JRF JOSEPH ROWNTREE FOUNDATION

WIDENING CHOICES FOR OLDER PEOPLE WITH HIGH SUPPORT NEEDS

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This study examines the experiences of older people with high support needs involved in support based on mutuality and reciprocity.

It shares the benefits and outcomes achieved for individuals, families, communities and organisations funding and providing this support. The findings are relevant to the future funding and delivery of long-term care, and the transformation of local services.

The report highlights how:

- A typology of mutual support describes the options covered; e.g. Shared Lives, Homeshare, cohousing, time banks, mutually supportive relationships, self-help/peer support networks, mutually supportive communities.
- Over 100 people across the UK shared their experiences of and outcomes achieved by these models.
- Such options work best when they are locally focused, personally delivered and connected to other services and networks.
- Significant change is needed in the way that services are commissioned and delivered so that current options for support are widened to include these models.

NDTi National Development Team for inclusion

INSPIRING SOCIAL CHANGE

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EXECUTIVE SUMMARY

Not A One Way Street was a collaborative research project designed to better understand the various ways in which older people with high support needs take up active roles within support arrangements based on mutuality and reciprocity. This report shares the findings of that study, which was funded by the Joseph Rowntree Foundation (JRF) and undertaken by the National Development Team for Inclusion (NDTi) and Community Catalysts (CC).

It offers policy and practice insights for a number of audiences and agendas. Two key areas where the study has direct relevance are: the future funding and delivery of long-term care; and the transformation of local services to offer greater choice of personalised support. It focuses on a population – older people with high support needs – for whom significant progress needs to be made to increase their voice, choice and control and widen their options for support.

The work ran from January 2011 until the middle of 2012 – an increasingly turbulent era for public services due to major changes to the ways in which they are commissioned and delivered, increased efficiency savings and cuts in funding affecting the availability of local services, and planned changes to welfare benefits which are likely to impact negatively on many older people. The study takes account of these issues and challenges, and highlights how support based on mutuality and/or reciprocity offers affordable, tangible benefits for older people, their families, local organisations and wider service systems.

These findings will be of interest to: commissioners and providers across all public services and sectors including health and social care; policy-makers and implementers developing plans and services that directly impact on current and future generations of older people; and those responsible for responding to and implementing the finer details of the *Care and Support White Paper* (Department of Health, 2012) which sets out the government's vision for a reformed care and support system, and the preceding Dilnot Commission into long-term care (Commission on Funding of Care and Support, 2011). People involved in wider community developments

associated with increasing civic participation, strengthening inter-generational relations and building community cohesion, housing needs and options, and neighbourhood/environmental planning will also find this report relevant to their work.

These agendas are not just a matter for the government, Treasury, professionals and agencies, or the current generation of older people with high support needs alone. Older people with and without support needs, family members and wider communities also need to be engaged and better informed so that alternatives are not only developed but actively sought out and promoted in their networks, neighbourhoods and homes.

Different models and approaches based on mutuality and reciprocity are often described using very similar terms, but they vary in the ways they are set up, who they (currently) involve or are targeted towards, and the ways in which they operate and are resourced. They are also not well promoted or widely known. As a result, and to provide clarity within this research, a typology of mutual support comprising the following categories was developed:

- mutually supportive relationships;
- mutually supportive communities (including KeyRing Networks);
- cohousing;
- Homeshare;
- Shared Lives;
- time banking;
- Circles of Support;
- face-to-face and virtual volunteering schemes;
- self-help and peer support networks.

The detailed typology, which can be found in Appendix 1, could be used to promote a very different kind of menu and range of options by commissioners, providers and – more importantly – older people and their families. An explanation of each model is provided in Appendix 2.

Study design and aims

The three main aims of this study were:

1   to develop a vision for and definition of 'mutual support and reciprocity' by assessing examples, experiences and practical steps required for them to work well for older people with high support needs;
2   to improve understanding of the intricacies involved in establishing and sustaining mutual support systems;
3   to examine issues of scale and replicability, including how to spread and sustain models and approaches based on mutual support and reciprocity that are shown to be effective or have potential to offer alternative approaches.

The focus was on arrangements where older people were living in their own home and had not had to move 'into care' to access support. One or more of those involved may have moved house or shared their home as part of the arrangement, but the key issue for this study was that individuals concerned were living in a domestic household that they regarded as their own.

Over 70 older people with high support needs shared their experiences across four fieldwork sites: Dorset, Swansea & Gower, Leeds and Oxford.

Another 50 people took part in six in-depth case studies examining the design, experiences and outcomes of specific models, including: time banks (in Bromley and an initiative across Northern Ireland); senior cohousing (in Fife and Glasgow); mutually supportive communities (in Suffolk); and self-help networks (in Cambridge). A literature search and open call provided evidence, lessons and insights from further afield.

Chapter 2 and Appendix 3 provide detailed information about the research design and methods, including how these participants were involved and different sources of information gathered and analysed to produce the findings shared in this report.

Key findings and messages

This work shows that there is huge potential for models of support based on mutuality and/or reciprocity to help older people with high support needs live well in later life. These models are valued greatly and achieve significant outcomes for individuals when they recognise, harness and use the assets of all their members. They work best when they are very locally focused and personally delivered and/or experienced. They also work well when they build on and link to other services, networks and systems (not just concerning care and support) rather than existing as discrete entities or as one-off initiatives and developments.

Chapter 3 highlights ten key findings which show that:

- a diversity of people, possibilities and approaches exists;
- support based on mutuality and reciprocity makes a positive difference;
- successful models are clear about their purpose and outcomes;
- knowledge, innovators and networks help to make this happen;
- nurturing relationships and trust are central to all models;
- mutuality and reciprocity mean different things;
- asset-based *and* community-led approaches matter;
- resources and resourcefulness are important;
- problem solving is a central, sustaining feature;
- there are challenges of scale and replicability.

Chapter 4 presents seven key messages about what needs to change in order to widen and sustain different options for support in later life. They have been developed to start the process of applying these findings and lessons, encouraging decision-makers to pay particular attention to the following critical issues:

- negative attitudes about and narrow perceptions of older age;
- public interest and professional scepticism;
- a diverse picture of support based on mutuality and reciprocity;
- clear outcomes that can be achieved from mutual support;
- five common features of mutual support;
- the need to integrate mutual support into local options for older people with high support needs;
- successful innovators and ambassadors of mutual support need to be celebrated and supported.

This report shares these findings and highlights these messages for a reason. It is intended to be used as the start of a process of major change, not to mark the end of a study. Significant change is required, both in the way

that older people with high support needs are seen and engaged in local developments, and in the way that local services are commissioned and delivered so that options are widened *and* actively promote mutuality and reciprocity. The policy world's current focus on how to fund more 'long-term care' needs to shift dramatically in order to stimulate this broader base that explicitly values older people's gifts and assets.

Chapter 5 shares priority actions for moving this agenda forward, and initial dissemination and facilitation activities to help to get people started at a local level. The priority actions include:

1   communicating and demonstrating the benefits;
2   raising public awareness and engagement;
3   tackling interfaces with other services;
4   replication and scaling out;
5   mobilising resources.

Visible signs of change will include a very different service profile for care and support at a local level, and what typically is offered or suggested to individual older people who need support.

If this happens, we believe that positive change will also be experienced by older people contributing to as well as receiving support, and by their families who are concerned for their welfare and well-being.

Innovators, organisers and providers will be encouraged and supported to design and deliver a much richer variety of support through virtual as well as very local mechanisms. These will include existing networks and infrastructures as well as exciting new developments drawing on joint financing arrangements from beyond increasingly limited health and social-care budgets.

It will be important to ensure that subtle details and intricacies that older people have told us really matter are attended to while keeping hold of their vision for a very different kind of service experience and model of support. Being personalised, small and very locally focused while delivering to and at scale is a significant challenge, but one that can be overcome if the key features and lessons from older people and others who are currently making it happen are observed.

1 BACKGROUND AND PURPOSE

Not A One Way Street is the name given to a collaborative research project designed to identify, examine and better understand the various ways in which older people with high support needs take up active roles within different support arrangements based on mutuality and reciprocity.

Mutual/mutuality: a term used to describe a reciprocal relationship between two or more people or things
— Free online dictionary

Reciprocity: the practice of exchanging things with others for mutual benefit
— Oxford Dictionaries online

Introduction

This report shares the findings of that study, which was funded by the Joseph Rowntree Foundation (JRF) and undertaken by the National Development Team for Inclusion (NDTi) and Community Catalysts (CC).

All three organisations share a concern that older people with high support needs are too often seen as a burden and a drain on resources rather than as individuals with gifts, skills, assets and contributions. As a result the support they receive is most often designed and delivered as a one-way street.

The study was designed to examine the options and approaches that currently exist, or have the potential to be developed and/or extended, to enable more older people to experience support which recognises and uses their skills and contributions as well as providing them with the help that they need.

Key contexts for this work

Not A One Way Street was commissioned in late 2010 and ran from January 2011 until the middle of 2012 – an increasingly turbulent era in public services that saw major changes to the ways in which public services are commissioned and delivered, for example, to increase choice and control over the support that older people need in their lives; increased efficiency savings and cuts in funding that have impacted on the availability of some local services; and planned changes to welfare benefits which are likely to impact negatively on many older people.

There have been numerous high-profile stories and debates around ageing and services for older people including concerns about the quality of home care, hospital and residential care services (Parliamentary and Health Services Ombudsman, 2011; J. Cornwell, King's Fund, 2012); the current and future funding of long-term care; and a growing recognition of the need to radically shift attitudes towards and understanding of the huge diversity of older people in our society today rather than focusing on numbers alone (see www.ncl.ac.uk/iah/research/areas/biogerontology/85plus).

The work was timely for other reasons, including a heightened focus on co-production and other forms of mutualism in civic life and public service delivery and design (see www.demos.co.uk/blog/john-lewis-vs-easycouncil); and the implications of the *Localism Bill* (introduced to Parliament in December 2010) for building community cohesion, ensuring that older and disabled people are fully included and their contributions valued in local developments.

Why this research matters

All of these issues and agendas formed a backdrop to the research, and the lives of those who participated in the study.

Early findings from the research were shared in an interim paper published in October 2011 (Bowers, *et al.*, JRF, 2011). That report and subsequent discussions have emphasised the need to state quite clearly the rationale and impetus for this research and why it continues to be important two years on from its inception.

While awareness is increasing about the potential for new and creative support options to achieve better outcomes for older people and local services, two significant barriers to their availability and future development remain. Firstly, the current typical service profile remains rooted in traditional forms of provision; and secondly, attitudes towards older people with high support needs are based on outdated stereotypes of 'the frail elderly' who need to be taken care of.

The following points set out some of the key challenges and trends that explain the focus within this work on access to, experiences of and outcomes from mutual support for older people with high support needs.

The predominantly limited range of options for support

This study is part of the work of the JRF programme, A Better Life, on "alternative approaches [to long-term care]", which is based on the findings of successive reports and feedback from older people, such as *Older People's Vision for Long Term Care* (Bowers, *et al.*, 2009). This found that:

The current typical service profile remains rooted in traditional forms of provision; and attitudes towards older people with high support needs are based on outdated stereotypes of 'the frail elderly' who need to be taken care of.

- the current range of options for older people who need a lot of support is still dominated by two main forms – care-home placements and intensive home care;
- the roles and contributions of older people often go unrecognised, unnoticed and therefore untapped both in the delivery of, and in developments associated with, care and support in later life.

Similar challenges remain since that work was published. Despite an ongoing focus on the personalisation of (particularly social care) services and support for older and disabled people, and successive calls to stimulate the market and commission a wider and more creative range of support, options remain extremely limited for older people (Think Local Act Personal, 2012). For example, personal budgets for older people have apparently not translated into widespread access to different, tailored services and support. There is a tendency to think of support only in terms of 'social care' rather the wide range of public services that make a difference to older people's lives (Raynes, *et al.*, 2006; Audit Commission, 2008). This is problematic for four reasons:

- An increasingly small number of people are assessed as eligible for local-authority-funded social-care services and they receive increasingly smaller amounts of support.
- Many older people with high support needs are not accessing different kinds of help and/or benefits (e.g. housing aids and adaptations) to which they are entitled.
- Most councils spend the largest proportion of their social-care budget for older people on residential care, which means they have few resources available for investing in stimulating the development of viable alternatives that provide greater choice from a broader range of options for those who need 24-hour care and support.
- There is a missed opportunity in not pooling budgets at a macro as well as an individual level to develop integrated services through joint financing arrangements (thereby alleviating pressures on individual departmental budgets such as social care).

Low expectations and levels of awareness

This study and previous related research have emphasised the low level of awareness about and familiarity with support based on mutual exchange and reciprocity among older people, their families, wider community networks and professionals, statutory and non-statutory agencies. This is influenced by the persistently low expectations of and for older people with high support needs, which means that looking for alternatives to those currently on offer (or checking whether existing options are what older people want) is not considered. At the same time, there is a prevailing attitude which frames demographic change (i.e. growth in numbers of people aged over 60, and 85 in particular) as 'burdensome' – on individual families, public services and society as a whole.

It is hardly surprising, therefore, that the above situation persists in spite of the evidence that increasing numbers of creative options do exist in some places – including options for support based on mutuality and reciprocity, some of which have existed for some time. However, even where such innovation exists, it still tends to be in a few areas involving small numbers of people.

Wider, positive signs of change around age and ageing

New structures and mechanisms for increasing the voice and influence of older people have emerged at a regional and national level (e.g. English forums on ageing, independent elders councils, Older People's Commissioners in Wales and Northern Ireland). There is renewed political commitment and policy profile around ageing in UK nations (e.g. a recent Ageing Well Programme run by the Local Government Association (LGA) in England; clear commitments in the Programme for Government and a forthcoming ageing strategy in Northern Ireland; a recent Housing Strategy for an Ageing Population in Scotland; ongoing work to implement a long-standing strategy on ageing in Wales). There is also ongoing global action in line with the World Health Organisation's Action on Ageing, for example the European Year of Active Ageing and Solidarity Between Generations (see http://europa.eu/ey2012).

However, these wider developments and positive signs of change regarding the status, profile and attitudes towards ageing and older people are often divorced from specific developments and experiences associated with care and support in later life. This mismatch needs to change, particularly if public services based on mutuality and reciprocity are to grow and be the norm across all ages and stages of life.

A push for public services based on mutuality and reciprocity

There is a genuine desire to promote, design, fund and enable more public services to be mutually beneficial, locally generated and owned. There are many high-profile policy documents setting out the vision and intent of reciprocity with initiatives to help to make this happen and demonstrate the benefits and value of mutualism — not least this government's vision for a Big Society (New Economics Foundation, 2010).

If these concepts and visions are to be realised for all citizens, regardless of their need for support or where they live, then everyone's gifts and assets must be valued and used. Such developments often overlook the gifts and aspirations of older people with high support needs, who are frequently characterised as burdensome and whose needs are emphasised rather than their assets (ideas, experience, contributions, skills and knowledge). As a *Not A One Way Street* Fieldwork Respondent commented, "People think that because I've got problems myself I've got nothing to offer!"

This work has therefore sought to highlight existing and emerging models of mutual support and reciprocity (e.g. time banks, Shared Lives, cohousing, Homeshare) that are or could be beneficial and attractive to older people with high support needs. In addition to finding out about the characteristics and success factors of such approaches, we have examined issues of replicability and progress in creating fertile conditions where successful models can thrive.

Developments often overlook the gifts and aspirations of older people with high support needs, who are frequently characterised as burdensome and whose needs are emphasised rather than their assets (ideas, experience, contributions, skills and knowledge).

Mutuality in an age of austerity

Cuts in services and an increasingly challenging economic climate combined with the above factors mean that the status quo is neither sustainable nor desirable. Significant change is required, and it is clear that there is a desire for change from many quarters. It is recognised that different sectors,

agencies and funding departments need to find different and more creative ways of pooling their resources while ensuring they stretch further.

At the same time, many of the (mainly third-sector) organisations hosting and enabling mutual support arrangements are facing serious financial reductions and in some cases closure. While recognising the challenges involved, this work was particularly relevant given concerns about the spiralling costs of care and pressures faced by those developing and providing alternative approaches.

Examining which models are based on sound business cases to generate both commitment and investment were therefore key features of this work.

Study aims

The three main aims of this study are summarised in Box 1.

> **Box 1: Aims of *Not A One Way Street***
>
> - To develop a clear vision for and definition of 'mutual support and reciprocity' by assessing examples, experiences and the practical steps required for them to work with and for older people with high support needs.
> - To improve understanding of the intricacies involved in establishing and sustaining mutual support systems, including how people resolve issues as they arise, and how resilience, rather than reliance, may be achieved.
> - To examine issues of scale and replicability, developing guidance for different audiences on how to spread, sustain and scale up models and approaches based on mutual support and reciprocity.

The study examined evidence about the experiences, aspirations and outcomes of reciprocal support available to, and accessed by, older people with high support needs. We focused on examples where those involved are both giving *and* receiving support, rather than more traditional services provided by professionals/organisations (which tend to be more 'one-way').

Definitions and parameters

The JRF programme, A Better Life, developed the following definition of 'older people with high support needs', which was used in this project:

> Older people of any age who need a lot of support associated with physical frailty, chronic conditions and/or multiple impairments (including dementia). Most will be over 85 years old. Some will be younger, perhaps reflecting the impact of other factors linked to poverty, disadvantage, nationality, ethnicity, lifestyle, etc. Some of the very oldest people may never come into this category.

It is a phrase that is increasingly used but is also often questioned. The more familiar phrases 'frail elderly' and 'people with complex needs' are still often used to describe this diverse population of people. However, just as the term 'mentally handicapped' has (thankfully) been lost in time, we hope that people will start to take more care in the way that they talk about

older people; not as one homogenous group that can be defined by the state of their health, their diagnostic label, condition or the services that they use. One of the ways to challenge the preconceptions and negative stereotypes of old age and older people is to use the term 'older people with high support needs' *where relevant* (this is a small proportion overall of the general population aged over 60). It reframes older age as a stage of life and recognises that people of all ages need support in their lives as well as having skills and contributions.

The term 'mutual support and reciprocity' also generated a number of queries at different stages of the research – about what this means and the different kinds of models and approaches that epitomise such arrangements.

An extremely rich picture of different kinds of support based on mutuality and reciprocity emerged in the study, with some important common characteristics that can be used to explain and better understand the intricacies of how they work and whom they benefit. For example, these are most often approaches and models that are run on a very small scale. They also currently exist in isolated pockets that are not always well connected to other forms of support.

Different models and approaches based on mutuality and reciprocity are often described using very similar terms, but when examined we found that they vary in the way they are set up, who they (currently) involve or are targeted towards, and the ways in which they operate and are resourced. If we included every term or description used to explain different schemes and models, it would be a very long list indeed!

For the purposes of this research, we identified nine categories of mutual support, within which we think most different types and descriptions fall.

Box 2: Categories of support based on mutuality & reciprocity

- Mutually supportive relationships
- Mutually supportive communities (including KeyRing Networks).
- Cohousing.
- Homeshare.
- Shared Lives.
- Time banking.
- Circles of Support.
- Face-to-face and virtual volunteering schemes.
- Self-help and peer support networks.

This study was concerned with which models associated with each of the above categories are currently enabling older people with high support needs to give and contribute and not just receive support.

Appendix 1 presents a typology describing the key characteristics of these categories. Appendix 2 provides a more detailed explanation of each category with examples of the different options/models that fit within them.

Research design and timescales

The study comprised six phases of work spanning a 21-month period (January 2011–September 2012) as follows:

1. **Coproducing the final design, scope and focus**. Agreeing questions to be addressed and criteria for including specific examples and models. An

application for ethical approval was approved during this stage.
(January–February 2011)

2 **A review of the literature and a call for examples of mutual support experienced by older people**, including a public meeting to gauge levels of awareness, experience and interest in support based on mutuality and exchange.
(March–July 2011)

3 **Fieldwork in four localities** in England and Wales, including in-depth interviews and small group discussions with older people and others directly involved in such arrangements. The study sites were: Dorset, Leeds, Swansea & Gower, and Oxford.
(August 2011–February 2012)

4 **Analysis and synthesis of findings**. Drawing out key findings and priorities to share and explore at a national 'sounding board' event.
(March–May 2012)

5 **In-depth case studies** of specific models including: senior cohousing in Scotland; time banks in Northern Ireland and London; mutually supportive communities in Suffolk, Cambridgeshire and on a virtual basis (DropBy).
(April–July 2012)

6 **Producing final reports and summaries** for different audiences about mutuality and reciprocity; sharing key findings, messages and recommended priority actions.
(July–September 2012)

Links to other projects in the A Better Life programme

A Better Life is a five-year programme (2009–2013) focusing on ways of ensuring quality of life for older people with high support needs in the UK. It comprises a number of strands of work including:

- Defining what makes 'a better life' by hearing what diverse older people with high support needs say about what they want and value.
- Improving residential and nursing care by building understanding of how to maximise older people's choice and quality of life in care settings, thereby influencing future policy and practice. This work, led by My Home Life, also includes direct work with managers of Joseph Rowntree Housing Trust care homes.
- Researching how housing with care schemes can support older people who have, or who develop, high support needs, in order to inform future policy and practice.
- Identifying alternative approaches by exploring other accessible and affordable models of support, housing and community for older people who have (or develop) high support needs. This strand looks beyond what is commonly available, learning from imaginative practice both in the UK and internationally, and is where this study is located.

2 METHODS

This chapter describes the questions examined in the study and different data gathered to answer them. It explains the methods used to obtain this information, who was involved and how different sources were analysed. It includes an overview of how initial findings were shared, tested and synthesised to produce the findings, lessons and conclusions shared in this report. It ends with a summary of how members of the project team and Project Advisory Group coproduced the research. Appendix 3 provides detailed information to read alongside this chapter.

Research design and methods

The research was set up to answer particular questions relating to the range of models, schemes, approaches and experiences where *all three* conditions apply (see Box 3).

Box 3: Research criteria

- At least one older person with high support needs is involved. Other people involved in the arrangement may be of any age.
- Two- or multi-way exchange is taking place as part of an agreed plan in which elements of giving and receiving have been made explicit, even if informally. We found it helpful to think of this exchange as being both intentional and 'active' (i.e. the giving and receiving are deliberate).
- At least one of the things being exchanged is *support*, by which we mean one or more of the following: practical, physical, personal and/ or emotional assistance, advice or help that enables someone to live their everyday life.

The focus was on arrangements where older people were living in their own home and had not had to move 'into care' in order to access support. One or more of those involved may have moved house or shared their home as part of the arrangement, but the key issue for this study was that individuals concerned were living in a domestic household that they regarded as their own. The experiences of people living in care homes or extra-care housing developments are the subject of other projects and strands of A Better Life.

Who was involved and how

The study used mixed methods for engaging participants and examining different aspects of mutual support experiences.

1 **A literature search** reviewed over 70 documents and other published information, including: reports on individual projects and pilots/initiatives; meta-analyses of other studies and related concepts; policy reports; essays, commentaries, blogs and think-pieces; newsletters; notes from phone conversations with project co-ordinators; social media e.g. Twitter feeds and Facebook posts.

2 **A 'Call for Information and Examples'** went out to over 300 contacts identified from pooling knowledge and advice from research and Project Advisory Group members. Each contact was also asked to forward the call on to their networks. This process elicited numerous responses from a wide range of people and organisations. However, only a small number (n=17) were assessed as meeting the research criteria; 5 of the 17 responses were from areas that became fieldwork sites. More information about the responses and their locations is provided in Appendix 3.

3 **Six personal stories** were written up to raise awareness about mutual support experienced by older people with high support needs. These are provided in Appendix 4. They were collected through responses to the call and other information gathered in the first two phases. These powerful personal accounts were instrumental in increasing understanding about what is involved in such approaches and arrangements and generated useful debate at a public meeting (see below).

4 **A public meeting** helped to gauge current levels of awareness and experience of support based on mutuality and reciprocity. Discussions highlighted that while there is huge interest in this area, there is currently a very low level of awareness and understanding about different options for support, mutual support, and specifically mutual support options involving older people with high support needs. The interim report published in October 2011 provides more information on the outcomes of this event. Participants are listed in Appendix 5.

5 **A mapping exercise** plotted examples of different approaches, experiences, models and schemes involving older people with high support needs, highlighting those that currently exist across the UK. This identified some geographical areas with higher numbers of known reciprocal schemes/arrangements, which informed the section on fieldwork sites.

6 **A typology of mutual support and reciprocity**. It became apparent from looking at the above information that there is an extremely wide and diverse range of models and descriptions of support based on mutuality

and reciprocity. A typology of different categories of mutual support, and typical characteristics associated with each of these, was developed to explain the models and the range. Appendix 1 gives a short overview of the main categories of mutual support covered by the typology, which is provided in Appendix 2.

7 **In-depth fieldwork** involving over 70 people took place in 4 study sites: 1 in Wales (Swansea & Gower) and 3 in England (Oxford, Leeds, Dorset). Information about these sites and how they were selected is provided in Appendix 3. In Dorset and Swansea & Gower, the fieldwork focused more on informal, relationship-based mutual support arrangements involving individuals (e.g. mutually supportive relationships and communities). In Oxford and Leeds the focus was more on organised schemes and models involving greater numbers of people (e.g. Homeshare, cohousing, Shared Lives, co-ordinated peer support and self-help networks). Experiences and characteristics of mutual support were examined using protocols based on detailed research questions (Appendix 7).

8 **Six in-depth case studies.** As the range of options available and experienced in any one geographical area is currently limited, six case studies were developed of models/approaches in the typology that were not covered by the fieldwork. This added breadth as well as depth to the study. These cover: senior cohousing; time banks; mutually supportive communities; and virtually supportive communities. The research questions were used to develop a case-study topic guide and template (see Appendix 8), ensuring consistency of approach while allowing specific issues and themes relating to particular models to emerge.

Analysis methods and approaches

Findings were analysed using grounded theory techniques, as follows:

- Items from relevant published and grey literature that met the research criteria were collated, and a thematic analysis of 72 items was completed to identify common themes, lessons and insights across different models of mutual support.

- Responses to the call were collated using the template issued to generate responses. Once this 'evidence grid' had been completed, we undertook a thematic analysis of the written and verbal material provided by respondents.

- Qualitative data generated through the fieldwork (interviews, focus groups etc) was transcribed and analysed using content analysis techniques to identify recurring themes and evidence of what works and doesn't work for those involved in the mutual support arrangements including older people, scheme co-ordinators and commissioners of local services.

- The case studies were developed using information gathered through interviews and focus-group discussions with small numbers of people intimately involved with the models, and background information provided by participating schemes and groups. Each case study was written as an overview of the model or scheme from the perspective of those directly involved in its design and delivery. The lessons and findings from all case studies were identified through a focused thematic analysis.

The findings from these analysed data sets were triangulated and synthesised to identify cross-cutting themes and messages, in order to address the key aims and research questions. Other sources of learning and feedback were also included in this overarching analysis – for example, project team diaries, feedback from participants involved in the open-meeting and sounding-board events, graphic templates and reflective diaries completed by some of the fieldwork participants in the four study sites.

Co-production in the research

The study was coproduced with members of the research team and Project Advisory Group and those participating in the public meeting, the call, case studies and fieldwork in four localities.

The research team of nine people included older people at different life stages with varying degrees of 'high support needs', staff and associates from NDTi and Community Catalysts. This team included:

- Five people who undertook qualitative research activities in the four study sites, including: two older 'peer researchers' from NDTi's associate network; a peer researcher recruited for the purposes of the fieldwork in Wales;[1] one NDTi and one Community Catalyst member of staff, each of whom led the work in two of the four sites. Fieldwork activities in each site were undertaken by the site lead and one of the peer researchers.
- Two senior members of staff from NDTi and Community Catalysts jointly led the project, sat on the Project Advisory Group[2] and promoted the work at a national level. They also undertook the case studies with a peer researcher from the fieldwork team.
- NDTi's research manager completed the secondary data analysis and led the design of research protocols, materials and tools, which was informed by all team and Project Advisory Group members.
- NDTi's research administrator maintained participant logs and contact with each of the fieldwork sites and case-study participants, organised the logistics associated with all research activities, and supported the Project Advisory Group.

Ethical issues and dilemmas

Ethical issues paid attention to in this work included:

- enabling participants to share and explore sensitive issues concerning their support, including relationships with partners, peers, friends, neighbours and paid staff;
- obtaining informed and ongoing consent for people who lack capacity, assuming capacity and finding creative and supportive ways to enable diverse people to participate;
- building in time and strategies for people to explore solutions to problems aired during the course of local discussions and interviews.

3 FINDINGS AND LESSONS

This chapter shares the findings from the fieldwork in four study sites, the six in-depth case studies, the literature search and call for examples of support based on mutuality and reciprocity.

Each of the primary and secondary sources of data in this study has generated intelligence and understanding about what is involved and what can be achieved through different models of mutual support – and what can be problematic and difficult. The first part shares **ten key findings** identified from the analysis of the fieldwork data and in-depth case studies. The second part sets out the **major lessons and insights from elsewhere**, gathered through the literature search and call for examples.

The pictures used to illustrate key points in this and the following chapter are taken from wall posters created at the sounding board event. A graphic facilitator worked with participants to explore these findings and lessons, and achieve consensus about the critical success factors for widening options for older people with high support needs.

Ten key findings about older people's experiences

The study has identified ten key findings drawn from older people's lived experiences and those of the innovators, co-ordinators and sponsors of different models and schemes examined (see Box 4).

A diversity of people, possibilities and approaches exists
This study has identified a huge diversity of experiences and situations in which mutual support arrangements and schemes currently involve older people with high support needs. Both the arrangements and the older people involved in them are equally diverse, indicating that mutual support arrangements/models are the direct opposite of a 'one size fits all' approach to service design and delivery.

Box 4: Ten key findings

- A diversity of people, possibilities and approaches exists.
- Support based on mutuality and reciprocity makes a positive difference.
- Successful models are clear about their purpose and outcomes.
- Knowledge, innovators and networks help to make this happen.
- Nurturing relationships and trust are central to all models.
- Mutuality and reciprocity mean different things.
- Asset-based *and* community-led approaches matter.
- Resources and resourcefulness are important.
- Problem solving is a central, sustaining feature.
- There are challenges of scale and replicability.

Householders ranged from their mid-40s through to their early 90s (the majority were in their 70s). They were seeking companionship and some support and – in particular – someone else being in their home at night.
– Co-ordinator for Homeshare scheme [now ended] in Oxford

The nature of arrangements and approaches explored in this study include:

- 'home-grown' arrangements using a blueprint of an existing model or scheme (e.g. one person's private Homeshare-cum-cohousing set-up);
- numerous informal but well-organised one-to-one mutually supportive relationships;
- neighbourhood- and street-based arrangements involving a handful of people;
- mutually supportive arrangements established through a community centre, café, church or other group;
- larger networks and schemes set up by an organisation, individual or group of people;
- more formally, organisations regulated schemes with established practices such as Shared Lives and Homeshare.

Numbers involved in these arrangements and schemes varied from two people in an informal one-to-one relationship or individual Shared Lives arrangement to hundreds, through neighbourhood-based networks of self-help and peer support.

The length of these experiences also vary from those whose relationship/ arrangement is relatively new (established in the last 12 months) to those lasting over 20 years. The largest group (10 of 22 responses to this question) have been in the mutual support arrangement for between 2 and 5 years. A similar number are in relationships that have lasted for up to twenty plus years. These are clearly long-term, sustainable arrangements that stand the test of time.

For example, Mary needs a lot of help over a 24-hour period, and lives with Margaret (a Shared Lives carer) in a Shared Lives arrangement, supported by St Anne's Community Services, that has lasted 18 years. Mary does not communicate verbally but makes it clear that she loves living with Margaret. Margaret says: "It helps me too, living on my own, and the money helps as I get older as well."

Support based on mutuality and reciprocity makes a positive difference

Evidence from study participants demonstrates that support based on mutuality and/or reciprocity benefits everyone involved. Those involved in the fieldwork and the case studies provided examples of benefits at different levels time and again. Some of the most common benefits and outcomes are described in Box 5.

Box 5: Benefits and outcomes for different people, networks and organisations

Benefits/outcomes for individuals
- Companionship and comradeship.
- Positive, supportive and nurturing, long-term relationships.
- Practical and emotional support through crises, loss and major life events, e.g. bereavement.
- A way to avoid and end loneliness, isolation and feelings of being alone.
- Recognition and use of existing, and development of new, skills, interests and knowledge.
- Older people feel valued and valuable, enhancing their own well-being and commitment to the arrangement.
- Financial gain/income, which is more acceptable to people when part of a formal arrangement or scheme.
- Physical, mental and emotional health benefits, e.g. help with alcohol addiction, avoiding suicide, improved mental health.
- Avoiding hospital admissions and moves to residential care.
- Shared cultural, spiritual and belief systems.

Benefits/outcomes for families and personal networks
- Being supported to age well 'in place', retaining friendships, relationships and networks.
- Being supported to live a 'normal family life' within a reliable and supportive environment.
- Safe and supportive arrangements/relationships that supplement dispersed family connections and support.
- An alternative to and support to cope with the complexities of family attitudes and dynamics.

Benefits/outcomes for local neighbourhoods (wider society)
- Stronger community cohesion as a result of bringing people together at a very local level.
- Better-connected individuals in local neighbourhoods, improving community well-being and health.
- Being directly involved in reciprocal arrangements helps people recognise their contribution, and the benefits of giving.
- Organised networks ensure no one gives too much and that everyone is supported in return, ensuring sustainability and avoiding burn-out.

Cost-effectiveness for services and the wider system
- Shared Lives, Homeshare and cohousing models effectively use scarce housing resources (which also benefits individuals).
- Shared Lives and Homeshare provide alternative, less expensive and more effective ways of providing care (compared to more traditional approaches involving care delivered through employed staff).

- Many people involved in mutually supportive relationships are inspired and motivated to get involved in other, similar work.
- Different approaches based on mutuality and reciprocity can foster creative, flexible ways of working among statutory agencies, professional networks *and* models/schemes established with and for older people with high support needs.

Older people involved in the fieldwork sites could articulate more clearly what they *gained* from their arrangement than what they gave, though it was clear from their responses that they are actively contributing to those arrangements. Bea and Pam are two active members of a local church-based group in Swansea & Gower. Bea says, "I get a terrific amount of support from the group … avoid pressure from family to move into a care home." Pam comments: "I avoid feeling like a burden."

The most common responses to questions about personal benefits and outcomes included: being able to live where you want to; being able to carry on living where you have always lived; and living in an environment or in a way that makes sense to you. In each of these cases, people felt that the arrangement or scheme was what enabled this to happen.

> It was an eco-friendly household with shared values. I had been thinking about sustainability a lot – personal and economic. Will I have enough to live on and to keep living in this way? I have a big house and I need full-time care and people to be able to assist me night and day. The communal house began in 2009 and ended in 2011. People were given rent-free accommodation and training in care and support from community physios and Occupational Therapists (OTs). I got assistance from a group of people who were much more organised than me! I met the costs of my care for two years. We created a community.
> – Woman with MS who set up her own Homeshare arrangement in Oxford with six or seven younger people living with her at any one time

A small number of people with complex needs talked about their arrangement having helped them to avoid crises, such as admissions to hospital or a care home, and deterioration in their mental health. Members of Southbourne Creative Hub talked about a woman who was supported through their network to stay living at home:

> Her life would be crushed if she had to give it [her home] up. She would not be able to keep her dog [in a care home]. She loves her little dog, it's her life.
> If someone else were in my position I would tell them to join it [Shared Lives] and not shut yourself away. Important to stay somewhere and meet different people. It is better than going into care.
> – Woman living in a Shared Lives arrangement, Dorset

Many respondents said that their mutual support arrangement had eased their sense of loneliness, or that they no longer felt alone or lonely. Others (such as scheme co-ordinators) talked about reducing isolation and/or loneliness being a motivator for having set up their scheme or network; that is, to help older people to connect with each other and get out and about.

Maria and Pat met each other through a local support group in Swansea & Gower. They talk about their experiences and how they came to realise that they needed and value the kind of support they receive and give through this network. As Maria says, "Big events like a bereavement can really change how you feel, diminish your confidence and previous skills." In Pat's case, "I feel I have a life now, I'm able to get out and be stimulated."

Paravar is a local group in Leeds that was established to give older couples and carers from Sikh and Hindu communities a chance to get together, socialise and support each other. Paravar means 'family' in Punjabi. It is supported and managed by an umbrella organisation with similar aims, called the Sangam forum. Sangam hosts four groups involving over 200 members who come together for regular meetings in local centres and halls across the city. People may initially meet through these gatherings, but the benefits experienced stem from the relationships, connections and mutual support that take place beyond these meetings. Members of Paravar shared their experiences of this support:

> A number of people are isolated and other older ladies in the Paravar would say "sister, you come here" and then they would come and have a chat with the other ladies. People make new friends and links.
> People come to meet people, share sorrows and happiness. Value the change of atmosphere, learn new things, help people who can't get out with their shopping.
> – Members of Paravar, Leeds

Successful models are clear about their purpose and outcomes

Where mutual support is working well and is sustained, there is clarity about the purpose of the arrangement, and the needs, contributions and expectations of everyone involved. These needs, contributions and expectations must match or be compatible in order for benefits to be clear and outcomes achieved.

This is the case whether the arrangement is informal, a one-to-one relationship or exchange, or a formal scheme involving more people. Needs, contributions and expectations may be clear and evident from the beginning or emerge over time. The crucial thing is that they are *all* present, and they become, or are made, clear.

For individuals
Fieldwork respondents emphasised that all parties had recognised that they each had needs and wants as well as things to offer and a desire to give or contribute, either at the beginning or very early on in the arrangement. The presence of all these things seems to be important in establishing and sustaining such arrangements.

> I contribute being physically stronger and can bend and reach. I am the hands of A to prune roses, open the milk waiting to be opened and do the shopping.
> B is somebody who listens and is spiritual for us to pray together.
> It works because I needed someone to be close to, to other people.
> – An older and younger woman who support each other, Swansea & Gower

Participants had a strong memory of the start or trigger points for their own arrangement(s). These typically included: a chance meeting or conversation about a shared interest or experience; a health crisis; concerns about existing

Where mutual support is working well and is sustained, there is clarity about the purpose of the arrangement, and the needs, contributions and expectations of everyone involved.

support arrangements not working; a conscious decision to find or create something different to what was readily available or made available to them; an introduction from someone else, as described above.

Maria and Pat met through a cardiac patient support group. Maria provides transport for Pat who can no longer drive following heart surgery. Both women are in their 80s. They struck up a friendship through their shared experience of learning to live and cope with disability, for Maria following a stroke and Pat her heart surgery:

> [knowing Pat] has helped me to rebuild my self confidence … I get conversation and support, and learning to accept help from others who share my love of poetry, art, walking and wildlife.What do we have in common? Like-mindedness and singing!

For schemes, initiatives and networks
For those involved in models, schemes and initiatives, this clarity is expressed as a clear vision of support based on mutuality and reciprocity. This vision typically stems from a desire for something different to existing options for support available to older people. Successful schemes and initiatives can also demonstrate clear principles that influence how that vision is taken forward and encourage members to get involved.

Box 6: Supportive communities

Mary Baker is the founder and driving force behind **DropBy**. She feels that "personal interaction is so important"; knowing that someone is out there can make a difference to people's well-being and sense of self. She believes that people need common interests in order to forge social links, communicate and socialise with each other. She believes DropBy offers this.

The **Debenham Project** is an example of a project building upon and designed to strengthen a mutually supportive community, enabling people with dementia to be and remain connected citizens. It is co-ordinated by a small group of volunteers, and has a clear vision and mandate from people in the local community.

The **Cherry Trees Club** in Cambridge was set up to tackle social isolation of older people who lived alone in the neighbourhood. This was identified as a key issue for local people in a 'new residents' survey of the ward.

The **Vivarium Trust, Fife**, was set up to explore ways of achieving a senior cohousing community in Scotland, and to learn how best to deliver this through learning from other communities overseas (none yet exist in the UK). The aim is for a fully inclusive community for people of different ages over 50 who want to live as part of a mutually supportive community.

The study found that more formal schemes and models (Shared Lives, Homeshare, time banks) typically set out clear expectations about what is being given/received, and what can be expected at the beginning of the arrangement. This seems to work well and is particularly important for people who have the highest or most complex support needs.

Cathy (Shared Lives carer) and John (an older man with long-standing mental-health problems) have lived together for 13 years.

> She makes sure I get my meals, nice food, that I take my medication. I can talk through any problems. Gives me support when I feel a bit wobbly. She looks after the house and my letters (e.g. bills).
> – John

> He looks after the garden, keeps it lovely. Also gardens for a family friend and other older people locally. He loves gardening. And he drives me around (as I don't have a car).
> – Cathy

> We sort of support each other I suppose.
> – John

These schemes also typically build in early and regular reviews of experience and progress, often using established person-centred techniques (e.g. what's working and not working for each of the parties involved).

Margaret (the Shared Lives carer involved in St Anne's Shared Lives scheme, see page 19) talks about the help she gets from her support worker:

> Anything I need to know or anything we want ... if Mary is poorly, she [the support worker] comes to see me and I couldn't be without her actually. They guide you through the bad times. It's invaluable – if you're unsure and want to know "am I making the right decisions?"

In summary, clarity of needs, contributions and expectations is important for individual and collective arrangements to work well. Clarity of vision combined with a story or explanation of how this might be achieved engages people and keeps them involved. For more organised schemes and models, systems for checking what's working from different perspectives are crucial.

Knowledge, innovators and networks help to make this happen

Having a vision and clarity about needs and contributions is important, but so too is the ability or capacity to do something about them. Older people and model innovators make this happen in different ways, but some common success factors stand out.

For individuals
In terms of setting up a mutually supportive arrangement or becoming part of a scheme such as Shared Lives, the following points are particularly significant:

- Knowing or finding out about what is around or available locally, e.g. through adverts, word of mouth, advice from others, or a referral from another service or organisation. As the founder/co-ordinator of Southbourne Creative Hub, Dorset, noted, "I thought ... there are 84 flats here, there must be some people who are interested in sketching ... but together, not in their flat on their own."
- Being introduced to a group, network or scheme through a well-known and trusted individual from a statutory agency or formal setting, such as their GP, a district nurse, someone from the local community or health centre. Importantly these individuals had not used formal referral

processes, but rather they had offered their personal opinion/advice and a named contact.

Sangam involves people from all over Leeds; members use their contacts to reach out and engage more people:

> Everyone is connected to the temple and people routinely move from temple to temple to attend different events, functions or celebrations.

> If we ask people for help they do it … word of mouth plus the trust … the biggest thing is the trust … if the person doesn't trust you he is not going to open his heart.
> – Sangam members

- The importance of having one highly committed person, or group of people, whose job it is to broker the arrangement or relationship – that is, ensuring good matches are made either on an informal or formal basis. St Anne's Shared Lives Scheme in Leeds matches people by comparing a list of individual's needs and gifts with that of the family's offer. The team's close knowledge of the individuals involved (on both sides of the arrangement), together with their considerable placement experience, play a fundamental role in the success of the scheme and their very low placement breakdown rates.
- The importance of having a range of options, including for people with more complex needs where more formally organised support makes a difference.

Box 7: Caring Together

Caring Together is a charity based in the Woodhouse and Little London areas of Leeds. It employs three full-time staff members, including a manager, and one part-time. It has a board of trustees comprising people of all ages, including members of Caring Together (80 per cent are older people; 60 per cent are local older people). To be a member you must be over 60 or have a disability and live in the local area. There are currently 350–400 members, the youngest of whom is 55 and the oldest is 101.

Many members are known to have 'quite profound mental ill-health' and others are living with dementia, including Alzheimer's disease. People are referred via many different routes including word of mouth, GPs, family members and self-referral. When people are referred to become a member, Caring Together staff visit them to give them more information and to make an assessment, exploring what they need and also what they can give or offer themselves. All roles are interchangeable. Not everyone actively 'gives', and some give more than others.

The charity is well connected to another 43 neighbourhood schemes across the city that together form a loose association convened by Leeds Older People's Forum, and funded by the council and local NHS partners. [Members said: "Always there for support/help", "People are valued for what they can offer" and "People believe in it".]

For schemes, initiatives and networks

The study identified the importance of key people able to translate their own or locally generated visions into tangible services or developments based on mutuality and reciprocity. Each of the models and schemes examined in the case studies in particular is being driven by the passions and energies of a highly committed person (often the founder and/or pioneer of the model) or small group of people with good connections, local credibility (with members, decision-makers, politicians and policy-makers) and lobbying/networking skills.

One of the stand-out qualities of this person, or these people, is their generosity of time and ideas, and sometimes money. They are givers themselves, being outward facing, keen to share their experiences and lessons as well as their ideals. They are also people who have insight and understanding of the importance of sharing and learning.

For example, each of the people who contributed to the **Debenham Project** case study has emphasised the importance of the project co-ordinator – Lynden Jackson – to the success of the project. They variously highlighted his energy and his commitment, his tenacity and his networking abilities.

A number of striking differences were observed in the timing, pace and style of working adopted by these people in achieving their visions. A common theme is a focus on being action- and outcome-focused, but within this, two main approaches are evident:

- A 'do it now', pragmatic approach focused on action and learning by doing. This approach is often faster but can be messy and often ends up with the initiative being reliant on one or two individuals. This approach is typical of mutually supportive communities such as the Debenham Project, DropBy and some cohousing groups.
- A very principled, deliberative and democratic approach that tends to be slow but which builds resilience, spreads the load and may increase the likelihood of sustainability over time. In these cases, people were often following a blueprint or template/framework of an existing model such as cohousing and time banks. Even within these different examples, different approaches were taken; for example, some cohousing groups are now getting going very quickly (for instance, finding a site and property to base a community within) while others are moving through a series of community-building processes and finding their way (e.g. Cambridge self-help groups, time banks and some cohousing groups).

Scheme founders and organisers also emphasised the importance of having – and the consequences of lacking – access to practical as well as conceptual advice relating to their developments, including technical guidance and mentoring from a trusted, experienced proponent. Where this advice was available, it had made a crucial difference to their early experiences, for example, in getting started; maintaining their energy levels and motivation to keep going; and helping them to secure resources and assets through a range of different means. In some cases, those who have benefited from such advice are now providing the same role to other groups, networks and schemes trying to do similar things, thus forming a model of mutual support themselves.

The study identified the importance of key people able to translate their own or locally generated visions into tangible services or developments based on mutuality and reciprocity.

Box 8: Time banks

Age UK Bromley and Greenwich (hosts of the **Bromley time bank**) continue to develop and expand the work of its time bank, learning from other time banks in the UK network. For example, it has adopted an idea from Camden Time Bank in which local organisations and companies are encouraged to share their facilities and resources with local people and each other. A description of the time banking model is included on page 68.

Volunteer Now, hosts of a new network of emerging **time banks across Northern Ireland**, have benefited from educational visits to Canada and the USA and hands-on advice and encouragement from others who have 'been there and done that'. They are clear that their links and relationship with Timebanking UK has been important in helping to get new time banks off the ground where none previously existed. Volunteer Now told us: "It's been a huge advantage learning from English time banks such as Gloucester Fair Shares, who told us 'don't expect anything in the first 6 months; hold your nerve!'"

Some case-study participants and fieldwork respondents holding a co-ordination role in local schemes and initiatives shared their frustrations with various aspects of technical, legal, regulatory and operational rules, procedures and hoops that they have had to negotiate or are still learning to live with. They stressed the benefits of having – and described the impacts from lacking – enabling rules, financial vehicles and legal levers to help them to establish their arrangement/model/scheme, to extend or expand it, and keep it going over time. They were each able to point to those places or models where such assistance has been available or been developed.

Box 9: Cohousing Advice Shops

A Cohousing Advice Shop is available in most towns in Denmark, where there is also a government department for cohousing. In Scotland there is political and strategic, policy-level support for the development of senior cohousing, although some of the planning requirements and legal frameworks are still obstructing progress. In Suffolk, the Debenham Project has worked hard to create strong partnerships and close relationships with statutory agencies to persuade health and social-care services to be delivered differently in order to support people living with dementia to remain active members of their community (rather than having to travel or move away to get help).

The wider context of policy, the law, business operations and financial probity are real and daily concerns in the world of mutual support options. Those involved need to equip themselves to some degree to find their way around these requirements, but there are times when rules have to be changed to make these arrangements happen and work well for the individuals involved.

Nurturing relationships and trust are central to all models

The majority of fieldwork respondents and case-study participants talked about the central importance of relationships in these arrangements,

highlighting the presence and importance of friendship, companionship, love, warmth, kindness, shared interests and passions:

> People get a great deal from being involved – they share their problems – sometimes enjoy a meal together, travel to Bradford to see Bollywood films [which aren't shown locally]. As older people we can feel as they feel.
> – Member of Sangam, Leeds

> These relationships draw new depths from yourself, qualities and thoughts you didn't know you had, and you grow too.
> – Member of informal neighbourhood support network, Swansea & Gower

They emphasised the organic, fluid, flexible and adaptable nature of their arrangements and relationships – and that these were features they particularly valued and appreciated:

> You can find people with shared interests and help each other out e.g. met and sorted out help at home from a 17-year-old, met an 87-year-old man via Alzheimer's Society – we shop and have lunch together once a month.
> – Pathways to Peace group, Swansea & Gower

Being flexible and adaptable is key, but so too is an underlying trust and confidence in the relationship and arrangement in question. Having *mutual* trust and certainty in and among each other was raised by all respondents and participants, for instance, the certainty that comes from knowing that what has been agreed will actually happen.

> People come for the companionship as much as anything else. Members ring each other. Help each other out with shopping, pensions, smoke alarms, a real lifeline. We laugh all the time. Members ring each other for help and advice. The organisation offers some active support, information and advice from paid staff; just to know there's someone there, that's a big thing for us. Helps you cope.
> – Caring Together, Leeds

Trust was also a common feature across the in-depth case studies, including: trust between the founder or small group of founder members and others involved (especially at the start of their initiatives); trust among members of the community/scheme/model; trust between those representing, leading or co-ordinating arrangements and funders, and other local organisations and agencies; and trust in the scheme/model/approach from policy-makers, commissioners/funders, sponsors and other people championing the cause.

It was equally clear that the absence of trust (or where trust has been weakened) has a huge and negative impact on people involved in arrangements and schemes founded on mutuality and reciprocity. Those involved in the case studies talked about the absence of trust manifesting itself as a focus on risks and problems rather than on solutions and experimentation, which are positive features of successful models of mutual support. This kind of risk-averse mindset runs the danger of becoming a self-fulfilling prophesy because it blocks trust from developing in the first place; a risk-averse culture kills these models and approaches.

Strategies and skills for building and sustaining trust are therefore central to the development and sustainability of models and options based on mutual support.

Mutuality and reciprocity mean different things

The study found that mutuality is the driving force behind all of the models, approaches, arrangements and developments covered, and that reciprocity is an important feature for a smaller number (e.g. time banks, Homeshare, some senior cohousing groups, DropBy). For example, DropBy has been designed to create a platform for people to interact and to support each other; reciprocity is central to its effectiveness. Numbers are growing but Mary, the founder of DropBy (see page 23), believes it may need to have more than a thousand members before peer support and communication can be achieved around the clock and be self-sustaining.

Older people involved in the fieldwork sites and case studies identified mutuality and the sense of 'being in it together' as something they valued most from the arrangement. They were also more able to articulate their experiences of mutual support, or mutuality, than to share examples of reciprocity. They seemed to differentiate these from each other. So, while participants emphasised the mutual benefits they experience through their arrangement/relationship, they are less interested in or concerned about the extent to which this is always reciprocated. In other words, they differentiate between mutuality and reciprocity, without exactly using those terms. It is more important to them for the arrangement to be mutually beneficial overall, than it is to be clearly reciprocal:

Older people involved in the fieldwork sites and case studies identified mutuality and the sense of 'being in it together' as something they valued most from the arrangement.

I like using what talents I have in a community sort of way.

The Hub has opened up my life. I go and clean occasionally [for another member]. She's writing a book, her life story. Another friend takes her shopping.

We're creating what community centres used to be like … it takes work, to keep it flexible. This is rare.
– Members of Southbourne Creative Hub

A lot of older people use this café – lots of informal support grows out of this. People notice that so and so hasn't dropped by of late and follow that up; or offer to help with shopping. A domino effect and a safe space to be together.
– A community café on the Gower Peninsula

These experiences illustrate that mutuality is values based and relationship driven, and can be between two people and many. Reciprocity is often talked about as a transaction that works best when it occurs in the same or close time period and is experienced as a direct exchange, but this often doesn't happen. Some models have tried techniques for delaying or spreading out the time period of the reciprocal arrangement (e.g. some time banks and the idea of 'care banks'). This hasn't always worked, especially when the mutual benefits haven't been reinforced or reasserted.

Participants' experiences also indicate that mutually supportive relationships and networks (which lie at the heart of many of these models) do not have to mean that those involved are close friends. This is an assumption that is often made about these models (for example, through the use of the term 'relationship'). It was equally clear that friendships often *are*

involved or evolve (as outlined above) and that mutual understanding, trust and shared values are crucial elements of successful arrangements.

Box 10: The Cherry Trees Club

The Cherry Trees Club in Cambridge was set up to tackle the social isolation of many older people living alone in the neighbourhood who didn't really know each other or anyone else very well. Families had moved away, people had been bereaved, people's networks had shrunk. The weekly club meeting provides a wider range of contacts from which relationships and sometimes friendships flourish. It encourages interaction, it gets people out. It provides members with roles and a sense of belonging, and ownership of the club. One member organised small group holidays; another member set up a toenail-cutting service in her own home with a chiropodist.

Members are proud of their self-help and mutual exchange system, which has enabled this club to meet weekly over the last ten years.

However, as senior cohousing groups and proponents emphasise in one of the case studies, this does not mean that you live in each others' pockets or that you agree about everything. For some models and approaches it is the close, geographical proximity that is important (e.g. senior cohousing, Cambridge self-help groups, the Debenham Project and time banks in Bromley and Northern Ireland); for others it is the shared experiences and interests that are of greatest importance (e.g. DropBy).

In summary, reciprocity can be mutually supportive and beneficial, but mutuality does not have to be directly reciprocal. Older people most often seem to be motivated by mutuality and relationship-based experiences; an explicit expectation of reciprocity can actually be a barrier to engagement and involvement for some of them.

Asset-based *and* community-led approaches matter

An 'asset-based approach' was common to all of the models, schemes and initiatives explored in this study. Founders and co-ordinators of schemes examined in the case studies spend much of their time discovering and unlocking the existing and/or potential skills, experiences and expertise of their members in order to achieve their vision. Having people involved who have a particular talent or interest in discovering and building assets within the community of interest or place is a key success factor for these models and approaches. As Hugh Hoffman from the Vivarium Trust says:

> It's been an exciting process – we've been going nearly nine years and now we're nearly there. A lot has happened and is always happening – it's very time consuming – each step involves a lot of time and energy and discussion. We're learning all the time.
> Group development and people management is key – everyone has something to contribute e.g. some people are financially literate and able to deal with banks, building societies, grants, housing associations etc.

Having the skills and tenacity for ensuring these assets are used to realise and live participants' vision is therefore another critical success factor.

Case-study participants also emphasised the importance of their model/ schemes being "community generated, led and owned". The founder and directors of the Debenham Project stress that people in the wider community defined the problem (a lack of local support for people living with dementia) and helped to shape the solution (a mutually supportive community). The project had a wide community mandate, which gave it sustainability and authenticity. Lynden, the founder, firmly believes that "a problem defined by a small group and with a solution imposed from outside is less likely to succeed".

For some, an insistence on community ownership has meant that the development of other, potentially vital partnerships, has not been as actively pursued. It is possible to compromise and retain a focus on community ownership while remaining a viable model of support – illustrated by the Bromley time bank, Vivarium's relationship with Kingdom Housing Association, and the range of partners being developed by Volunteer Now in order to foster and promote a network of time banks across Northern Ireland.

Box 11: Time banking in Northern Ireland

The time-banking programme in Northern Ireland consists of a variety of different opportunities for communities, organisations and networks to establish time banks with and for older people.

Five small one-off seed grants were allocated to help different places/ groups set up a time bank with support from Volunteer Now (VN) from April 2012. The aim is to establish and support five new time banks a year in this way over the next three years. Each time, the group receives up to £3,000 to develop a time bank with older people at the heart, with support from VN to do this. Those established so far, and applications received for the next round, have all been from people who really believe in the aims and principles underpinning time banks and a desire to be part of this as older people and/or involving older people. The first five time banks to be established in this way are:

1 Newry and Mourne in the South East – with a focus on carers of older people (re)gaining their sense of self and identity, and getting respite support.
2 First Step North Belfast – with a focus on recently bereaved partners, typically older people who have tended to have very traditional roles; it aims to be a skill swap, enabling those who are bereaved to develop new skills and confidence.
3 Newtownstewart Time Trade – with a focus on sustainability and becoming a transition town.
4 Omagh Time Bank – a large, well-established time bank for the whole town started by older people but providing a wider community infrastructure for mutual support and reciprocity.
5 Clough Mills – a community-based environmental project using redeveloped land to provide allotments, with a focus on engaging older men.

Some participants are clearly struggling to make their approaches visible and their voices heard. They feel their asset-based and community-led approach is a world apart from the more traditional mechanisms for commissioning and providing support. As members of a self-help group in Swansea & Gower

commented, "Nobody's really asking people what it is they want – lots of people in the professional sector have little idea of how to involve people to address their needs."

Resources and resourcefulness are important

All respondents talked about access to resources in one form or another, but they were not always talking about or referring to money. Resources and assets most frequently mentioned and valued included: having a home, being part of a family, local knowledge and know-how, networks, groups, information, advice, services and amenities, transport, other people who were able to help out, welcoming places to meet, etc. A member of Paravar, Leeds said, "We learn from each other; if someone is well equipped with information I will ask for their help. People give each other a lift in the car. We draw on our strong community knowledge."

More formal and co-ordinated schemes and networks did talk about money and infrastructure – both how helpful they are and how scarce they are. They talked about the impact of recent cuts and their uncertainty about ongoing funding.

Box 12: Pauline and Sue, Shared Lives, Oxfordshire

Pauline is a Shared Lives carer in Oxfordshire; Sue is a 77-year-old woman with a history of mental ill-health who has lived with Pauline for nine months as part of a Shared Lives arrangement. Another, younger woman with a learning disability also lives with them. The arrangement is working well, with Sue saying "I want a future and a life now … she [Pauline] makes me feel safe and that I have a future here." Pauline describes how the three women "live together and operate as a family … we just all muck in".

Pauline and Sue receive support from the Shared Lives scheme, which they describe as "very good … they are there for you whenever you need them". Support structures are built into the Shared Lives arrangement but Pauline feels that funding cuts are undermining these. For example, they receive support from the local community mental-health team, but despite excellent staff, a recent reduction in team resources has had a real impact. "They have helped to make this arrangement viable … they used to make weekly visits but now they are much too stretched. A Shared Lives arrangement like this costs the state a lot less [than residential care] but they do need to back it up well for it to work well."

The co-ordinators and founders of such schemes and models also emphasised the importance of having a profile, sponsorship in its widest sense, and strategic support. They talked about how important these kinds of resources are, both when they are present and when they are absent.

> There has been some fantastic support from some local councillors. There are several hundred people on the database for the scheme, plus the scheme has received a good deal of media coverage (local and national) and is part of the UK cohousing network.
> – Threshold Centre, Dorset

Most of these co-ordinators and founders, however, felt they did not have the strategic support and profile that would enable them to reach, involve and support more people:

It's a constant source of frustration to me that we're out there and no one knows about us. I think it [Shared Lives] is brilliant, and we are like a team worth getting up for!
– Shared Lives Scheme, Dorset

It's been a battle getting the concept accepted among policy-makers. The challenges have been huge compared to Denmark where cohousing is and has been a normal option since the 1970s and where there is a network of advisors and a cohousing government dept. Vivarium have had a lot of help from advisers/consultants in Denmark.
– Hugh Hoffman, Vivarium Trust

Fieldwork respondents living in rural areas explained that the scheme or arrangement they were involved in had helped to resolve difficulties in accessing the full range of amenities due to the lack of local transport infrastructures. For some, this support had helped them to carry on living where they wanted to, for example, by pooling or sharing transport, clubbing together to make things happen locally, taking it in turns to visit each other, providing local employment, etc.

We feel safe asking for/receiving support with others in the same network. Members swap various skills, [do] clothes swaps, car sharing, support each locally in the neighbourhood, [do] dog walking, cat sitting, share washing machines and tools.
– Threshold Centre, Dorset

Many of the people we talked to were creative and resourceful about finding and then making the most of different sources of funding. As a member of a self-help community in the Gower put it, "It's about sharing resources".

Case-study participants were adept at sourcing and securing money from different, atypical sources (e.g. Timebanking NI/Volunteer Now, Bromley Time Bank, Vivarium Trust, Debenham Project); and at levering in assistance and support from others (DropBy, Cambridge self-help networks). They were also doing a lot with relatively little, and making a little go a long way – qualities and skills that were especially valuable at the start-up phase of these arrangements (e.g. Vivarium, Debenham, Cambridge).

However, they all also had concerns and anxieties about their future and long-term sustainability, and recognised the need for a more secure funding base as they moved into a more operational era. (For example, the Debenham Trust's long-term vision is focused on developing a strong business case.)

The majority of models and developments covered in the case studies were funded largely through project or philanthropic sources (to date). The main exception to this rule is the Bromley Time Bank; Age UK Bromley and Greenwich have deliberately integrated the time bank into their core activities and therefore their core funding. This has helped to secure its place within the wider organisation. Most of the other developments did not have a host organisation like this, although the embryonic time banks in Northern Ireland are currently associated with and being supported through a grant that is held by Volunteer Now (which is actively exploring future funding

sources with time-bank members across Northern Ireland as a way of sustaining those that are found to be effective).

Problem solving is a central, sustaining feature

We were struck by the number of times that respondents mentioned the role of problem solving in their arrangement or relationship. The ability to sort out problems and overcome life's obstacles was seen as being central to the mutual support arrangement; something that it enabled the different parties or members to do and that helped it to work and last.

> We're a network – feel safe to share any gripes or problems ...
> one member has a relative with drinking problems, another has a
> youngster with autism, someone else is very depressed. We get
> together, relax, meditate for half an hour.
> – Pathways to Peace group, Swansea & Gower

> We have a shared sense of survival – mutual experience of women
> having lived through a lot.
> – Maria and Pat, Swansea & Gower

> We are like a team, it's brilliant.
> – Shared Lives carer and older person, Oxford

Like many personal relationships and partnerships, older people involved in mutual support arrangements identified the features in Box 13 as those that help them to keep their arrangement going over time.

Box 13: Keeping things going over time

- Mutual respect and trust.
- Friendship, companionship, love and warmth.
- Comradeship; a sense of being in it together.
- Shared interests, passions and values.
- Being genuinely interested in each other even if specific interests or preferences are not shared.
- An openness and ability to discuss and air concerns, to 'keep talking' in good and bad times.
- Having a deep knowledge and understanding of each other.
- Making time for fun and having fun together, not just focusing on difficult or practical issues.

Specific issues that were flagged up as needing particular attention within such arrangements, but also where the mutual support arrangement and supporting infrastructure was helpful, included:

- help and advice with health-related issues;
- paying attention to, sharing and understanding cultural identity, needs and differences, gender roles and experiences;
- organisational red tape and bureaucracy, such as CRB checks and servicing governance requirements of more formal or established entities;
- individual and group dynamics.

Box 14: Reflections on a Homeshare scheme, Oxford

People involved in a Homeshare scheme in Oxford (which no longer exists) shared their reflections and lessons about what worked and why the scheme was difficult to sustain:

What worked well?
Sharers tended to be younger people seeking accommodation. In the strongest matches, relationships developed and grew as common interests were shared, such as music or a language. Where matches worked they were transformational, for instance, an Iranian sharer and a householder who had travelled a lot in Iran who made and ate Iranian food together. A sharer who was a young musician was matched with a householder who had been a professional conductor, and introduced the sharer into various musical circles, which helped to advance his career.

These matches gave the householder a sense of purpose, peace of mind for family/carers of householders, and combated loneliness (for both householders and sharers). They resolved problems, giving a sense of safety and personal security. Dogs got walked, cats got fed. One householder had fallen downstairs and would have stayed there for hours if the sharer hadn't been around.

What didn't work?
Some elements of the formal arrangements were bureaucratic and did not fit with the ethos and purpose of the scheme (e.g. a Homeshare agreement was drawn up by lawyers that mirrored a licence agreement; CRB checks were conducted for sharers but not householders; references for householders were hard to get because most people had left employment a while ago). As a result it took a long time to build up a head of steam and people often doubted whether their plans were going to become reality. You need a large pool of both householders and sharers; sharers tended to be looking for accommodation 'right now', and by the time matches were arranged they had often found an alternative. The expectations of householders sometimes didn't meet those of the sharer.

What would help next time?
Ensuring compatible systems are developed between funders and providers; keeping the focus on swift, effective matching; and integrating Homeshare with other options and mechanisms, such as personal budgets, would help everyone.

People were keen to share their experiences, advice and tips about how to set things up, resolve problems, keep things going and talk through issues and concerns. One member of a self-help network in Swansea & Gower noted: "Got to NOT say 'we need a volunteer for' ... but rather 'do you believe you have skills to offer?'"

The final fieldwork question in interviews and discussion groups asked respondents to share their advice and tips with others – for example, with those interested in support based on mutuality for themselves, and with commissioners, providers and organisers of such schemes/models.

Box 15 provides a summary of the most commonly shared 'top tips'.

Box 15: Top Tips For Widening Mutual Support

For older people
- Go for it – just do it, you won't regret it! It's better than the other 'care' alternatives on offer.
- Equip yourself and plan ahead: arm yourself with knowledge and talk to others who have done it before you.
- It's a difficult truth but families don't always 'get it'; it can be easier to be honest about your needs and your contributions, and to work out mutually beneficial solutions, with friends and others outside your close family whose concern for you can override your choices and decisions. Keep connected: wider networks and personal interests continue to be as important, if not more important, to your sense of self and well-being.

For commissioners/funders
- These models need a strong profile, i.e. better public and professional awareness of different opportunities and options.
- More information and advice is needed about all of these models/ options: what they are, what they offer, what's involved and how to access them.
- These models need sound and secure resources *and* flexible resourcing arrangements.
- Economic modelling and evaluations are needed that demonstrate which models work best in different circumstances and for which groups of older people.

For scheme organisers and co-ordinators
- Accessible, arms-length support (e.g. helping people to recognise when they need a break and being there in a crisis) is a much-valued role of the schemes that sit behind more formal models (e.g. Shared Lives, Homeshare, time banks).
- Familiarise yourself with the benefits and outcomes that can be achieved; use these to promote your scheme to older people and commissioners.
- Capture the outcomes, costs and savings involved in running your scheme, and share these with funders and members.
- Manage the tension between being clear about what's involved and being very flexible and open-minded (e.g. when to have a formal agreement or contract and when to have 'no house rules').

For everyone involved
- Mutual trust is essential and takes time to grow: don't expect miracles to happen overnight.

[Study participants] emphasised that they constantly grapple with two questions relating to size and scale: how to reach *more* older people who want to be involved and would benefit from being involved; and how to retain the benefits of being small and locally focused while reaching more people.

There are challenges of scale and replicability

The stories and examples shared in this study indicate that these models and arrangements work best when they are very locally focused and delivered or experienced on a small scale.

Some of the study participants had very clear ideas about the optimum size and scale of their reach and membership, while others were less sure or prescriptive about what this should be. They also each emphasised that they constantly grapple with two questions relating to size and scale: how to reach *more* older people who want to be involved and would benefit from being involved; and how to retain the benefits of being small and locally focused while reaching more people. They all believe that they can and should be

available to more people, and they are also conscious that extending their reach could entail them growing in size and capacity.

There is also a common desire to help others engaging in similar projects to flourish (for example, to be the mentors and coaches that they themselves have or wish they had). People involved in the Debenham Project and Vivarium are keen to aid replication rather than grow in size and stature themselves, an approach that they feel risks the creation of just another 'one size fits all' mentality. They 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.

Scaling *out*, therefore, is more important in terms of spreading and sustaining what works than scaling *up*. This is more about having a process that aids replication rather than a literal translation or imposition of one approach in different places.

The senior cohousing community of interest that exists in Denmark, Netherlands and USA has understood this need for not just a blueprint but also a design process that facilitates and helps others to follow suit, but in their own way and through building their own assets and capacity (Durrett, 2006).

Box 16: The need for a senior cohousing blueprint

Early pioneers of senior cohousing in Denmark endorsed the need for a blueprint of the model, in order to:

- establish senior cohousing as an option for everybody;
- identify and solve key problems that older people interested in this option are likely to encounter during the process;
- enhance the social aspects of the process, which in turn have been found to foster strong and durable communities;
- make it easier and more satisfactory for developers and local authorities (including officials as well as local politicians and community leaders) to start and support senior cohousing projects;
- guide the process from start to finish and beyond.

In the UK, Shared Lives is one of the few models which has achieved scale (10,000 individuals are currently involved) without losing individual focus and a localised, domestic basis.

Lessons and insights from elsewhere

This section shares lessons and insights drawn from the literature search and call for examples of mutual support experienced by older people with high support needs. The combined knowledge and learning from these secondary sources of data formed an important part of the study, helping to shape the fieldwork (e.g. to focus on identified gaps); highlighting differences between fieldwork, case study and call respondents' experiences and those identified in the literature; and adding an international component to the work (in the literature search).

The following themes summarise the key lessons and insights from looking across these two sources. This combined information has deepened our understanding about why different people in different circumstances may be more attracted to and to opt for some forms of mutual support over others. The detailed literature review is available as a separate document on the NDTi and Community Catalysts websites.

How older people with high support needs are seen

Older people with high support needs still tend to be widely regarded as recipients of care, as beneficiaries rather than assets and contributors, and as people to be taken care of rather than to contribute or lead the development of new approaches to designing and delivering support.

Even the literature about models founded on principles and practices of reciprocity such as time banks tends not to regard older people with high support needs as active members who give (as well as receive) in equal measure to other members (Boyle, 2011; Slay 2011; Collom, 2008).

There are some signs of recent change, for example in the series of publications and papers developed through A Better Life, in some of the responses received to the call for examples, and in the fieldwork for this study.

In addition, the literature offers evidence of an interesting paradox: if you are an older person and you need a lot of support in your life, then it is not considered appropriate that you access preventative or 'low level' support even though help with shopping, gardening, household chores and repairs is the kind of help that older people – regardless of their complexity and level of needs – most value and want (Raynes, *et al.*, 2006; Blood and Pannell, 2012). This finding resonates with the fieldwork and case-study findings that models of mutual support have often arisen as a result of people's disappointment and frustration with the current 'offer' typically available to them.

Understanding mutuality and reciprocity

Many different words, phrases and interpretations of the terms 'mutual support', 'mutuality' and 'reciprocity' are used in the literature. There appears to be a lack of clarity and some confusion about what these mean in practice, especially in relation to current and potential future forms of care and support. We concluded that mutuality and reciprocity are:

- experienced on an individual as well as a collective level;
- defined as shared ownership and control;
- based on shared, underpinning principles and values linked to specific practices and practical considerations;
- used interchangeably but do not always mean or involve the same thing(s).

References to and examples of *mutuality* were more evident in the call responses than reciprocity or specific reciprocal arrangements. Opportunities to contribute and to feel valued, and for a sense of achievement and 'comradeship' were all highlighted as important experiences and outcomes for different people involved in these arrangements – rather than things that were gained or exchanged. These responses emphasised the links between a sense of mutual benefit and members' or participants' health, well-being and general happiness.

Though much hyped in the literature (especially policy documents and best practice guidance), mutuality and reciprocity experienced by older

people with high support needs have often been difficult to evidence in reality. For example, few responses to the call fully met our criteria, not only in relation to older people but also in terms of evidence of mutuality and of reciprocity. The fieldwork in four study sites and the case studies have helped to fill this gap by enabling us to capture and learn from the lived experiences of older people with high support needs, and to better understand the different models and approaches.

Understanding different models based on mutuality and/or reciprocity

The examples covered in this study are not new concepts or models, but the language is often used interchangeably and new phrases emerge and become fashionable, which can imply that they are new: for example, mutuality, community capital, social capital, co-production, social glue, asset-based approaches, social entrepreneurs, to name a few. Many of these models remain unfamiliar to many people, but this is not because they are new.

Some models of mutual support are tightly defined (e.g. Shared Lives, time banks, Homeshare, cohousing) but can seemingly accommodate many different interpretations and adaptations within an overarching framework or blueprint for their design and delivery. Informal, under-the-radar arrangements and approaches, on the other hand, are by definition much looser and harder to pin down – both in the literature and in reality. It is therefore not surprising that, although much has been written about benefits to be gained from informal, mutually beneficial arrangements, such as the Partnership for Older People Programme (POPP) and Link Age Plus pilots, they are often not acknowledged as existing as valid forms of *support*. They do not feature strongly in the literature on mutual support, are not generally conceived of as 'models', and are often not trusted or invested in with regards to enabling older people with high support needs to actively engage in or initiate them as part of a wider package of support. The fears and anxieties of others (e.g. family members who are caring at a distance) about vulnerability and frailty, combined with the perceptions of older people with high support needs, outlined above, may explain why risk-averse commissioning and delivery practices still dominate (Andrews, *et al.*, 2009; Burke, 2010).

While some of the tightly defined models were originally developed as generic models, the extent to which older people with high support needs are taking up active roles within these models is currently limited. The case study on time banks was developed for this reason, to learn from those places where older people – and older people with high support needs in particular – are actively contributing as well as receiving support.

Other models and approaches were initially developed with specific groups in mind and although there is enthusiasm to roll these out for other groups, there are limited examples of where this has happened. For example, KeyRing Networks (Department of Health, 2009) were developed to support people with a learning disability; while there is enthusiasm and belief that this model would work well with older people, no such networks yet exist in the UK. Circles of Support also originated and have become established in the learning-disability and criminal-justice fields, and there have been some recent developments to extend and adapt this model for older people.

Shared Lives is one model that has been successfully rolled out for a diverse range of people, including older people with high support needs. It also features significantly in the fieldwork sites. This may be because it has a robust, published business case (NAAPS and IESE, 2009; Valios, 2010; IPC,

2011) and is a regulated form of support, so is regarded as being on the spectrum of familiar care and support options.

Responses to the call emphasise the importance of matching and brokerage functions in models and schemes based on mutuality and/or reciprocity – for example, to ensure that strong and successful links are made between members. They emphasise the importance of the skills and knowledge required to do this well; and the personal connections, common points of interest and relationships between members. As the fieldwork findings show, this does not necessarily mean or imply that members have to be close friends – although the responses illustrate that friendships often do develop as a result of the connections and matches that are made.

The profile of existing support and where mutuality fits

The literature identifies a service profile that remains dominated by largely traditional forms of care and support for older people, which tends to scoop people up into silo'd services. The literature also highlights that:

> traditional approaches (care homes etc) do not meet the needs and wishes of their residents ... integrating older people into local communities (rather than building ghettos) has to be part of the solution.
> – Burke, 2010

It is clear that the established policy and practice intent is to move away from 'one size fits all' solutions, including residential care, and to develop personalised, creative alternatives – particularly those founded on social capital. There is successive evidence that this is also what older people want. As the fieldwork findings illustrate, where options are widening this is not occurring on a large scale and alternatives such as mutual support are not yet integrated into the mindsets and practices of most commissioners.

A number of founders or co-ordinators of schemes who contributed to the call shared their experiences of and strategies to deal with resistance from others towards the model, scheme or arrangement. This resistance was usually experienced in the early days and largely from professionals, other organisations in the area, and some family members.

While there has been some progress in ensuring that older people's priorities are influencing broader public service developments (e.g. Age Friendly Cities), their influence over commissioning decisions relating to care and support options remains limited. The *Care and Support White Paper* (2012) reinforces the government's intent to engage local people in designing affordable, personalised solutions which offer greater choice. This study shows that there is a lot of work to be done to help deliver this and older people's own vision for alternative kinds of care and support (Bowers, *et al.*, 2009; Blood 2010). It also highlights the need to look beyond social care resources and commissioning arrangements in promoting a diverse local market offering solutions that older people find attractive.

From their experiences of initiating and then managing the responses to the call for examples, the project team identified that entrepreneurs and innovators in this field tend not to be people who write up the great things they are doing and experiencing (other than in very brief, often opaque, promotional flyers and leaflets). They don't usually have the time to provide information for someone else to write it down, as discovered when this facility was offered by the team.

Finding alternative, time-efficient and creative ways of doing this is crucial for profiling and widening options for older people with high support

needs, who find it difficult to find information about these models. It would also help to bring them to the attention of different funders, sponsors and commissioners.

Evaluating outcomes and demonstrating benefits

In spite of a belief from government (expressed in policy documents and reports) that the benefits of mutuality and reciprocity need to be tangible and quantifiable, there is little evidence about the outcomes and impact of mutual support generally, and involving older people specifically. This picture was consistent across the literature review, and calls for examples and fieldwork findings, although clear outcomes and benefits were identified and shared by fieldwork and case-study participants.

Various papers in the literature share lists of benefits and positive experiences of mutually supportive relationships and arrangements (Volunteer Development Scotland, 2007; IPC, 2011; Slay 2010; Manthorp, 2010), but evidence of individual, community and service level *outcomes* is harder to find – especially in relation to older people with high support needs. Most published studies in the literature focus on collective forms of mutual support rather than informal, one-to-one or direct arrangements, with an implicit assumption that collective forms/networks are more beneficial as they reach more people.

Much of the recent literature examines the different dimensions and dilemmas associated with size, reach and scale – and the relationship between these dimensions and effectiveness of models in terms of engagement, take up, outcomes, economic viability and long-term sustainability (Burke, 2010; Colligan, 2010). A common finding, as with the fieldwork, is that these models thrive and flourish when they are small and locally focused; a major challenge is securing investment when many funders set criteria for investment based on volume-based measures of effectiveness (i.e. numbers served not outcomes achieved and sustained). Different kinds of outcomes and impacts are likely to be identified through the kinds of community-generated and led developments associated with formal or organised models of mutual support, and those schemes designed to facilitate more informal arrangements. A key challenge will therefore be to develop outcome indicators and measures that satisfy both the requirements of investors and commissioners and the founders and members who 'own' these models/schemes.

Most models and schemes based on mutuality and reciprocity in the literature and in the call have not been formally evaluated (O'Sullivan *et al.*, 2010; Boyle, 2011; Slay 2011), especially those that exist on a small scale. One exception is Shared Lives; there has been some research demonstrating its outcomes (NAAPS and IESE, 2009). Few schemes responding to the call assess their own impact on a regular basis, for example, to inform and influence local commissioners, or to profile their scheme. While most of these respondents could articulate clear benefits at different levels, they could not *evidence* them. This is understandable given the lack of capacity and evaluation expertise that exist at this level, and the focus within these schemes on delivery and development. However, without this evidence it will be difficult to sustain these schemes and models and/or extend their efforts to reach more older people.

Funding sources and resourcing issues

A number of sources in the literature highlight the problem of short-term funding, often project or grant funding, which can mean a 'stop-start', hand-to-mouth existence is a feature of these developments. There does seem to

be a difference (as identified in our case studies) between those models that manage to secure more sustainable funding streams (e.g. Shared Lives and Bromley Time Bank) and those that continue to depend on repeat grant or project funding.

Most schemes in the call were funded as projects, so sustainability of these approaches is a key concern; those that keep going are those where organisers have continually explored different funding sources, including members paying a fee and widening the number of partners and networks involved. As referred to earlier, these respondents also identified a need for greater awareness, understanding and confidence in models/approaches based on mutual support; all of them have experienced the 'what is this?' syndrome. The lack of profile and familiarity with these approaches is clearly linked to respondents' shared concerns with funding streams and future investments.

Even where models have become more established, the literature on co-production and project implementation emphasises the need for a seismic shift in the culture as well as the practice of local commissioners – a key message for new and emerging commissioning structures (clinical commissioning groups and health and well-being boards).

Enabling drivers for widening options for mutual support

Box 17 summarises key points drawn from a number of different references in the literature that highlight the need for a range of enabling drivers to be in place to support this shift in culture.

Box 17: Enabling drivers for change

- Political will and legal legitimacy.
- Visionary policy frameworks and agendas.
- Informed commissioners who share this vision.
- Competent commissioning practice by people who understand what is required.
- Informed providers who also share the vision.
- Knowledgeable and enthusiastic 'providers' from a range of backgrounds and sectors.
- Greater public knowledge, familiarity and confidence in the range of alternatives that are possible and do exist.

When thinking about different models of mutual support as viable, legitimate options within the spectrum of available support, it is sobering to think that most of the above are missing in relation to older people with high support needs.

A key difference noted between the fieldwork findings and insights drawn from the literature is the role and place of problem solving within mutual support arrangements and models. The literature includes references to initiatives and developments that ended as soon as a major problem or crisis occurred or where older people's involvement in a particular model ended if their needs or condition changed or deteriorated. This is in stark contrast to the fieldwork and case-study findings where people shared their experiences of active problem solving and crisis resolution; where these arrangements had enabled them to avoid crises and/or 'stay put' in difficult times.

The importance of having clear drivers and motivators were identified in a number of responses to the call (as well as the fieldwork). Appealing to older

people's altruism seems to be a successful hook both for innovators and for participants/members of such models and schemes. Another common motivator for getting involved in (or initiating) different mutual support arrangements and schemes is a shared and explicit understanding of each party's needs as well as their contributions. In other words, when there is a mutual need, and there are ways of meeting this need by coming together (whether on a one-to-one basis or by joining a wider network/group), the arrangement is more likely to become established and to be sustained. This is also a key finding from the fieldwork and case studies shared in Chapter 3.

Key success factors

Responses to the call illustrate that successful models have an obvious entrepreneurial spirit and style both in the design of the scheme/model and the people developing and engaging in them. This entrepreneurial approach is demonstrated by an assertive approach to problem solving and finding creative ways to overcome barriers and resistance. The models work best when this entrepreneurialism is combined with pragmatism, that is, making things happen on the ground.

Geographic location and context are also key factors for success; most of the call's responses were about models and approaches that are very locally based around a small, geographical area. In one example of a nationwide model (Homeshare), it was noted that local schemes tend to work better than those organised on a county-wide basis; networking and recruitment of participants and communicating the benefits proved easier when organised through familiar and known routes.

Linked to the above, those respondents who had developed or found ways of connecting their scheme/arrangement to existing infrastructures and networks (e.g. to recruit members, link people to other support groups, secure funding or promote their model) were more successful in sustaining their approach over time.

As with the fieldwork and case-study findings, call responses from organised models and schemes (rather than informal arrangements) often had energetic, motivated, well-known, liked, respected and credible founders and/or co-ordinators as well as a healthy membership base. Each of these responses could also articulate a clear vision and underpinning principles shared by all those involved. Both informal and formal models and arrangements shared an assets-based approach, where people involved are seen as assets regardless of their age, disability or need for support. However, as mentioned earlier, older people with high support needs were still most often described as recipients and beneficiaries rather than as active contributors (or even founders).

A subtle but important message about hope and recovery was evident in some of the responses to the call – for example, providing hope is a key principle of the Flexicare model.

Finally, there are valuable lessons to be learnt when things have not gone according to plan. Due to limited capacity, these lessons are not often absorbed and applied in order to enable these schemes/models to carry on operating or scale out. Some developments stopped when major problems at a scheme level were encountered (compared to individual examples from the fieldwork where problem solving is an essential and sustaining element for those involved).

International lessons and perspectives

A number of fascinating insights and important lessons can be gleaned from looking at international examples both of the same models explored in this

study, and variants of these approaches that have evolved in the context of different cultural, social, political and legal environments.

On first reading, it appears that an extremely wide and rich range of different alternatives and models exists in different countries; however, closer examination indicates that while this is true globally, within different countries and cultures a different pattern of care and support exists within which specific alternative models appear to thrive.

These differences are influenced by a number of variables, summarised in Box 18.

Box 18: Variables that influence the success of models

- The history of alternative approaches and models available in different countries.
- The length of time and experience within those countries of when and how different models became established and promoted.
- Prevailing cultural and social norms – and the extent to which these are diverse and inclusive, i.e., open to new ideas.
- The presence of political, financial and legal drivers and enablers (and consequently also the lack of certain obstacles and barriers).
- Experience in developing and sustaining models that value 'complementary currencies', e.g. Local Exchange Trading Systems (LETS), time banks, Fureai Kippu in Japan, and mutually supportive communities (e.g. Elderplan, member to member and the Village Movement in the USA, and the French Villa Family Programme).
- Shared demographic and economic challenges and pressures.

4 OVERARCHING MESSAGES

This chapter sets out **seven overarching messages** about what needs to change and principles to be adopted in order to widen and sustain different options for support in later life. They are drawn from the findings, lessons and insights across all sources of data and analyses, and have been developed to start the process of applying the research findings.

Box 19: Seven overarching messages

1 Challenge negative attitudes about and narrow perceptions of older age.
2 Raise public interest and address professional scepticism.
3 Work with diverse models of support based on mutuality and reciprocity.
4 Demonstrate the clear outcomes that can be achieved from mutual support.
5 Adopt the five common features of mutual support.
6 Integrate mutual support into local options for older people with high support needs.
7 Celebrate and support successful innovators and ambassadors of mutual support.

1 Challenge negative attitudes about and narrow perceptions of older age

One of the main barriers to older people accessing different options for support, including models based on mutuality, is the assumption that older people with high support needs have nothing to give or contribute; their perceived and/or actual needs dominate. In reality, this is an extremely diverse population spanning different generations, communities, groups and

individuals, with widely different experiences, expectations, aspirations, needs *and* gifts, skills, talents, networks and resources to contribute.

From the earliest stages, the research team encountered narrow and negative perceptions of, and attitudes towards, older people with high support needs. Older people with high support needs are largely perceived as people 'in need of support' who 'need to be taken care of' rather than citizens with rights, responsibilities, skills and contributions to make themselves. The prevailing belief is that older people with high support needs are likely to be recipients of care for whom mutual support is not relevant or appropriate.

Where older people are identified as a target population for or by schemes described as mutually beneficial (e.g. some time banks and community volunteering schemes), they are still often described as recipients and it is other, younger members who are doing the giving. This is counter to the responses received from and experiences shared by older people participating in this study.

2 Raise public interest and address professional scepticism

There is a great deal of interest from older people (and some families) about the concept of mutual support, and enthusiasm for discovering how to make it happen for themselves and others. We have learnt a huge amount from older people with varying and complex support needs who are actively seeking, developing or thriving on different models of support they have instigated themselves or engaged in on a formal or organised level.

Among professionals and professional bodies, however, there is hesitation and scepticism about the extent to which such models and approaches are suitable, affordable and practical for older people with high support needs, especially those who need 24-hour care.

Among family members, there is also hesitation and anxiety about the models outlined in the typology. We think this is mainly due to their lack of knowledge of and familiarity with such models, combined with their concerns for ensuring their relative is being supported in a reliable and consistent way. We believe this is a confidence issue rather than scepticism about what is possible, although some fieldwork respondents also shared their experiences of grappling with overt resistance from family members who oppose their interest in alternative models or informal arrangements they have developed themselves.

We recognise that models of reciprocity, given their inherent reliance on relationships, can be seen as problematic and non-sustainable, especially within current, risk-averse commissioning and procurement environments. The concern that relationship-based services are less sustainable because if the relationship fails, the service fails, is a barrier to the development of models based on mutual support. The mismatch between the realities of those who are experiencing these options and those in a position of power to commission, deliver or point people towards them, is flagged as a priority for action in Chapter 5.

3 Work with diverse models of support based on mutuality and reciprocity

An extremely wide range of different types of models of, and approaches to, support based on mutuality and on reciprocity has been identified, including some that are actively involving and led by older people with high support needs. This diversity is both a strength and a challenge, given that they are not currently well known and are not generally well promoted. The main issues are outlined in Box 20.

Box 20: Working with a diversity of models

- Communicating what 'mutual support' is about, what is involved and the benefits and outcomes it can deliver.
- Acknowledging why (and how) support based on mutuality and on reciprocity is different to more traditional forms of support.
- Strengthening the evidence base and developing a business case for each model.
- Widening access to, and availability of, such options.

This study has shown that mutuality is not the same thing as reciprocity – and that they influence, incentivise and support different people in different ways. The terms are often used interchangeably, even when describing models and arrangements that are different in design, style and experience. Study participants talked more about their feelings and benefits of 'mutuality' and seemed less interested in directly reciprocal exchanges. People stressed what they gained but found it harder to articulate what they gave. At the same time, we observed, identified and analysed many examples of people contributing a range of things, including a significant amount of their time and energy to participate in individual, group and community-level arrangements and schemes.

We have also found that the rhetoric of mutuality and reciprocity is much stronger than the current reality. Much is spoken and written about the centrality of mutualism to public service design and delivery, and the role of co-production in the transformation of social care and associated support. Close inspection of this literature and responses to the call for examples, reveals that the reality on the ground for many older people with high support needs is very different.

An extremely rich and diverse picture of mutual support therefore exists, yet there is a lack of familiarity and, often, initial confusion about what is involved in each of the different examples. This exploration of different models and experiences has deepened our understanding, but there remains a need for further work to translate these findings into more practical tools, including those that can be used to assess their impact and future returns on personal and public investments in these models.

The typology has helped and needs to be made translated and published in a format that is widely accessible and available. We believe this would help more people make sense of the different options and make informed decisions about those they want to pursue (in the case of older people and their families) and promote (in the case of commissioners, other funders and sponsors).

4 Demonstrate the clear outcomes that can be achieved from mutual support

It is often assumed that innovative, relationship-based models are not and cannot be evidence based, or stand up against more familiar traditional models of care and support.

This study has shown that it *is* possible to measure, assess and capture benefits, outcomes and impacts for both individual arrangements and collective schemes, in contrast to the literature, which indicates that the impact is usually only discernable at a collective level.

Further work is needed to quantify and link benefits and outcomes identified for different people and organisations to personal, public and potentially commercial investments in making them available.

Each of the models shares common features but also differs across a range of dimensions (as illustrated by the typology in Appendix 1). They vary in formality and infrastructure requirements in particular, which means that costs and resourcing arrangements also differ widely.

The examples covered by this study have also varied in the investments they have attracted and secured. It is therefore a complex task to draw out clear business cases, and virtually impossible and meaningless to do so across models.

Box 21 aims to start this process by summarising the key benefits and outcomes identified for individuals, families, communities, organisations and local services; these benefits and outcomes are those that were common to the majority of all models and approaches.

> This study has shown that it *is* possible to measure, assess and capture benefits, outcomes and impacts for both individual arrangements and collective schemes.

Box 21: The case for widening options for older people with high support needs based on mutuality and reciprocity

- Older people stay living as part of their chosen community, with better health and well-being, continuing to play an active role in family and community life.
- Loneliness and isolation are reduced, including support for people in rurally isolated places and those with the most complex needs.
- Older people's skills, assets and talents are used and appreciated rather than wasted.
- Locally generated and owned arrangements and developments bring community and economic benefits to local people, schemes and organisations, who take pride in seeing their ideas and developments take root and survive over time.
- A sense of achievement and well-being for all of those involved (in both informal, individual arrangements and more formal schemes involving a number of people).
- Where more formal, statutory services and teams are engaged with these developments and arrangements, they can see and feel the benefits for those involved and their services (e.g. reduced reliance and therefore pressure on increasingly tight resources and service systems).

In terms of the economic as well as the social benefits, the following points illustrate the different kinds of evidence used to make the case for different models and approaches in the typology.

- Pooled personal budgets provide greater economies of scale for individuals involved (and also for the support organisations offering

advice, advocacy and brokerage services); there are particular social and economic advantages where direct payment holders join a co-operative (or other form of mutual) to share risks and pool the costs of personal as well as infrastructure support.

- A significant number (42 per cent) of time-bank members are retired citizens earning time credits – illustrating the economic value of reciprocity among the general older population (most of whom do not currently have high support needs as previously discussed). Time banks have the potential to generate savings at a local and national level, improve skills and participants' employability and reduce people's reliance on paid and unpaid support (especially health and social care support). A conservative estimate is that the £450 annual cost per participant of running a time bank generates over £1,300 of economic benefit per person in return.

- Evidence from senior cohousing communities in Denmark (where such schemes are well established) show that reliance on formal care services reduces for older cohousing members, which is a cost saving for them as well as for the state.

- The Homeshare model has "clear benefits, is popular internationally and enables both parties to benefit financially. Relatively small amounts of investment would allow the expansion of services (in response to demand) that would be self sustaining."

- Shared Lives has a robust business case and experience of providing a means of delivering support based on mutuality, which is shown to be cheaper than alternative support such as residential care. Research carried out in 2009 estimated that this model could generate net savings of £13 million by reducing the need for costlier services, in particular residential care.

- Some well-organised mutually supportive communities have estimated that they save local authorities £750,000 per annum as a result of reduced need for social care funding and support.

A key lesson, therefore, is that different models and approaches each require a clear business case to be developed, and communicated, which captures the social as well as economic benefits (including costs incurred and savings accrued individually and collectively) – with a particular focus on their design for and use by older people with high support needs.

5 Adopt the five common features of mutual support

We have distilled the critical success factors and lessons about effective models/arrangements into five common features that apply across the typology. The five common features are:

1 All parties involved recognise they have **needs as well as contributions and assets** that will help to meet these needs. In coming together – by design or by chance – they recognise the mutual advantages and benefits in working together to meet or address their (shared or different) needs in ways that enhance their sense of self and build shared values.

2 The **ability to problem-solve** and work together to overcome barriers and 'life's obstacles' (as one respondent described it) means those involved are better prepared to avoid crises and sustain their own as well as each other's health and well-being. We think that promoting this very practical component of mutual support would appeal to a wider base of

people than those currently involved. It would also help to 'sell' different models to decision-makers, commissioners and other influential people.

3   Mutual support models and arrangements have **'co-design', 'co-production' and 'collaboration'** at their heart. They are generated, designed, owned and led by those directly involved, regardless of the formality or informality of the arrangement. This is more explicit and acknowledged in some models than others. This feature manifests itself in different ways, for example:
   – Shared Lives arrangements entail a different kind of relationship and therefore balance of power than those typically experienced in more traditional models of social care;
   – mutually supportive relationships are socially inclusive in a way that other models are not;
   – older people are brought together and connect with each other on the basis of shared interests and points of reference in mutually supportive communities (rather than on the basis of age alone).

4   Mutual support is **characterised by relationship-based delivery and/or exchange** of support that can be experienced at many different levels (one-to-one, small numbers of known people, street or neighbourhood based, communities of interest). Aspects of these relationship-oriented arrangements that are particularly valued include:
   – an ability to share confidences, hopes, fears and anxieties;
   – an ability to interpret and understand people's support needs on a personalised basis, based on their knowledge of people's histories and lives;
   – an experience of these models/arrangements as organic and evolutionary, whether they occur by chance, over time, or are formally organised or brokered. Many participants involved in informal arrangements emphasised the power of their organic and natural friendships. Caring Together in Leeds achieves a degree of organisation that facilitates ongoing connections that enable informal, small-scale or one-to-one mutual support to be experienced by many people across different neighbourhoods in the city. Shared Lives arrangements are warmly regarded by those involved because they *feel* informal even though they are very organised and part of the regulated care system.

5   Mutual support **enables and facilitates 'ageing in place'**, meaning that older people with high support needs are able to remain living and active in their communities of choice, connected to their friends, families and neighbours. Ageing in place is known to be protective and is what the vast majority of people want as they age and/or if their needs change. For many participants, mutual support resolved their isolation or loneliness; enabled them to get out and about for practical and social reasons; provided a means to retain and share their cultural histories and spiritual beliefs; and meant that they did not have to move or be constantly travelling to get the help they needed.

6 Integrate mutual support into local options for older people with high support needs

The models and approaches examined in this research are important options for older people with high support needs who would otherwise be regarded as 'needing long-term care'. They demonstrate a way of delivering support

that builds on and uses people's skills, gifts and assets and helps them to avoid expensive care services.

At present these models either serve small numbers of older people or are available in only a few places. Some models are not yet established in the UK while others only exist for a small number or a particular group. Many models have the potential to be replicated and need to be nurtured and sustained if they are to become *and be seen* as viable options within the spectrum of care and support.

In order for this to happen the following issues require close attention:

- Ensuring a **clear vision** is developed for each model and that guiding principles inform their design and delivery to secure positive experiences and outcomes.
- These approaches and options work best when they are **very small and very local** – which raises particular challenges in terms of scale and replicability. In replicating any one of these models it will be important to ensure that the focus on their vision and guiding principles does not get lost – especially as more players and partners get involved.
- The models work best when they **build on, use and become part of the web of existing networks and infrastructures** rather than existing as a separate entity or adding a new layer of structure to the local range of mainstream goods, services and facilities.
- **Current commissioning practice is a barrier** to ensuring more options based on mutual support are available to older people. Many councils continue to plan for traditional models of care but some are prepared to commission for innovation. Some models are established but not officially recognised or valued as part of the network of options available to older people with high support needs (e.g. self-help, peer support, mutually supportive communities). Achieving sustainable, creative funding arrangements and an enterprising market where mutual support can flourish requires courageous leadership and commissioning practice.
- Peer learning between different authorities and partnerships will help to support this shift. **Opportunities to learn** from those councils that are actively supporting such innovation and those models that have achieved recognition of their value are vital.
- **Technical, legal, financial and regulatory experts need to work with and alongside innovators and entrepreneurs** to ensure effective models are sustained and replicated. Particular barriers and obstacles need to be overcome for different models and creative solutions sought – hence a meshing of these two very different skills and mindsets is required.
- **Guiding frameworks or blueprints** aid initiation and replication of these models, enabling local ownership and interpretation while providing clear direction and practical guidance to start up and involve people who share values and/or want a different living or support experience.

7 Celebrate and support successful innovators and ambassadors of mutual support

We have been struck by the multiple roles played by dedicated people who initiate, promote, champion, co-ordinate and sustain (sometimes with their own money) a wide variety of networks, models and arrangements based on mutuality and reciprocity. Successful models and schemes involve two main types of people:

Achieving sustainable, creative funding arrangements and an enterprising market where mutual support can flourish requires courageous leadership and commissioning practice.

- founders who have a vision and passion for a different kind of support system, options, community or way of life;
- organisers who can take this vision, make it happen and embed it in the real world.

Models that remain dependent on their founders do not survive, particularly in an increasingly competitive environment for scarce resources, political profile and attention. The skills, expertise and achievements of both types of people need to be celebrated and promoted.

It is also important to recognise and acknowledge the roles and achievements of individual older people with high support needs who actively plan for the future *they* want, and create various informal and 'under the radar' arrangements with others. Fieldwork respondents who had successfully established and maintained such arrangements were keen to share their stories and advice with others.

Greater public education and access to practical information and advice will help to make more people aware of the possibilities and potential of mutual support arrangements — which will help to create an encouraging and receptive environment for more and more people.

5 PRIORITIES FOR ACTION

This chapter shares priority actions and recommendations that we believe will move this agenda forward and help address the specific messages and themes in Chapter 4.

We start with a summary of the central lessons arising from this work, followed by a suggestion of the key audiences and groups who will be interested in implementing changes. A set of priority actions follows, with recommended steps that can be taken to progress these. We end with an outline of some of the activities and actions that have been agreed to help take this work forward from 2013.

Important lessons from doing this work

This work has shown that there is potential for models of support based on and designed to foster mutuality and reciprocity, which can help older people with high support needs live well in later life.

They work best when they are very locally focused and personally delivered and/or experienced. They also work well when they build on and link to other services, networks and systems (not just for care and support) rather than existing as discrete entities or as one-off initiatives and developments. They are valued greatly and achieve significant outcomes for individuals when they recognise, harness and use the assets of their members – including older people with high support needs.

Some models and schemes currently exist which display all of these features, but they are not well known, promoted or accessed by many people (especially older people with high support needs). Where they are flourishing there are opportunities to learn, both from the individuals involved, and those who promote and fund them. A key lesson is that different models support different people in different ways – so good information and knowledge about which one suits your circumstances and is likely to meet your needs is crucial. Further work is needed to distil the critical features in a way that will speak to the different audiences who will be interested in them.

A key lesson is that different models support different people in different ways – so good information and knowledge about which one suits your circumstances and is likely to meet your needs is crucial.

Some of these audiences (funders and sponsors, including commissioners of care and support services) will expect evidence of clear outcomes for the investments they make in such models. Some models are already using persuasive business cases to generate ongoing investment (e.g. Shared Lives) but each one requires a business case that reflects its values and means of achieving the outcomes its members want and need.

Significant change is required:

- in the way that care and support services are commissioned and delivered so that they actively promote mutuality and reciprocity;
- in the way that older people with high support needs are seen and engaged in local developments;
- to creative fertile conditions for developing, nurturing and sustaining a wide range of alternative options and opportunities for mutual support;
- to provide conceptual, practical and technical advice and assistance to establish some models that do not yet exist;
- to shift the current policy agenda and focus away from 'long-term care' towards valuing people's gifts and assets regardless of their age and need for support.

Key audiences for sharing these findings and implementing these changes

These findings will be of interest to: commissioners and providers across all public services and sectors; policy-makers and implementers developing plans and services that directly impact on current and future generations of older people; and those responsible for responding to and implementing the finer details of the *Care and Support White Paper*, 2012 (and the preceding Dilnot Commission into long-term care), which sets out the government's vision for a reformed care and support system.

People involved in wider developments also have a part to play, including those associated with: building social capital and civic participation;

- new commissioning structures and arrangements for local authorities and NHS organisations;
- strengthening inter-generational relations and building community cohesion;
- plans for addressing future housing needs and improving the supply and quality of housing for all ages;
- and those designing neighbourhoods and communities that are inclusive and welcoming of all ages.

All those involved in this work have emphasised that these agendas are not just a matter for the government, Treasury, professionals and agencies, or even this generation of older people alone. These are fundamental concerns that involve us all, which need to be explained, explored, examined and expanded upon as part of a much wider public and societal engagement exercise. Older people, family members and wider communities also need to be engaged and better informed so that alternatives are not only developed but actively sought out and promoted in their networks, neighbourhoods and homes.

Priorities for future action

We have identified five key priorities for future action and development to address the specific messages and themes set out in Chapter 5, which are presented in this section. These are:

1 communicating and demonstrating the benefits;
2 raising public awareness and engagement;
3 tackling interfaces with other services;
4 replicating and scaling out what works;
5 mobilising resources.

1 Communicating and demonstrating the benefits

We have shared a key finding and repeated an important message in this report about the low profile and lack of familiarity with the diverse range of mutual support models/arrangements and how they can benefit older people with high support needs. We have therefore identified this as our first priority.

The benefits, outcomes and experiences of older people with high support needs (and others) need to be captured and disseminated through a range of routes to ensure that commissioners, funders, local and national leaders and politicians including other influencers, commentators and decision-makers understand what is involved and what can be achieved through and across different support models and arrangements based on mutuality and on reciprocity.

Different specific messages will appeal to different audiences identified in Priority 2 – for example, messages about the certainty, quality and safety of support will appeal to family members as well as to older people with high support needs (and practitioners/providers currently supporting them). Evidence about outcomes and cost-effectiveness will strike a chord with commissioners and funders – and politicians and policy-makers. Information about what is involved in establishing, initiating and becoming involved in such models/arrangements will be of interest to older people, their families and the growing number of social entrepreneurs and commentators who believe in the principles even if they are less familiar with the practicalities of mutualism and reciprocity.

Messages about personal planning and taking control of your own life and support are notoriously hard to hear and respond to, and are addressed in the second of our priority actions.

2 Raising public awareness and engagement

Two important target audiences within all of this are families and the general public (the latter being a diffuse population encompassing current and future generations of older people with and without high support needs).

A number of respondents and participants in this study have repeatedly stressed the importance of directly engaging the public in order to raise their awareness and understanding of different options for support generally and of mutual support options in particular – and why they matter. With increasing media and trade press attention on the negative implications of an ageing population, such a move would help to redress the doom and gloom scenarios painted about the increasing burden and financial catastrophe that awaits us all as we age and grow frail and dependent. It's time for a grounded campaign which inspires people and offers them practical advice at the same time. The message should be: you may need support as you age but there are ways of designing and shaping this yourself, or getting

involved in schemes where your voice matters and your membership makes a difference.

Both project stakeholders and study participants emphasised the importance of personal, life and support planning – different but connected approaches each with existing tools and techniques which tend not to be well known outside professional and sector circles. We found that even when used, this was on an informal and low-key basis. We believe that those involved would have benefited if these tools had been more assertively offered and applied, and if people were assisted through the process of reflecting and identifying what's important to – as well as what's important for – their own health and well-being in later life. These tools and processes exist on a scheme and model level as well, for example, the senior cohousing community-building process. However, even in more formal models (e.g. Shared Lives), the use of tried and tested support planning tools was not overtly evident.

3. Tackling interfaces with other services

The people involved in these models and arrangements find that engaging with other services can be both a lifeline and an endless source of frustration and disappointment. We have talked about the importance and success of those models that develop strong relationships and partnerships with the wider web of local services (not just those associated with care and support). Those that become integrated into the local network and infrastructure of goods, services and facilities tend to survive and thrive. Those that sit outside and rely on time-limited grants and project funding do not.

Some models and schemes – such as Shared Lives, some time banks and some Homeshare schemes – are inextricably linked to and part of more formal care and support service systems. Respondents still had concerns and frustrations with the layers of bureaucracy and professional fiefdoms that get in the way of promoting, signposting and enabling older people with high support needs to access their model or scheme. Sometimes this is attitudinal and sometimes it is structural (e.g. complicated referral arrangements), and often it is both. Professionals and agencies from all sectors will start to take these models seriously and consider them part of *their* landscape when a) they know about them and b) they are required to use them. Many people who play a key role in brokering, organising or gatekeeping access to different services do not yet know about many of these options and models. They need to be seen as local target audiences for actions set out in Priority 1 about communicating about the models and the benefits and outcomes they can achieve.

Shared Lives is part of the current regulatory framework for care and support services. As more diverse models of support are developed and accessed by older people with high support needs the interfaces with regulatory bodies and frameworks will need to be considered (for example, for those who are eligible for social care funding; or those considered to be vulnerable to abuse and subject to safeguarding arrangements). Regulators and regulatory bodies will need to be mindful of the underpinning values and ethos on which these models and arrangements are based. Attempts to shoehorn them into the same kind of registration and inspection regimes as other services are likely to create tensions and uncertainties about 'appropriateness' and risks. Risk-averse cultures and practices stifle creativity and block or damage mutual trust (a prerequisite of mutually supportive relationships). Person-centred thinking and planning tools can be helpful in teasing out specific issues and considerations at an individual level (e.g. as part of a person-centred support plan) and setting out how specific support

arrangements (e.g. Homeshare or Shared Lives, Circles of Support or a time bank) can meet that individual's needs.

Those involved in and responsible for commissioning, procuring and regulating local services and support packages also need educating and supporting to build a wider range of mutual support options into their repertoire. They will need access to technical information and advice as much as those trying to establish and sustain them. Contemporary developments for developing a more diverse market of personalised services and support are relevant here; specific guidance to commissioners and others involved in commissioning activities may help to improve the experiences of scheme/model organisers and 'providers' as well as older people with high support needs who want to access them.

4. Replicating and scaling out what works

We have emphasised the importance of learning from what works and finding ways of replicating or scaling out those models that are not well developed, used or known about so that more older people with (and in some cases without) high support needs can access and benefit from them. This includes addressing the underdevelopment of some models and approaches generally, for example, Homeshare, pooled personal budgets and cohousing (including cultural as well as structural barriers to their replication); as well as addressing the limited access to and promotion of specific models and schemes to older people with high support needs (e.g. senior cohousing, Shared Lives, time banks, KeyRing Networks and Circles of Support).

We have distilled some of the key characteristics and success factors of both formal and informal mutual support arrangements, but there is still a key gap, which is the development of hard evidence of their cost-effectiveness (outside the remit of this qualitative study); this could be used to make decisions about which support arrangements to scale out and prioritise for investment. Frameworks for investment based on robust business cases would help these models to achieve recognition and status on a par with other more traditional models of care and support. It would make them visible as well as compelling.

We have also drawn attention to those models that are already well developed and which combine an extensive reach with very individualised experiences of mutually supportive relationships (e.g. Caring Together). Creating a blueprint for these and other mutual support models/ arrangements in the UK with clear signposts to sources of practical, personable assistance and mentoring advice would make it easier for similar models to be established in other areas.

All of this requires fertile conditions in which mutually supportive relationships and models of mutual support can grow and develop. These conditions have been well documented in the literature on asset-based community development and co-production, as well as in the evidence about particular models such as time banks, Shared Lives and KeyRing Networks.

There is a tendency to place the onus on replicating and scaling out community-based models of mutual support on local authorities and the third sector. Project respondents and stakeholders have rightly emphasised the need to engage with, promote and secure investment in and commitment to these models from a much broader base of investors, promoters and sectors. They have identified clinical commissioning groups and individual GPs, health and well-being boards, mainstream community and leisure facilities (e.g. pubs, cafés, arts and music venues), commercial enterprises (e.g. supermarkets, high-street traders, insurance companies) and

Those involved in and responsible for commissioning, procuring and regulating local services and support packages also need educating and supporting to build a wider range of mutual support options into their repertoire.

broader networks rather than the usual limited range of organisations that are often seen as having an interest in older people (e.g. think U3A networks rather than lunch clubs).

It should also be remembered that the source of funding and values base of investors is of primary concern for many of the founders and initiators of these models. If those who invest in these models seek to change these values or influence their ownership and control, as seen in the cohousing and Debenham Project case studies, it can be very damaging.

5. Mobilising resources

While a few of the models included in this study are generally well resourced (e.g. Shared Lives), the majority of examples and initiatives – especially those that are delivering at scale – are not well resourced and are achieving significant benefits and outcomes with relatively little, often through time-limited or uncertain funding arrangements. Many members of the (often third-sector) organisations and groups that are running schemes or facilitating networks to foster mutual support have shared their feelings of desperation as their existing resources had recently been or are predicted to be cut.

This is not generally regarded as a conducive environment in which to establish new, or expand existing, models that are not well evaluated or backed up by robust business cases; but there are opportunities and incentives to try new things, build on or change existing groups, networks or service models that are already engaging with older people with high support needs.

> **Box 22: Shared Lives schemes and investment**
>
> Shared Lives has a robust business case for investment which is driving further investment. However, those involved in providing Shared Lives schemes and facilitating arrangements have warned of the dangers of investments that are linked to unrealistic expectations about growth that could ultimately damage the features that make such models work.
>
> Remember the finding that these models work best when they behave and are experienced as if they are very small and very local.

There are valuable lessons to be learnt from those individuals and models who have successfully sourced and secured a wide range of different investments, including those who have been able to move from project to sustained or core funding (e.g. Bromley Time Bank). These are people with good networks, influential contacts and ideas for different ways of generating necessary resources and finding different routes to achieve their vision (e.g. DropBy). They also have relentless energy, inner resourcefulness and resilience; they know how to hold their nerve and 'regroup' in difficult times in order to consolidate and continue over time (e.g. Isaac Pennington Trust).

These innovators, skilled enablers and facilitators should be nurtured and supported, and new ones need to be found, encouraged and mentored to ensure these models can continue to be developed and extended with and for older people with high support needs.

Many of the initiatives designed to promote and inspire the social entrepreneurs of the future (e.g. the charities NESTA and RSA) have led to some of these models of mutual support being developed. However, there

are four key lessons that have emerged from this work that we think call for a slightly different approach to supporting the next generation of mutual support innovators and leaders.

1 It is crucial that models and arrangements of mutual support are locally generated, led and owned by the members for whom they are designed to benefit and involve.
2 The focus needs to be maintained on opportunities for older people with high support needs to be seen and engaged as active contributors and leaders themselves, not just as passive recipients and receivers.
3 Founders and organisers don't always easily co-exist so they may be found in different places and need different approaches and practical support for developing their skills.
4 A common trigger for each of the people who have contributed to this research is their own personal connection to and understanding of the need for a different kind of support to that which is currently on offer – often shaped by their own lived experiences or their reflections on their future. In other words, these are people who have been around; they are not the new kids on the block. Maybe it's time for older entrepreneurs to take centre stage?

Next steps

A multi-pronged dissemination programme is currently being developed to ensure that the findings and insights from this study are used to widen options and opportunities for older people with high support needs to access and experience support based on mutuality and reciprocity.
      These activities are designed to:

- share the detailed findings, messages and lessons from the project with the key audiences outlined in Chapter 5; and in particular engage a diverse range of stakeholders and decision-makers at a local and national level (recognising the different contexts and policy agendas of the UK nations);
- support commissioners, providers and older people from the fieldwork sites to apply the findings and develop plans that will result in better outcomes for older people with high support needs and their service systems;
- develop targeted briefings for different audiences on specific messages; for example, to stimulate a much wider debate around the roles, contributions and aspirations as well as needs of older people with high support needs;
- produce practical materials and resources (e.g. commissioning 'Widening Options' workshops) that can be used by any local area/partners;
- showcase examples of good practice and innovation identified through the call for information, fieldwork, case studies and literature search.

NOTES

1   This recruitment was organised through the Involving People initiative in Wales (http://www.
    wales.nhs.uk/sites3/home.cfm?orgid=1023) and OPAN (http://www.opanwales.org.uk), a
    network of older people involved in ageing research and development in Wales.

2   The Project Advisory Group provided independent advice and guidance from a range of
    expert advisers, practitioners, academics, older people and commentators familiar with
    models of mutual support. Members are shown in Appendix 9.

3   A simple, easy-to-read version of the research questions in diagrammatic form.

4   As described by Merriam, 1988.

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APPENDIX 1

Not A One Way Street typology of models/options of support based on mutuality and reciprocity

Characteristics Type	Is the mutual support/exchange direct or indirect?	How many people are involved?	Is this a one-off or ongoing arrangement?	Is mutuality intentional (planned) or consequential (unplanned)?	Is the arrangement formal or informal?	Is it organised & co-ordinated or organic & fluid?
Mutually Supportive Relationships	Usually direct	1:1/small numbers	Either	Either	Informal	Organic/fluid
Mutually Supportive Communities	Both	Many	Mixture	Intentional	Varying degrees	Usually organised/co-ordinated
Homeshare Schemes & Developments	Direct	Usually 1:1/small numbers	Ongoing	Intentional	Either; most are formal	Organised/co-ordinated
Cohousing Schemes & Developments	Both	Many	Ongoing	Intentional	Formal	Organised/co-ordinated
Shared Lives	Direct	1:1/small numbers	Can be either	Intentional	Formal	Organised/co-ordinated
Time Banking	Both/often indirect	Mixture of 1:1 & many	Mixture	Intentional	Either; mostly formal	Both
Volunteering Schemes	Both	Mixture of 1:1 & many	Mixture	Intentional	Either; mostly formal	Both
Circles of Support	Both	1:1/small numbers	Ongoing	Intentional	Degrees of formality	Co-ordinated/organised
Peer Support	Both	1:1/small numbers	Mixture	Mixture	Mixture	Mixture
Pooling Financial Resources	Direct	1:1/small numbers	Usually ongoing	Intentional	Degrees of formality	Organised/co-ordinated

APPENDIX 2

Understanding the models/options of mutual support

The term 'mutual support and reciprocity' has generated a number of queries about what this means and the different kinds of models and approaches that might or could be involved in such arrangements. An extremely rich picture of different kinds of support based on mutuality/exchange/reciprocity is emerging, as illustrated by the typology in Appendix 5.

These models are often run on a very small scale or in isolated pockets that are not well connected to other forms of support. In addition, these different approaches are often described using very similar terms, but when examined, the different models/approaches vary in the way they are set up, who they (currently) involve or are targeted towards, and the way in which they operate.

For the purposes of this research, we focused on the following main types, or categories, of mutual support:

Mutually supportive relationships
These are personal, often informal arrangements developed between two or more individuals (often friends, neighbours or relatives). While these are typically informal in nature, such arrangements may evolve and become more formal or organised over time, for example if one of the participants develops greater need for support than the other(s).

Mutually supportive communities/neighbourhoods
Mutually supportive communities are those "where people of all abilities live and work together, contributing whatever they can to the well-being of their fellow community members". They are most often designed to help people to develop social relationships and foster integration with the wider community, implying that these are often communities which are set apart from local neighbourhoods.

Cohousing developments
These are collective housing arrangements set up and run by their members for mutual benefit. Members are consciously committed to living as a community; developments are designed to encourage social contact and a sense of neighbourhood; common spaces facilitate shared activities such as community meals; and other amenities such as laundry, heating, transport, etc may also be shared. They are very much about the living arrangements and the mutuality of shared living experiences, which may or may not include

support. An independent commission, set up in 2008, explored the historical role of housing co-operatives and plotted their important mutual features (*Bringing Democracy Home*, Commission on Co-operative and Mutual Housing, 2009). This emphasised the characteristics of developments that are democratically owned, including managed housing, where those living in them "take more responsibility and feel a greater sense of belonging, identity and ownership". Importantly, while some co-operatives include cohousing arrangements, not all cohousing arrangements are co-operatives. Shared costs and responsibilities for accommodation and contributions to the immediate neighbourhood/community are other key features. As above, these developments do not always involve aspects of care and support.

Homeshare

Homeshare schemes involve the offer of housing in return for help in the home, which is arranged on an individual basis. Most Homeshare schemes in the UK are not for or about people with high support needs, although there is one example of a scheme in Bristol that involves people living with dementia (apparently this is a very informal arrangement). It is more common overseas than in the UK – especially in the USA, Spain, Portugal and Australia. It is currently unregulated and cannot involve personal care as part of the arrangement.

Shared Lives

The emphasis here is on the care arrangements and the carer, rather than the housing/community living arrangement. These schemes are also mainly set up as individual rather than collective arrangements. Participants use the carer's home as a resource, and the relationship between the person needing support and the person providing the accommodation and support is key. It is the largest form of support for people with a learning disability in Belgium. There are increasing numbers of Shared Lives carers in the UK, where it is regulated.

Time banking

Time banking is a pattern of reciprocal service exchange that uses units of time as currency. A 'time bank', also known as a service exchange, is a community that practises time banking. The unit of currency (an hour's worth of any person's labour) used by these groups has various names, but is generally known as a time dollar in the USA and a time credit in the UK.

Circles of Support

A Circle of Support is a small group of people (often family and friends) who come together to assist someone who needs support to identify what they need or would like to do in their life, and then work out how to make it happen. Mutuality and reciprocity lie at the heart of successful circles, which can be formal or informal. Co-ordination and planning are also central to success, regardless of the formality involved.

Volunteering

Examples of volunteering included in this research are those where support is provided and received on a voluntary (unpaid) basis, typically through an organised scheme where the volunteer support is reciprocal in nature.

Peer support

This refers to a range of approaches, groups and networks where members support each other on the basis of having shared experiences. This can

include arrangements where people with more experience coach or mentor those with less experience.

KeyRing networks

KeyRing (see www.keyring.org/home) is a model of community- or neighbourhood-based supported living involving people of any age who need a lot of support in their lives. A KeyRing network is made up of ten ordinary homes; people who need support live in nine of them. These people are KeyRing Members. They help each other out and meet up regularly. A Community Living Volunteer lives in the tenth home. The volunteer is a person who helps members out with things such as reading bills, forms and letters. The volunteer supports members to explore what's going on in their neighbourhood and get involved. Many existing networks include members who have a learning or physical disability. KeyRing networks were not included in the typology as we did not locate any existing networks that specifically focus on or include older people within them, although we did learn of the intention to develop these. We have included them here in this summary, as we believe it is an option that would be worth pursuing, and which has similarities to a number of the other models outlined above.

APPENDIX 3

Data sets and methods of analysis

This study includes a number of different data sets, each of which has generated a large amount of rich, qualitative information. Each data set contributes knowledge and understanding, adding depth as well as breadth to the work:

- The fieldwork in four study sites captured the direct, lived experiences of mutuality and reciprocity from older people with high support needs who have accessed, are currently accessing and/or who have designed these options themselves.
- The case studies ensured coverage and greater understanding of specific models that were not covered in the fieldwork sites or well addressed in the call or literature with regards to older people with high support needs.
- The literature search and call for examples provided a robust base from which to explore specific questions and to examine particular models in the fieldwork. The call for examples in particular generated specific schemes and experiences not covered in the literature or the fieldwork.

In order to make sense of this information, identify findings and develop a clear set of messages, a group analysis was conducted to identify cross-cutting themes across all sources. This included fieldwork data including interview notes, completed questionnaires, graphic templates and reflective diaries; and research-team diaries completed and shared with all team members after each fieldwork visit. It included feedback from participants involved in the public meeting and sounding-board events. Notes from case-study interviews/visits, the literature search and call for examples were also included.

Initial findings, themes and messages developed through this group analysis were shared with the Project Advisory Group in its final meeting, to develop the priority actions and recommendations shared in Chapter 5.

A description of each data set, participants and information involved, and how this was gathered and analysed, is provided below.

Literature search
The literature search examined a wide range of models and approaches defined as mutual support, including relationship-based services and models of public and community engagement based on reciprocity.

72 items were reviewed including:

- 28 meta-analyses of the literature on mutuality and reciprocity, including policy-level reports/papers/strategies;
- 11 further documentary sources from academic papers, promotional materials, online searches;
- 19 reports about specific schemes and projects;
- 14 documents which provided commentaries and shared authors' thoughts on related subjects, e.g. essays, think pieces, blogs and other commentaries.

An evidence grid was developed comprising detailed notes made from each reviewed item, and a thematic analysis was conducted by three members of the research team. A separate paper containing the detailed findings of this review is available; the key lessons and insights are provided in Chapter 3.

Call for examples

Of the 17 call responses assessed as meeting the research criteria:

- Six were assessed as clearly meeting the criteria; two of these were from areas that then became fieldwork sites.
- Six were assessed as *probably* meeting the criteria, depending on the detailed nature of delivery and the extent to which older people with high support needs were giving as well as receiving support. This was not always clear.
- Five were assessed as meeting the criteria but had not got going at the time of receiving the response. These were often the most innovative and exciting examples, and had not been written up or published elsewhere. Some of these examples were also different from those captured in the fieldwork and case studies (e.g. micro-volunteering, CareBank and pooled personal budgets involving older people).

Within these 17 responses, there was a fairly good spread across the different types of mutual support covered by the typology in Appendix 1.
A summary of these responses is provided in Table 1 on page 72.

Table 1: Responses to the call for examples

What	Where
Homeshare	Eden, Cumbria
Elder/senior cohousing	Cheshire (Uniitee)
Micro-volunteering (web-based)	Wales/worldwide
Time bank	Colchester
Timebank UK	National perspective from UK Project Manager
1:1 informal mutually supportive relationship	Swansea & Gower
Pooled Personal Budgets involving five older people	East Sussex
Mutually supportive community/ organised self-help group	Southbourne Creative Hub, Bournemouth
Mutually supportive community/ organised self-help group	Sangam and Paravar, Leeds
Shared Lives	Kirklees
CareBank	Pilot in Windsor & Maidenhead
Volunteer exchange organised around existing day/community centre	Surrey
Volunteering	RSVP UK wide
Mutually supportive relationship	Carmarthenshire, Wales
Volunteering project	Wales, funded by Big Lottery AdvantAGE scheme
Inter-generational volunteering	Nottinghamshire
Mutually supportive and caring relationships	Flexicare schemes in London, Japan and New York

Fieldwork in four sites

Information about the fieldwork sites is provided in Appendix 3.

Of the 71 people who took part in the fieldwork described in Chapter 2, 66 were directly involved in some form of a mutual support arrangement. Between them the 71 participants were involved in 27 different mutual support arrangements, as set out in Table 2.

Table 2: Fieldwork respondents' engagement in examples of mutual support

Type of mutual support arrangement	No. separate arrangements in this sample	No. research participants involved …	… of which this number were people in leadership roles)
Informal 1:1	8	14	0
Informal 1:1 (family)	1	1	0
Informal community	5	9	3
Formal peer support/self-help group	2	16	2
Cohousing	1	3	1
Shared Lives	6	15	2
Homeshare	2	4	3
Older Person with High Support Needs main carer for disabled children	1	1	0
OPwHSN playing role in helping to run support services	1	3	1
General stakeholder (no specific arrangement described)	n/a	5	2
Total	**27**	**71**	**14**

Similar numbers of people were involved in each study site; Oxford had the fewest participants and Leeds the greatest, as illustrated in Table 3.

Table 3: Fieldwork respondents by study site

Site	No. participants
Dorset	18
Leeds	24
Oxford	10
Swansea & Gower	19
Total	**71**

Different respondents took part in different opportunities to participate in the research, as shown below.

- 41 face-to-face interviews (most people took part in just 1 interview, 2 people took part in 2 interviews)
- 11 phone interviews (2 people had 2 calls, 7 had just one)
- Group discussions took place (1 at each site), involving 27 people
- 9 people (already counted above) were involved in a combination of the above, e.g. taking part in a discussion and a follow-up interview
- 5 people completed a questionnaire or reflective diary (for 4 of them, this was their main means of participation)
- 7 people completed graphic templates (for 3 of them, this was their main means of participation).

Some people did not want to take part in an interview or group discussion, but did want to share their experiences. For these participants, we offered the chance to complete a questionnaire (n=5) or a 'graphic template'[3] (n=7)

which could be completed with one of our research team present, or at a later date and posted back to us. Only two people completed and returned a personal log of their experiences and thoughts (reflective diaries). Each of these formats covered the same research questions (Appendix 7), but provided different ways for people to take part, and to answer questions in an order and at a pace that suited them.

We were not able to analyse the fieldwork data sources in the same way across all formats, because of the different ways in which people had shared or recorded their responses to the (same) questions. For this reason, we carried out a detailed, tabulated and thematic analysis of written records from 32 face-to-face interviews involving 41 people to better understand the intricacies of setting up, living in, experiencing and maintaining their mutual support arrangement. Key findings from this analysis are shared below (responses to completed and transcribed questionnaires, graphic templates and reflective diaries were included in the group analysis of all data sources to identify cross-cutting themes and messages, presented in Chapter 5). We therefore analysed the data from the four fieldwork sites in two main ways:

- tabulating responses to the research questions provided by interview and focus-group participants, and completing a thematic analysis of this rich, qualitative data to identify recurring themes and messages;
- collating and theming responses to a specific question about 'top tips' and advice to others interested in accessing support based on mutuality and reciprocity.

In-depth case studies

Six in-depth case studies were undertaken to ensure coverage of all models in the typology (Appendix 1) and improve understanding of specific models not covered by the fieldwork sites, or sufficiently addressed in the call and literature with regards to older people with high support needs. The aim was to explore the origins, take-up and experiences of models in the case-study sample by older people with high support needs; and the evident or likely implications for widening access, and extending the scale and scope of such models to a greater number of older people with high support needs in the future.

Case studies were completed of the following models and schemes:

- time banks in Bromley and Greenwich, and a network of new time banks being established with older people across Northern Ireland;
- a self-help, peer-support network established by older people in Cambridge;
- the Debenham Project, a mutually supportive community in Suffolk focused on enabling people with dementia to remain integrated members of the village and family life;
- DropBy, a virtual network of members across the country aged 60+ who provide mutual support, information and opportunities to develop friendships and interests online;
- senior cohousing developments emerging in Scotland, including the Isaac Pennington Trust and the Vivarium Trust.

The case studies enabled us to:
- ensure coverage across the majority of the approaches/categories outlined in the typology;

- probe deeper into some of the responses to the call and other examples that emerged over the course of the study, e.g. through Twitter;
- include Northern Ireland and Scotland to make the study UK-wide;
- explore issues associated with planning ahead for an ageing population (e.g. members of cohousing developments growing older or developing support needs over time);
- capture personal stories, concerns and solutions from those involved in such developments – including those commissioning, providing and using/experiencing these models;
- undertake a thematic analysis of this additional data set, to enhance information gained in the call, literature search and fieldwork sites.

Case studies typically examine the interplay of different variables involved in a given situation in order to provide as complete an understanding of that situation as possible.[4] This type of comprehensive understanding is arrived at through a process known as 'thick description', involving an in-depth description of the subject (in this case specific models of mutual support) being evaluated, the circumstances under which it is used, the characteristics of the people involved in it, and the nature of the community in which it is located. Thick description also involves interpreting the meaning of demographic and descriptive data such as cultural norms and mores, community values, ingrained attitudes and motives.

APPENDIX 4

Personal stories and examples of mutual support

1 A Mutually Supportive Relationship – Viv and Miriam

This is a personal account from a young woman, Viv, who developed a mutually supportive relationship with an older woman, Miriam – and what works for them as a result. It is told by Viv in her own words.

"I am a single mum in my 20s and Miriam is a very old lady (91) and our relationship is based on a mutual need for friendship. From my end, I'm much younger than Miriam and feel I give out very little, for example, helping with showering, picking up the odd thing, helping with shopping etc. But we have both a need to be listened to, the freedom to be who we are without someone trying to rush in and overtake us or rescue us.

The reason our relationship has been so successful is that it is based on understanding each other, not feeling sorry for each other or trying to be a hero to each other. I had to be very careful I didn't patronise her by stepping in too readily – that frustrated her – and I had to learn early on that she was very set in her ways and was extremely good at looking after herself. It might have seemed backwards to me sometimes and I knew how to do things quicker but it wasn't about that, it was about allowing her to maintain control and independence while having the security of someone there to oversee just in case it backfired or went wrong, which it almost never does.

I support her physically and emotionally and she supports me emotionally, and on a deeper level she gives me the relationship I lack with anyone else in my life. She learnt quickly that I was struggling with many things in my own life, and she was extremely careful to make me feel valued. There were times when I went there to do something for her and she would see that I was tired so we would just sit and talk, sometimes have a cry, sometimes talk about God, sometimes just eat fish and chips and look at her beautiful roses. She would never pressurise me into doing things for her if she could see that I was worn out, and that would always give me the desire to help her more because she was helping me by showing me she cared.

Miriam gives me the chance to commit myself to a person through thick and thin, and that helps me mature and feel normal, if that makes sense. She is the reason why all us neighbours still have a relationship. We are a little community because of her need and our need to be needed, it's quite beautiful really. Marjorie up the road always gives her off-cuts of meat and has her up her house once a week and they share magazines, and in turn Marjorie still feels a sense of community in the street. Dave does odd jobs and in turn has not wasted away in retirement. Sally fills in her catalogue orders, picks up bits from the Co-op, and in turn she hangs on to the last

thread of one of her mother's relationships. And together we have a very understated relationship that only felt its value when Miriam went to hospital and we were all thrown back into our own corners.

I am young and she is old and I suppose on the surface it looks like I'm the one doing all the giving. That is not the case at all. I don't think she will ever understand how much she gives back in return. I have learnt so much, like what it's like to be an ageing woman; what matters when you're that age and what things am I wasting my time on. I can remember asking her what she felt when she looked in the mirror and what she thought of her old skin. It has been one of the most interesting relationships I have ever had. I have asked her if she is afraid of dying, how she has coped with her son growing up and being so far away, her husband dying, his last moments, how she coped, how she felt, how she survived.

She has taught me how to enjoy the simple pleasures in life like watching a rose grow and enjoying its scent, how to observe and enjoy the changes of the seasons, what different foods are good through the year. There are about a gazillion little things that she has taught me that no person any younger could have done, and I'm extremely grateful for the opportunity to have a 91-year-old as my best friend.

We all need to be needed, that is most important thing. I know she needs me and she knows that I need her and that is why it works. If it were one-sided it wouldn't have lasted or been as productive a relationship as it has been."

2 Circles of Support – Jakob's Story

Jakob is 78 years old and lives in a council flat in Portsmouth. He is originally from the Ukraine, and was a refugee in Germany before coming to the UK in the 1970s. English is his third language. When we first met Jakob he didn't know anyone else in Portsmouth and he told us he had no living relatives. Although he was not eligible for any social services support, he was ringing the duty social work number several times a week in great distress. He was reluctant to leave his flat and desperately lonely, anxious and unhappy. When social workers visited him (following his calls) he did not want to pursue anything they suggested in the way of local support, clubs or general help. Jakob's only other contact was with his Tenancy Support Worker – Julie – who worked with him to build his confidence and a better understanding of his needs and goals and what he could offer others, using a Circle of Support.

Description of the arrangement and how it came about
Circles of Support is an established model of enabling older and disabled people to lead the lives they want to lead, ensuring that the person is in the driving seat of key decisions about their support. Circles of Support build upon people's natural networks in their local communities, including family members, neighbours, friends and volunteers, as well as paid staff. The aim is to provide shared support to help people to carry on living in their local communities. A key feature is that the person's circle is developed from the network of people they already know, however small or large. They often start by asking the questions: "What's working and not working for you at the moment? What would you like to change? Who can help you do this?" Circles often start small and develop organically as the confidence and experience of the people involved grows.

What this arrangement enables Jakob to do
To begin with Julie was the only other person in Jakob's life – she was his Circle! Through gentle reassurance and using a structured approach to

thinking through his problems and possible solutions, Jakob identified that he wanted to meet other men his age who share his passion for chess. Julie found out about a local social club for older men, and accompanied Jakob there on his first trip. He is now a regular fixture, travelling there on his own using public transport. He plays chess regularly with a man he met there who speaks his language and shares his love of the game. Jakob has also recently started to teach chess to other people he has met at the club. As a result of his increased confidence, Jakob now goes to his local pub, on his own, for a quiet drink and has joined a local 'good neighbours' volunteer scheme. He no longer calls the duty social work team and his anxiety and sense of loneliness has eased. Julie stays in touch with Jakob, and has adapted her work to include the Circles of Support approach with other tenants she supports in council and sheltered housing schemes in the city.

3 Circles of Support – Richard and Marian's Story

Richard is 80 years old and lives with his wife Marian, who is 76. They met when working for the same building firm and lived for most of their married life in Dorset, moving to Portsmouth 7 years ago. They have two children: a son in Manchester and a daughter in the USA with 3 children. Marian has been Richard's main carer since he was diagnosed with Parkinson's disease ten years ago. In recent years Richard has become immobile, unable to bear weight, and he finds it difficult to communicate verbally. Marian often acts as his voice; they have a warm and loving relationship, and are keen to stay living together at home. Marian has recently been diagnosed with an essential tremor, making day-to-day chores tricky, but is determined not to let this get her down.

Arrangements for mutual support and how these came about
Thinking about their Circle of Support highlighted that their biggest challenge was where to go for help on a variety of issues. They are determined and practical people, but didn't know where to start to find out what was available locally or what they could access to help them.

They also discovered that Richard (at that point) was completely reliant on Marian and his (paid) carers. His life was dominated by services that enabled him to continue living at home but which left little room for other interests and relationships. Marian's network was much broader, involving a mix of friends and the local Baptist church where she is an active member.

What the Circle of Support enables Richard and Marian to do
Working together and with a services co-ordinator from a local voluntary organisation, Richard and Marian plotted who was in their lives and their personal as well as their shared goals and need for support. These included getting help with the garden, more contact with their family, and redecorating their home. Marian is now learning to use the Internet so she can Skype their grandchildren in the United States.

Richard explored how to work with his carers so he can get out and about more. His routine is crucial to this; if his carers don't arrive on time it completely disrupts his day and he becomes stressed. Being able to share this in a constructive way with his carers has meant they have made changes to make this happen. The garden is also under control since Marian made contact with the council's garden waste collection service (discovered through conversation with their circle members). As Marian says, "it's one less thing to worry about, easily sorted".

Importantly, the process has helped them to be clear about how they support each other and what other help they need from people in their circle so they can carry on with their interests, activities and roles.

4 Homeshare – Mark and Sarah's Story

Mark and Sarah are in their 80s and live in a large house in a rural county of England. They were feeling quite lonely and needed some help in the house. They contacted a local Homeshare scheme after hearing about this from their daughter (who works in social services), and through them established a Homeshare arrangement with a young Homesharer called Dan, which lasted a year.

How the arrangement came about
Mark and Sarah liked the idea of helping someone out who needed somewhere to live. The Homeshare Co-ordinator matched Mark and Sarah with Dan, a 27-year-old American student who was studying at the local university. Dan lived with Mark and Sarah, gaining rent-free accommodation in exchange for helping out around the house and simply being around. The three people forged a relationship.

What this arrangement enabled Mark and Sarah to do
Dan had led a life that was very different to that led by Mark and Sarah and had very different experiences. Mark and Sarah were very interested to talk to Dan to learn more about this. Dan helped out with general tasks around the home such as putting the rubbish out, emptying and unblocking the shredder and accompanying Mark and Sarah to the supermarket every weekend to help carry the shopping. After Mark had a stroke Dan would also go for a daily walk with him until he was well enough to go alone. Both Mark and Dan were able to speak German and they used their time together on these walks to practise their language skills.

What helped this arrangement happen and work well?
Homeshare is a matching service run by a Homeshare scheme through which someone who needs some help to live independently in their own home is matched with someone who has a housing need and can provide a little support. 'Householders' are often older people who own or are tenants in their own home, but who have reached a stage in their lives where they need some help or companionship. 'Homesharers' are often younger people who cannot afford housing where they work. The Homesharer agrees to provide an agreed level of help and support to the Householder while living in their home for an agreed period of time. Homesharers are not charged rent, but usually agree to contribute to household bills and it may be agreed that other costs such as food will be shared.

The match came to an end after one year when the Dan's course finished and he returned to the USA.

5 Shared Lives – Susan and Joyce's Story

Susan is an 84-year-old woman living on her own in a small rural community, who was diagnosed with dementia some years ago. She was struggling to live on her own at home, and is now living with a family friend – Joyce – as part of a Shared Lives arrangement.

Description of the arrangement and how it came about
When Susan was living in her own home she received some informal support from Joyce, who would visit twice a day to make sure that she had taken

her medication, had eaten and lit her fire etc. Susan had been a friend and regular visitor to Joyce's house for over 50 years; they were long-standing friends who supported and cared for each other. Susan now gets the care that she needs in a warm family environment, and she also contributes her love and support – in a similar way to a close family member.

Over the past winter, Joyce had become increasingly concerned because Susan was letting her fire go out, not eating regularly, becoming more disorientated and struggling with her personal care. She alerted social services, which resulted in Joyce being trained and approved as a Shared Lives carer with the local Shared Lives scheme. Susan moved in with Joyce and the fact that they had known each other for so long meant that Susan felt at home straight away. She was familiar with the house as well as the people in Joyce's life, and this familiarity meant she did not become disorientated by the move. Susan has been able to keep all of her friendships and connections in her local community, meaning she has been able to retain much of her independence; and Joyce gains the benefit of their continued friendship. Susan's care manager and family have commented on how happy and settled Susan is, and that she has been doing really well.

What helps this arrangement to work well?
Shared Lives is a service through which a family or individual is paid a modest amount to include someone in their family and community life who needs a lot of support. In many cases that person becomes a permanent part of a supportive family, although Shared Lives is also used by people who need help during the day and to give people a break away from the family home.

Shared Lives carers are recruited and approved by Shared Lives schemes, which are regulated care providers. Shared Lives is unique in adult support, in that Shared Lives carers are paid a flat weekly rate rather than by the hour, are expected to form two-way relationships including mutual links to family and social networks (as opposed to the highly boundaried, more traditional one-way 'professional' support relationship), and because it is based on matching mutually compatible carers and individuals.

6 Time banking – Joan's story
Joan is a 75-year-old woman, originally from Scotland, who has been attending a drop-in centre run by a local charity called Holy Cross for a number of years. She was diagnosed with 'paranoid schizophrenia' and is supported by the local Community Mental Health Team. She also has Type 2 diabetes and arthritis. She lives independently in a housing association flat. Joan has improved her health and her outlook on life through being involved in time banking.

Description of the arrangement and how it came about
As part of the exchange, Joan has been rewarded with time credits for her contributions to gardening. She has spent the credits on trips to Sadler's Wells theatre and attending concerts at the Wigmore Hall, which she enjoys immensely.

Joan and several other people at the drop-in centre were initially sceptical about time banking. She was anxious about what might change, and how it could benefit "a woman like me in my 70s". She began to attend time-bank meetings run by the centre. At first she remained cynical, but she saw how other people were benefiting socially and psychologically. She often voiced her displeasure with the local community garden where she lives, which had fallen into a state of neglect. At a meeting, she complained again about the garden. One of her peers agreed with her and asked her

what she was going to do about it. Joan is an immensely proud woman and she said that she wanted to lead the clearing of the garden. Other volunteers and people involved at the centre agreed to work in the garden a couple of afternoons a week. Within six weeks the garden had been cleared. Joan was enthused by the change to the garden and wanted to continue her endeavours by planting seedlings and generally making the space more welcoming and hospitable for other people. Again, she successfully led these activities and a new peace garden is now thriving.

What this arrangement enables Joan to do
Metaphorically, like the garden, Joan has blossomed. The activities she has undertaken have improved her general physical well-being, but more striking is the improvement in her mental health. She has become more confident, and has begun using her IT skills in the computer room at the drop-in centre. She takes tremendous pride in these activities, which have impacted positively on her self-esteem. Her general outlook on life and the future have become more positive. She has something to look forward to and her interactions with other people involved in the scheme have improved. Instead of influencing others in her dissent, Joan has become a champion of time banking.

APPENDIX 5

Mapping support based on mutuality and/or reciprocity

A mapping exercise was carried out by the research team in conjunction with the Project Advisory Group, to plot examples of different approaches, models and schemes involving older people with high support needs, identified through the call for examples, early discussions to pool knowledge and contacts among team and advisory group members and the public meeting in Abergavenny.

This exercise was carried out to inform the location of the fieldwork study sites, highlighting those that *currently* exist across the UK in order to find those areas with higher numbers of known reciprocal schemes/arrangements (rather than one scheme alone). The key variables for selecting the four study sites included:

- a mix of urban/rural environments;
- to cover Wales and England;
- at least one area/approach involving older people from black and minority ethnic communities;
- at least one area/approach based in a deprived/economically challenged area – both in terms of community resources and agency resources/services.

The mapping exercise highlighted clusters of options in some areas, which helped the team to pinpoint existing approaches/examples involving older people with high support needs. These clusters offered the greatest potential for engaging people with a range of lived experiences of different forms of mutual support, and to get under the skin of these different arrangements to better understand them.

This resulted in a long list of areas where more than one or two approaches/models involving older people with high support needs were identified, including:

- Leeds/Bradford conurbation;
- Oxford city;
- some London boroughs (spread across Greater London);
- East Sussex;
- Dorset;
- South Wales and, within this, smaller clusters around Swansea & the Gower, Carmarthenshire and Pembrokeshire.

Further discussions and follow-up conversations identified the final list of four fieldwork sites which met the fieldwork criteria outlined earlier. These were: Dorset, Swansea & Gower, Leeds and Oxford.

Other interesting points about the overall spread of examples arose from this exercise:

- Different *kinds* of clusters emerged, e.g. housing-related in urban areas and more informal and volunteering examples in rural areas.
- Some areas appeared to have no examples at all. These may well have relevant approaches/examples and we just did not locate them in the time available. It is recognised that some of the examples are notoriously hard to locate, a challenge which is explored in the main body of the report.
- The above map (like the typology) locates options by the different *categories* of approaches/models rather than specific examples and how they differ *within* categories (e.g. time banks vary by area and type/focus).
- Project Advisory Group and team members, as well as respondents to the call for examples, could identify more examples that were not currently involving older people generally, or older people with high support needs specifically.
- The importance of local contexts and histories – for example, what stimulates or leads to different approaches developing (both in those areas where clusters are apparent, and where nothing seems apparent).

Background information about each site and the options included in the fieldwork in each of these areas is provided below.

1 Dorset

Dorset is a sparsely populated, rural county area in South West England, with a population of 407,800. The number of older people is above average and the working-age population is below average.

Older people play an active role in shaping and developing the services they need. As part of the Partnership for Older People's Project (POPP), older people are helped to support both themselves and their communities. POPP is a continuous programme of change for older people's services led by the needs and wishes of local older people, including local community leaders who challenge and change the way that services are provided and who work with service providers and older people to identify gaps in service delivery, as well as opportunities to develop services. A Wayfinder Programme employs people over 50 to work in local areas to provide signposting and support to services that older people may need (e.g. welfare benefits and pensions, social activities, exercise opportunities, transport, toenail cutting, telecare, carers' issues). The success of the programme relies on effective information, using an extensive email contact network that sends out information through partners in all sectors, and small local groups, networks and key individuals. Dorset POPP works very closely with the countywide network of 17 Senior Forums, reaching in excess of 5,000 people.

The fieldwork focus was on neighbourhood networks, mutually supportive communities, informal relationships/arrangements (often initiated through more organised networks), volunteer networks, Shared Lives for people living with dementia, and cohousing. Specific schemes and networks where respondents were involved included: Shared Lives Plus in Blandford Forum; Southbourne Creative Hub; the Threshold Centre, Gillingham; individuals responding via information and invitations to participate circulated through the Dorset Age Partnership and POPP networks as outlined above.

2 Swansea & Gower

The Swansea and Gower region is an extremely diverse area which is home to Wales' second largest city, Swansea – also the sub-regional capital of South West Wales – and the Gower peninsula, an area of outstanding natural beauty with 50 beaches and coves, nature reserves and sites of special scientific interest. The urban area of Swansea city has an estimated resident population of 229,100 (in 2008), making it the third-largest unitary authority in Wales. Of the population of the total area, 82 per cent were born in Wales, and approximately 37 per cent of the population is aged over 50. The 2008 Welsh Index of Multiple Deprivation identifies 13 per cent of Swansea's local areas as falling within the top 10 per cent most deprived in Wales.

Swansea and Gower's Community Strategy for 2010–2014 (Shared Ambition is Critical) identifies the following challenges (from a number) that are relevant to this study:

- reduced funding;
- partnership working;
- affordable housing;
- demographic change;
- changing communities;
- social inclusion.

The fieldwork focus was on informal, largely one-to-one arrangements and relationships including those established by neighbours and friends, local church groups, community cafés, and older people's networks (such as the seven older people's groups supported by the social services department across the area).

3 Leeds

Over 750,000 people live in Leeds, an ethnically diverse city with more than 130 nationalities including a black and minority ethnic population of just under 11 per cent. It includes rural areas such as Harewood and Wetherby, where most people are relatively well-off; and densely populated, inner-city areas where people are poorer and housing quality is a big problem. Although improving, the health of people in Leeds is generally worse than the national average, with big differences across the city.

A Leeds Neighbourhood Index is being developed to help local public services to understand the specific issues facing different communities, how best to tackle them and how to measure if they have made a difference. A recent Place Survey showed that satisfaction levels in Leeds compare well with similar cities. Older people in particular are more satisfied than elsewhere, with over 80 per cent saying that they are satisfied or very satisfied. However, there are big differences, with people in the north-east of the city much more likely to be satisfied with their area than people in the south or west.

There have been a number of neighbourhood networks established across the city over the last few years, including and/or focusing on older people. The fieldwork used these networks and the city council's networks to make contact with groups of older people and invite them to participate in the study. The focus here was therefore on mutually supportive communities through these neighbourhood and community groups (e.g. Sangam and Paravar, Caring Together, Creative Support); and more formal schemes such as Shared Lives.

4 Oxford city

The city of Oxford is a major tourist attraction with a rich cultural heritage and university, located at the heart of Oxfordshire. With just over 153,900 residents in an area of 46 square kilometres, it is the largest urban settlement in the county. The city's population is relatively young, with a higher-than-average number of people of working age and a low proportion of older people. The population is relatively diverse, with numbers of black and minority ethnic groups above the regional and national average.

The Oxford Strategic Partnership brings together the public, business, community and voluntary sectors to shape a vision for the city, and is developing a long-term approach to building a world-class city providing high-quality services and excellent value for money for all. Oxford city has to provide public services in a challenging environment owing to the large and diverse population; it has twice the national average of young people and the third-highest minority ethnic population in the South East in a densely packed urban space. While Oxford is a generally affluent city, this masks high deprivation, with nine areas having deprivation that ranks among the worst 10 per cent of areas in England.

The city council's agreed priorities relevant to this study are: more and better housing for all; tackling inequalities and supporting communities; improving the local environment, economy and quality of life; reducing crime and anti-social behaviour; transforming Oxford City Council by improving value for money and service performance.

The focus of fieldwork in Oxford was on Shared Lives and Homeshare, and a small number of informal arrangements involving people who made contact through local voluntary organisations such as Age UK Oxfordshire.

APPENDIX 6

Public meeting participants

Alison Atkinson
Jonathan Bidmead
Liz Casson
Susan Dryburgh
Ann Edmunds
Alison Evans
Liz James
Sara Keetley
David Kenny
Sarah Lloyd
Sian Lockwood – Community Catalysts
Pen Mendonca – Graphic Facilitator, NDTi
Marc Mordey – NDTi
Dr Gareth Morgan
Marion Pearse
Martyn Pengilley
Bernard Roberts
Jenny Sutherland
Neil Thomas – NDTi
Alun Toghill
Louise Tovey
Michael Trickey
Sandra Trimarco
Rosita Wilkins
Valerie Wood-Gaiger MBE

APPENDIX 7

Questions and topics covered in the fieldwork

What was the plan or arrangement that was set up or that evolved?

- How many people are directly involved (i.e. participating in the giving and receiving of support) – and what are their genders/approximate ages?
- How and when did this arrangement begin? What, or who, made it happen?
- Is any external funding or resources involved? If so, from whom?
- What was each person aiming to contribute?
- What was each person aiming to gain?
- How, and at what stage, was this relationship made explicit and agreed?
- How was/is the giving and receiving of support organised and resourced, and by whom?

How is it working?

- What has worked well (or is working well) for each person involved?
- What has not worked so well for each person?
- What are the most valued aspects of the relationship? Why? Have there been any other costs and benefits (financial and non-financial)?
- What problems has the 'mutuality' solved?
- How did the fact that it was designed as a mutual relationship (rather than one way) make a difference?
- Has it affected, or benefited, anyone outside the mutual support arrangement?
- Has it changed any other service or support being received by those involved? If so, how?

Keeping it going

- How long has the arrangement lasted so far/how long did it last?
- What has helped make it work? How/why?
- What has got in the way of making it work? Why?
- How do people sort out problems? Do you plan ahead or solve them as they arise?
- How is the relationship reviewed over time? Who takes/took the initiative in these discussions?
- Has the arrangement changed over time? If so, how?

'If we did it again ...'

- Would you do anything differently? If you could change anything that you do now, to make things work better, what would that be?
- What would be your top tips for other people wanting to do something similar?

'If we did it again ...'

APPENDIX 8

Case-study template

Q1: Important contextual and background information

- Purpose, design, scope, membership criteria, defining features.
- When established, how established, by whom.
- Degree of formality-informality; organised-fluid.
- Profile of membership/client base.
- Resources involved and funding arrangements (for individuals and the scheme overall).
- Membership and access criteria, rules and requirements.
- Number and profile of staff (if relevant) and volunteers (if relevant).

(Via: published information and online documentation, website, Facebook, Twitter, evaluation/other reports, discussion manager/co-ordinator to probe/check understanding and gaps.)

Q2: Key values underpinning the scheme/model:

- Are mutually valued relationships a primary focus or a 'byproduct' of this scheme/initiative/development? (i.e. were/are they an intentional aim or a consequential but important outcome?)
- Is there a difference between the public information about this scheme/model and what managers and participants say?
- What does the organisation/scheme see as the benefits of mutually valued relationships?

(Via: review of information; discussion with manager and participants.)

Q3: Main (desired and actual) outcomes from the scheme/model

- What are the main outcomes/other benefits and for/by whom are these experienced? (Check level of outcomes: individual, scheme, funders etc.)
- How is this known/determined? (What evidence is there that the outcomes claimed for the scheme/model are being achieved?)

(Via: published information/evidence e.g. evaluation reports plus interview with manager.)

Q4: What is working well? What could be better?
(Via: discussion with manager and participants.)

Q5: What is helping or preventing scale-up?
(Via: discussion with manager.)

APPENDIX 9

Project Advisory Group members

Vera Bolter	Newcastle Elders Council
Helen Bowers	NDTi
Ollie Buckley	Cabinet Office
John Crook	Department of Health
Philly Hare	JRF – Project Advisory Group Chair
Sam Hopley	Timebanking UK
Elizabeth Jenkins	York Older Citizens Advisory Group
Rachael Litherland	Innovations in Dementia CIC
Sian Lockwood	Community Catalysts
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Angela began her career as a nurse before moving on to manage nursing, residential and day services and supported living projects. She has managed a large Shared Lives service and in 2005 moved to head up project development for NAAPS UK. She wrote the *Homeshare Practice Guide* and the *Practical Guide* for local authorities interested in stimulating and supporting local micro-enterprise. Angela led the fieldwork for this study in Leeds and Oxford.

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Dorothy has been a long-time campaigner, lecturer, community worker and latterly advocate/adviser as an older person. She enjoys participation in a number of activities in her new home at St Oswald's Village, an Extra Care Village for 220 people between the ages of 55 and 102, where she works as an elected residents' representative. Dorothy undertook fieldwork in Oxford and for two of the in-depth case studies in this study.

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Sylvia has had many years' experience working in family issues at both policy and practice levels. She has worked for both central and local government and a range of statutory and voluntary agencies, both directly and as a consultant. Sylvia has been a local evaluator and peer researcher with NDTi for the last six years, working on different research and evaluation initiatives designed to deepen understanding and test new approaches for widening options and enhancing the life chances of older people.

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Neil had a varied career as an Occupational Health and Safety Ergonomist, working across the UK and internationally. Since retiring, Neil has worked with older people who need high levels of support, both as a carer for his wife and as a volunteer. He is a member of the Community Health Council in Swansea and Gower, the brain injury charity Headway, Linden Church, and the Mumbles Development Trust and Tourist Association. Neil undertook fieldwork for this study in Swansea & Gower.

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Claire is an experienced and professional administrator, providing logistical and research administrative support across a wide variety of projects based at NDTi. She is also a musician and music teacher, juggling interests and careers working with and supporting people across different ages and stages of life – from pre-school through to old age.

Scott Dalziel, Admin Office, NDTi

Scott is a professional administrator and is usually the first point of contact for the organisation. He also provides logistical and administrative support across a wide variety of projects based at NDTi. Scott is a confident communicator at all levels. Scott also works in his family business, looking after rental accommodation and all that entails.

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