

foundations

Low intensity support: preventing dependency

Older people and disabled people often don't qualify for full social services assistance. Yet many clearly do need help. Low intensity support can help prevent people reaching crisis point and enable them to sustain their own homes. But it is important to strike the right balance between helping people and controlling their lives. This **Foundations** considers how users perceive their services and needs, and highlights some innovative approaches to support. It assesses what users want, discusses what best practice might be and investigates some of the dilemmas for providers and the implications for policy reform.

The problem

- Care in the community reforms have focused provision on those with the greatest needs
- Targeting can mean people get little or no support until their needs become acute
- Preventive low intensity support is a low priority for cash-strapped local authorities
- The Government has yet to issue national policy directives on preventive support
- Long-standing services such as home help for older people are being run down
- Innovative low intensity services for other groups tend to be one-off pilot schemes
- Providers often define people's 'independence' by their physical/mental capabilities, rather than their ability to exercise choice and control over their own lives

Solutions being pioneered

- Locally based support workers who help people engage in the community, provide budgeting and lifestyle advice and liaise with all the key agencies
- 24 hour telephone support to back up day-time service and contact
- Mutual support networks, serviced by support workers but also promoting contact and skill-sharing amongst people using the service

Lessons for new providers

- A good relationship with workers/volunteers can make it easier for people to accept help
- If support is negotiated, people are more likely to respond to and gain from the service
- It is important that people fully understand the link (if any) between their tenancy and the support service
- Support needs are often assessed at a time of personal crisis. These should be reviewed regularly with users' full participation
- Providers often see housework as unskilled and low priority. But to older women, home helps are experts whose support is as important as personal care
- Older people want help, not care. Being 'looked after' can symbolise loss of independence. Providers should be sensitive in their use of language

Reforms to community care have emphasised independence, choice and dignity. But the focus has been on those with the greatest needs. There has so far been no attempt to issue national strategic directives on preventive services.

Residential care continues to dominate for many people with learning difficulties and low intensity support services - such as help with housework for older people - continue to be downgraded as a priority. Resources remain scarce for investment in pilot projects which could test the cost-effectiveness and viability of low intensity support services.

Research for the Joseph Rowntree Foundation has tracked a number of low intensity support schemes that prevent older or disabled people (including those with mental health problems and learning difficulties) losing control over their lives. Other groups may also benefit from this kind of support, for example, people recovering from drug and alcohol dependency and young people leaving care.

Typically involving occasional but regular contact with staff or volunteers, these services enable people to care for themselves and maintain their homes, reducing the need for costly residential care. Yet social services departments are often reluctant to divert resources to promote quality of life and community integration as an end in itself, without clear evidence of cost-effectiveness.

But those involved in schemes that are up and running - new pilots and existing (sometimes threatened) services alike - are convinced they work. This is the view not just of providers, but of users too.

Support on whose terms?

The users' perspective

It is critical that providers assess low intensity services from the recipients' point of view. Those who benefit most usually cite a good relationship with their support workers. This will often be based on a sympathetic approach to users' own priorities. For example, older people may particularly value help with cleaning their homes, disabled people may want a regular visit to the pub and so on. Social activities are particularly valued. A successful scheme will promote social inclusion by helping people integrate with the wider community.

In-depth research into users' views also often identifies shortcomings in how people are supported within mainstream housing. A recent study of 'floating support' services in Scotland found widespread satisfaction, but a lack of clarity about funding and entitlements. For example, many tenants were unaware that they were paying for support through rent or service charges.

Helpers or friends? Befriending schemes

There is a continuing debate amongst providers of support services over how appropriate it is for the professionals involved to form friendships with their clients. Yet people almost always prefer this. Befriending recognises this. It is one of the lowest intensity support services available, a low-cost complementary service rather than a substitute for home care or other support.

Befrienders are volunteers. Recent research suggests that people value the fact that others choose to spend time with them, rather than being under professional or family obligation to do so. Matching is the key to success. It is ideally based on shared interests, living near one another and similar personalities and age. But selecting users can compound social exclusion if those thought 'difficult' are rejected. Once matched with a user, the befriender typically meets them once a week, although the nature and frequency of contact will vary according to the scheme and the priorities of those involved: *"I really enjoy having somebody who will take me out to the pub for a pint, especially on Sundays."*

Befriending relationships typically last over a year, which implies some success, and they are valued by those receiving the service. Volunteers also report benefits: improved job prospects, new leisure opportunities and wider social networks. A number of users would like to become volunteers in the future. Befriending organisations encourage this to promote their inclusion in community life.

The study found that those voluntary organisations that offer befriending usually provide other services too (for example, advice and advocacy, personal care, campaigning and 'good neighbour' services). Over 60 per cent of schemes receive some local authority funding, with 30 per cent of schemes provided on a borough-wide basis. However, 60 per cent of schemes report problems recruiting volunteers, 20 per cent problems attracting users.

There was also a perceived link between the tenancy and ongoing support, especially among younger people: *"I had to agree to get help so I could get my house and I did want help but I'm not sure what would happen if I didn't need help any more."*

Many of the participants in the Scottish study had had their support needs assessed at a time of personal crisis. In retrospect, they felt they had not been able to participate fully in planning their future support needs. Most were not aware of their formal care plans. This illustrates the importance of regularly involving people in their own support and checking their knowledge of what has been agreed.

The way the wider community is introduced to people's needs is also crucial to users. At its worst, neighbours have been 'warned' when users move in. This is considered a harmful breach of confidentiality.

Other key findings included:

- Although information may be available to users, it is not always understood
- An out-of-hours service is needed, even if just telephone-based
- People may know how to make a complaint, but not all have the confidence to do so
- Some support workers may not have sufficient awareness of mental illness to support people newly discharged from psychiatric hospital
- Users want the service to help the wider community understand their needs
- There is little evidence that people have a choice over the support they receive

Older people's priorities

Some people using low intensity support services will have come from institutional care into the community, others will have moved from parental homes to other protective environments. Many older people though, will already be established within mainstream housing. Everyday help - with housework, gardening, laundry, home maintenance and repairs - can help them stay there.

Older people do not equate their needs for help with loss of independence. Tasks which they can no longer manage alone are usually willingly given up - but only

if the service does not try to carry out tasks they can still do for themselves. People set their own parameters: for some it is doing their own shopping, for others cooking or housework.

"I think the time to go into a home is when you can't cook for yourself."

They are also sensitive to being 'taken advantage of'. Having unknown men doing maintenance and repair work can lead to fears for safety. The services provided by Care and Repair organisations are highly valued because people feel they can trust the workers involved.

Key lessons

- Professionals often see housework as unskilled and low priority. But older women feel home helps are highly skilled. To them, housework is as important as personal care

Housework is real work

Research shows that the home's appearance is particularly important to older women. Keeping the house up is akin to keeping themselves up. Help with housework can sustain this self-respect as well as practically preventing/delaying the need for residential care. So older people see the withdrawal of this help as social services failing to understand what is important to them:

"There's lots of things they [social services] don't understand. They don't think housework is necessary. You're just supposed to sit here and look at it."

Undone housework can be a constant reminder of what older people can no longer do. This can have a negative impact on their mental health and motivation to manage:

"You go down if you let the house go down, don't you?"

Although older men may be less concerned than women about the appearance of their homes, some will take on more housework tasks to help their wives maintain the home's appearance as the couple get older. When widowed, the grief experienced by women can be exacerbated by the loss of this help.

- Having to rely on their family can undermine older people's sense of independence. Asking for help can feel like an admission they can't cope. Access to alternative forms of assistance overcomes this
- Those with higher levels of need who meet eligibility criteria often only get minimal help with housework. This is because the 'personal care' element of their care package uses up the resources allocated to them

Group support networks

For many people, independence can in practice also mean isolation. One way to tackle this is to offer support services to groups rather than just to individuals. Mutual support networks have been pioneered in a number of low intensity support services, with some success, notably KeyRing and Home-Link (see boxes).

Networks of tenants in general needs housing are supported by a community worker and also by the mutual support of the group members. Access is typically agreed three ways by social services, housing and the agency itself. Staff are appointed to help people settle into the network, and to provide continuing support. They provide one-to-one support to their clients, helping tenants budget and deal with

the official world. But they also ensure that the members of the network meet each other regularly.

This is not meant to be a substitute for professional assistance, but to increase the resilience of the networks and ensure they are as cohesive as possible. Success, however, requires a balance between tenants willing to take a lead and those who may be more passive. Although generally not a problem, too many of the latter can undermine a network's effectiveness.

Tenants in mutual support networks are often anxious that professionals should not interfere too much. Support can be offered and negotiated, but not imposed. As a result, the service is more likely to be approved of by those who use it.

Key lessons

- The sort of support provided by KeyRing costs around £50 a week per user. A network is self-financing if only three out of nine tenants in each network would be in residential care if the service were unavailable
- Purchasers need to think carefully about the kinds of neighbourhoods in which schemes are located, and how people are supported to manage their relationships with members of the local community

The KeyRing approach

The KeyRing agency is one of the pioneers of mutual support. It currently has 15 'living support' networks, most in Greater London. Services are primarily targeted at people with learning difficulties who have basic self-care skills, but still need continuing or intermittent support. Everyone in the network (usually nine people) knows where everyone else lives and has their phone number.

Networks are co-ordinated by community living workers, who spend 10 to 12 hours a week with members and live in the same area. In return, they get free accommodation and help with some household bills. Although most work part-time in other jobs, they are far more accessible than in many equivalent services. Telephone support is available during the evenings and at weekends.

KeyRing also helps tenants manage their relationship with a much bigger network - the local community. For the model to work, KeyRing needs to find neighbourhoods where there is sufficient turnover of social housing for a network to become established within a reasonable timescale. This sometimes means supporting people in environments that are not always ideal. KeyRing carefully audits communities where a new network is being considered, helps tenants to develop defensive strategies, and supports those who wish to take action if they have experienced any harassment.

The Home-Link model

Help for people with mental health problems in general needs housing

Home-Link is an inter-agency service based in the East Riding. It provides permanent housing and low-level, practical support to people with enduring mental health problems - including mutual support networks.

The **housing department** allocates secure tenancies to people, usually near each other. Many properties are connected to a highly valued, 24-hour 'lifeline' service. People contact their workers freely between visits for advice or reassurance.

Home-Link workers spend around 5 or 6 hours with each user a month, providing help with budgeting, bills and other household matters. They are deliberately not qualified as mental health professionals, to avoid a medical emphasis. Home-Link has also learnt from KeyRing and introduced mutual support networks.

Benefits to users

Over half of those interviewed had felt an improvement in their mental health since joining the scheme. Many thought the support had helped reduce their anxiety and strengthened their ability to be independent.

"If I'd have had to set up on my own, I might not have managed it. I might not have made the move."

Benefits to agencies

Health and social services staff feel that Home-Link helps free up professional time to concentrate on people with more severe needs. Housing staff feel there have been management benefits: no complaints have been received about any of the Home-Link users or their neighbours, and no rent arrears have built up. Inter-departmental

communication and understanding has also been improved. These benefits have led to the service being expanded throughout the East Riding of Yorkshire.

Clear aims and objectives are seen to have contributed to the success of the scheme:

Aims

Home-Link aims to provide people with enduring mental health problems with the opportunity to live in permanent, good quality housing with support. Home-Link aims to provide a service which will:

- Integrate people into the community
- Promote independent living and reduce isolation
- Increase options in the range of supported accommodation
- Prevent a deterioration of people's mental health condition, thereby hopefully reducing the need for admission to hospital
- Deliver flexible support to people in permanent, good quality accommodation

Objectives

- To develop good working partnerships between health, housing, social services and voluntary agencies, using existing organisational networks, in order to deliver integrated housing and support services
- To allocate or help secure good quality ordinary housing for people with mental health problems which offers security of tenure
- To provide continuous support to Home-Link members, as appropriate
- To provide advice and assistance to facilitate access to and take up of other resources and services
- To foster the development of social links and contact with outside organisations via a Home-Link network

What works best

Providers seeking to learn from pilot schemes' best practice should consider:

- Drawing up key principles behind and aims and objectives for their scheme
- Benchmarking schemes against those already operating, for example, KeyRing and Home-Link
- Carrying out initial and ongoing cost-benefit analysis of preventive services against the costs of curative care
- Designing services around the needs of users rather than professionals
- Ensuring a 'whole system' approach influencing work practices of all relevant agencies
- Adopting appropriate terms and language, for example, 'help' not 'care'
- Helping people to manage their relationships with members of the local community
- Supporting people to minimise the risks of abuse or intimidation and helping people deal with any difficulties that do arise

- Monitoring services to ensure people can exercise true choice over the support they receive

The experience from the pilot schemes also shows up a number of dilemmas that providers need to overcome (see box).

Dilemmas for providers

- Should support workers be qualified 'professionals' or does this undermine their relationship with those whom they support?
- Should relationships between people and their support workers be kept at a distance or allowed to flourish as they prefer?
- Users value staff voluntarily taking part in social activities, but these are rarely funded. Should they be?
- Support arrangements are often set up when people are at their most vulnerable. How can mistakes be avoided in the assessment process?
- Should support be a condition of a tenancy - and vice versa?
- If not conditional, should tenants be better informed of their rights to refuse support without losing their homes?

Policy reform

The fundamental lesson for policy-makers - at a national or local level - is a common-sense one. Prevention is better than cure. It is cheaper and more effective to provide low intensity support services than to allow situations to deteriorate until people need high intensity/residential care. If they follow agendas that people set for themselves, low intensity support services improve the quality of people's lives; increase the degree of their social inclusion; and promote choice and control over how their needs are defined and met.

Low intensity support helps shift the focus of community care from crisis management to crisis prevention. Even where crises occur, it helps to prevent them from taking a long-term hold on people's lives. Means-testing and rationing of services may make short-term sense to agencies with tight budgets. But it will often prove a false economy. Carefully planned, low intensity support services can even free up resources and time to help those with greater needs.

How to get further information

The following reports, published in the association with the Foundation, give further details about the schemes mentioned. All of these titles are available from York Publishing Services Ltd

Users' views

Living independently with support: service users' perspectives on 'floating' support, Anne Douglas, Charlotte MacDonald and Mary Taylor, The Policy Press in association with *Community Care* magazine (ISBN 1 86134 093 1, price £13.95). 'Service users' perspectives on 'floating' support', *Findings* F498, April 1998.

Befriending

Supporting community participation? The role and impact of befriending, Jo Dean and Robina Goodlad, Pavilion Publishing (ISBN 1 900600 85 4, price £12.95). 'The role and impact of befriending', *Findings* F038, October 1998.

Older people

'That bit of help': The high value of low level preventative services for older people, Heather Clark, Sue Dyer and Jo Horwood, The Policy Press in association with *Community Care* magazine (ISBN 1 86134 118 0, price £13.95). 'The importance of 'low level' preventive services to older people', *Findings* F768, July 1998.

Home-Link

A life in the community: Home-link: Supporting people with mental health problems in ordinary housing, Deborah Quilgars, The Policy Press in association with *Community Care* magazine (ISBN 1 86134 117 2, price £13.95). 'Supporting people with mental health problems in ordinary housing', *Findings* F948, September 1998.

KeyRing

Living support networks: The services provided by KeyRing, Ken Simons, Pavilion Publishing (ISBN 1 900600 22 6, price £11.95). 'Low support options for people with learning difficulties', *Findings* F528, May 1998.