration	Distinct project, dedicated resources, specialist knowledge and skills	Organizational change made taking on new ideas difficult; practical issues; management structures Distinct project, perception time-limited
	Interactional workability	Dedicated project manager	Crisis-driven model, unhelpful external organisations
	Relational integration		Routinized working practices; perception not appropriate or practical for client group in some cases