

WIDENING CHOICES FOR OLDER PEOPLE WITH HIGH SUPPORT NEEDS

What's the Issue?

Older people with high support needs want greater choice and control over their life and a wider range of options. This study identifies the benefits and potential of options based on mutuality (people supporting each other) and / or reciprocity (people contributing to individual and group well-being). Formal (e.g. Shared Lives, Homeshare, Time Banks) and informal (e.g. mutually supportive relationships) models and arrangements can be found throughout the UK, but they usually operate under the radar of public sector commissioners and on a very small scale.

Ways Forward

- Spending time identifying and understanding existing local models and arrangements will help commissioners widen their range of options.
- Adapting tools and frameworks from other countries, e.g. Denmark, could stimulate further development and investment in models such as co-housing and Homeshare in the UK.
- Planning, contracting and procurement rules need to be revised to stimulate the development of different models and ensure smaller-scale, relationship-based services are not damaged.
- Communicating the range and benefits of different models to older people, their families, the wider public and frontline staff will raise awareness, increase take up, and drive local developments.
- A mix of some core funding and resources from a range of sources will ensure their sustainability, and avoid them becoming skewed in order to meet new or changing funding criteria.
- 'Scaling out' these options is likely to be more effective than 'scaling up', as demonstrated by Time Banks and Shared Lives.
- Gathering evidence of the economic and social impact of each approach will help sustain and promote them.

Author

Helen Bowers, National Development Team for Inclusion (NDTI)

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BACKGROUND

This work was funded by the Joseph Rowntree Foundation (JRF) and undertaken by the National Development Team for Inclusion (NDTi) and Community Catalysts (CC).

The three main aims were:

- 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;
- To improve understanding of the intricacies involved in establishing and sustaining mutual support systems;
- 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 did not need 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 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 co-housing (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.

Different models and approaches based on mutuality and reciprocity are often described using very similar terms, but 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. They are 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);
- Co-housing;
- Homeshare;
- Shared Lives;
- Timebanking;
- Circles of Support;
- Face-to-face and virtual volunteering schemes;
- Self help and peer support networks.

The detailed typology and description of the above models is provided in the annex to this Solutions paper. This can be used to promote a very different menu of options by commissioners, providers and more importantly older people and their families.

Key findings

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. They are valued greatly and achieve significant outcomes for individuals when they recognise and use the assets of all their members, providing opportunities for everyone involved to contribute. 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 about care and support) rather than existing as discrete entities or as one-off initiatives and developments.

Significant change is required if these models and arrangements are to be made available to more older people with high support needs.

Change is needed:

- In the way care and support services are commissioned and delivered so that they actively promote mutuality and reciprocity;
- In the way older people with high support needs are seen and engaged in local developments;
- To create 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.

The study identifies five priority actions to make these changes happen and work well for older people with high support needs:

- Communicating and demonstrating the benefits;
- Raising public awareness and engagement;
- Tackling interfaces with other services;
- Replication and scaling out;
- Mobilising resources.

Communicating and demonstrating the benefits

An extremely rich and diverse picture of mutual support therefore exists, yet there is a lack of familiarity and often 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 of mutual support helps raise awareness and understanding of the different models, and could be used to generate greater interest among older people, their families and commissioners, funders and sponsors.

This study has shown that mutuality is not the same thing as reciprocity. 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. At the same time it was clear that many older people are 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.

The study 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 the literature and responses to the call revealed that the reality on the ground for many older people with high support needs is very different.

Characteristics and critical success factors

The critical success factors and lessons about effective models / arrangements have been distilled into five common features:

- 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.
- 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 in your life.
- 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-informality of the arrangement. This is more explicit and acknowledged in some models than others.
- Successful models are characterised by relationship-based delivery and / or exchange of support that can be experienced at many different levels (1:1, small numbers of known people, street or neighbourhood based, communities of interest). Aspects 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, are formally organised or brokered.
- Mutual support enables and facilitates “ageing in place”, meaning that older people with high support needs stay 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. 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 travel far to get the help they need.

Making the business case

It is often assumed that more 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 impact is usually only discernible 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 they also differ across a range of dimensions (as illustrated above). They vary in formality and infrastructure requirements in particular, which means there is a wide variation in costs and resourcing arrangements.

The examples covered by this study have also varied in the investments they have attracted and secured. Many had time-limited funding and needed to spend considerable time and energy 'chasing money' to survive. In these times of financial constraints, both existing schemes and new developments will need to make a strong business case for new and on-going investment. Any business case will need to include a focus on the benefits and outcomes for individuals as well as local services and organisations. The following points summarise the key benefits and outcomes identified in the study for individuals, families, communities, organisations and local services across the majority of models and approaches examined:

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 wellbeing, continuing to play an active role in family and community life.
- Loneliness and isolation is 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, appreciated and not 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 wellbeing 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).

Raising public awareness and engagement

Everyone involved in this study has stressed the importance of directly engaging the public in disseminating the findings and taking local action – both to raise their awareness about different options for support and to increase their interest in mutual support options in particular. With increasing media and trade press attention on the negative implications of an ageing population, such a move would help to redress the dominant and unhelpful messages about the increasing burden and financial catastrophe that awaits us all as we age, grow frail and dependent. It's time for a grounded campaign which sets people alight 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.

The study also emphasises the importance of personal, life and support planning – different but connected approaches that use tools and techniques to help people plan and / or make changes to their lives, but these are not well known outside professional and sector circles. Even in more formal models (e.g. Shared Lives), the use of tried and tested support planning tools was not overtly evident among older people. These tools and processes also exist on a scheme and model level, e.g. the senior co-housing community building process. Greater promotion of these tools and techniques would help more older people and their families to make informed, proactive decisions and stay in control of their lives.

Tackling interfaces with other services

Those 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. The study highlights the importance and success of those models that develop strong relationships and become integrated into the local network and infrastructure of goods, services and facilities. Those that sit outside and rely on time-limited grants and project funding do not survive.

Some models and schemes (Shared Lives, some Time Banks and some Homeshare schemes) are part of or inextricably linked to formal care and support service systems. However they still experience frustrations with the layers of bureaucracy that can 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. Those who play a key role in brokering, organising or gatekeeping access to different services, also need to be seen as *local* target audiences for communicating the benefits and outcomes these models can deliver.

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 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 to create 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.

The need to replicate and ‘scale out’ what works

The study emphasises 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 can access and benefit from them. This includes addressing the underdevelopment of some models and approaches (for example, Homeshare, pooled personal budgets and co-housing); 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 co-housing, Shared Lives, Time Banks, Keyring Networks and circles of support).

This study draws 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. These developments require fertile conditions in which mutually supportive relationships and models of mutual support can grow and thrive. These conditions have been well documented in the literature on asset-based community

development and coproduction, 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 for replicating and scaling out community-based models of mutual support on local authorities and the third sector. Study participants 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 identified clinical commissioning groups and individual GPs, health and wellbeing boards, mainstream community and leisure facilities (e.g. pubs, cafes, arts and music venues), commercial enterprises (e.g. supermarkets, high street traders, insurance companies) and broader networks rather than the “usual suspects” (e.g. think U3A networks rather than lunch clubs).

It should be remembered that the source of funding and values base of investors is a primary concern for many of the founders and initiators of these models, for example if it changes or influences the values and ownership of the model.

Mobilising resources

Whilst a few of the models covered by this study are well resourced (e.g. Shared Lives) the majority of examples – especially those delivering at scale – are not well resourced. They are achieving significant benefits and outcomes with relatively little and often time limited or uncertain funding arrangements. Many of the (often third sector) organisations and groups who are running schemes or facilitating networks to foster mutual support shared their feelings of desperation as a result of cuts to their existing resources.

This is not generally regarded as a conducive environment in which to establish new, or expand existing, models – especially those that are not well evaluated or backed up by robust business cases.

However, there are opportunities 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. There are valuable lessons to be learned from those individuals and models that have successfully 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 “re-group” in difficult times in order to consolidate and continue over time (e.g. Isaac Pennington Trust).

These innovators, skilled enablers and facilitators need nurturing and supporting, and new ones need to be found, encouraged and mentored to ensure these models are further developed and extended. Many of the initiatives designed to promote and inspire the social entrepreneurs of the future (e.g. NESTA, 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:

Firstly, 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.

Secondly, 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.

Thirdly, 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.

Finally, 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 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 key audiences; 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 and develop plans that result in better outcomes for older people with high support needs and their services.
- 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 Alternative Approaches Workshops) that can be used by any local area/partners to do the same.
- Showcase examples of good practice and innovation identified through the call for information, fieldwork, case studies and literature search.

About this paper

This paper summarises the findings from a two- year study of support options available to older people with high support needs. Capturing the experiences of formal and informal models of support based on mutuality and / or reciprocity, it sets out the potential for viable alternatives to traditional forms of long-term care, how to widen support at a local level and overcome cultural and structural barriers that older people face.

FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF.

The main report, **Widening choices for older people with high support needs** by Helen Bowers, is available as a free download at www.jrf.org.uk

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Joseph Rowntree Foundation
The Homestead
40 Water End
York YO30 6WP
Tel: 01904 615905

email: publications@jrf.org.uk
w www.jrf.org.uk
Ref: 2852