

The early years of supported living in the UK

The last five years have seen an increasing interest in the idea of supported living; enabling people with learning difficulties to live in their own homes as an alternative to shared residential care. Ken Simons and Linda Ward set out to review the way that supported living has developed in the UK over this period. The main findings from this review are:

- f** Some individuals, including those with the most complex needs, have been successfully supported in their own homes, using detailed 'personal futures' planning and focused personal assistance.
- f** Supported living has opened up access to a much wider range of housing options for some people with learning difficulties, including 'general needs' social housing and even home-ownership. Strategically, supported living represents a way around the current 'special needs' housing bottleneck.
- f** Although it is too early to make an overall judgement about the relative cost of supported living there is evidence that this is not unmanageable; for some individuals the cost of their housing and support arrangements has actually been lower than the residential care they were previously using.
- f** The separation of housing and support featured in supported living makes additional sources of funding available. This both eases the pressures on purchasers' budgets and ensures that most individuals with learning difficulties will have a higher disposable income than would be the case in residential care.
- f** Supported living does not involve one simple 'blueprint' for services: this has led to significant misunderstandings about the concept amongst both critics and some supporters.
- f** Some of the opposition to supported living is based on the concern about the lack of protection through registration and inspection. This is despite the fact that many supported living arrangements have additional checks and balances built in that are missing in registered settings.
- f** Some people have effectively been denied the right to live in their own homes because of controversial interpretations of the requirement to register.
- f** Because of continuing 'perverse incentives' the number of people who have been able to access supported living is still relatively small.

Background

For the last decade and a half the debate about 'residential' services for people with learning difficulties has primarily been in terms of the shift from long-stay hospital to 'community settings' in general and 'ordinary housing' in particular.

However, while the properties used may have been relatively 'ordinary', what happens inside them is often not; many small staffed homes have retained institutional characteristics. Most occupants will not have had a chance to choose with whom they live. They will be licensees, not tenants; with correspondingly little security of tenure. Because of the link between registration and the benefit system, people there will have minimal disposable incomes, often severely limiting their capacity to make use of local community facilities. In organisational terms, the housing which they occupy and the support they receive there are inextricably bound up together; it is impossible to change one without changing the other, making it difficult to adapt the services to the individuals involved.

The development of supported living

Reflecting an increasing frustration with the inherent limitations of residential care, the last five years have seen increasing interest within the UK in the idea of 'supported living'; enabling people with learning difficulties to live in their *own* homes, providing flexible, individualised support to people wherever that might be.

Following a Harkness Fellowship visit to the US by Peter Kinsella, the National Development Team established a programme to promote the idea of supported living, providing for the first time a much more coherent framework for developing these ideas.

Kinsella set out five basic principles for supported living services. These included:

- *separating out housing and support*
Instead of having to take on packages of residential care, more flexible combinations of housing and support can be developed.
- *focusing on one person at a time*
By moving away from the model of the group home, and using detailed 'personal futures' planning to provide services that are genuinely individualised.
- *zero rejection*
Nobody should be seen as 'too disabled' to live in their own home.

- *providing people with much more control over their homes and their lives*
People's homes are centred on their own concerns, not those of the organisations providing services.
- *a focus on relationships*
People's links (their family, their friends, their community) are the starting point in designing services, not an afterthought. Through the use of 'support tenants' (who share the home with the disabled person and can provide or seek assistance as necessary) and circles of support, people's relationships are kept right at the forefront.

Gary Hignell was assisted to take over his father's housing association tenancy, enabling him to remain in the community in which he has spent his entire adult life. Gary now shares his home with a non-disabled 'support tenant', has support from the local social services department, and is helped to use money from the Independent Living Fund (ILF) to employ his own personal assistants.

After difficult experiences in residential care Anna Andrews was enabled to buy a share in her own home. Like Gary, Anna lives with a support tenant and uses ILF funding to employ her own supporters.

In the past the only options for Gary and Anna would have been restricted to some form of shared residential care. Now they experience a very good quality of life, using services focused closely around their own specific needs and wishes. This is despite the fact that both Gary and Anna need considerable amounts of assistance. Indeed in Liverpool, supported living is increasingly being used as an alternative to medium secure provision for people who are seen as very challenging to services.

The significance of separating out housing and support

Although all the principles are crucial in defining the character of supported living, the idea of separating out housing and support plays a central role.

The separation of housing and support is a key factor in avoiding the requirement to register a home. This has a number of significant repercussions, including:

- increasing individuals' incomes
- opening up different sources of funding
- promoting security of tenure

Housing options

Most of the more traditional residential options for people with learning difficulties rely on 'special needs' funding mechanisms to generate housing for people with learning difficulties. However, the demand for places far exceeds supply. The flexibility of supported living has enabled agencies to open up a much wider range of options than the traditional specialist housing providers, including:

- the private rented sector
- 'general needs' social housing
- home-ownership options (including access to the Housing Corporation's shared ownership programme)

Strategically, supported living represents a way around the current 'special needs' housing bottleneck.

Costs of supported living

There have inevitably been concerns that such 'micro' services will be more expensive than traditional approaches. While it is too early to make any clear judgement about the overall impact of supported living in the UK, the experience from the US is that it has been possible to manage supported living within the same overall budget as residential care. Certainly there is evidence in this country that for some individuals supported living can be as cheap as or cheaper than the residential care they were previously using.

The flexibility of supported living arrangements can allow a more focused and efficient use of resources than residential care. On the other hand, the detailed planning that is a key part of supported living inevitably requires more intensive care management than would currently be the norm for people using residential care.

Misunderstandings

Supported living does not involve some simple blueprint for new services. Rather, it requires the application of a radically different way of thinking about housing and support. This complexity has inevitably led to some confusion both amongst critics and supporters of the idea. For example, supported living has erroneously and variously been described as:

- only about people with learning difficulties living on their own
- completely informal ('We don't have any procedures here.')

- relying entirely on 'commitment' without the need for skilled or experienced personal assistance

Because supported living is seen as 'progressive' some organisations have been keen to use the term for services that do not meet the criteria outlined earlier.

At the same time there has also been some active opposition to the development of supported living, including for example:

- a housing department refusing to pay housing benefit to people with high support needs on the grounds they 'ought' to be in residential care
- a social services department that announced that people whose financial concerns were being managed by the Court of Protection would not be able to hold a tenancy

These arguments are often based on entirely inappropriate 'blanket' assumptions about the capacity of people with learning difficulties. Implicitly, they represent an attempt to limit the rights of one group of people to live in their own home.

There has also been a more general concern that the 'avoidance' of registration is dangerous; that registration and inspection represent a crucial protection mechanism for vulnerable people. However, far from offering substantial protection, registration can *undermine* the security of individuals.

People who live in registered settings often:

- have less security of tenure
- are isolated (living in 'enclosed worlds')
- are poor
- have standards imposed on them that are inappropriate in people's own homes

In addition, there is no *duty* for local authorities to inspect small homes, and many lack the resources to do this; registration can be just a paper exercise. Similarly, the ultimate sanction of de-registration can be so traumatic that it is only ever used in extreme situations.

This is not to imply that supported living should be unregulated, or that people in supported living situations would not be abused. Indeed many involved in setting up supported living arrangements had established a range of structural mechanisms for ensuring that people have some protection.

These include:

- 'voluntary' registration and contract compliance to higher (and more appropriate) standards than required through registration
- ensuring people are not isolated or under the control of one organisation
- the checks and balances inherent in having a separate landlord and support provider
- greater security of tenure
- more control for the person with learning difficulties

In particular, the separation between housing and support makes it possible to change one without having to change the other. This in turn could make it much easier to change services that are not working as they should.

Strategic development

As yet, the numbers of people using genuine supported living arrangements are small. Despite a widely accepted policy goal of enabling people to live in their own homes, the system generally does not make the development of supported living-style arrangements easy.

There are further risks in the offing, including:

- further proposed changes to the housing benefit regulations
- the current discussion of regulatory reforms (for example, the Burgner Report) which has assumed a neat divide between residential care and 'domiciliary' services; in reality supported living currently occupies an uneasy position midway between the two

The new Government's plans to extend registration to all community care services may carry the risk of closing off the possibility of supported living arrangements.

In the meantime, some purchasers are trying to encourage the development of supported living through:

- bringing stakeholders together, in particular including both people with learning difficulties and the strategic housing authorities
- investing in more intensive specialised care management or service brokerage
- encouraging cross-agency learning

About this study

During 1996 Ken Simons and Linda Ward carried out a series of brief visits to supported living services, and carried out extensive interviews and discussions with people in the field. A full report, entitled *A Foot in the Door*, is available from The National Development Team, St Peter's Court, 8 Trumpet St., Manchester M1 5LW. Tel: 0161 228 7055 (price £12.50 plus £1.25 p & p, please send cheque with order).

Later this year a *Plain Facts* on supported living (a summary specifically for people with learning difficulties) will be produced. For further details about this, or about the research, please contact: Ken Simons, Norah Fry Research Centre, 3 Priory Rd, Bristol, BS8 1TX, Tel: 0117 923 8137.

Related Findings

The following Findings look at related issues:

Social Care

- 66 Housing and support for people with learning difficulties (Apr 95)
- 81 Housing, support and the rights of people with learning difficulties (Mar 96)

Housing

- 148 The relationship between community care and housing benefit (Jun 95)
- 168 Housing choice and community care (Feb 96)
- 206 Housing benefit and supported housing (Mar 97)

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