

**JRF programme paper:
Better Life**

**Not a one way street: Research into older people's
experiences of support based on mutuality and
reciprocity**

Interim findings

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This paper:

- explores alternative approaches to planning, funding and providing long term care for older people with high support needs;
- focuses on the ways older people with high support needs take up active roles based on 'mutuality and reciprocity';
- provides stories and situations where those involved are giving and receiving support, rather than more traditional services provided by professionals / organisations;
- contributes to emerging discussions and developments associated with 'mutuality and reciprocity'.

The Joseph Rowntree Foundation (JRF) commissioned this paper to contribute ideas for its five-year Better Life programme into quality of life for the growing number of older people with high support needs in the UK.

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This paper was commissioned to inform the work of the JRF Better Life programme, a five-year investigation into improving the quality of life for older people with high support needs.

The Joseph Rowntree Foundation is supporting this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy-makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of JRF or the Better Life programme.

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1. Introduction and summary of key messages

This paper shares emerging findings and key messages from the first two stages of an action research project - *Not A One Way Street* - set up through the Better Life Programme at the JRF (<http://www.jrf.org.uk/work/workarea/better-life>). The research is one of several projects exploring alternative approaches to planning, funding and providing long term care for older people with high support needs.

Not a One Way Street focuses on the various ways in which older people with high support needs take up active roles within different support arrangements based on 'mutuality and reciprocity'.

'Mutuality and reciprocity' refers to arrangements designed to enable those involved to give and receive support, compared to those where one individual or group of people is intended to be the recipient(s) of services / support provided by another person or organisation. These arrangements may be formal or informal, and / or highly organised or fairly fluid.

As well as sharing early findings, this paper has also been produced to contribute to current debates on some of the big issues and concerns for Government and communities relating to older people and to the provision of support for those who need it. Examples include the Dilnot report on long term care, the vision for adult social care as set out by the Department of Health in November 2010, and the Ageing Well programme developed by the Department for Work and Pensions and the Local Government Group.

In addition, the Better Life Programme team would like to invite contributions to, and thoughts about, this study. The work continues until August 2012 but is already highlighting a number of opportunities and challenges associated with developments designed to enable older people with high support needs to have a good life, with access to a wide variety of different kinds of support which recognise and maximise their own contributions.

These initial findings will be of interest to those involved in commissioning and providing services and support (across all public services and sectors); policy makers and implementers who are developing plans and services that directly impact on older people; and those responsible for responding to the recent Dilnot Commission into long term care. People involved in related developments, for example building community capacity and personalising health and social care services, will also find the paper of interest, as will older people's organisations and groups.

Summary of interim messages

Very diverse models: An extremely wide range of different types of models of, and approaches to, support based on mutuality and reciprocity has been identified during the first two phases of this work. This diversity is a strength and a key challenge. The main issues are: communicating what ‘mutual support’ is about and what is involved; acknowledging why (and how) support based on reciprocity is different to more traditional forms of support; and widening access to, and availability of, such options. A typology of the main categories (i.e. different models and approaches) of mutual support has been developed to help catalogue and make sense of this diversity. The typical features, or characteristics, associated with these categories are set out in the typology. These include: the numbers of people involved; the degree of formality or organisation required; the nature of exchange that lies at the heart of each category; and the extent to which this exchange is intentional (planned) or consequential (unplanned).

Low levels of awareness: A key message so far is the low level of awareness about, and familiarity with, support based on mutual exchange and reciprocity. This may be partly influenced by the diversity of options and arrangements outlined above. A more dominant concern, however, is the prevailing perception of older people as ‘passive recipients’ for whom mutual support is not relevant or appropriate. This is counter to the responses so far received from older people, as indicated below.

Different reactions: interest, enthusiasm and some scepticism: There is a great deal of interest from older people and their families about the concept of mutual support, and enthusiasm for finding out more about how to make it happen for individuals and local communities. Amongst professionals and professional bodies, however, there is some hesitation and scepticism about the extent to which such models and approaches are suitable, affordable and practical to achieve for older people with very high support needs.

Importance of flexibility: One of the common characteristics across different categories is the capacity of support based on mutuality and reciprocity to adapt to changing – often uncertain – circumstances and needs over time. This adaptability appears to be a key success factor regardless of the degree of formality / informality (etc) involved.

Negative influence of attitudes and perceptions: Whilst the range of mutual support options is wide, the research has also found that perceptions of, and attitudes towards, older people with high support needs is narrow, as indicated above by the attitudes of some of the professionals involved in or contributing to the study to date. Older people with high support needs are still largely perceived as people “in need of support” who need to be “taken care of” - rather than as citizens with rights, responsibilities and contributions to make. In reality, this is an extremely diverse population spanning different generations, communities, groups and individuals, with widely different experiences, expectations, aspirations, needs *and* gifts, talents, skills, networks and resources to offer.

Relevance to policy and societal debates: We believe these early findings are relevant to a number of important, high profile contemporary debates, including: the future funding and provision of long term care; the ongoing personalisation of social care; wider community developments associated with the Big Society; implications of the Localism Bill; strengthening inter-generational relations and community cohesion; plans for addressing future housing needs; and improving the quality of housing and neighbourhood / environmental design in order to adapt to the reality of an expanding and ageing society. All those involved in this work also feel strongly that these debates are not just a matter for Government, Treasury, professionals and agencies. These are fundamental concerns that involve us all and which need to be explained, explored, examined and expanded upon as part of a much wider public and societal debate.

Navigating this paper

Section 2 of this paper provides further information about the project and what is involved.

Section 3 shares the research activities undertaken so far and the early findings arising from these.

Section 4 sets out our reflections on the research process and methods to date.

We end this paper, in Section 5, with a summary of conclusions so far and opportunities for taking these debates forward.

2. About This Project

Not A One Way Street is 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 arrangements based on ‘mutuality and reciprocity’.

The research, which is funded by the Joseph Rowntree Foundation (JRF), is being undertaken by the National Development Team for Inclusion (NDTi) and Community Catalysts. 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.

Aims of the research

1. To develop a clear vision for and definition of ‘mutual support and reciprocity’ by assessing examples, experiences and the practical steps required to work with and for older people with high support needs;
2. 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;
3. 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.

Important definitions

The Better Life Programme has developed the following definition of ‘older people with high support needs’, which is being 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.

The research is part of the Better Life Programme’s work on “alternative approaches [to long term care]” and 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) which found that:

- a) the current range of options for older people who need a lot of support (as outlined / defined above) is still dominated by two main forms – care home placements and intensive home care; and

- b) 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.

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

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, 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 are focusing on the following main types, or categories, of mutual support:

- **Mutually supportive relationships.** This refers to personal, often informal arrangements developed between 2 or more individuals (often friends, neighbours or relatives). Whilst 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 develop social relationships and foster integration with the wider community, implying that these are often communities which are set apart from local neighbourhoods.
- **Co-housing 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 like community meals; and other amenities like 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.

- **Co-operative and mutual housing.** 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 Cooperative 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, whilst some co-operatives include co-housing arrangements, not all co-housing 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. They 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.
- **Timebanking.** 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 practices 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 help someone 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 volunteer (unpaid) basis, typically through an organised scheme where the volunteer support is reciprocal in nature.

- **Peer support / mentoring.** 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.

Further details including the timetable, criteria for including models / examples of mutual support and questions being explored, are in Appendix 1.

3. Research Activities and Early Findings

This section summarises the key activities undertaken during Phases 1 and 2 and specific issues emerging from these sources of information and evidence gathering.

Research activities

A Call for Information went out to over 300 contacts. This call elicited responses from a wide range of people and organisations. However, to date, only a small number (n=18) has been assessed as meeting the research criteria set out in Appendix 1. These examples, however, provide useful case studies and leads for follow up work during the fieldwork stage. They also include personal accounts providing powerful stories of what is involved for the individuals concerned. These examples have also highlighted the importance of understanding why different people in different circumstances may access, prefer or be drawn to some forms of (mutual) support over others, as the following example illustrates:

Self help groups in south Leeds

Self help groups for older women and learning groups for older men from black and minority ethnic communities have been running in south Leeds since 2003 and 2004 respectively. Members expressed a need for a unified forum which could support all the self help groups in the city. It was agreed by community members, faith leaders and group members that this would promote unity as well as opportunities to share knowledge, skills and experience. The Sangam (“joining together”) Forum was formed as a result. However, older Sikh women felt the need for a group that could also be open to the partners that they were caring for. The Parivar (“family”) Lunch Club was the outcome.

“It is unique as there isn’t any group running for older carers, older women, older couples to come together to socialise, give and provide support to each other, share information and take part in activities to improve their mental and physical health”.

A focused literature search included at least 60 references, documents and other sources of published information. A preliminary analysis of these references has identified a number of key themes and issues relating to existing, tried and tested schemes / approaches where older people are involved in mutual support arrangements, both in the UK and internationally. This has highlighted the importance of understanding local cultural and historical contexts within which different arrangements and models exist and have thrived for some time. For example, more co-housing and Homeshare developments exist

in Norway than in the UK and the USA. In Norway, public (state) funding is available to stimulate and provide such developments, whereas in the UK and USA such funding has to be found via private, personal or charitable / philanthropic routes (and this trend is likely to continue or increase).

The following quote, taken from an evaluation of the experience of setting up social enterprises, including those run by and for older people, highlights the importance of understanding and responding to very local geographical and community contexts:

Older people in remote and rural areas may rely on existing high levels of informal help [with each other]: some people are well connected to social networks that they are comfortable drawing on, but others do not have access to these resources. The former do not want to formalise the model of helping and the latter do, causing tensions within communities

(Munoz S.A., Farmer J., and Stephen K. (no date) Achieving Social Enterprise Development in Rural Communities O4O Policy Briefing no. 2, EU Northern Periphery Programme Project, Centre for Rural Health UHI)

A mapping exercise has plotted specific examples of different approaches, experiences and models / schemes based on mutuality and reciprocity – showing where such opportunities currently exist across England and Wales. This has highlighted some geographical areas where there are higher numbers of known reciprocal schemes / arrangements, and so this mapping has helped to inform the location and design of the fieldwork in 4 study sites (see below).

A public meeting was held in Wales to gauge current levels of awareness, experience and engagement in relation to support based on mutuality and reciprocity. Discussions at this lively event highlighted that, whilst there is huge interest in this area, there is currently a very low level of awareness and understanding about the potential (and actual) range of different options for support that exist; and about mutual support; and specifically about mutual support options involving older people with high support needs. The event also highlighted differences between the views and aspirations of older participants and those of professionals and agency representatives. The former were keen to explore and find out more about what is involved in support based on mutuality and reciprocity – even where current awareness and familiarity appeared low. Professionals on the other hand appeared wary and sceptical about the feasibility and desirability of developing broader options for support; the emphasis for them seemed to be on securing increased resources to expand what is already available.

The following picture is drawn from one of the feedback posters produced at the public meeting by a graphic facilitator working with participants to capture key points, questions and issues which will be further examined in the next stages of the project. This poster focuses on the question ‘What helps promote mutual support with and for older people with high support needs?’



Figure 1: What helps promote mutual support? Feedback poster from the public meeting

Early Findings

The following headings summarise the key messages and themes which are emerging from our analysis.

High interest-low awareness

Across all of the above sources of information, it is clear that there are high levels of interest in the research and enthusiasm for the concepts behind it. However, in contrast, there are also low levels of awareness, understanding and direct experience about support based on mutuality and reciprocity. In particular, it has become increasingly apparent that the focus on *older people with high support needs* is a very new lens through which to examine these schemes and approaches.

So whilst there is interest, there is a lack of awareness and understanding about what is involved and how mutuality can be applied to / for / with older people with high support needs. For example, a number of responses to the call have been about developments that

are being “thought about” or are under development but don’t yet exist. Some models of mutual support *have* been implemented and developed with other groups of people (e.g. people with a learning disability) but have not yet been extended or promoted to include older people with high support needs.

Six real life stories have been produced to explain and illustrate, and therefore raise awareness and understanding, about mutual support as experienced by / developed with older people with high support needs. These are provided in Appendix 2. They have been collected through the responses to the call and other information / examples gathered so far. They were used to help generate debate at the public meeting, and proved a useful tool for increasing understanding about what is involved, both in the research and in informing the future development of such approaches and arrangements.

A typology of mutual support and reciprocity

A central finding from looking across the different sources of information and experience gathered to date - and discussions generated within the research team, the Project Advisory Group and at the public meeting - is the extremely wide spectrum and diversity of interpretations and permutations of support based on mutuality and reciprocity.

An initial typology of different categories of mutual support and the ‘typical’ characteristics associated with each of these has been developed to help plot these different examples and approaches, and to make sense of the breadth of approaches identified. This is provided on the following page. In addition to key categories and characteristics, it also highlights the similarities and differences between the different kinds of models and examples found so far.

In reality each of these examples is multi-dimensional and dynamic in nature. Many of the responses to the call and examples sourced in the literature search encompass different features associated with different models outlined in this table. For example, some co-housing developments involve or promote peer support or volunteering; some informal, mutually supportive relationships have evolved over time into more organised circles of support (and so on).

This fluidity and capacity to adapt to changing (often uncertain) circumstances and needs over time appears to be one of the most important and common success factors identified.

Notes to the following table:

- * The number in the 'Type' column on the left hand side (n=) refer to the number of each main category found so far across England and Wales, both from the Call for Examples and the Literature Search. We believe there are actually many more examples of each type to be found across the UK, so we also hope that sharing this information at this stage will stimulate people to contact us and share their own experiences directly.
- ** Direct exchange is where mutual support is directly exchanged / experienced by those involved e.g. from one person to another. Indirect exchange is where support is exchanged / experienced among a number of people, for example in Timebanking schemes where support is banked or pooled and then drawn down as and when needed.

CHARACTERISTICS TYPE	DIRECT OR INDIRECT EXCHANGE OF SUPPORT**	NO. PEOPLE INVOLVED	ONE OFF OR ONGOING ARRANGEMENT	INTENTIONAL (PLANNED) OR CONSEQUENTIAL (UNPLANNED)	FORMAL OR INFORMAL	ORGANISED / COORDINATED OR ORGANIC / FLUID
MUTUALLY SUPPORTIVE RELATIONSHIPS (n=3)*	EITHER / BOTH	1:1/SMALL NO.	EITHER	EITHER	INFORMAL	ORGANIC/FLUID
MUTUALLY SUPPORTIVE COMMUNITIES / NEIGHBOURHOODS (n=4)	EITHER / BOTH	MANY	MIXTURE	INTENTIONAL	VARYING DEGREES	USUALLY ORGANISED /COORDINATED
HOMESHARE SCHEMES & DEVELOPMENTS (n=5)	DIRECT	USUALLY 1:1/ SMALL NO.	ONGOING	INTENTIONAL	EITHER, MOST ARE FORMAL	ORGANISED/ COORDINATED
CO-OUSING SCHEMES & DEVELOPMENTS (n=2)	DIRECT	MANY	ONGOING	INTENTIONAL	FORMAL	ORGANISED/ COORDINATED
COOPERATIVES / MUTUALS (n=0)	DIRECT	MANY	ONGOING	INTENTIONAL	FORMAL	ORGANISED/ COORDINATED
SHARED LIVES (n=13, incl 3 under development)	DIRECT	1:1/SMALL NO.	CAN BE EITHER	INTENTIONAL	FORMAL	ORGANISED/ COORDINATED
TIMEBANKING (n=7)	EITHER / BOTH	MIXTURE	MIXTURE	INTENTIONAL	EITHER, MOSTLY FORMAL	BOTH
VOLUNTEERING SCHEMES (n=11)	EITHER / BOTH	MIXTURE	MIXTURE	INTENTIONAL	EITHER, MOSTLY FORMAL	BOTH
CIRCLES OF SUPPORT (n=8, incl 3 under development)	EITHER / BOTH	1:1/SMALL NO.	ONGOING	INTENTIONAL	DEGREES OF FORMALITY	COORDINATED/ ORGANISED
PEER SUPPORT/ MENTORING	EITHER/BOTH	1:1/SMALL NO.	MIXTURE	MIXTURE	MIXTURE	MIXTURE
POOLING FINANCIAL RESOURCES (n=1)	DIRECT	EITHER	USUALLY ONGOING	INTENTIONAL	DEGREES OF FORMALITY	ORGANISED/ COORDINATED

This typology has the potential to be used as a personal checklist by those interested in developing and / or accessing these options; and as a tool for commissioners and providers to help them think through what is currently available or could be developed to meet the needs and aspirations of local communities and older people with high support needs.

We also think that this typology, once enhanced by our learning from the direct experiences of older people participating in the fieldwork, could be used to produce a practical guide, including 'top tips' for those considering which route to take themselves. It will, undoubtedly, continue to evolve over the course of the research.

In addition to the 'typical characteristics' summarised above, each of these options or categories also comes with a set of considerations which need to be addressed by all partners and stakeholders with an interest in, and responsibility for, planning and funding (or securing funding) for 'long term care' in the future – care which is sustainable, desirable, affordable and doable. These considerations will be explored within the fieldwork taking place in the 4 study sites, described below.

Next Steps

The study is now entering its third phase, in-depth fieldwork in 4 study sites, to examine and learn from the direct experiences of older people and others involved in a range of different forms of mutual support.

The fieldwork will involve 1 study site in Wales and 3 in England:

- Swansea & Gower;
- Oxford City;
- Leeds;
- Dorset.

In Dorset and Swansea & Gower, the fieldwork will focus more (though not exclusively) on more informal and fluid mutual support arrangements involving individuals / relationship-based exchanges (e.g. informal, personal arrangements, peer support and volunteering developments).

In Oxford City and Leeds, the focus will be on more organised schemes and coordinated models involving greater numbers of people (e.g. Homeshare, co-housing and Shared Lives).

We will also be running one 'virtual' study site in one of the Northern European countries (Denmark, Norway or the Netherlands) where examples of schemes and approaches based on mutuality and some element of exchange are more widely established, formalised and longstanding.

In each of the study sites, and the virtual site, we will further examine the key characteristics outlined earlier, the questions set out in Appendix 1, and the following considerations, drivers and barriers identified from the call for information, the public meeting and the literature search.

Considerations for promoting, sustaining and replicating mutual support options with and for older people with high support needs

1. Understanding and knowing what is being (or can be) offered and exchanged, for example:

- time, energy and commitment;
- experience across a range of life events and dilemmas;
- knowledge & skills including: organisational / chairing etc skills, art and craft skills, IT, photography skills;
- shared language and cultural knowledge;
- shared interests and hobbies;
- living space; and / or a safe and stress free space to visit;
- friendship;
- practical support / help;
- personal care and support;
- emotional support;
- money (e.g. via a personal budget or private funds).

2. Personal preferences and circumstances

- Are these known, and is this information aggregated to inform Joint Strategic Needs Assessments / other community-led needs analyses?
- How have personal preferences emerged over time, both in relation to specific options / categories and generally in relation to mutual support?
- How are changes in people's circumstances, and their preferences, accommodated and responded to?
- How are people's personal preferences, as well as their needs, understood, acknowledged and taken into account if they do not receive public funding / support and are not linked to established groups?

3. Local history and familiarity with different categories (see Typology), models and possibilities

- What is the local knowledge, understanding and familiarity with different categories and specific examples within them?
- How established is this knowledge / understanding and is this shared among / across different commissioners, providers, interest groups, communities and networks?
- What cultural issues and norms may be involved?

4. Level of public awareness, education, promotion and communication

- How are the benefits, challenges, outcomes and possibilities associated with each category and specific models communicated and publicised both to the general public and local services / agencies?
- Are older people with high support needs seen purely as recipients of support (within families and communities as well as by professionals), or is there an explicit recognition that they can and do contribute gifts, talents, skills, experience and resources of their own?

5. Ease of implementation / provision

- Which are the potential groups or individuals likely to display most interest (i.e. be potential early adopters)? Which other groups need to be targeted / involved?
- What incentives exist locally and / or nationally to help promote, develop and embed different models / approaches based on mutuality?
- How are these incentives being used to increase or stimulate developments involving older people with high support needs?
- What are the barriers to promoting, developing and embedding different models / approaches?
- How are Fair Access to Care Services (FACS) eligibility criteria and thresholds impacting on older people's access to information and advice about local options and opportunities for mutual support?

6. Scale and scope

- What is the current scope and scale of different models and approaches in general, and specifically in relation to those involving older people with high support needs?
- What would it take to increase the scope (where target groups are identified and limited) and the scale of what's currently available? (The answer to this question will inevitably reflect all of the above points, and the drivers / barriers referred to below. It is highlighted as a separate consideration as a reminder that scale and scope are key

factors that characterise the current situation, where there is low awareness but high interest in support based on reciprocity).

Drivers and barriers to mutuality

A number of key drivers and barriers to initiating, sustaining and replicating mutual support arrangements have been identified from the evidence gathered to date. These factors are summarised below under the headings of Drivers and incentives; What helps?; and Barriers and obstacles.

Drivers and incentives

- Wider population and societal drivers, which, combined with economic factors, mean that the status quo cannot and should not be maintained. These include more people living longer, more people with care and support needs (at all ages), lack of affordable and / or suitable housing, less money due to the economic crisis and public sector cuts, changes in family structure and familial relations / ships, and the desire for support that is more imaginative and tailored to meet individual needs and circumstances.
- Evidence of older people's desire to contribute, and be seen as active citizens with responsibilities and roles as well as rights – including older people with high support needs.
- Key policy developments and frameworks such as personalisation, Big Society and the Localism Bill (although it should also be noted that some participants at the public meeting also felt these could become barriers if enabling infrastructures and resources are not mobilised or available, or locally driven developments further exclude and isolate certain groups rather than deliberately reach out and include them).
- Availability of funding, together with opportunities to renew this for the longer term where needed and appropriate.
- A local infrastructure / source of information and support which will enable and encourage mutual support to be initiated, developed and sustained.

What helps?

- Clarity over what is needed (in terms of support) and what is possible and can be achieved - individually and locally and within specific schemes.
- Having a variety of ways that help people become and stay connected to others.
- Having a variety of ways and places where people can come together to build relationships, mutual understanding and trust.
- Public / general education and awareness about what is possible and what already exists.
- Knowledge and understanding about who needs / wants help and what is needed (in particular to help matching arrangements).

- Keeping things local and personal.
- Imaginative and open minded care and support providers and commissioners.
- Positive images and approaches towards understanding ageing / growing older, as well as about mutual support and wider options for support - and images of possibility, examples and stories of how others have gone about it or made it happen.
- Making it clear that this is for, and involves, all ages.
- Community transport and different ways of getting out and about and keeping in touch face to face as well as virtually.
- A strong sense of community at a local level really does make this easier but it's important to ensure that everyone is included and involved.

Barriers and obstacles

- Older people with high support needs not being seen as people with something to offer or contribute.
- Time and resources involved in establishing matches, especially where people do not already know each other, and in those options / schemes where people with accommodation who need, or can offer, support are matched with people needing accommodation or who can provide / offer support.
- Geography / location, both in terms of accessibility and proximity to centres of population, and people who are keen, willing and able to exchange.
- Certain aspects of local neighbourhoods / environments make it harder or easier to engage with others and feel / stay or become connected.
- The imposition of 'strict care lines' by funders and regulators, such that once people cross this line into needing some form of support they are perceived differently by statutory agencies, providers and others.
- Formalising informal supports, i.e. imposing constraints or formalities where they are not naturally evolving, desired or essential.
- Conflicting messages from policy makers and in the media, e.g. the importance and benefits of volunteering versus an enforced retirement age and focus on 'burden of ageing / older people'.
- Cultural attitudes and beliefs.
- Fears about quality and safety among professionals, families, older people and communities.

- Regulations and legislation designed to solve a big problem which – often in their implementation or enforcement – inadvertently impact upon smaller, informal and unusual models of support.
- Inadequate understanding among funders / commissioners of the cost-benefit of these different models / approaches (often because this information does not yet exist in the form most familiar to those funders / commissioners).

Following analysis and synthesis of findings, and exploration of the initial conclusions at a national 'sounding board' event, the intention is that the final report of this study will be published in late 2012.

4. Reflections on the research (design and process)

This is a complex and exciting area of research which has engaged everyone who has contributed so far. The following summary outlines five key challenges and lessons identified as a result of undertaking the study so far.

First, the approach taken to co-produce the research with members of the research team and Project Advisory Group, and those participating in the public meeting, the call for information and the fieldwork in 4 localities has helped to shape the design of the research, check out understanding and meanings about 'mutual support', and keep the focus on the experiences, needs and aspirations of older people with high support needs.

Second, we have learned to accept that sourcing actual, lived experiences of the full range of models cannot be hurried and takes time to build (a feature which we believe is directly linked to the finding about low levels of awareness and understanding). As a result we have extended the deadline both for the call and for the literature search so that these elements will run throughout the study and alongside the fieldwork.

Third, the importance of using mixed methods and mechanisms for engaging diverse audiences in the work; and of different networks and ways of providing and contributing information / evidence. We will focus on widening access to the project through the use of different social media (Facebook, Twitter, blogging) in the following phases, as well as continuing with more traditional routes such as websites, email, letter and phone.

Fourth, the process of obtaining formal ethical approval for the fieldwork in 4 localities identified specific issues and challenges around hearing the direct voices and experiences of older people with high support needs, including those who may lack capacity. It also highlighted specific challenges in designing action research which is co-produced throughout all stages of the work, necessitating a fluid and adaptable design which has the capacity to evolve during the lifetime of the study. This is counter to formal research ethical approval processes, which require specific methodologies to be identified and adhered to once approved. For the purposes of this study, we were able to compromise through the use of a menu of stated methods, from which specific fieldwork activities and tools will be chosen once the final sites and models are selected (this selection had not been confirmed at the time of the ethical approval submission).

Finally, in preparing for the fieldwork elements, the team has identified the importance of understanding the key characteristics of local contexts / environments; and the importance of using a range of different networks and flexibility in recruiting research participants (e.g. rather than relying on a small number of known routes or gatekeepers) in order to reach and involve a wide range of diverse participants.

5. Conclusions

We end this paper by setting out the key issues which we believe need to feed into, and inform, contemporary policy and practice debates; and which can help to stimulate local discussions and developments associated with mutual support and reciprocity.

The low levels of awareness about mutual support and reciprocity involving older people with high support needs identified in this paper indicate that this research is generating new knowledge and insights, and will inevitably highlight not only existing models, but also the need for further work into people's experiences and aspirations. However, we also believe that important issues and opportunities for promoting and widening access to different kinds of support will emerge from this initial piece of action research.

As a result, this work can also helpfully feed into and inform contemporary policy and practice debates – those more obviously connected with the research topic (e.g. the Dilnot Commission, Ageing Well, Big Society and building social capital, the Localism Bill, ongoing personalisation developments and the vision for adult social care); and wider developments including housing design, expansion and the built environment; and transition town and other environment sustainability movements.

In relation to the former, there is a particular need to draw attention to alternative approaches and options for support when (in this case older) people need ongoing or 'long term' care. Within this, there is a pressing need for more direct discussion and ongoing dialogue with diverse older people across different generations and along the spectrum of low to high support needs. Hearing from those of different ages and at different stages of life with experience of reciprocal support will help to shed light on what does and doesn't work; and the possibilities, challenges and economic implications of extending the scope and scale of models and approaches that currently exist in the UK.

In order to raise awareness, increase understanding and engage more people in this study (through direct and indirect means), we have learnt that sharing stories and examples of lived experiences of reciprocal support really helps – both in terms of diversity and scale of people's involvement, and in examining the intricacies involved from different perspectives. We are therefore planning to establish an online community of interest connected to the study, which we hope will continue to exist beyond the lifetime of the project. This forum will help facilitate the above debates but also collect stories and invite further contributions and examples to the study.

As part of this development, we will also design a template that can be used by local communities, groups, organisations and networks to hold their own public meetings about this topic, which can feed into the research as well as helping to generate interest and stimulate local developments.

Appendix 1: Research Phases and Design

Not A One Way Street consists of five Phases of work spanning a 20-month period (January 2011- August 2012) as follows:

1. Coproducing and finalising the design, scope and focus of the research, and agreeing the key questions to be addressed and criteria for inclusion of specific examples and models in the study. *January-February 2011* (The project team consists of 3 staff members from NDTi; 2 staff members from Community Catalysts; and 3 older, peer researchers drawn from NDTi's network of associates across England and Wales. The Project Advisory Group comprises leading thinkers, commentators and experienced practitioners working to promote support based on mutuality and reciprocity including older people)
2. Issuing a call for information and examples / stories of people's experiences; and starting a secondary analysis of the literature on existing models and best practice examples across the UK and internationally. Holding a public meeting to gauge current levels of awareness, experience and interest in the concept as well as practicalities involved in services / support based on mutuality and exchange. *March-July 2011*
3. Undertaking action research in 4 localities (study sites) in England and Wales, including multi-stakeholder discussions about the benefits, risks and outcomes associated with different models / examples of mutual support experienced by older people with high support needs; and in-depth interviews and small group discussions with older people and others directly involved in such arrangements. *August 2011- February 2012*
4. Analysis and synthesis of findings, drawing out initial conclusions and potential ways forward to share and further explore at a national 'sounding board' event. *March-May 2012*
5. Producing final reports and summaries for different audiences about mutuality and reciprocity, and future implications for older people and the provision of long term care. *June-August 2012*

The work is currently at **Phase 3** – identifying and initiating contact with 4 study sites, selected on the basis of key findings and the emerging issues and themes arising from Phases 1 and 2 which are shared in this paper.

Criteria for inclusion of models / examples of mutual support

The research has been set up to address specific issues relating to models, schemes, approaches and experiences where all three of the following apply:

- 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** where a plan has been agreed and elements of giving and receiving have been made explicit, even if informally. We find it helpful to think of this exchange as being both intentional and 'active' (i.e. the giving and receiving are both 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.

As the focus in this work is on alternatives to 'long term care', we are particularly interested in arrangements where older people are living in their own home and have not had to move 'into care' in order to access support. One or more of those involved may have moved house or are sharing their home as part of the mutual support arrangement, but the key issue for this project is that individuals concerned are living in a domestic household that they regard as their own. The experiences of people living in care homes or extra care housing developments are the subject of other projects funded through the Better Life Programme.

Questions being explored in this work

1. Beginnings: what was the plan or arrangement that was set up or which 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?

2. 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?

3. 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?

4. “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?

Appendix 2: Stories and Examples of Mutual Support

1. A Mutually Supportive Relationship - Viv and Miriam's Story

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 whilst 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 learned 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 learned 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 ninety-one-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 mutual support 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 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 supported 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 10 years ago. In recent years Richard has become immobile, unable to weight bear 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 and priorities for 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 Richard (at that point) was completely reliant on Marian and his (paid) carers. His life was dominated by services which 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. This 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 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 explained that they often felt quite lonely and needed some help in the house. They also liked the idea of helping someone out who needed somewhere to live. The Homeshare Coordinator 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 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 practice their language skills.

What helped this arrangement happen and work well?

Homeshare is a matching service run by a Homeshare Scheme where 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 whilst 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 mutual support 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 similar way to a close family member.

Over the past winter, Joyce had become increasingly concerned as 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 where a family or individual is paid a modest amount to include someone who needs a lot of support in their family and community life. 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 bounded, more traditional one-way “professional” support relationship), and because it is based on matching mutually compatible carers and individuals.

6. Timebanking - 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 Timebanking.

Description of the mutual support 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 Timebanking. She was anxious about what might change, the relevance to and how it could benefit “a woman like me in my 70”. She began to attend Timebank meetings run by the centre. At first she remained cynical, but she saw how other people were benefitting 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 wellbeing, but more striking is the improvement in her mental

health recovery. 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 positively impacted upon 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 Timebanking.