

Housing and support for people with learning difficulties

Most people with learning difficulties have little choice about where they live; regardless of its appropriateness, residential care remains the dominant option. Using informal networking, Ken Simons set out to find and describe innovative examples of housing and support for people with learning difficulties. The result is a source book which explores a wide range of alternative approaches, focusing in particular on situations where people were able to live in their own homes.

f Although the Government's community care reforms were intended to do away with the 'perverse incentives' in favour of residential care, there are still major structural factors which make it difficult to support people in their own homes. Many of the examples of good practice described existed despite the system, not because of it.

f Focusing on one person at a time was a key theme in several examples. Gearing a support system to a specific individual meant that 'independent living' was an option even for those with the greatest needs.

f The chance to buy a home was just one of a range of options in existence, which are rarely thought of for people with learning difficulties.

f Autonomy and control for people with learning difficulties were a marked feature of a number of services.

f Initiatives set up by people with learning difficulties have become increasingly common.

f Building links with people in the local community was a key theme.

f So far most of these options have only been available on a small scale. There was no simple blueprint. Services which respond to individual needs will, by definition, be 'different'.

Introduction

The examples of innovative practice described here were selected on the basis that they meet either some or all of the following criteria. The people with learning difficulties:

- were living in their own homes
- were using support systems which focused on them as individuals
- had as much control over their lives as possible
- were linked in to their local communities.

Focusing on individuals

The idea of ensuring that services reflect 'individual needs' has been a key feature of services for people with learning difficulties over the last decade or more. However, when the support systems are organised around buildings, the opportunities for really focusing on individuals are limited.

The three examples described here represent a very different approach. In each case the housing and support (and indeed the budgets) had been linked to one particular adult with learning difficulties. All required high levels of support and all risked ending up in large, institutional settings had these very individualised packages of services not been developed.

- With the assistance of friends and supporters, Gary Hignell was enabled to take over his father's housing association tenancy. By using money from the Independent Living Fund, along with support from social services, it was possible for Gary to employ his own supporters.
- For many years John Bukowski has had the reputation of being someone with very challenging behaviour. His family were convinced that John would end up in a special hospital. However, with the aid of the Kidderminster Intensive Support Team, John now lives in his own house rented from a local lettings agency. Staff are trained especially to work with John. Although the support system is expensive, it costs less than the hospital-based alternative.
- An initial attempt to place Marilyn Gordon in a group home did not work. As someone with autism she appeared to find the pressure of living with other people with learning difficulties to be too great. Using an ordinary rented house, paid support tenants who live with Marilyn, and carefully structured staff arrangements, Southwark consortium and the Blue River Agency have been able to create a much more consistent environment which suits Marilyn.

Focusing on choice

The examples outlined in this section all offered a range of choices which are rarely thought of in relation to people with learning difficulties. In particular there were no less than three different contexts where people had been helped to buy their own home.

- Kirsten and Ronald Smith both work in a nursery run by SHAW in Northumberland. Because of SHAW's commitment to pay real wages, Kirsten and Ronald were able to get a mortgage to buy their home.
- After getting married Reg and Amelia Bernards found their hostel really did not offer them the privacy they wanted as a couple. With the support of the Chichester, Bognor and District Community Team for People with Learning Disability, they were able to get a mortgage using income support to cover the interest payments.
- The same Community Team also helped Charlotte Newman buy her own flat. After the death of her parents Charlotte had been placed in an old people's home, which she hated. However, Charlotte had a legacy held in Trust for her, and she and members of the team managed to persuade the Trustees to buy her a flat. Quite a few people with learning difficulties are left money but few are helped to use that capital to their best advantage.
- After the sudden death of Mrs Thomason, The Hadfield and Glossop Community Living Project (the Hadfield Rd Project for short) were able to provide intensive emergency support in the family home, enabling Martin Thomason to carry on living at home, and Mr Thomason to carry on working.
- As people with learning difficulties age, or develop ill health, they are often forced to abandon independent living. By responding very flexibly, staff from the Hadfield Rd Project have enabled Marion Flint to take advantage of Independent Living Fund money to stay in her own home.

Emphasising autonomy

All the examples described in this section emphasised providing maximum autonomy to people with learning difficulties.

- The Edinburgh Action Group is a membership-based voluntary organisation that provides a range of services to people with learning difficulties. Staff working with the Action Group always try and start by finding out what kind of help those they support want. Pat Smyth, Jeanette Stanners, Eric Sinclair and Ian Elliot all appreciate the degree of autonomy offered by this approach: "I decide ... I want to live my life my way."

- The Southwark Consortium has developed a number of mechanisms to try and ensure that people have as much control over the services they use. These include the provision of service brokers to help people influence the design of support packages, a local services charter, and an increasing shift to individualised contracts with local service providers. They are also experimenting with direct payment - giving people with learning difficulties the money to buy the service they want directly.
- SWALLOW is a small, independent organisation based in South Wansdyke. People with learning difficulties play a very active role in the organisation, making up 50 per cent of the Management Committee, and two people with learning difficulties - John Gotsell and Debbie Liddell - are employed as part of the staff team. SWALLOW has also managed to attract the support of many local families, showing that user participation need not be at the expense of involving carers.
- Something like 500 million people world-wide live in some form of housing co-operative, yet this is a form of housing that is not often considered in the UK. However, the Plymouth Independent Living Co-operative is now a well-established group which offers disabled people (including people with learning difficulties) an almost unique say in their own affairs. Ultimately, as directors of a limited company, they each have a potential veto over all decisions. There has been more interest in the idea in Eastern Europe, and Wayne Bassett, one of the Plymouth tenants with learning difficulties, spent five months in Bucharest helping to set up a co-operative in the Romanian capital.
- A lack of information often makes it difficult for people with learning difficulties to make informed choices. Biza Kroese, the Head of Clinical Psychology Division for Learning Difficulties for Priority Health (an NHS provider unit in the West Midlands), felt that many of the people she works with were having to make decisions about residential care homes without knowing what was on offer. She has tackled this problem by producing an accessible guide to all the local homes.
- As a young gay man who needs some accessible housing, Neville Bellows has no interest in going into a group home. He has been acting as his own 'care manager' trying to put together a housing and support package that will enable him to live independently in the way that he wants to.
- Members of Avon People First are beginning to build links with the Avon Coalition Of Disabled People. As a result, a number of people with learning difficulties have been involved in setting up a Centre For Integrated Living in Avon. Doris Clarke and Kate Eldon are keen to see the idea of personal assistants become an option for people with learning difficulties in the area.
- Powerhouse, a group of women with and without learning difficulties, are well on their way to establishing the first refuge for people with learning difficulties who have either experienced or are at risk of abuse.
- Many members of Advocacy in Action have had poor experiences of housing services in the past, including racial discrimination and incarceration in large institutions. They draw heavily on these experiences in their current work, which includes training for both professionals and other people with learning difficulties, and evaluations of the housing and support provided by various organisations.

Making links

Integration and inclusion are key themes in the idea of 'community care', yet many traditional approaches to housing have failed to help people with learning difficulties either develop or preserve links with their local communities. This last set of examples all involve situations where a key objective has been to build such links.

- Keyring, a small independent provider, organises small distributed networks of people with learning difficulties, who are supported by someone living 'round the corner' as part of the local community. Rather than setting up something separate and distinct, the aim is to provide a support system which merges into the neighbourhood.
- 'Life-sharing' is based on the idea of enabling people with learning difficulties to live with non-disabled people on an equal basis; not just sharing a house but also leisure and social activities. In return for a fee or subsidised accommodation, the life-sharer is expected to make a long-term commitment to the person with learning difficulties. Many life-share arrangements have additional support from professionals. The experience in Clwyd, where a

Doing it yourself

Housing and support is just one of the many areas where people with learning difficulties are starting to take the initiative themselves.

- Brian Stoker of London Boroughs People First has been working with a local self-advocacy group in order to order to encourage people to: "*Stick up for your rights.*"

number of life-share situations have been established over the years, is that life-sharing is difficult to do well, but - where it does work - can offer a very positive way of organising support.

- Ensuring that people have strong links with people who care about them is one way of protecting people. Janet is an elderly woman who lives an unstaffed house. As her health has declined staff who knew her worried that she was vulnerable to being moved from the house she loves into a nursing home. They managed to persuade a local group to find Janet a citizen advocate to help her views be heard.
- The National Federation of Supported Living Groups is an umbrella organisation based in the North West which aims to promote the development of local 'not-for-profit' groups which will provide high quality services for people with learning difficulties. The local groups are made up of a partnership between carers, users, professionals, and local supporters. The groups are small (no more than 25-30 people); the aim is to ensure that people with learning difficulties are able to remain within their own community. The Federation provides assistance to people (in particular families) who want to form a local group.

Conclusion

There are still many barriers to developing alternatives to residential care for people with learning difficulties. Nevertheless, the examples included show that:

- There are all kinds of options that, given the right conditions, are both feasible and affordable.
- So far most of these options have only been available on a small scale. For many people with learning difficulties the kinds of choices described in this book are not on offer.
- There is no simple blueprint, no standard answer. Services which reflect individuals will be, by definition, be 'different'.
- Relationships matter. Many of the examples described revolve around the kinds of connections that the people with learning difficulties have. The support systems described are labour-intensive rather than capital-intensive.

About the study

Informal contacts with a variety of networks were used to try and trace examples of innovative work. Recommendations were followed up with a brief visit, during which Ken Simons talked to the professionals, the people with learning difficulties, and the families directly involved in each example. No formal evaluation was undertaken; the object was to explore the ideas underlying each approach and to look briefly at how they worked in practice.

Further information

More details are available in the form of a report, *My home, my life: innovative ideas in housing and support for people with learning difficulties*. This is published by Values Into Action, costs £8.95 including post and package, and is available from: VIA, Oxford House, Derbyshire Street, London E2 6HG. Tel: 0171 729 5436

Related Findings

The following *Findings* look at related issues:

Social Care

- 40 Continuing institutional care for people with learning difficulties (Oct 93)
- 41 Community living for people with learning difficulties (Oct 93)
- 42 Citizen advocacy and people with learning difficulties (Nov 93)
- 43 Community care plans and supported housing (Dec 93)
- 57 Living in the community after leaving long-stay hospital (Oct 94)
- 64 Moving from hospital into the community: an evaluation by people with learning difficulties (Mar 95)

Housing

- 57 Provision of supported housing by housing associations (Mar 92)
- 58 Housing and community care (Mar 92)
- 99 Shared living in supported housing (Nov 93)a

For further information on these and other *Findings*, contact Sally Corrie on 01904 654328 (direct line for publications queries only; an answerphone only).



Published by the
Joseph Rowntree Foundation
The Homestead, 40 Water End
York YO3 6LP
Tel: 01904 629241 Fax: 01904 620072
ISSN 0958-3815

The Joseph Rowntree Foundation is an independent, non-political body which funds programmes of research and innovative development in the fields of housing, social care and social policy. It supports projects of potential value to policy-makers, decision-takers and practitioners. It publishes the findings rapidly and widely so that they can inform current debate and practice.