JRF programme paper:
A Better Life

A better life: Alternative approaches from a service user perspective

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Shaping Our Lives

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This paper:

- reports on a small-scale consultation with service users and disabled people;

- makes recommendations in relation to the context of older people's lives and support needs and alternative forms of housing and support;

- suggests specific activities for the JRF to take forward.

The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its 'A Better Life' programme, to stimulate and inform thinking on alternative approaches to a better life for older people with high support needs.

JOSEPH ROWNTREE FOUNDATION

This paper was commissioned to inform the work of the JRF's 'A Better Life' programme, a five year programme of work focusing on how to ensure quality of life for the growing number of older people with high support needs in the UK.

The Joseph Rowntree Foundation has supported 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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Summary

Thirty-seven service users were consulted during this review. They had a wide range of different backgrounds, identities and experience. We asked people what could be learnt from the experiences of service users and disabled people that might help find a way to ensure older people, particularly those seen as having 'high support needs', a better quality of life. This is what people told us:

- Our society is ageist. It does not treat old people well or equally. It often ignores their human and civil rights. We see this everywhere, in the language that is used, in health care and in social care and more broadly in attitudes and arrangements in society. People have sometimes been and sometimes still are treated like this as disabled people, but we came together and demanded change. Being able to talk to each other and do things together made us stronger. Older people include many disabled people. But as a group, older people are not given enough chances to meet each other and more needs to be done to help them to form their own groups and find their own voices.

- As service users and disabled people, we know how important access is. Older people need access too. Access to services, to support, to transport, to amenities, a social life and access to money. Access to such things, however, tends to be reduced as people grow older and many public policies tend to make this worse rather than better.

- There are many public policies and laws which make things more difficult for older people rather than better. Sometimes this is not intentional, but it happens. For example, if you look after your parents and they die you might have to give up your home because of inheritance tax.

- It can be unhelpful to draw sharp distinctions between older people and other groups of service users because many of the problems they face are shared and solutions can be transferrable.

- The 'level of support' an older person needs is affected by how supportive mainstream policies and services make local life and communities. The need for 'support' is not simply a personal characteristic. It depends on the nature of the society and communities we live in. Policies which are detrimental to the needs of older people also often work badly for other groups too.

- There is a serious shortage of fully accessible housing in Britain. This has a bearing on the scale of older people's need for alternative support and housing.

- If older people are to be able to make real choices about what kind of support and accommodation they prefer to live in, then they will need an initial level of capacity-building or personal empowerment to be able to think through what might be best for them individually.

- Older people are an incredibly heterogeneous group. They vary widely in terms of income and expectations as well as in relation to equality issues. Taking full account of cultural issues relating to equalities is key to offering a wide range of alternatives. Where someone's identity means that they may face more than one form of jeopardy, for example, as a lesbian older person, the barriers are disproportionately magnified and they may face a 'double jeopardy'.

- There are many ideas for making things better for older people. These include:

  - KeyRing communities, where people living near each other are supported to look out for each other and have a support worker.
  - Overseas holidays and cruises as cost-effective means of offering supportive accessible living which could be in more supportive climates and environments.
  - Cooperatives, where people have their own houses and are independent but where they could get support and help.
  - House sharing, where older people could be put in touch with other people to share their house and offer accommodation in exchange for support.
  - Telecare systems, which could be used to support older people in their own homes. People were, however, worried that they might be used to replace contact with 'real' people as a cost-saving measure.

1. Recommendations

A series of recommendations were both suggested by participants and emerged from their comments and ideas. These address three areas:

- the context of older people's lives and support needs;
- alternative forms of housing and support;
- specific activities that the Foundation might want to take forward.

Older people themselves need to be more fully involved in discussions and developments to challenge existing ageism and discrimination. This could help examine ways of increasing pride in age.

Service users including disabled people highlighted the commonalities between their position and that of older people. It thus follows that important lessons learnt over the last forty years by disabled people and other service users may be readily transferable to the situation of older people today and need to be more systematically identified and learned from in the interests of older people. This needs to be explored.

There needs to be greater encouragement that older people seen as having high support needs, just like anybody else of any age, can and do contribute in many ways. Ways of fostering the greater recognition and support of their contribution through living and support arrangements need to be examined.

Service users saw a real need for opportunities for older people to be able to come together and talk, network and share ideas. Service users know how important this is and yet there are very few older people's organisations which are truly user controlled and those that are tend to be less securely resourced. The role of big traditional older people's charities needs to be reassessed. To impact on policy and practice better for the future, strengthening the direct voice of older people is essential.

Some older people have no voice at all. Participants said there was a need for older people with high support needs who are and are not in residential care to be supported appropriately to have opportunities to become involved in participation schemes.

There is increasing political support for ideas like 'place shaping', to maximise the positive impact of expenditure and resources for any local area. At present however, many public policies actually work against the sustainability of local amenities and resources that support older people's independent living. This needs to be monitored and ways of reversing such negative trends identified. The importance of older people's total environment for support needs to be given greater weight.

Service users saw the need for an impact assessment on policies and practices that affect the older population, both directly and indirectly, such as loss of mobility allowance and other benefits over a certain age as well as the impact of policies like shopping, transport, learning, recreation, banking etc.

The strength of local communities is a major resource for the independence of local people. Ways need to be explored, identified and developed to support and sustain such community networks and resources, which recognise and support their diversity and which take particular account of what helps more disadvantaged neighbourhoods. Community development and support approaches need to be developed further in this context.

More work needs to be undertaken to identify how all housing can be made more accessible to meet people's access and support needs as they grow older so that physical, electronic and other access aids can be incorporated as required as simply and cost-effectively as possible.

If older people are to be able to identify, opt for and make better use of creative alternative methods of support, then they will also need an infrastructure of support in terms of effective and independent advocacy, information and advice services for this to be possible for all, regardless of age, difference, impairment or experience. This is especially important if self-management is to be maximised and prolonged.

The Foundation's idea of ensuring 'that little bit of help' and encouraging 'ordinary' tasks of support are maintained in older people's lives has an important bearing on older people's longer term support needs. Narrowing eligibility criteria have worked against this. Twenty-four hour support services are being lost or cut, but they are crucial to maintaining older people's independence, control and choice.

The concept of 're-ablement' is being advanced as a means of ensuring that dependence in older people is not encouraged or perpetuated. It is important to monitor and evaluate this development to ensure that it is developed in a way that is consistent with the philosophy of independent living, rather than leaving older people to manage on their own.

Different approaches to support, tenure and forms of housing management which have been developed by and for other social groups and service users should be explored in more detail to be trialled in association with older people and their organisations.

The market of support for older people should be seen in broad terms as anything that could help meet their needs, from beauty parlours and gardening services to dedicated support schemes. Some support needs may not be amenable to 'for profit' market approaches and this needs to be examined and acknowledged if necessary.

Entitlement is key for support to work effectively. This principle is embodied in the government's Right to Control initiative and the Trailblazer scheme now about to start.[1] This development needs to be linked with the exploration of alternatives for older people seen as having high support needs.

The safety of environments, including public environments, is key for older people. There needs to be more rigorous evaluation of hate crime against older people.

Developing alternative approaches to the support of older people identified as having high support needs will need to be associated with workforce reform and developing education and training for it, which fully involves service users and service user trainers to develop cultural change consistent with such alternatives, based on the values of independent living and the social model of disability.

Schemes which encourage inter-generational contact and support seem to work well, to be productive and to be valued and should be explored and supported accordingly. One specific idea was that the Foundation should bring together young and older people with support needs, both living in and outside residential care to explore their ideas about alternatives.

Some policies and approaches like independent living and personal budgets do not seem to be reaching older people as fully as they should. It would be helpful to bring a diverse range of older people together to explore why this is so and how it can be overcome.

The Foundation could support innovation in running one or more residential or nursing home differently in a more participatory and empowering way. One suggestion was through supporting mutual ownership schemes where everyone has ownership of the home – the workers and management and also the people who use its services. This could transform internal culture, and help to embed real democratic accountability and a renewed sense of community responsibility.

It is crucial to think outside the box when considering possible alternative ways of meeting older people's support and accommodation needs, as service users highlight with ideas about overseas holidays and cruises. There should be a preparedness to think radically in this context.

2. Carrying out the consultation

This small scale national consultation was commissioned by the Joseph Rowntree Foundation and undertaken by Shaping Our Lives, the independent, national service user controlled organisation and network, which has a track record of undertaking such work.

The main purpose of the consultation was to explore with a diverse range of service users what, if anything, we could learn from our experiences of being service users, that might inform alternative approaches to support the well-being of older people identified as having 'high support needs'. This, in turn would be used by the Joseph Rowntree Foundation to contribute to and inform their thinking when they came to identifying priorities in the 2010 funding stream.

Shaping Our Lives

Shaping Our Lives works with service users and their organisations. This means that we work with a broad range of service users, including people with physical and/or sensory impairments, people with learning difficulties, older people, survivors/users of mental health services, people living with life limiting conditions, with HIV/AIDS, young people with experience of being 'looked after', and people who have had experience of using alcohol and substance abuse services. We are developing links with organisations run by homeless people and with refugees and asylum seekers.

Shaping Our Lives is experienced in involving older people in a meaningful and accessible way. Our National User Group has a significant proportion of older people across equality groups. We have always sought to involve older people in our work. Four specific pieces of recent work illustrate our commitment to addressing this: The Standards We Expect; Beyond the Usual Suspects: developing diversity in involvement; and two consultation projects carried out for Cumbria County Council and Cumbria Primary Care Trust. The first of these involved older people in residential care settings and the second explored what 'younger older' people wanted for their future well-being and support. This work has provided insights into the barriers to independence and well-being faced by older people when considering existing options for care and support.

The people who took part

The consultation adopted three different methods of ensuring that a diverse and broad range of service users could take part. One discussion group was organised, which included seven service users. All the people who took part in this event were experts through their own experience of using services as well as being trainers, advocates, educators and active members of the disabled people's and service user movement. Sixteen named service users were invited to contribute electronically, and two people with learning difficulties had a discussion facilitated by their support worker. A number of older people, some with high support needs, contributed to the consultation, but to the best of the author's knowledge no one from any age group had dementia.

SOLNET, Shaping Our Lives' networking website, with over 350 user controlled organisations as members was also employed to reach more service users. A notice was placed on the site's notice board inviting people to contribute and share their thoughts and opinions. Participants included people with physical and/or sensory impairments, people with learning difficulties, people with experience of using alcohol and/or mental health and palliative care service users. In addition participants reflected diversity in terms of age, gender (including transgender), sexuality, cultural background, ethnicity and faith.

In total, 37 service users participated in the consultation. This report is based solely upon what service users told us. No names are used and any identifying comments have been omitted or changed. People's comments and quotations are reported to highlight issues they raised and general themes they emphasised.

Making key connections

Shaping Our Lives was asked by the Joseph Rowntree Foundation to explore 'alternative approaches', from service users' perspectives, to the more commonly available options of the traditional care home and the newer extra care housing model. The key question the Foundation wanted answered was: What really exciting/promising approaches are already happening somewhere in the UK or internationally which might offer real hope for a better *life* (not just better *care*) for older people with high support needs, including approaches used with other groups that could be adapted for older people with high support needs?

What we quickly found out in the consultation was that such questions could not be asked in isolation. We could not helpfully think only of specific options for support. These had to be located in the broader context of attitudes and policies towards older people and how general developments, policies and practices might affect older people. In this report we have sought to highlight the insights that service users bring on both these issues: a) particular alternatives that might have much to offer older people, as well as b) broader considerations that also need to be addressed, if older people are to have as good quality lives as possible and existing resources, policies and practices are to be consistent with this.

3. Findings

People are always searching for the magic bullet, but there isn't one. People want to live ordinary lives but that's not headline news.
(Service user participant)

Ageism, or discriminating against people purely on the grounds of their chronological age, is deeply embedded and very widespread in our society.
(Baroness Sally Greengross, Chief Executive of International Longevity Centre UK)

The context

Ageism

Underpinning the discussions and correspondence that took place in this small scale project was a shared understanding that our society discriminates against older people. In healthcare, the discrimination is evident when older patients in the NHS are treated differently from younger people. This includes omitting older people from clinical trials or denying particular treatment or operations on the basis of their chronological age. Respondents said:

> *What happened to the idea of valuing people 'from the cradle to the grave?' This seems to have been forgotten. Different messages are being given. In hospital when you have a baby you are given a financial reward, you get 'bounty bags' and there is a £250 trust fund payment, but nothing when you get old. The message is loud and clear: 'if you're young you're valued; if you're old you are not'.*

> *It is sad when a child gets cancer and dies. I am not suggesting it isn't, but when an older person gets it, it is common for people to say 'Oh well, they had a good innings'.*

Currently arbitrary age barriers mean older citizens can't participate in many voluntary and civic activities, such as being a magistrate after a particular birthday. As consumers, older people may have difficulty hiring a car, getting insurance or borrowing money just because they have reached a certain age. Ageism permeates the fabric of our society.

Participants wanted to make it clear that this discrimination must be recognised and acknowledged in order to look at alternative approaches for a better life for older people. They said:

> *Everything tells us to deny being older because there are such negative connotations. There is a culture of despising older people.*

> *Trying to stay young is the new religion. It is a multi-million pound business – just in anti wrinkle cream alone! But you know, this is serious: it is another*

way that says being old is crap. Somehow you spend all this money, put on this cream, fill your face with Botox and you won't get old. It is portrayed so negatively.

People talked about how negative language is used in our culture about age:

The language needs to be tackled – 'the problem of old age'; 'the plague of an aging population'.

Yes, I agree. Old people are always referred to as 'a burden' that the young will have to carry.

Old people are not seen as a resource, a mine of information gathered over many years.

I [as an older person] like to think of myself as a 'survivor'.

When I first became disabled, I didn't want to associate with other disabled people. I couldn't find anything positive in belonging to this excluded group … It's the same for old people. I know people in their 80s who don't think of themselves as old and who deny the fact that they are old, who find nothing positive about it. We need to be positive about being old – 'you've lived all those years, you must have learned something'!

People commented on how being old was 'like coming from another planet'.

It's about an attitude. People think that when someone becomes 'old' that they are a different type of person - but they are not.

Older people aren't different. What's good for older people is good for everyone, like access.

People like to think that old is different. They don't like to be reminded of their own mortality.

Participants agreed that fear of old age was a serious factor in how we, as a society, view older people:

We can't ignore the issue of fear – fear of Alzheimer's disease, fear of having to go into a home, fear of isolation due to lack of mobility…

Fear of becoming helpless and dependent…

There is a fear of forgetting who you are, a fear of ending up in one of those homes.

There is fear that once someone is in any part of 'the system' they are on the 'conveyor belt of care', with the inevitable end of being in an institution.

Isolation. Being on your own… loss of dignity, loss of everyone you love, loss of yourself.

All participants agreed that there is nothing intrinsically inherent in aging that should cause us to disrespect older people. Most of the people we talked to could give examples of cultures that revered older people:

In Greece the head of the family is the oldest man, regardless of how old he is, he is honoured as the head.

Yes, in Italy it is the same.

I think it is particularly so when the society, the family, the structures are not so strong with families living apart you know… the break up of the extended family.

The disabled people's and service user movement

Disability activists within the disabled people's and service user movement have acknowledged for many years now that our culture is disablist, discriminatory and perpetuates practices that are prejudicial, exclusionary and inequitable. However many disabled people and service users recognise that together we have shifted the debate from one which was purely focused on medical concerns to one that now addresses human rights, independence, choice and control and people's lives as social beings. In looking at alternative approaches to well-being for older people, there was unanimous agreement that we can learn much from the experiences of disabled people and service users. Participants drew parallels between their experiences as disabled people and those of older people, whether disabled people or not:

As disabled people we have fought hard for independence. People should be enabled to live in their own homes for as long as they like.

I recognise that there are some impairments or combinations of impairments that are more common for older people, but the basic approach should be the same as we have always argued for.

We must draw on work that has already been done: by the disability movement, by Shaping Our Lives, by JRF.

There needs to be an understanding of grassroots issues. There are problems but there is lots of potential.

People used to say that independence is doing everything for yourself. We, as disabled people, know that is not true. Independence is about being able to make choices about what you want to do. It is the same for everyone whatever your conditions, wherever you live, whatever your age.

Advocacy, advice and empowerment

At the heart of the disabled people's movement lie the organisations controlled and run by disabled people and service users – what have come to be called 'user led organisations' (ULOs) by government. It is from here that the slogan 'Nothing about us without us' came from, and it is from these groups that disabled people's collective empowerment emerged. Throughout the discussions and correspondence for this project, the recurring concern was that older people, particularly older people with high support needs, do not have a voice.

> I am deeply concerned that older people – those called 'frail' – we never get to hear what they think.

> People need support to do the right thing for themselves. There needs to be capacity-building so that people feel they can request support when they need it.

> Communication and empowerment is key.

> People need advice – younger disabled people have more of an idea about how to get advice than older people often do. If you acquire an impairment as an older person you may not be aware of your entitlements.

> Because of the way that old age is generally viewed people don't want to be 'a burden' and put up with situations they shouldn't and don't need to.

> Some older people need advice. Near us a retired teacher and his wife from Islington moved to Hampshire because it seemed a lovely place to retire to. However he and his wife ended up going back to visit Islington so much they eventually went back to live there again. They hadn't realised the effect of leaving behind long established social networks.

> People need choice, they need to be able to buy in the support they need. There needs to be more support with advocacy and brokerage.

Access

The people we talked to said that access in its broadest definition was the cornerstone to alternative approaches for the well-being of older people.

> If you can't get in because the door is too small, it doesn't matter haw fantastic the décor inside is!

> By inclusion we mean having accessible facilities in a broad sense, it is a lot more than just physical access. For example, a local accessible café where you can meet people or go on your own or whatever but the staff respect you, they know your access requirements. Obviously the physical access has to be right but it is also about accessible transport to get you there and it's about financial access so you have the choice if you want to go there.

Transport is a fundamental problem in rural areas, unless you are rich you can't get about if you are an older person or teenager who doesn't drive.

My mother felt that her social life had come to an end because she was no longer able to drive. Older people are often reluctant to use taxis because they are considered extravagant even though it might make financial sense in comparison with keeping a car on the road.

It is difficult to stay independent if you can't drive. Local transport is pretty inaccessible in the main, if it exists at all.

Access to services themselves was often problematic. People consulted said that there were different problems depending on where you lived:

Sheltered housing in your own area for example is more difficult to find if you live rurally.

And it is not always culturally appropriate. It can be more difficult if you come from a black or minority ethnic community.

Where you live can also affect the services you might need:

I know an older mental health service user living in the Cotswolds. He has said to me that everyone is always very helpful at his local train station, but that at St Pancras 'if you fell over people would just step over you'.

People were clear that meeting access requirements included being aware of attitudes, assumptions and atmosphere:

I use two cafés near me because they understand my access requirements and are respectful of them.

Some local shops can be really good with people. I saw them helping out a person with learning difficulties who was having trouble counting out his money and they were really helpful, not rushing him or anything.

It can make a real difference when people are not embarrassed or awkward or over-helpful or anything. Just treating you as an equal.

There is hate crime against disabled people. Particularly for people with learning difficulties… there have been some very tragic and awful cases in the media lately. I wonder if older people are victims of hate crime. I know there is abuse in homes. Both residential and in people's own homes.

Access to a social life can be difficult for many reasons. People spoke from their own experience:

There are many barriers to participating in groups and clubs. The University of the Third Age (U3A) has lots of things going on, but tend to be in people's homes which are usually not accessible for people with physical impairments so they are excluded.

It would be good to be able to join local clubs and use local facilities via direct payments but lots of facilities are not accessible.

I started a bridge club. But as it grew people started to meet in their own homes, which I can't get into.

The people we spoke to were very aware that access, whether physical, communicational, emotional, financial, educational, cultural or procedural, was a fundamental issue that will have to be addressed if the wellbeing of older people is to be improved and for them to have a wide range of support options.

Networking

Disabled people and other service users and their organisations have long known the crucial importance of networking. That is to say, that they recognise the importance of people being able to get together to do things together, work for change and support each other. Hand in hand with this is the central need to make their voices heard; to be able to speak and make decisions for themselves; to be able to develop their own discussions, knowledge and ideas. (Barnes *et al.*, 1999; Barton, 1996; Branfield *et al.*, 2006; Campbell and Oliver, 1996; Oliver, 1996). People who contributed to this project equally recognised this as a necessity for older people if the goal is to develop alternative approaches to their well-being.

It is very important to support local independent groups run by older people themselves.

There needs to be a lot more support for older people to be able to come together and discuss things with each other. We know how important this has been for us [disabled people].

We need to develop forums, little local groups, there is a need for peer to peer support.

We need to focus on developing locally based community infrastructure.

Social networks and invisible networks are very important.

People had ideas about how to encourage networking. They said that the built environment needed to be planned with this in mind:

There needs to be informal places where people can meet.

Communal spaces are so important. In Holland, roads are closed off, trees planted, children can play out, older people can meet up outside.

Park benches. You don't see as many anymore, not in parks. You know, when you want to sit down and have a chat.

Service users said that existing structures could be utilised more effectively:

There is a need to develop local communities.

There needs to be more support for community centres and indoor spaces for people to meet and socialise.

What's important is the expectations of society. What inclusive practices are there already? Culture is very important.

There are existing structures such as neighbourhood forums, neighbourhood watch schemes and so on which could be used to promote community co-operation in wider areas like supporting older people.

We should use what's existing in the community – newsagents, post offices, libraries.

But we can't forget that 'old fashioned' things like doorstep milk deliveries, local post offices, shops and newsagents can play a big part in enabling people to stay independent and happy at home. But a lot of them are closing.

People should be encouraged to meet up and discuss before they get too old. I mean younger older people need to become involved now so that the structures and supports are there for when they are older.

I think we can learn from other cultures living in this country. For example the communal support amongst the Bangladeshi community in Oldham is good.

Policy

People discussed social care policy, the impact that it has on service users and how it reflects government values.

We need to challenge the way benefits are reduced at age 65.

I will lose the mobility allowance. Do they think that when you reach a certain age you don't want to go anywhere anymore?

We need to look at what goes wrong due to how policies work in practice. I know of someone who cared for her mother. Her mother died, she had been living with her but she wasn't able to get the tenancy transferred so she had to move away from all her social networks.

Policy should help rather than make everything such a difficulty.

There could be policies to support people who are living with and supporting their parents, like inheritance tax benefits. You can lose your parents and then your home.

We've lost a lot of common sense due to unhelpful policies.

We need to look at how policy is set. The agenda is dominated by large charities, like for example, Scope, Leonard Cheshire, Age Concern. Given the demographic changes that have long been known about, why haven't Age Concern/Help the Aged been demanding this level of debate before now?

Within the Disability Movement there is fragmentation but there is a good voice that the Disability Movement challenged the large charities for. I have grave concerns about Help the Aged/Age Concern (now merging to form Age UK) being the leading voice 'for' older people rather than 'of' older people.

Older people are mentioned in the [Government's] Independent Living Strategy, but not in a very up-front way. It would be really useful if someone experienced could comb through existing key legislation to pinpoint aspects that are relevant to older people, even in a peripheral way. It could be an 'impact assessment of key legislation'.

'Little things' that matter

The service users we spoke to were keen that we reported the importance of the ordinary. They felt that when looking at any alternative approaches to care, support and well-being, small things sometimes got overlooked. What they said complemented the finding from the JRF's Older People's Inquiry, which highlighted the importance of 'that little bit of help', in enabling older people to live their lives fully and independently for as long as possible. They said:

It's about being able to live in a community, to go out in the community, to feel safe in the community. It's about being able to go out shopping and do the things we want to do, when we want to do them.

We lack leadership, common sense and training for people to do the ordinary.

Ordinary things are not seen as being in the role of the professional, despite their importance.

I have a friend who lives in a residential home. I asked her what she would like more than anything else in the world and she said she would like to "go out for ten minutes a day or every other day to feel the fresh air on my face, and eat a nice roast potato".

Thinking about the importance of 'ordinary things', we could build up a resource of case studies of solutions e.g. getting meals from a local pub instead of meals on wheels.

It is not rocket science to sort out ordinary things and it shouldn't be more costly.

Alternative approaches

The participants in this consultation had many ideas and experiences that they had gained and developed in a disability/service user context that they thought would be transferable and make a positive contribution to the well-being of older people, including those seen as having high support needs.

KeyRing community networks

KeyRing communities (www.keyring.org) are a network of local flats and houses with people linked in terms of a commitment to support each other. KeyRing communities were developed specifically with people with learning difficulties in mind but participants cited KeyRing schemes as a good example of what could be achieved for the well-being of older people. KeyRing supports people to develop relationships with each other in the KeyRing neighbourhood and a support worker is appointed who also lives locally and supports members on a flexible basis. KeyRing communities are thought to be particularly useful for tackling isolation; for using community facilities and promoting independence and well-being.

People said:

This is a good model because it can be developed without people needing to move house.

Moving house for anyone is a traumatic experience and then to have to move to somewhere you don't really want to go to… leaving not just your home, but all your memories can be tied up with the family home.

People could still have their own homes and be as independent as they could be. They might also have other networks and neighbours that they can still be part of.

It would also help the community generally.

People would feel safer knowing there were people they could call on.

We all look after an elderly neighbour who has Alzheimer's and lives on his own. He has alarms and a telecare system for gas, electricity, smoke which alert one of three local contacts to go and investigate if something seems wrong. He has friends and church contacts, a paid cleaner, his meals paid for. Neighbours help with medication. His family are very supportive and think it's worth taking the risks associated with him being 'on his own' rather than him moving to an institution. He is happy in his own home. I am aware that this wouldn't be possible for everyone but where it is possible it should be supported.

I have a friend whose father has advanced Alzheimer's. He lives at home with his wife, has a large informal network of friends including people from their Methodist church. They used to run the village shop so they know everyone where they live. They have some formal support but mainly informal.

The main issue for people with Alzheimer's is that you need to enter their world, and not expect them to be in your world.

Respondents generally thought that KeyRing communities were a very good idea and should be encouraged and developed. It was felt that not only would they benefit a lot of older people but, in general, they could be good for everyone.

Naturally occurring retirement communities

The phrase 'naturally occurring retirement communities' (NORC) was coined in America and refers to local communities taking care of each other as they need support (www.albany.edu/aging/norc.htm) (www.seniorresource.com/ageinpl.htm). It can take as many different forms as there are local communities, but generally means that people who have lived in the same area and grown old together support one another. As one of our respondents put it:

This form of 'community care' used to be what happened when there were communities. Before people were spread all over the country, the world. It is about caring for your neighbours and in some places this still happens but unfortunately you can't always rely upon it.

There was a lot of agreement in the group discussion that people nearly always wanted to remain at home. This led to many other ideas being explored:

We can't expect the market to provide everything. It doesn't happen. Councils, because of lack of funds, are stopping handyman services and gardening – which means that now it can be very difficult for people to get help with small things such as weeding a front garden or changing a light bulb.

… Which is why LETS [Local Exchange Trading System where skills and services are swapped for free] *schemes can help build social cohesion and overcome stereotypes of people. Everyone can find something to offer and can benefit in return. It could be a good solution for things like the loss of 'handyman' services and to get a bit of gardening done.*

Some good schemes are running in some areas like young people who want allotment space being paired up with older people who can no longer manage their garden. This is mutually beneficial, the older person gets their garden looked after and may well benefit from the company, the younger people also benefit from new relationships as well as space for growing things.

I know that in Hastings – hotels have a lot of people who would otherwise be in residential homes.

Yes, that did always used to happen. Especially if the wife dies and men can't fend for themselves! I didn't know it was still the case.

I know of a man who bought a house in India (he had links there) for his parents and arranged for them to be looked after in a way that couldn't be afforded here.

There is something to say about people going on out of season holidays in Spain, cruises, excursions to race courses – all of which make efforts to meet access requirements in a broad sense including attitude and affordability as well as physical access considerations.

House sharing

Some respondents commented on the idea of house sharing as a way for people to be able to stay in their own home.

There are barriers in terms of council tax and health and safety regulations that make it complicated for people to share a house with someone, for example a lodger, even though it may be a mutually beneficial arrangement.

In principle it could be a really good thing. Older people with a big house that they don't really need and perhaps don't use the upstairs and in return they get not just company but safety, some care, maybe a meal, whatever level of care was needed.

It would need to be negotiated and some sort of safety checks in place, but that could be done. Some kind of organisation that matched people or something.

Older people could be introduced to younger people for house sharing – the young person has somewhere to live, perhaps pays lower rent in return for offering some support for the older person. There would need to be vetting procedures.

Many of the participants were aware of 'adult placement schemes', and some contributors felt that this system could be used successfully for some older people identified as having high support needs. One participant said that she found these schemes 'very useful' and a positive alternative to other mental health services. A person with learning difficulties also reported that her experience of an 'adult placement scheme' was good.

One person wrote to us:

Residential alternatives are very limited and the accredited accommodation is generally used as a back-up to care in the community. With care in the community the range is limitless, but many are limited by budget considerations, general availability, and a lack of imagination within the grossly over bureaucratised care planning system.

I would say they are less specific support systems but a movement towards self directed care where most people are given the support, information and resources to plan their own system. This would free up enormous time and wasted resources focused around professionals planning for people who are perfectly able to plan for themselves. The energy and released resources could then be directed to situations where there is significant complexity or disagreement or lack of capacity.

This may not help, but I think of my father-in-law at 93, who uses things like the local swimming pool, weight watchers, and church groups as his support system.

There are simply far too many people tied up in a system that no one understands because of its complexity and the emphasis is on doing things that will not lead to being drawn into a legal conflict.

Cooperatives

Housing cooperatives were discussed and seen by many participants as a possible positive alternative to 'warehousing' solutions. It is worth noting that people used the terms 'housing cooperatives' and 'housing communities' to mean the same things.

People knew of housing cooperatives that were 'naturally occurring retirement communities'. That is to say they knew of cooperatives that had been running for many years and the founding residents were now entering 'old age'. The need for extra support that they might require in the future was now an agenda item for the management committee and people thought this might be an interesting case to follow. A contributor, by email, wrote about the discussions they were having at the co-op:

These conversations about the co-op have tied into a developing interest that I and other co-op members have about what we can do collectively to make our lives as elderly people as comfortable and safe as possible. I should explain, not many people leave this co-op and it seems that the majority of us are all in our fifties now.

Other people said:

The cooperative idea is interesting in that it doesn't necessarily have to involve a building or group of flats/houses; it can be a cooperative community of people living where they already are but being linked by common values and willingness to support each other.

I have heard of an older women's cooperative.

This raised an interesting question:

A co-operative scheme for older women – is that divisive or is it simply focused?

We need to be careful that ghettoising or segregation by interest groups or whatever by our choosing and we don't return to special spaces for certain marginalised groups in society.

Can co-ops pool direct payments?

I know that a group of people got together and pooled their direct payments to hire a regular art therapist. It would be really good to do that, take that principle and share your care with the co-op, with what you decided were services you needed.

An achievement of the disabled people's movement is that people are around and not ghettoised in institutions.

There is an issue of double jeopardy – if you fit into two categories for example, disabled and LGBT then it is common to experience multiple discrimination. So you might want to live in a disabled LGBT cooperative.

People should be able to have support the way they want it – either with people they feel are 'like them', or the wider range of people. There should be that choice.

An important point which needs further exploration was raised by another electronic contributor who wrote:

I should like to see the linked issues of power and powerlessness addressed: in a family-cultural, hetero-normative world, how can elderly lesbian women be given respect and most of all a voice to demand care on our own terms? This is not the same thing as addressing LGBT issues, which are extremely diverse, and tend to focus on gay men. Elderly gay men do not appear to arouse the amused condescension of mental health nurses in the way that elderly lesbian women may do. I speak from recent hospital experience.

The consensus at the end of this short section of the debate was that people need choice. Some people may want to be in communities with other people similar to themselves (and self-defined), others will want to be in a more diverse setting. This person sums up what the discussion group concluded:

There isn't necessarily coherence amongst older people because it is a diverse group. The diversity needs to be embraced. There can be useful discussion without having to seek agreement.

Direct payments and individual budgets

Although direct payments schemes are available for older people to access, the take-up generally is still low.

Direct payment schemes have been developed by the disabled peoples' movement and that experience could be useful in the context of older people.

I think it could be used more widely and older people encouraged to take it up.

Individual budgets could open things up, but there are pitfalls, for instance money being allocated to things like agency staff to supervise medication (when there could be other solutions like the help of neighbours), rather than allocated to things that could allow intellectual independence.

They value ideas of 're-enablement', emphasising physical not intellectual independence.

I am worried that the market won't provide the diverse services that people want. People thought that personal budgets would help develop the market, but in fact the market is very suspicious about personal budgets. There are worries about the security of funding for providers.

My concern about personal budgets is how they are being discussed in the health service. They are being overly prescriptive.

Service users are conscious of the ambiguous implications of personal budgets and self-directed support. Yet we know that where efforts are made to support older people's access to positive self-directed support schemes, as for example, has been happening in a pilot area in Hampshire, Basingstoke, a high proportion of people accessing personal budgets may be older people.

Telecare systems

None of the corresponding participants mentioned telecare systems as an alternative approach to enabling the well-being of older people. However, in the group discussion there was some focus on the pros and cons of these systems:

Telecare and other technological solutions can be used to enable people, or can be used to save costs and isolate people.

It worries me, the whole Big Brother approach. If people are monitored and deemed not to be coping, they may be persuaded to leave their home – 'if you're not doing things right you'll get switched off'. I don't think it is a good alternative.

Some technology could be used to good effect for example mobile phones to keep people in touch with each other.

Although there was some cautious agreement that these systems might have a place, people agreed that:

Bricks never emptied bedpans! You can't do away with people!

People's contact with people, both through formal and informal support was seen as crucial for ensuring positive assistance for older people identified as having high support needs.

4. Conclusion

Different approaches to support, tenure and forms of housing management which have been developed by and for other social groups and service users should be explored in more detail to be trialled in association with older people and their organisations.

Entitlement is key for support to work effectively. This principle is embodied in the government's Right to Control initiative and the Trailblazer scheme now about to start. This development needs to be linked with the exploration of alternatives for older people seen as having high support needs.

Schemes which encourage inter-generational contact and support seem to work well, to be productive and to be valued and should be explored and supported accordingly. One specific idea was that the Foundation should bring together young and older people with support needs, both living in and outside residential care to explore their ideas about alternatives.

The Foundation's idea of ensuring 'that little bit of help' and encouraging 'ordinary' tasks of support are maintained in older people's lives have an important bearing on older people's longer term support needs. Narrowing eligibility criteria have worked against this. Twenty-four hour support services are being lost or cut, but they are crucial to maintaining older people's independence, control and choice.

Some policies and approaches, like independent living and personal budgets, do not seem to be reaching older people as fully as they should. It would be helpful to bring a diverse range of older people together to explore why this is so and how it can be overcome.

The Foundation could support innovation in running one or more residential or nursing homes differently in a more participatory and empowering way. One suggestion was through supporting mutual ownership schemes where everyone has ownership of the home – the workers and management and also the people who use its services. This could transform internal culture, and help to embed real democratic accountability and a renewed sense of community responsibility.

It is crucial to think outside the box when considering possible alternative ways of meeting older people's support and accommodation needs, as service users highlight by raising ideas about overseas holidays and cruises. There should be a preparedness to think radically in this context.

Notes

1. Right to Control is a shake-up of the way disabled people can use the funding they receive from the state and is part of the Government's radical welfare reforms. Trailblazing local authorities are being invited to help shape the way services are delivered to disabled people.
www.odi.gov.uk/right-to-control

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