The View From Arthurs Seat: A Literature Review of Housing and Support Options 'Beyond Scotland'

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A NOTE ON TERMINOLOGY

Language and labelling are sensitive issues. In this report we have chosen to use the term learning disability. This is largely because this is the term adopted by the Scottish Executive, and has wide currency within the UK. However, in consulting colleagues from other countries we usually used intellectual disability (the terminology adopted by the World Health Organisation). Inevitably in the text we will have sometimes used terms that reflect practice in specific countries. For example, People from the US will often refer to services for people with ‘developmental disabilities’; although it is worth noting that this can sometimes refer to a slightly wider group (for example, it may include people with acquired head injury or with cerebral palsy). Although it may sound uncomfortable to UK ears the term mental retardation is still widely used in the US, and may crop up in quotes.

We are aware that some people with the learning disability label would wish to abandon the use of such terminology altogether (‘label jars not people’) or would prefer the use of the term learning difficulties (indeed this is a term we have often used in previous publications). We acknowledge the concerns about labelling and indeed the inherent definition problems in the whole concept. However, it is difficult to imagine not having some collective term to describe a group of people who seem particularly at risk from all kinds of social exclusion. We specifically chose not to use learning difficulties because of the international nature of the study and of the potential for confusion; in the US learning difficulties would primarily be used in relation to be people who have dyslexia or related conditions (for example an internet search using this term is likely to generate far more US hits for sites relating to dyslexia than those for learning disability oriented resources).
SUMMARY

CONTEXT

The recent history of services for people with learning disabilities is one of considerable change and upheaval. In the UK, policy has been rather confused, dominated by the pragmatic concerns of hospital closure and deinstitutionalisation (a process which has been the defining feature of policy in many countries) with a degree of confusion about what the alternative services might look like. As a result, services in both the UK and US are marked by a number of common features:

* an overall shortfall in services
* provision still dominated by settings that are larger than ‘ordinary homes’
* marked variation in access to services

These general features of services provide an important backdrop to the development of new strategies for further reform. Some effort will have to be made to rectify the inequalities and access and the overall lack of resources as part of any modernisation programme. Certainly, resources will have to be used as efficiently as possible. While a focus on civil rights and discrimination may well help to move things forwards, attention will have to be paid to the wider policy context if developments in learning disability services are not to be blown off course.

EVIDENCE RELATING TO GROUP HOMES/SMALL STAFFED HOMES

On the basis of the evidence (let alone any argument based on principle) it seems safe to conclude that there is no basis for a reversal of the current trends towards small staffed houses and for a return to the use of larger settings. Indeed, there is some evidence that very small is better than small: amongst other things it appears to be associated with greater choice and autonomy. However, while being small might be a necessary condition for better services, it is not a sufficient one; the overall quality of these services is very variable.

The debate about determinants of quality has led to an increased emphasis on the way paid supports are deployed, coupled with increased operational sophistication. This has led to the development of the ‘active support’ model (a framework for training and managing staff). There is emerging evidence that the active support approach can make a positive contribution.

THE DEVELOPMENT OF SUPPORTED LIVING

The last decade has seen the development of a distinctive critique of services, reflecting frustration at the failure of many services to live up to the notion of an ‘ordinary life’, along with increased expectations of what an ordinary life might involve. The assumption that life in a group home could necessarily be ‘ordinary’ was coming under fire. As a result there has been increasing interest in the structural reform of services (as opposed to a strategy based on a refinement of existing approaches).

The result has been the emergence of what is now widely known as supported living. This represents an attempt to rethink service based principles of citizenship and inclusion. In practice this has meant developing a range of approaches to supporting people in their own homes (as opposed to shared living arrangements in a home owned or managed by an agency). Supported living arrangements are typically based on a combination of:
To date, there have been relatively few formal evaluations of supported living arrangements. However, on the basis of the information available, supported living can claim to be a practical as well as a principled option, one that has a legitimate claim to be a key part in any commissioning strategy.

At the same time the development of supported living represents a challenging agenda for services. It is not a panacea; although the flexibility of supported living arrangements offers opportunities for focusing on relationships and community, it is also clear that enabling people with learning disabilities to develop or extend their social networks continues to be an unrealised goal for many services. Indeed, such a task clearly cannot be solely the concern of housing and support services; the co-ordinated use of other resources (for example, supported employment) will be required.

Finally, reform and refinement need not be alternative strategies. There would appear to be a case for synthesising supported living approaches with developments like active support.

**OTHER OPTIONS**

A truly comprehensive housing and support strategy would need to incorporate a range of options beyond the small home/staffed house. As well as the kind of flexible supported living arrangements outlined in chapter 4 there would appear to be a place for:

* low intensity support options
* adult placement schemes
* an effective range of family support services, based on a more sophisticated understanding of the needs and the experiences of carers.

Any judgements about village communities should perhaps await the findings from a forthcoming study on the subject, although it is difficult to see how it would be possible to re-create them using former long-stay institutional sites. Nevertheless, there does seem to be a case for further thought on how some form of intentional communities could be accommodated by commissioning and regulatory structures. Some rethinking of the regulatory framework for adult placement services is also required. There would also appear to be a case for further exploration of the range of family support services available in the US and Canada.

**REGULATION AND PROTECTION**

Staying safe is an important issue for people with learning disabilities. Yet the existing systems for regulating services and providing protection have a number of significant disadvantages. In particular, they:

* are partial, inconsistent and arbitrary
* fail to regulate for diversity
* stifle innovation
* promote dependency and isolation
have unfortunate side-effects.

However, there is scope for developing a reformed system which:
* pays more attention to rights
* recognises diversity
* regulates in partnership
* involves a whole system approach.

**SELF-DETERMINATION**

There is considerable interest, both in the UK and the US in finding ways to enable people with learning disabilities (and their families) to have more control over services. Strategies for promoting self-determination include:
* the development of collective advocacy
* the development of participant driven supports (including direct payments)
* the provision of information, advice and technical assistance to enable people with learning disabilities and their families to make use of ‘participant driven’ resources
* the development of home ownership options
* the development of housing co-operatives
* tenant participation
* participation in the strategic development and commissioning of services.

**COSTS AND FUNDING SYSTEMS**

The available evidence suggests that in general small staffed houses and supported living style arrangements are both financially feasible, and there is little evidence that a return to larger settings will present any cost savings, at least not without significant compromise on the quality of the service provided.

However, the funding systems in both the US and the UK share a number of disadvantages, including:
* a pro-institutional bias
* excessive rigidity
* primarily geared to political and organisation concerns
* are inefficient.

The net result is a system that is neither equitable, nor does will it be able to deliver the changes needed. However, there is also need for a substantial rethink of the way services are researched, and the way these resources are deployed. This would involve:
* use of a whole system approach to cost control
* levering in additional resources
* drawing on and complementary natural supports
* ensuring support is organised and targeted as flexibly as possible
* developing more extensive low support options
* making better use of ‘assistive technology’
* maximising individual income
* developing competence and autonomy, and promoting effective ‘participant driven support’.
Central government will have a significant role to play, not just in ensuring that wider policy developments are consistent with these aims, but by providing technical assistance and supporting further research to ensure that more coherent approaches to resourcing services are developed, evaluated and disseminated.

**THE LINK BETWEEN HOUSING AND WORK**

Some European countries have placed a much greater emphasis on inclusion through productive work. As a result, access to housing and support services have been primarily through organisations whose primary function is work, and most users of such services are able to combine full-time work with a range of housing and support options. While there is not a case for attempting to replicate these models in the UK, they do stand as an important reminder of the potential role work can play. For example, in France the possibility of combining wages and benefits is one factor in the more extensive use of mainstream housing.

In the UK the system effectively makes full time work and many housing and support options mutually exclusive alternatives for people with learning disabilities. Working out how to flexibly combine both sets of opportunities should be a major policy objective.

**CONCLUSION**

Although the gains for people with learning disabilities over the last decade or two have been significant, it is clear that as far as housing and support services are concerned, further reform is needed; the momentum for change needs to be maintained. On the basis of this report it is possible to see what a ‘modernised’ housing and support system would look like. For example it would:

* be based on the principles of citizenship and civil rights
* be comprehensive and inclusive
* draw on a synthesis of the supported living models and developments like ‘active’ support
* be based on person-centred planning, along with community development strategies to open up a wider range of opportunities
* take the issue of self-determination seriously
* use resources efficiently, and flexibly
* require the creation of a coherent funding base
* involve regulatory reform
* be complemented by a range of other services (including employment, continuing education and supported leisure services).

Some change is inevitable, given the probability of radical change in the wider policy framework. This represents both opportunities for people with learning disabilities, and risk: there is always the danger of unintended ‘side-effects’ in such wholesale change. For this reason there is a case for:

* piloting and systematically evaluating new systems and structures
* ensuring there is a clear focus on learning disability services within government, through the development of a national strategy.

One obvious possibility would be to build on the lessons of the All Wales Strategy, launching an All Scotland Strategy for the new millennium.
CHAPTER 1: SETTING THE SCENE

INTRODUCTION

A decent home life would feature highly on most people’s criteria for developing a good quality of life. It might not be the only thing (a decent job and income, and good quality of personal relationships of various kinds would probably feature quite highly too) but being able to genuinely feel ‘at home’ where one lives would be pretty critical; for most people it will be a necessary condition for maintaining their psychological well-being. This is likely to be as true for people with learning disabilities as any other citizens. Indeed, given that they may have difficulty accessing paid work and developing a wide and varied network of relationships, a satisfying home life might be even more significant for many of them. So, it is fairly safe to say that residential or housing and support services (we will pursue this distinction later) are a key component in the wider range of supports for people with learning disabilities.

The Scottish Executive is currently carrying out a review of services for people with learning disabilities in Scotland, and perhaps not surprisingly they chose to commission a specific review of the literature on housing and support services. This report is the result of that commission. Interestingly, in the brief for the work, the Scottish Executive chose to specify that this literature review should be international in perspective, focusing ‘beyond Scotland’. We explore the implications of this later in this chapter.

The Scottish Executive has announced a number of principles on which their review is to be based. These are that everyone with learning disabilities should:

* have the same human rights as anyone else and the right to lead fulfilling lives;
* have recognition of their individual needs;
* be consulted about their needs, involved in decisions about the services they receive and able to exercise choice, wherever possible;
* receive help with communication where required;
* have access to mainstream local services that meet their needs, are non-segregated and age appropriate. Specialist services should enhance and not replace mainstream services.

The families of people with learning disabilities should be informed and consulted about the services available.

We have tried to reflect these principles in this review. For example, we have taken as given the assumption that people with learning disabilities should be able to live in some form of community based setting.
‘Beyond Scotland’

We took the injunction for concentrating on the literature ‘beyond Scotland’ quite literally; we have not included any material that specifically related to a Scottish context. We should very much like to emphasise this is not because we do not value material from Scottish sources. On the contrary, Scottish writers and researchers have made a very significant contribution to the literature on learning disability services (as indeed have colleagues in Wales). We have assumed that people working in this field in Scotland will be contributing directly to the review.

Inevitably though much of the material produced in the UK is not country specific; more or less by default it is assumed to apply to the UK as a whole. This is actually a dangerous assumption, for two reasons:

* Scotland already has a distinct set of administrative and legal structures. Just to take one example, Scotland has ‘social work’ departments, rather than the ‘social services’ departments of England and Wales. Sometimes such structures can be considered as equivalent, but sometimes they cannot;

* the development of devolution for Scotland (not to mention Wales and Northern Ireland).

This report was written in the immediate run-up to the opening of the new Scottish Parliament. We are not constitutional experts, and so our grasp of the full implications of these changes is inevitably limited.\(^1\) We understand that responsibility for many aspects of learning disability services will lie with the Scottish Parliament, while others (eg social security benefits) will remain within the remit of Westminster.\(^2\)

It seems reasonable to assume that, given this context, the situation in Scotland is likely to become more, rather than less, distinct from other parts of the UK. It also appears that the respective roles of the Scottish and UK parliaments have yet to be fully defined, and will gradually evolve over the next few years.

This adds some complexity to our task, particularly in chapter 10 where we discuss the wider policy context. We are inevitably most familiar with the material produced by the relevant Government Departments in Westminster. While some of the documents we refer to in chapter 10 have specific appendices that relate to Scotland (‘Supporting People’ is a case in point), others have quite separate Scottish equivalents with which we were not familiar.

Here, as an example, we would point to the recent White Paper *Modernising Social Services*. The Scottish version (*Aiming for excellence: modernising social work services in Scotland*, Scottish Office, 1998a) is a substantially different document. Presumably, those drafting the

\(^1\) We found the following web sites helpful in exploring the issue of devolution:
- Scottish Constitutional Convention: http://www.cybersurf.co.uk/cscoparl/scc/scc-rep.html
- http://www.scottish-devolution.org.uk/

\(^2\) Although even here the Scottish Parliament will still have a role in implementing UK wide legislation.
Scottish version had to avoid making commitments on behalf of the yet-to-be formed Scottish Parliament; its conclusion includes the telling qualification “if enacted by the Scottish Parliament”.

It is important that readers are aware of these caveats. It cannot be assumed that Scotland will necessarily opt for the same approach as England. Even if Scotland does move in the same general direction, the details will sometimes be different.

The context of devolution provides both challenges and opportunities for Scottish people with learning disabilities, their supporters, and the services they use. On the one hand it adds in a layer of complexity and uncertainty. On the other it represents a chance to forge a system that is both distinctively Scottish (and therefore sensitive to the particular concerns of Scottish people) and which is able to draw on positive lessons to be learnt from elsewhere. On balance this seems an enviable position to be in.

**The View from Arthur’s Seat: The Implications of Doing an International Review**

The idea of an international review shows a commendable willingness to be open minded. Unfortunately from our point of view, the concept of ‘beyond Scotland’ is a formidably open-ended one. Not least, there was an interest from the Scottish Executive not just in material that had been formally published, but also any relevant resources that might exist on the internet. This was a very brief, time-limited piece of work. We have tried to make it as systematic and as comprehensive as possible. However, both the breadth (a genuinely comprehensive survey of housing and support services would have to cover many different issues) and the scope (material published anywhere in the world) meant that it could never be exhaustive. Fortunately, the Scottish Executive relented a little. We were to focus primarily on material published since 1995, although we were invited to include significant material from earlier if appropriate. Even more fortunately, we were only required to cover material published in English.

We explain how we set about the task of gathering the material in Appendix 1. Here we want to briefly spell out the implications of sticking to English language materials. Inevitably there will be a distorting effect. In searching for a suitable analogy for this effect, one of the authors was particularly struck by an illustration that appeared in the Guardian Newspaper. This showed an old cover of a New Yorker Magazine. Entitled ‘View of the world from Ninth Avenue’ it was particularly striking. The foreground consisted mainly of a detailed drawing of an intersection on Ninth Avenue complete with recognisable buildings, cabs, street furniture and so on. There were some details of Tenth Avenue, but the rest of New York was at best implied (certainly there was little detail). In the medium ground there was a strip (divided from the foreground by the Hudson River) that represented the rest of the US. The presence of the odd city or state was indicated, along with the occasional symbol (cactus for Texas, the odd mountain), but in comparison with the foreground there was almost no detail. Canada and Mexico were only represented in terms of a notional boundary. In the far distance there

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3 We do include the odd reference to material in other languages.
was the Pacific Ocean with just the merest outlines labelled respectively Russia, China and Japan. Other parts of the world were not depicted at all.

This seemed to offer the ideal template for illustrating the world of learning disability services seen through an English language filter. Therefore, taking a metaphorical stance on top of Arthur’s Seat what would the view be like? Well, perhaps inevitably a significant proportion of the foreground would be taken up by the rest of the UK. However, it would be a rather lopsided version of it. Wales, for example (there has been an extensive study of the All Wales Strategy - see Felce et al, 1998a) would appear to be relatively large and well defined, whereas Northern Ireland would be almost invisible. Significant amounts of fog (reflecting gaps in information) would cover parts of the landscape, obscuring the otherwise fairly detailed view of England. Somewhat disconcertingly, the Atlantic would appear to have vanished. So, looming over the foreground would be the Rocky Mountains. Clearly the air at altitude is rather clearer because some parts, at least, stand out in remarkable detail. This is partly a reflection of the wider availability of official data in the US, but also their enthusiastic embrace of the world wide web. Armed with a few key sites it is possible to download a vast array of material from the US. For those armed with an internet browser and sufficient time and patience we have included details of some of the most useful addresses in Appendix 2. The Canadian end of the Rockies is clearly marked out, as is Ayers Rock (Australia) and the tops of the New Zealand Alps. However, the trouble with mountains is they obscure the view. As a result most of the rest of the world is simply not visible. Through the odd pass in the Rockies we would be able to make out faint indications that the world goes on (the top of the Eiffel Tower, an Austrian Glacier, a Swedish Ski Lift, even the tip of a Dutch windmill or a Hong Kong skyscraper), but it is difficult to get a more rounded picture of these countries; by definition the view we have of them is extremely partial.

We hasten to add that this situation is not the fault of the efforts of colleagues in these countries. Our requests for information were responded to generously and enthusiastically by almost all of those we approached. However, the task of translating the range of material needed to build up a more comprehensive picture was quite beyond the scope of this exercise. It remains the case that in the UK learning disability services we know a lot about, and have been significantly influenced by, developments in North America, whereas we know scandalously little about what happens in much of Europe (let alone the developing world). Given that human services constitute a significant industrial sector, and that we are part of the European Union, it is somewhat surprising that this situation is still true, and it is difficult to see how this can continue for much longer.

Inevitably, there are dangers in drawing too many conclusions when so little information is readily available. However, even if we were better informed about, for example, the non-English speaking countries in Europe, there would still be the need for caution. International comparisons are fraught with dangers. Some of these are obvious. Terminology is a case in point. Even within countries a given term can mean many different things to different people. What, for example, within the UK is a group home, and how does it differ (if at all) from a small staffed house or a residential care home? In some contexts the term group home would be used specifically to refer to houses that were ‘unregistered’ or which are not staffed 24 hours a day, but equally, there will be many places where ‘group home’ is a generic term for

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4 See, for example, David Braddock’s 1998 compendium of data *The State of the States*
any small, or relatively small, shared living arrangement, including intensively staffed registered residential care homes.

There are more subtle, less obvious difficulties. Even assuming it is possible to do an international search using a concept like ‘group home’ and end up with things that looked similar in terms of criteria like staffing, it would still be dangerous to assume that the experiences of people living in those services would necessarily be similar. Services for people with learning disabilities do not exist in isolation. They are bound to reflect (to some degree at least) the wider social, political and cultural contexts within which they operate.

For example, in many European countries renting is still the most common form of tenure. This is increasingly less so in the UK (Wilcox, 1998) and the US (TAC/CCD, 1996), where typically around two-thirds of people now own their home. If in these countries professionals were to assume that home ownership is not a feasible option for people with learning disabilities (something that happens all too often), they would at a stroke be effectively limiting options to less than a third of the total housing stock. Further if, as is commonly the case, it is automatically assumed that any housing for people with learning disabilities will necessarily be from the social rented sector (public and not-for-profit housing providers with a specific ‘social’ remit), then choice is narrowed even further. If only schemes specifically designated for people with learning disabilities are considered (and these will typically involve congregate living) then it is far from clear how relevant the concept of ‘choice’ will be. Perhaps it is therefore not surprising that in both the UK and the US home ownership programmes for people with learning disabilities have started to emerge (see later). We found just one instance of home ownership elsewhere (Sweden - Kent Ericsson, personal communication).

Welfare systems, in particular, are likely to have very significant impact on the lives of people with learning disabilities. Not least, the issues of the costs of housing and support services, the way they are funded, and the ways in which the incomes of the individuals involved are maintained, are all bound up with the wider social security structures (indeed, if the UK is anything to go by, the interaction will be extremely complicated). In terms of its wider welfare system, the UK is still probably closer to its European partners than to the US, although welfare reform is an increasingly significant and controversial topic in many countries.

Finally, the very notion of ‘housing and support’ represents just one way of dividing up the world. For many in both the UK and the US, residential provision represents a kind of core service; a fundamental that has to be got right, with other services following more or less as an adjunct. Indeed, this was to some extent the implication of our opening paragraph. Typically, other provision (for example day services or employment related assistance) will be quite separate and distinct, and will be delivered through very different organisational arrangements. There are of course exceptions to this; some people in the UK do receive ‘day services’ in the place they live. However, it remains unusual, and is often seen as a potentially risky arrangement (too much of a ‘closed world’ lacking the checks and balances offered by contact with professionals who have different organisational allegiances).

In fact there is some evidence that this basic set of premises would not necessarily hold in some other European countries (see the brief chapter on France and Germany). Here there is a much greater emphasis on ‘inclusion’ through work. Therefore many of the key services are the various forms of work oriented provision and ‘residential’ services are accessed through and provided by organisations for whom housing and support is not their main function.
The point we are trying to make is that the wider context will be important in developing and sustaining (or otherwise) community services. Therefore, even in the case of North America where the linguistic differences are less significant (though still there!) it cannot be assumed that models of service provision are either directly equivalent or will transplant easily.

Within this review there is no space to do anything other than raise these issues on the principle ‘forewarned is forearmed’. What is important is that the reader is aware of the dangers and is prepared to critically evaluate the information we set out. Even allowing for the possible pitfalls, there is still a lot of value in being outward looking; the metaphorical climb of Arthur’s Seat should still be worth the effort.

THE ROLE OF RESEARCH AND LITERATURE REVIEWS

There is increasing interest in the idea of ‘evidence-based’ services; developing services in ways that can be justified by clear and reliable evidence about their effectiveness. So called evidence-based reviews (often referred to as Cochrane style reviews) have become increasingly important. However, in this context they tend to have rather a specific meaning. Drawing extensively on the models developed in Health, evidence-based reviews typically involve evaluating studies published in peer reviewed journals against pre-determined criteria. They tend to be concerned with quantitative data obtained using research designs that offer some explanatory power (predominantly randomised control trials) using measures that are amenable to evaluation in terms of validity and reliability, and reported according to formal scientific conventions. We have elected to take a rather wider approach to the task.

Firstly, from a very pragmatic point of view, if we restricted ourselves to a narrow definition of ‘evidence’ this review would be very short indeed. Cochrane style reviews are most appropriate in terms of very specific, well defined interventions (a particular drug, a medical protocol). By no stretch of the imagination could the wider concept of housing and support for people with learning disabilities be reduced simply to an ‘intervention’. It is worth adding that a search of the Cochrane database of systematic reviews found nothing that was even remotely relevant to this report.

We feel there is a strong case for retaining a much more plural approach. We have therefore incorporated material that reflects a much wider range of methodological assumptions and approaches (including case studies and qualitative research). Indeed, we have also specifically chosen to include material that reflects debates and discussions, as well as research.

This is not to suggest we are not interested in evidence. Indeed we would argue there is still a widespread failure to assess and document the outcomes (what actually happens to people) for many services provided to people with learning disabilities. Indeed, some within the field are resistant to formal evaluation; research is often perceived as too ‘mechanistic and rationalistic’, failing to represent the reality of people’s lives. There is also a concern about the issue of ‘rights’. The development of many housing and support options has not just been a case of evolving the right techniques. It has been driven as much by a moral vision: people with learning disabilities should not be denied the opportunity to live in their communities of origin, they should not be excluded from the options that most of us take for granted, they should be able to live in their own homes, and so on. There is a lingering suspicion that the
emphasis on evidence fails to take into account this wider rights based agenda. Implicitly, there is the concern that a lack of evidence will be used as an argument to stifle attempts to explore ways of implementing these principles. This certainly happens. For example, the lack of formal research evidence has been used as an argument against the kind of ‘supported living options’ we describe in chapter 3.

However, a rights based agenda and a concern with evidence and outcomes are not necessarily incompatible. As we have argued elsewhere (Simons and Watson, 1999):

*The key question is not ‘whether’, but ‘how’.*

A commitment to rights necessitates an attempt to find effective ways of delivering services that meet these principles, and which optimise the process, enabling more people to take advantage of them. Research evidence of all kinds can make a significant contribution to that process.

**THE ISSUES FOR CHILDREN**

The literature on housing and support options for people with learning disabilities inevitably focuses on the experience of adults, and indeed by default this will be true of the rest of this report. Yet children with learning disabilities will have housing and support needs too. The prevalent assumption is that the best place for children is with a family (whether their own or with a substitute family), but inevitably some disabled children do end up in residential settings of various kinds. Further, some families with disabled children will have problems with housing.

A full discussion of the issues is beyond the scope of this report. However, we feel it is important to acknowledge the issues and to provide at least some pointers to those wishing to follow them up. The literature on children’s services is extensive, but relatively little of it focuses specifically on the experiences of disabled children. An important exception is the recent study *Still missing?* by Jenny Morris (1998a and b). There is also some material on quality in short-term residential care (Robinson et al., 1996), along with an as yet unpublished study on the use of hospices by children with complex needs (Robinson and Jackson, 1999).

**THE STRUCTURE OF THE REPORT**

In order to provide a structure for this material we have divided the report into 10 chapters. Some are rather shorter than others, reflecting the distribution of the material.

* **Chapter two** provides some context. It focuses on how some of the original agenda of deinstitutionalisation has progressed, and explores the distribution of services.

* There have now been a huge number of studies which focus on small group homes and staffed housing. We therefore devote **chapter three** to trying to summarise this material.
Most of the services we described in chapter three would involve some form of residential care - effectively services where the place people live and the support they get are bound up together. In chapter four we look at the emerging literature on supported living which tries to disentangle housing and support. Effectively supported living arrangements are a form of intensive domiciliary services.

Although the literature is dominated by material about group homes and, more recently, supported living, they are not the only options. In chapter five we therefore look very briefly at what material there is on low support options, adult placements, village communities, and services to families.

Chapter six picks up the theme of ‘self-determination’ and explores ways that people have been enabled to have more control over the services they use.

Ensuring vulnerable people stay safe is an important component of any residential or housing and support service, so in chapter seven we explore the issue of regulation.

Chapter eight deals with the critical issues of costs and how services are funded.

Chapter nine provides a brief look at some material on France and Germany which explores housing services provided by organisations with particular focus on employment.

Finally, chapter 10 attempts to draw some conclusions about the direction for future development.
CHAPTER 2: PROVIDING SOME CONTEXT

INTRODUCTION

As we suggested in chapter 1, some aspects of residential or housing services are over-represented in the literature, while others hardly feature. Because of this there is a danger of a false impression being created; one might assume that most people with learning disabilities lived in small group homes or staffed housing, with a substantial number already living in their own home. The reality is actually rather different. The aim of this chapter is to provide some context to put what follows later into perspective. We set out some of the data on the overall patterns of services, along with a very brief description of the wider policy context.

Quite clearly, we do not have space for a full history of learning disability services. However, it is worth remembering that, in their current form, such services are a very modern invention. Given the importance of material from the US in this review, we also felt it was worthwhile adding a brief description of the main structures in the US.

Braddock dates the start of the modern era in US services for people with learning disabilities as the early 1950s, which saw the formation of a national parents advocacy organisation (known as The Arc) and which is broadly the equivalent of MENCAP in the UK, along with the introduction of social security benefits for disabled people (known as Supplementary Security Income or SSI). The election of President Kennedy in 1960 also saw a big upsurge of interest at a federal government level. In 1961 Kennedy established the President’s Panel on Mental Retardation, which went on to make a number of significant recommendations, which in turn were subsequently incorporated into legislation. For example, for the first time states were required to produce comprehensive plans for the development of improved residential, community and preventive services. From the beginning the President’s Panel was committed to the principle of developing community based services:

... as close to the mainstream of independence and “normalcy” as possible.
(cited by Braddock, 1998)

1963 also saw the establishment of the University Affiliated Programme, a network of university based research and development facilities designed to promote innovation and quality in local services. The early 1970s saw the requirement for each state to establish developmental disability councils as a condition of federal funding (these councils are responsible for the strategic planning in each state), followed by the formation of the independent state advocacy and protection agencies. The latter are primarily a vehicle for ensuring that vulnerable people have access to legal advocacy, and for investigating any possible complaints of neglect or abuse.

The 1970s also saw the introduction of federal Medicaid funding (the Intermediate Care Facilities/Mental Retardation programme (ICF/MR) designed to help states improve conditions inside the state institutions (the equivalent of the long-stay hospitals in the UK) and

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5 Details of the full programme, including contact details of most centres in the States are available on the web site given in Appendix 2.
develop community based alternatives. This was followed in 1981 by the introduction of a second stream of federal Medicaid funding specifically focused on community based services (the Home and Community Based Service Waiver - HCBS). This effectively completed the key structures that continue to shape US services today.

It is worth noting the contrast with the UK, where the development of policy on services for people with learning disability has been somewhat less focused. There is no equivalent in government of the President’s Panel, nor at a local government level is there the equivalent of the developmental disability councils. In many ways, the development of services in the UK was rather more entwined with the development of the wider welfare state, in particular the formation of local authority social services departments (social work departments in Scotland). Although undoubtedly influenced by developments in the US and (to some extent) Scandinavia, UK government policy on learning disability services has been rather more equivocal about the desired direction of reform (see later).

THE PRE-EMINENCE OF DEINSTITUTIONALISATION AS A FOCAL POINT FOR POLICY

The most consistent theme over the last two decades has been the primacy given to deinstitutionalisation and the ‘reprovision’ of the large institutions. This steady decline in the institutional population over the last two decades is apparent not just in the UK and the US, but also a number of other countries, including Norway, Sweden, Finland (Mansell and Ericsson, 1996) and Australia (Griffin and Parmenter, 1999).

Some brief facts (taken from Mansell and Ericsson, 1996) illustrate the point. Between 1970 and 1995 the number of people in institutions (expressed in terms of places per 10,000 population) fell from approximately:

- 150 to less than 50 in Sweden
- 120 to about 25 in England
- 90 to about 40 in Wales
- 90 to about 25 in the US
- 140 to around 10 in Norway

However, there is at least one country for which we have comparable information that appears to have bucked this trend: the Netherlands. Van Gennep (1997a) reports that the number of places in Dutch institutions rose steeply during the 1960s and early 1970s. After 1975 the rate of growth slowed, but the total was still rising even as late as 1995. There are still over 32,000 people with learning disabilities in these very large settings (anything between 100 and 1,000 people). While there has been considerable growth in the provision of large group homes (10-30 people), with some ‘socio-homes’ (6-10) people, and even a small number of supported living arrangements, the numbers of people using these services is still only around half the size of the institutional population. As a result the Netherlands is now very much out of line with the English speaking and Scandinavian countries. It is not clear why this is the

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6 The process of hospital closure started later in Norway (the institutional population stayed roughly constant until the late eighties) but then went faster and further than elsewhere.
case. Van Gennep mentions resistance from families to institutional closure, plus concerns about the costs of closure, but to greater or lesser extents these were features of most of the other countries that pushed ahead. The current policy appears to be one of decentralisation (slowly disaggregating the bigger institutions) rather than closure.

As the figures given earlier show, even amongst the more enthusiastic countries, the process of deinstitutionalisation is still not complete. There are currently around 7,400 people living in long-stay hospitals in the UK (see Felce, 1999), of which a disproportionately large number (over 3,000) are in Scotland (Stalker & Hunter, 1999). Similarly, according to Lakin (1999), in 1997 there were still over 57,000 US citizens with developmental disabilities living in large institutions, while Braddock (1998) lists only seven (out of 51) states that had closed, or had planned to close, all of their large public institutions. Even as late as 1993 Missouri was opening a new institution. Even in Scandinavia there is still a very small residual population (about 5% of people with learning disabilities) in large institutions (Kebbon, 1997).

Because of this there are some who advocate a continuing role for some form of institutional provision (see for example, Nesbitt and Collins, 1998 or Kumar and Agarwal, 1996). They point to, amongst other things, the continued admission to institutions of people with challenging behaviour and the concentration of people with more complex needs in the residual institutional population, with the implication that some form of specialist institutional provision is required for individuals for whom community based support is unmanageable. However, such arguments appear not to take account of the evidence that even people with very complex needs can be effectively managed in community settings (given a sufficiently comprehensive and competent local service - Mansell, 1993), which would include structures designed to preclude admissions through the provision of effective crisis support (Van Minnen and Hoogduin; 1998; Colond and Wieseler, 1995). There will be significant questions about what should happen to the tiny minority of individuals with learning disabilities who need to be in some form of secure accommodation because of offending behaviour, but even here there seems a good case for questioning the use of large scale institutions (see Flynn and Bernard, 1999).

For most countries the end of the large institutions might be in sight, even if it is not here yet. Deinstitutionalisation has been a complicated process, involving a huge effort and tying up very considerable resources. A critical lesson to be learnt from this process is the importance of ensuring that future generations of service provision are sufficiently flexible, so that they can be easily reconfigured or converted if and when they outlive their usefulness.

WHAT KIND OF VISION?

As Felce et al (1998a) comment, the UK policy of hospital closure was driven largely by the scandals that beset the system in the early 1960s and 1970s; these effectively ‘removed their last vestiges of legitimacy’. However, this does not necessarily imply there was a clear vision of what might replace them. Although ‘community care’ emerged as the policy aim following the publication of the 1971 White Paper for England and Wales Better services for the mentally handicapped, there was a striking lack of clarity about what that might mean in
practice. Policy in the UK has been essentially permissive rather than prescriptive, with guidance sanctioning a ‘range’ of provision, including segregated institutions (see for example, DHSS, 1977). Coupled with concern about the lack of central direction, as Felce and colleagues comment, there has been considerable criticism at the failure to back up the broad direction of policy with the appropriate ‘organisational and funding mechanisms which were required to engender significant reform.’

Although the 1971 White Paper (DHSS, 1971) had included specific targets for the levels of service provision, these were effectively abandoned. The lack of overall strategic planning was compounded by other policies. For example, just at the time when local authorities were taking on increased responsibility for services for people with learning disabilities, they were also facing an unprecedented and sustained squeeze on their overall spending.

There was one important exception to this general pattern in the UK: the All Wales Strategy (AWS). Launched in 1983, the AWS represented an attempt to radically reform services throughout Wales by the articulation of a national policy backed by a commitment of additional resources targeted on reform. For the first time in the UK, official policy was committed to the principle that people with learning disabilities had ‘a right to an ordinary life within the community’ (Welsh Office, 1983). Critically the AWS sought to drive policy change by the creation of innovative community based developments, rather than simply through hospital closure (it was to be pull rather than push).

Latterly the AWS has been somewhat overtaken by both the wider community care reforms of 1993 (following the 1990 NHS and Community Care Act), and by local government reorganisation. The AWS undoubtedly helped shape the distinctive character of services in Wales. As we note later more people are likely to be living in small ‘ordinary housing’ than is the case elsewhere in the UK, and similarly supported employment has also grown as fast or faster in Wales than elsewhere. However, it is also the case that the AWS achieved less than was initially hoped for (indeed at one stage rates of deinstitutionalisation actually lagged behind England). However, despite its limitations, the lessons to be learned from the AWS (extensively documented by Felce et al, 1998a) are worth absorbing, particularly in the context of devolution of power from Westminster to both Edinburgh and to Cardiff.

Given this level of policy drift, it is perhaps not surprising that the UK service delivery system is creaking at the seams. Given these differences between the UK and the US, it is therefore perhaps surprising how similar the wider patterns of service development are. Both countries are left a legacy of:

* an overall shortfall in services

According to Mansell (1997) the numbers of places for people with learning disabilities in UK residential services in 1994 was probably lower, and almost certainly no higher, than in 1969. Further, the 1994 figures for England and Wales were well short of the targets set out in the 1971 White Paper.

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The Scottish equivalent was the Peters Report (Scottish Home & Health Department & Scottish Education Department, 1979).
Similarly, based on a survey of 10 local authorities, Watson (1996) concluded that there was a significant shortfall of places. Emerson and Hatton (1998) applied these findings to the population data found and concluded that something between 20,000 and 25,000 new places were required, a conclusion endorsed by the Mental Health Commission Committee of Inquiry into learning disability services (MHF, 1996). There is a similar picture in the US, where Lakin (1999) estimates there are now over 80,000 people on waiting lists for residential services. It is worth noticing that relative to population, the US and the UK appear to providing roughly the same levels of service for people with learning disabilities. For example, Emerson and Hatton (1998) report that the 1991 census showed that there were approximately 122 places per 100,000 population in the UK. Allowing for the relatively small number of people likely to have been living in their own home or in adult placements, Felce (1999) concluded this would leave a combined figure of around 130 per 100,000. For the US Lakin cites a figure in the order of 125 places per 100,000 in 1997, adding that this figure has stayed remarkably constant over the last decade.

These estimated shortfalls only take account of current demands. In both countries demand is projected to rise because of demographic changes, not least the increasing extent to which children with very complex needs are now surviving into adulthood (Parrot et al, 1997).

* provision still dominated by settings that are larger than ‘ordinary homes’

As part of their research on the impact of the All Wales Strategy Felce et al (1998) carried out a longitudinal study of the services used by a sample of over 400 people with learning disabilities between 1986 and 1990. They found some evidence of a shift from ‘atypical’ to ‘typical’ housing, but the rate of movement was slow; the researchers concluded that at this rate of progress it would take over twenty years to complete the transformation.

Similarly, in their analysis of the 1991 census Emerson and colleagues found that while most UK residential care facilities were relatively small, most people were in larger settings. Only just over 13% of adults with learning disabilities were in homes with fewer than five residents. A further 38% were living in homes with between 5 and 9 residents, leaving a fraction under half in settings with 10 or more residents.

Lakin (1999) cites some rather more up to date US data (for 1997). Here, just under a third of people with learning disability are living in settings for between one and three people, with a further 21% occupying homes for between four to six people. In contrast, there were still a third of the learning disabled population in facilities with 16 or more residents.

Despite the recent interest in supported living, the availability of such options still appears to be relatively limited. In England, Cambridge et al (1994) reported that just over 4% of people resettled from hospital into demonstration community care projects were ‘living independently’, with an almost identical figure being reported for a resettlement programme in Northern Ireland. In her survey of 10 local authority social services departments Watson (1996) found that only around 8% of people with learning disabilities were living in their own home. Somewhat surprisingly, although the proportion of people in the US who rent or own their own home is higher, it is (or rather it was in 1997) still only 15% (Lakin, 1999):

... supported community living is still an unrealized ideal for most people ...

* marked variation in access to services
Perhaps one of the most striking features of both the UK and the US is the regional variation in both the levels and type of service provision. For example, Emerson and Hatton (1996) found that within England, the numbers of people with learning disabilities in residential care in 1991 varied by a factor of two, from 92 per 100,000 population in the North East Thames Health Region to 180 in the South West Health Region. This degree of variation in service levels cannot be purely a function of demographic variation; what commentators in the US rather graphically called ‘fiscal effort’ will have played a substantial part. Similarly, the proportion of people in very small homes (1-3 people) also showed marked variation (from just over 7% in Scotland to 20% in Wales) suggesting very different levels of commitment to the ideal of an ‘ordinary life’.

If anything, the variation within the US is even greater. For example, Braddock (1998) reveals that the proportion of people in very small homes ranges from just over 10% in Mississippi (where no less than 83% of people were in settings with 16 plus residents) to over 90% in Hawaii and Vermont, with just about every stage of graduation in-between. Both Hawaii and Vermont are relatively small. However, some of the larger states are also approaching the point where there is a similar focus on very small homes: for example, Michigan (with over 11,000 people with learning disabilities assisted) has 89% of people with learning disabilities in such settings.

The inevitable conclusion is that, for someone with a learning disability, where you live will very much determine what kind of service you get. However, even this is not the end of the story. Some groups appear to have very different rates of access to services. For example, Emerson and Hatton (1998) report that young Black men were more likely to be in residential care than their peers from other ethnic groups, while in contrast, young Asian men and Asian women were likely to be significantly under-represented in all services. Lakin (1999) similarly points to evidence for differential rates of access, with people from some minority ethnic groups typically over represented in institutional settings and under represented in the more flexible home and community support programmes.

Before moving on to the next point it is worth noting that much of the UK material in this section was based on the 1991 census. The Department of Health recently carried out a survey of local authorities which should soon provide a more up to date picture. Things will have changed since 1991, although it may well be a mistake to assume that the picture is radically different.

**HUMAN RIGHTS, IDEOLOGY AND PRINCIPLE VERSUS BUREAUCRATIC PRAGMATISM AND INERTIA**

As we suggested in chapter 1, the debate about the most appropriate form of housing services for people with learning disabilities can never be just a technical discussion of the relative merits of one or other model; of necessity the debate will have a moral or (in the positive sense of the word) ideological content: they touch directly on what it means to be a *citizen* (see Ericsson, 1996 and Simons 1998a), and are increasingly being construed in the context of civil rights.

This is most clearly articulated in the US, where the courts have played a significant role in developing services for people with learning disabilities. In the UK scandals in the old long-
stay hospitals led to Government enquiries and slow changes in national policy but by and large it has not been possible for people with learning disabilities and their supporters to force change through the legal system. Yet as far back as 1970 a US District Court was ordering sweeping reform of an institution based on the notion of *a right to rehabilitation in the least restrictive environment*. This was very much just the start of the process. For example, in his overview of the history of services in the US, Braddock (1998) was able to identify no fewer than 27 ‘key Federal lawsuits promoting deinstitutionalisation and community integration’ over the period 1970 to 1996.

This process of developing clearly articulated rights has continued, and there are now three distinct pieces of US legislation that give Americans with learning disabilities certain specific rights to access housing services (see TAC/CCD, 1998 for details). These are:

* **Section 504 of the 1973 Rehabilitation Act**
  Requires recipients of all federal housing subsidies to make their programmes accessible to people with disabilities.

* **the Americans with Disabilities Act**
  Aside from generally prohibiting discrimination against disabled people the AD specifically extends the protection provided by Section 504 to all federal and state run housing programmes.

* **the 1998 Federal Fair Housing Amendment Act**
  The Federal Fair Housing Act prohibits discrimination in the provision of housing services. The 1998 amendment extended the provisions of the Act to include disabled people. It was designed to end segregation and provide disabled people with a right to choose where they live. Landlords are expected to provide reasonable accommodation to ensure that disabled people can secure and enjoy appropriate housing.

As a result, in the US there is some substance to the notion that people with developmental disabilities have a right to live in their own home. There is increasing interest in the idea of such a ‘right’ in the UK, and indeed in other parts of Europe. However, to date this is more a moral imperative (people with learning disabilities should be able to live in their own home if they so choose) rather than any substantive legal right. In terms of access to housing and support arrangements, the UK Disability Discrimination Act may have some impact in the future (particularly when the Disability Rights Commission is fully implemented), but as yet it is difficult for people with learning disabilities to challenge the discrimination they undoubtedly experience.

Indeed, in the context of the UK, access to community care services reflects a complex patchwork of legislation and case law (see Morris, 1997), and is far from clear cut. Indeed, most of the legislation is framed not in terms of rights to individuals, but as a range of duties for local authorities (see Roberts, 1997). Further, a 1995 decision in the House of Lords confirmed that local authorities were able to take resources into account when assessing or reassessing whether an individual is in need of community care services, and in setting eligibility criteria for such services. As Brammer (1997) points out this is likely to compound the existing variation in levels of provision, and risks reducing the duty on local authorities to provide services to a discretionary power.
A word of caution needs to be added here. While the lack of a clear legal framework in the UK represents a substantial problem, it does not follow that the introduction of improved civil rights would, in themselves, necessarily change things, other than for those in a position to resort to the law. The existence of a legal right to access housing does not necessarily mean it can be exercised. As we showed earlier, even in the US, still relatively few people with learning disabilities live in their own homes.

However, there is some provision within the US system for access to legal advocacy through the state protection and advocacy system. So for example, in her description of the Californian system for monitoring services Diesfeld (1997) mentions that the regional centre (the local commissioners) who have placed an individual in a facility are required to provide the services of a ‘Clients’ Rights Advocate’ for any individuals with developmental disabilities, and that advocate is required to investigate and pursue any complaints made. There is no direct equivalent in the UK system. Local authorities are required to assist any individual who wishes to make a complaint about services provided or purchased by it. However, that help would not necessarily mean independent advocacy of any kind. As Simons (1995a) has pointed out, complaints about ‘third-party services’ (services purchased but not provided by the authority) are often handled in very inconsistent ways. This is particularly the case with complaints about independent sector residential services. The 1986 Disabled Person’s Act did contain provision to establish the right for individuals to appoint their own advocate, but this part of the Act has never been implemented.

The tension between rights and reality is but one example of a wider phenomenon within the learning disability field, where the proclaimed adherence to principles or theories has not translated into direct action; there is often a remarkably wide gulf between the ‘mission’ statement of many organisations and the services they actually provide.

Ideas like normalisation and social role valorisation, along with the ‘ordinary life’ principles articulated by the King’s Fund (1980) and the widely cited framework of the five accomplishments (O’Brien, 1987), have undoubtedly had a profound effect on the development of learning disability services in much of the English speaking world (and indeed to a greater or lesser extent in other parts of the world as well). In the case of normalisation it has often been described as the ‘dominant ideology’ (see for example, Chappell, 1992). However, while these philosophical approaches may have had a prominent role in academic discourse about services, it is far from clear that they have ever been systematically used in the design of service systems. All too often the principled approaches have run into bureaucratic pragmatism and inertia and a wider policy framework based on very different assumptions and imperatives. As Felce and his colleagues (1998a) comment:

... principles are a weak device when faced with long-standing rationing of services.

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8 See Wolfensburger 1972 and 1983. For those interested there is a selected reading list on normalisation and the social theory of disability available at http://geocities.com/Athens/6975/normal.htm

9 It is worth noting that some of the original authors of the theory of normalisation were from Scandinavia (see Nirjie, 1970 and Banks-Mikkelson 1969). However, normalisation appears to be less influential in southern, central and eastern Europe (Ramon, 1996).
IMPLICATIONS

These existing features of services provide an important backdrop to the development of new strategies for further reform. Some effort will have to be made to rectify the inequalities and access and the overall lack of resources as part of any ‘modernisation’ programme. Indeed, there is some recognition in the latest White Paper for England and Wales (DoH, 1998) that unjustifiable variation in access to social services is a problem (though this was not specifically in relation to learning disability services).

Quite how these wider contextual problems can be addressed is another matter. Felce (1999) argues the case for further investment in learning disability services:

\[ \text{Now that the end of deinstitutionalisation is in sight, it is essential that the Governments of the UK do not conclude that the priority for investment can be relaxed.} \]

In this context, the failure to ring-fence NHS resources that were previously invested in learning disabilities is a matter of concern. According to Towell (1997) around £30m per year of the ‘old long-stay money’ is at risk. Certainly, with or without further investment, there will be a need to use resources as efficiently as possible, a theme that we return to in chapter 8.

While it is likely that changes in broader policy will be helpful (see the last chapter), as will an increased emphasis on civil rights, one lesson of the past is the danger of new developments being blown off course unless attention is paid to the wider policy context. What happens to people with learning disabilities in the new millennium will be determined as much by issues like the success of welfare benefits, and the pressure on local authorities to contain their spending, as by the service principles adopted within the field.
Chapter 3: Shared Living Arrangements: Small Staffed Houses and Group Homes

There is now a very substantial academic literature on the use of ‘community based alternatives’ to institutions, focusing in particular on small staffed houses and group homes. We are therefore fortunate to be able to draw on an extensive and authoritative review carried out by researchers at the Hester Adrian Research Centre (Hatton and Emerson, 1996) which summarised the main findings from 118 formal studies published (mostly in peer reviewed journals) prior to about 1995/6. These provide a useful starting point, which enable us to concentrate on those published since that date. This is still a demanding task, not least because of the varying contexts in which these studies took place. While some focus exclusively on a particular kind of service, others set out to compare a range of models, including larger institutions and hostels. Similarly, definitions of ‘small’ are of course relative. There simply is not space to reflect all these issues in perhaps the depth they deserve. However, in the summary table at the end of the chapter we have tried to retain as much of this contextual information as possible.

There has been much interest in the last decade or so in defining, operationalising, and measuring the ‘quality of life’ for those who live in such services (some of the more recent journal articles on the subject include Perry and Felce, 1995a and 1995b; Rapley, Ridgway and Beyer 1997 and Felce, 1997). There has been some debate about the feasibility and the desirability of relying exclusively on formal ‘objective measures’ of quality of life (see Rapley and Ridgway, 1998; Rioux, 1996; Hatton 1998) although there is a general consensus on the importance of evaluating services on the outcomes for individuals. All the studies included in this chapter were selected because they report on one or more of such outcomes.

Hatton and Emerson summarised their material over 12 different domains. Reflecting the changing patterns of the more recent publications, we have focused on a smaller subset of issues, grouped into four specific areas: changing behaviour, participation in domestic activities and staff support, presence and participation, choice autonomy and the views of residents.

Changes in Behaviour

Most services have an avowedly developmental component; one of their aims is to increase the competence of the people using the service, and decrease behaviours that might lead to them be excluded from community settings. As a result, the impact of services on both ‘adaptive’ and challenging behaviour has been one of the main key focal points for much research. On the basis of their review Hatton and Emerson (1996) concluded in general the data showed that people moving out of institutions were likely to show modest gains in adaptive behaviour, which were likely to be ‘maintained (but not built on)’. Overall, moving from an institution into a community based setting had relatively little impact on challenging behaviour, although there was ‘trend ... for observed levels of challenging behaviour to decrease ...’.

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10 This in turn was based on an earlier study (Emerson and Hatton, 1994).
This broadly positive picture is reinforced by the most recent research. For example, positive changes in adaptive behaviour were noted by Connealy et al (1992), INICO (undated), Lowe et al (1998), and Maisto and Hughes (1995). Felce and Perry (1996) found scores on an adaptive behaviour measure increased significantly over a two year period in small staffed housing, particularly for people with the greatest needs for support. Joyce (1994) reported that the levels of adaptive behaviour for people living in ordinary homes were higher than for those living in hospital settings and as high as those in hostels, even though they were significantly more intellectually impaired than the latter. In a Dutch study of community based facilities van Gennep (1994) noted improved ‘developmental levels’ where pro-active staffing methods were used (a ‘pedagogical’ approach). Heller et al (1997) suggest more variety and stimulation was associated with increased adaptive behaviour. Finally Conroy (1996), when comparing very small staffed houses with the more intensively regulated Intermediate Care Facilities (ICF/MRs typically serving eight people), found significant gains in adaptive behaviour in the former settings, but not in the latter.

In those studies that focused on the issue, the move from institutions generally appeared to have little impact on overall levels of challenging behaviour, although some positive developments were recorded by Fernando et al (1997), Collins and Halman (1996), Lucyshyn et al (1995) and Connealy et al (1992).

There are inevitably exceptions to this pattern. Bowen and Gerry (1995) report no discernible changes in adaptive behaviour following a move from an Australian institution into five-place community residences, while at the same time there were substantial increases in challenging behaviour. They feel a more individualised approach to the process of deinstitutionalisation was needed here. Salovita (1996) found some evidence of a ‘transfer trauma’, with increased levels of maladaptive behaviour, and some concern about the stability of the community arrangements. However, all negative effects had gone by the time of a follow-up six months later.

It is worth noting that while a change in adaptive behaviour can be viewed as an outcome of services, it also appears itself to be an important predictor of other outcomes, particularly in areas like participation within the house and in the wider community, or self-determination. A number of studies report less good outcomes (on a range of measures) for people with lower adaptive behaviour scores (see for example, Tossebro, 1995; Felce, Lowe, et al, 1998; Rapley and Beyer, 1996). In other words, making sure that people with the most needs for assistance share in the opportunities that are opening up remains a substantial challenge for services, a point we return to in the section on the implications of this research.

**PARTICIPATION IN DOMESTIC ACTIVITIES AND STAFF CONTACT**

Hatton and Emerson (1996) found generally higher levels of participation in meaningful activity within community based services than in institutional settings, although there was marked variation in the levels in all settings. At the same time, they noted that people in community based settings were likely to have greater direct contact with staff than in hospital, although once again, there was likely to be considerable variation between settings of the same type. Since ‘engagement’ and support are likely to be closely connected we look at the two issues together.
A number of complex points emerge. Firstly, the general pattern of greater participation or engagement in community settings (in comparison to more institutional settings) was generally confirmed (Connealy, et al, 1992; Felce, Lowe, et al, 1998). However, the level of engagement in many community settings was still often low (Joyce, 1994) and indeed in some instances, very low (for example, Rapley and Beyer, 1996).

Further, the extent to which people are supported or assisted to be involved in activities appears to be less a function of the overall staffing levels, than the way such resources are deployed. For example, Hatton et al (1996) found residents with greater skills got more staff support. In other instances the level of staff contact with residents was low or variable, with little evidence of practical assistance or encouragement (Rapley and Beyer, 1996).

Felce, Lowe et al (1998) found residents in small houses were getting direct contact from staff for an average of only 13 minutes every hour, although it was still higher than in traditional settings (average five minutes per hour). They also discovered that staff:resident interaction was actually higher in some community services with below average staffing levels, although the differences were not statistically significant. As a result of their analysis of the complex interactions between a number of factors, the authors concluded that many outcomes were largely ‘dually determined’ by ‘differences in resident ability and what staff did’.

Hatton et al (1996) found that positive staff:resident interactions and engagement in a service for people with complex need were a function of four factors: community location, specialised service orientation, cognitive abilities of residents and a high level of scheduled activity.

Finally, Emerson at al (1999) indicate that the provision of practical support to residents with severe learning disabilities and/or sensory impairments was associated with increased probability of engagement.

**PRESENCE AND PARTICIPATION IN THE WIDER COMMUNITY**

Perhaps not surprisingly, Hatton and Emerson (1996) had found the use of community based services was typically associated with greater presence in the community, with people making greater use of ordinary community facilities than their institutionalised counterparts. Nevertheless, the greater presence did not necessarily translate into greater participation. There were few differences between different settings in the level of friendships with people outside the service, nor was there much evidence of increased levels of involvement with families in the community settings.

Turning to the more recent research, there were some positive findings here. For example, Fernando et al (1997), Dagnan and Ruddick (1997), Joyce (1994) and Knobbe et al (1995) all found increased levels of activity and contacts within the local community after a move. Dagnan et al (1998) report similar findings, although they noted levels of participation appeared to have reached a plateau when followed up 53 months later.

However, in most studies there was a qualification; the extent to which people had been able to extend their social networks was often still limited. For example, in Sweden Ericsson (1999) commented that although most residents had relationships with people in the community that were neutral or positive, very few had friends outside the service. Murphy et al (1996) found that for a group of people with learning disabilities who had been previously
detained in a secure setting, overall scores on a quality of life measure approached those for a comparison group from the wider population (a group of unemployed people) in the less restrictive settings, although it increasingly fell short of this standard as placements become more restrictive. However, even in the better scoring placements, the people with learning disabilities had much more limited social networks than the comparison group. Using the same measure, Hughes et al (1996) found a similar pattern for a second group of ex-hospital residents now living in community settings.

There were also some community based services in which residents appeared to remain very socially isolated (Rapley and Beyer, 1996; Rapley and Hopgood, 1997). This is of particular concern in view of the findings from Campo et al (1997) that having a large circle of friends and family is an important predictor of other measures of quality, including a more personalised home environment and greater participation in activities both at home and in the community. The authors conclude that positive staff attitudes to friends and family is important in promoting relationships.

Heller, Miller and Factor (1998) found people living in community homes had higher levels of integration than those remaining in nursing homes. Like Campo et al they also point to the importance of the staff role in counteracting social isolation: they found that more resident involvement in policymaking, along with greater variety and stimulation, was associated with higher levels of social integration.

CHOICE, AUTONOMY AND THE VIEWS OF RESIDENTS

The review by Emerson and Hatton found that people in community settings typically had more choice over everyday aspects of their lives than those in institutional settings, although the difference was often relatively small. This was a pattern that was broadly replicated in the more recent studies that explored the issue (Dagnan et al, 1996; Fernando et al, 1997; Stancliffe and Abery, 1997; Joyce, 1994; Stancliffe and Lakin, 1998). In one of the more striking findings Tossebro (1995) concluded that reducing the size of the living unit was associated with greater levels of self determination and less ‘deprivitisation’ (a measure designed to tap into differences between a home and a facility). However, it was not a linear effect; it was only found in settings with five or fewer people. Stancliffe (1997) reported a broadly similar link, and also added that residents had appeared to have more choice in settings where staff were absent for periods of time. Although, as Lakin (1999) warns, it would be dangerously simplistic to assume that simply by cutting staff hours people will gain more autonomy, it does seem that the presence of staff can sometimes be a barrier for people with learning disabilities taking more control.

Although Stancliffe and Lakin had failed to find any relationship between the size of community settings and choice, they acknowledged that most of the community settings in their study were larger (averaging over six persons) than what may well be the critical point.

Finally Schwartz (1995) compared the experiences of people living in group homes and in supported apartments. People in the apartments were found to be more independent and had more opportunities to exercise choice in everyday life.

Clearly, the important people in all this are the people with learning disabilities themselves. Hatton and Emerson (1996) found a number of studies that incorporated the view of people
living in residential services and concluded, on the basis of their review, that people with learning disabilities were generally positive about the settings in which they lived, although residents in community-based services (particularly group homes) tended to be more enthusiastic than those still in institutional settings. They added that where they have a choice or a point of comparison most people would appear to prefer to be living in some form of community based setting.

We found that relatively few of the studies published since the Hatton and Emerson review reported the views of people with learning disabilities in depth, and several of those that did, while not contradicting Hatton and Emerson’s conclusions, complicated the picture slightly. For example, Mattika (1996), in a large scale Finnish study was somewhat surprised to find almost no link between type of residence and perceived quality of life. Instead, ‘happiness’ (the measure of quality of life used) was more a function of the characteristics of the people with learning disabilities themselves. Indeed greater happiness was associated with a positive self-image, with self-esteem and with a sense of autonomy. Equally, feeling stressed was associated with low self-esteem and a desire for more autonomy. He also found that gender was a factor, with women markedly more stressed than men.

Reiter and Bendov (1996) compared the views of people with learning disabilities living in group homes and those living at home with their families. Both groups were found to have a broadly positive self-concept and perceived quality of life. For those in the group homes, their feelings about themselves were bound up with a sense of competence and independence, as well as their perceived social integration. Reiter and Bendov also found that staff rated the users as more independent and integrated than the users themselves.

Issues of control and autonomy were particularly salient for the group of people with learning disabilities interviewed by Murphy et al (1996), all of whom had previously been detained in a secure setting. Although they were said to have appreciated some features of their past care, they also expressed strong feelings about the aspects of their former regime which had restricted their liberty.

Finally, in a small scale qualitative study of people in a range of settings, Holland and Meddis (1997) found that four out of the six people with learning disabilities they interviewed were broadly positive about their current service. For people who liked the service, having choice and freedom were among its important features. However, four also expressed a desire to leave. In each case they wanted to move to an option that would provide greater independence. The desire to move appeared to reflect a combination of inter-personal issues (for example, dislike of other residents, a partner they wanted to live with, or tension between themselves and a carer) plus a knowledge of the alternatives.

**IMPLICATIONS**

Given the sheer volume of data now accumulated, it would be difficult to disagree with Hatton and Emerson’s conclusion:

*Where robust differences are apparent, it is clear that smaller community-based homes are associated with better performance and more positive outcomes than either hostels or hospitals.*
Certainly none of the studies that have been published since then even remotely challenges that basic position. There are, of course, some dissenters. As a way of exploring the robustness of our conclusion we look at instances of this dissent in a little more depth. Two recent sets of papers, both from the US, have argued against the general trend. In both cases they were the focus of a debate in the journal *Mental Retardation*. The issues of concern were:

* statistical interpretation
Conroy (1996) had presented data which, he argued, demonstrated that the more flexible and less intensively regulated community living arrangements (CLAs) outperformed the more highly regulated provision funded (and therefore licensed) through the Intermediate Care Facility programme (generally known in the US as ICF/MRs). This paper was subsequently the subject of an article in the same journal (Crinella, McCleary and Swanson, 1998) which rejected these findings on methodological grounds. Essentially they argued that the result reflected a flawed research design, and concluded that Conroy’s paper undervalued the ICF/MRs.

The same edition of the journal included both a response from Conroy (effectively both sides accuse each other of, respectively, pro and anti-institutional biases) and a rather more measured evaluation of both papers commissioned by the journal (Heifetz, 1998). The latter concluded that the paper by Crinella and colleagues provided no substantial evidence against Conroy’s findings, although Heifitz added that his analysis required a small reduction in Conroy’s pro-CLA results, and some more substantial questions about their generalisability.

* mortality
An analysis of mortality in California by one particular research team generated a similar pattern of debate. Strauss et al (1998a and 1998b) claimed there was evidence of higher mortality rates in community settings than in institutions, particularly for people with poor mobility or self-help skills. This was in contrast to a number of other studies which had showed lower rates of mortality in community settings (Conroy and Adler 1998; Hayden, 1998) and was also challenged by a team from the same institute (O’Brien and Zaharia, 1998) who re-analysed the data and came to the opposite conclusion; there was no increased risk of death from a community placement and that mortality in community settings (unlike in the institutions) had shown a declining trend. Even so, the debate served to underline the importance of adequate health care wherever people live (Lakin, 1998), a point echoed by Christian et al (1999) who found the majority of the community based staff had not received any systematic training in the use of psychotropic medication.

Therefore on the basis of the evidence (let alone any argument based on principle) it seems safe to conclude that there is no basis for a reversal of the current trends and a return to larger settings. Indeed, there is some evidence that very small is better than small (see also chapter 4), though as always this needs to be qualified: size might be a factor in determining quality, but it is only one of many.

However, Hatton and Emerson’s second conclusion also (rather unfortunately) appears still to hold. That is, while small homes might be better than more institutional settings, they are not consistently good; the quality of these services is very variable.
Given the variable quality of so many services, there have been a number of attempts to find organisational responses which would ensure more appropriate services. The development of specialist challenging behaviour support teams is a case in point (Allen and Kerr, 1994). However, their successes have been rather mixed. For example, Lowe et al (1996) found that improved outcomes for individuals with challenging behaviour did not necessarily follow from the introduction of such services. They point to the continuing limitations of the residential settings in which people were living, and conclude that such specialist teams will have difficulty influencing the development of services without resources to reshape and restructure them.

The focus of attention therefore has inevitably returned to a debate about the factors that will make a difference in terms of ensuring the basic quality of small housing services, particularly for people with the greatest needs for assistance (see for example, Ashman, 1997). In the UK at least, the emphasis has been on increased operational sophistication:

... the key determinant of quality of residential care is the way staff provide support to individual service users; therefore the improvement of services requires management focus on staff training, leadership and practice, instead of on buildings and location.

(Mansell, 1998)

... if as the research seems to show, supporting people with learning disabilities is not an intuitive skill, it will be the adoption of effective working methods, backed by good management and staff training, which will result in the delivery of support, not a further appeal to ordinariness.

(Felce, 1999)

One result of this analysis has been the development of what is generally now called the ‘active support’ model. This essentially combines a form of person-centred planning with activity planning and staff training. The latter places particular emphasis on ensuring that staff know how to facilitate and support the participation of people with severe learning disabilities using a range of techniques that do not simply rely on verbal prompts. There is now some evidence that the use of active support training in small houses can help ensure that support is targeted on those who need it, and that it significantly increases the engagement of people with the greatest needs for assistance (Jones et al, in press; Tindall, 1999).

Active support appears to be a promising direction. However, as even its proponents recognise, it is unlikely to be the whole story (see Felce, 1999), an issue we pick up in the next chapter.
<table>
<thead>
<tr>
<th>Year</th>
<th>Authors</th>
<th>Type/size of residence</th>
<th>Sample size</th>
<th>Country</th>
<th>Move from inst.?</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>Bowen and Gerry</td>
<td>5 bed community residence</td>
<td>10</td>
<td>Australia</td>
<td>yes</td>
<td>Used Adaptive Behaviour scale and found no discernible changes in adaptive behaviour. Substantial increases in maladaptive behaviour. Argues for a more individualised approach to overcome this situation.</td>
</tr>
<tr>
<td>1997</td>
<td>Campo, Sharpton, Thompson and Sexton</td>
<td>Community-based homes of 4-5</td>
<td>60</td>
<td>USA</td>
<td></td>
<td>Quality of life a function of three factors: individualisation, incorporation of integrated activities, balancing independence and interdependence. The number of family and friends in social networks was positively associated with more personalised home environment as to greater participation in home and community integrated activities. Positive staff attitudes towards family and friends were also important in promoting social relationships.</td>
</tr>
<tr>
<td>1996</td>
<td>Collins and Halman</td>
<td>Small homes, 4-7 beds</td>
<td>16</td>
<td>UK</td>
<td>yes</td>
<td>No dramatic or automatic decrease in challenging behaviour. Rates of aggression towards residents decreased significantly, and aggression towards staff and self-injurious behaviour showed non-significant downward trends but destruction of</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Setting Description</td>
<td>Participants</td>
<td>Country</td>
<td>Results</td>
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<tr>
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<tr>
<td>1992</td>
<td>Connealy, Boyle and Smyth</td>
<td>5 bed group home and 6 bed group home</td>
<td>11</td>
<td>Ireland</td>
<td>Increased levels of adaptive behaviour and decreased levels of maladaptive behaviour. The residents were found to engage in more purposeful activities when they had moved to a smaller setting.</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Conroy</td>
<td>Small staffed homes larger ICF/MRs</td>
<td>51 matched pairs</td>
<td>USA</td>
<td>Staffed homes superior on 10 out of 35 measures including gains in adaptive behaviour, plus more autonomy, greater presence, and better ratings of procedures.</td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Dagnan and Ruddick</td>
<td>Small staffed homes of 3-4</td>
<td>52</td>
<td>UK</td>
<td>Found that 92% of residents had at least one person in their social network, mean was 3.1. 29% had contact with people without disabilities. Relationships with family and friends were maintained when they moved to the community. Relationships were not affected by their level of disability.</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>Dagnan, Ruddick and Jones</td>
<td>3-4 bedroom homes</td>
<td>29</td>
<td>UK</td>
<td>Increases in levels of social activity and contacts in the first 41 months, levelling out at 53 months (older people).</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Dagnan, Trout, Jones and McEvoy</td>
<td>Small unit in community for challenging behaviour</td>
<td>4</td>
<td>UK</td>
<td>Quality of life improved substantially, especially in areas of activity, choice and dignity.</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Dagnan, Trout, Jones and McEvoy</td>
<td>Small unit in community for challenging behaviour</td>
<td>4</td>
<td>UK</td>
<td>Used more unsegregated facilities and their quality of life improved</td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Setting</td>
<td>Sample Size</td>
<td>Country</td>
<td>Results</td>
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<tr>
<td>1999</td>
<td>Emerson, Hatton, Robertson, Henderson and Cooper</td>
<td>Specialised services in community, various types.</td>
<td>40</td>
<td>UK</td>
<td>Residents had severe difficulties and/or sensory impairments. Results indicate that practical support was associated with an increased probability of engagement of participants.</td>
<td></td>
</tr>
<tr>
<td>1999</td>
<td>Ericsson</td>
<td>Community housing</td>
<td>266</td>
<td>Sweden</td>
<td>Most people (82%) had relationships with people in the neighbourhood that were neutral or positive. However, very few had friends outside the service.</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Felce and Perry</td>
<td>Small staffed houses</td>
<td>51</td>
<td>UK</td>
<td>Used Adaptive Behaviour Scale over 2 year period. ABS scores increased significantly over time, especially amongst the least able.</td>
<td></td>
</tr>
<tr>
<td>1997</td>
<td>Felce and Perry</td>
<td>1-7 residentia l services</td>
<td>14</td>
<td>UK</td>
<td>Higher PASS scores were generally associated with smaller size of residence, plus resident ability. While houses were reasonably ‘home-like’ staff lacked ‘organised means and competancies’ to promote personal development and participation.</td>
<td></td>
</tr>
<tr>
<td>1998</td>
<td>Felce, Lowe, et al. (see also Lowe et al, 1998)</td>
<td>Family homes, specialist community housing and traditional services</td>
<td>39</td>
<td>Wales</td>
<td>Highest levels of engagement were found in the community homes. These levels were associated with a higher percentage of qualified staff and below average staff/resident ratios. Community based services ‘preferred</td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Type of Setting</td>
<td>Sample Size</td>
<td>Country</td>
<td>Success</td>
<td>Results</td>
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</tr>
<tr>
<td>1997</td>
<td>Fernando, Kohen, Sebaratnam and Mathew</td>
<td>Community-based homes</td>
<td>22</td>
<td>UK</td>
<td>yes</td>
<td>Found improvements in stereotyped behaviour and symbolic activities, though also deterioration in levels of incontinence and mobility. Also some improvements in social interactions. In the community-based homes, it was found that residents had a wider choice in the range of activities available.</td>
</tr>
<tr>
<td>1996</td>
<td>Hatton, Emerson, Robertson, and Cooper (see also Hatton et al. 1995)</td>
<td>Move from inst. to Small staffed</td>
<td>40</td>
<td>UK</td>
<td>yes</td>
<td>Factors relating to more positive staff:resident interactions in service for people with complex needs: community location, specialised service orientation, cognitive abilities of residents and a high level of scheduled activity. Some evidence of inverse care law: residents with greater skills receive more staff support, even though services designed for less able.</td>
</tr>
<tr>
<td>1998</td>
<td>Heller, Factor, Hsieh and Hahn</td>
<td>Nursing homes and community-based housing</td>
<td>232</td>
<td>USA</td>
<td>yes (67 of sample)</td>
<td>Those that moved to the community showed improvements in community functioning and increases in lifestyle functioning.</td>
</tr>
<tr>
<td>1998</td>
<td>Heller, Miller and Factor</td>
<td>Community-based facilities compared to nursing home</td>
<td>249</td>
<td>USA</td>
<td>yes (50 of sample)</td>
<td>Residents of the smaller facilities had greater adaptive behaviour than those in larger. More variety and stimulation was associated with greater adaptive behaviour. More</td>
</tr>
</tbody>
</table>
resident involvement in policymaking, along with greater variety and stimulation, associated with higher levels of social integration.

<table>
<thead>
<tr>
<th>Year</th>
<th>Authors</th>
<th>Study Description</th>
<th>Sample Size</th>
<th>Sample Type</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>Holland and Meddis</td>
<td>Community-based residences from other various settings</td>
<td>6</td>
<td>UK</td>
<td>3 of sample</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Four of the six interviewed were broadly positive about the service they were using, although four also wanted to leave. In each case they wanted to move to an option that would provide greater independence. The desire to move reflected interpersonal issue, plus a knowledge of alternatives. For people who liked the service having choice and freedom were among the important features.</td>
</tr>
<tr>
<td>1996</td>
<td>Hughes, McAuslane and Schur</td>
<td>Hospital to ordinary homes</td>
<td>41</td>
<td>UK</td>
<td>yes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Used life experiences checklist to compare experiences of people with learning disabilities living in ordinary housing with those of a range of sub-groups from the general population (including people with similar socio-economic status). In many areas (home, leisure opportunities and freedom) the score for the people with learning disabilities was similar to or better than the comparison groups. However, this was not the case with relationships, (people with learning disabilities</td>
</tr>
</tbody>
</table>
were much less likely to have a partner, or to have had friends to stay at least once a year).

<table>
<thead>
<tr>
<th>Year</th>
<th>Author(s)</th>
<th>Setting</th>
<th>Sample Size</th>
<th>Country</th>
<th>Deinstitutionalised</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Undated</td>
<td>INICO</td>
<td>Group home (5)</td>
<td>5</td>
<td>Spain</td>
<td>yes</td>
<td>Improved Adaptive behaviour</td>
</tr>
<tr>
<td>1994</td>
<td>Joyce</td>
<td>Hospital, hostels and ‘ordinary houses’</td>
<td>68</td>
<td>UK</td>
<td></td>
<td>Engagement levels did not differ significantly between the three types of service. On other measures (including autonomy, presence, community contacts and possessions owned and used) houses scored better. People in houses also had higher levels of adaptive behaviour despite higher levels of intellectual disability. However, there was also some evidence of institution oriented practices and over-formalised management of the homes.</td>
</tr>
<tr>
<td>1995</td>
<td>Knobbe, Carey, Rhodes and Horner</td>
<td>Community-based homes</td>
<td>11</td>
<td>USA</td>
<td></td>
<td>Significant improvements found in social networks and opportunities for integrated activities.</td>
</tr>
<tr>
<td>1995</td>
<td>Lucyszyn, Olson and Horner</td>
<td>3 bed house. 2 residents, 1 staff</td>
<td>1</td>
<td>USA</td>
<td>yes</td>
<td>Problem behaviours were at a low level for long periods and incidences of self-injurious behaviour reduced.</td>
</tr>
<tr>
<td>1995</td>
<td>Maisto and Hughes</td>
<td>Group homes. Some previously in inst., other not</td>
<td>80</td>
<td>USA</td>
<td>yes (42 of sample)</td>
<td>Both groups (ie those previously institutionalised and those not) had a significant increase in overall adaptive behaviour. The deinstitutionalised group functioned at a higher</td>
</tr>
<tr>
<td>Year</td>
<td>Authors</td>
<td>Study Details</td>
<td>Sample Size</td>
<td>Country</td>
<td>Findings</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>1996</td>
<td>Mattika</td>
<td>Group homes, own homes, family homes, institutions and foster homes</td>
<td>619</td>
<td>Finland</td>
<td>7% of sample; Almost no connection found between living conditions and perceived quality of life. Happiness was used as a QOL variable and was found to be associated with a positive self image and others’ view of self, with self-esteem and with a sense of autonomy.</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Murphy, Estien and Clare</td>
<td>Move from secure service to a variety of community-based housing</td>
<td>26</td>
<td>UK</td>
<td>yes; Although the overall score on the quality of life measure approached those for a comparison group from the wider population (a group of unemployed people) in the less restrictive settings, it increasingly fell short of this standard as placements become more restrictive. However, even in the better scoring placements, the people with learning disabilities had more limited social networks than the comparison group. This was a group that had previously been in a secure setting, and although they appreciated some aspects of the service, they had strong feelings about the features of their past care which had restricted their liberty.</td>
<td></td>
</tr>
<tr>
<td>1996</td>
<td>Rapley and Beyer</td>
<td>Supported houses</td>
<td>14</td>
<td>UK</td>
<td>yes; Found evidence of disengagement and isolation; most people had no contact with non-disabled people and few friends. More dependent</td>
<td></td>
</tr>
</tbody>
</table>
Residents very reliant on staff support, with less social and recreational activity outside home. Domestic participation levels were low to non-existent. Staff were found to be involved with clients for one-third of the time observed but not generally assisting or encouraging people.

<table>
<thead>
<tr>
<th>Year</th>
<th>Authors</th>
<th>Setting</th>
<th>Participants</th>
<th>Country</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1997</td>
<td>Rapley and Hopgood</td>
<td>5 residences for 34 people</td>
<td>34</td>
<td>Australia</td>
<td>Rural area. Found restricted scope for domestic participation, little autonomy and impoverished community membership, especially for those with lower ability levels.</td>
</tr>
<tr>
<td>1996</td>
<td>Reiter and Bendov</td>
<td>Group homes and family homes</td>
<td>65</td>
<td>Israel</td>
<td>Both groups were found to have a broadly positive self-concept and perceived quality of life. For those in the group homes, their feelings about themselves were bound up with sense of competence and independence, as well as their perceived social integration. Reiter and Bendov also found that staff rated the users as more independent and integrated than the users themselves.</td>
</tr>
<tr>
<td>1996</td>
<td>Salovita</td>
<td>5 bed community residence</td>
<td>83</td>
<td>Finland</td>
<td>‘Transfer trauma’ caused an increase in maladaptive behaviour and 47% had concerns about the stability of their living arrangements. All negative effects had gone by 6 month follow-up.</td>
</tr>
<tr>
<td>Year</td>
<td>Author(s)</td>
<td>Setting Description</td>
<td>Sample Size</td>
<td>Country</td>
<td>Outcome</td>
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<td>---------</td>
</tr>
<tr>
<td>1995</td>
<td>Schwartz</td>
<td>Group homes and apartments</td>
<td>120</td>
<td>Israel</td>
<td>People in the apartments were found to be more independent and had more opportunities to exercise everyday choices.</td>
</tr>
<tr>
<td>1997</td>
<td>Stancliffe</td>
<td>Supported residents of 1-5</td>
<td>65</td>
<td>Australia</td>
<td>Significantly greater choice was exercised by individuals in smaller settings. More choice was displayed in settings where no staff members were present for periods of time.</td>
</tr>
<tr>
<td>1997</td>
<td>Stancliffe and Abery</td>
<td>Large ICF/MRs to small ICF/MRs and small community houses</td>
<td>127 (56 movers and 71 stayers)</td>
<td>USA</td>
<td>yes</td>
</tr>
<tr>
<td>1998</td>
<td>Stancliffe and Lakin</td>
<td>Large ICF/MRs to small ICF/MRs and small community houses</td>
<td>187 (116 movers and 71 stayers)</td>
<td>USA</td>
<td>yes</td>
</tr>
<tr>
<td>1995</td>
<td>Tossebro</td>
<td>Commun 591 Norway</td>
<td>591</td>
<td>Norway</td>
<td>Concludes that facility</td>
</tr>
</tbody>
</table>
ity based homes, mean size 6.5 people

<table>
<thead>
<tr>
<th>Year</th>
<th>Author</th>
<th>Setting</th>
<th>Number</th>
<th>Country</th>
<th>Results</th>
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<td>1994</td>
<td>van Gennep</td>
<td>Group homes, socio-homes and small institutions</td>
<td>50 groups of residents</td>
<td>Holland</td>
<td>Improved developmental levels were found when a new, pedagogical approach was used but not when there were no changes taking place in the living units. Reductions in numbers of residents below 5 had a large impact, associated with more self-determination and less ‘deprivitization’.</td>
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CHAPTER 4: A HOME OF MY OWN: THE LESSONS FROM SUPPORTED LIVING SERVICES

INTRODUCTION

In chapter 1 we described supported living as a form of intensive domiciliary service (support provided to people in their own home). Inevitably this represents a gross over-simplification. However, before moving on to discuss supported living in more detail, it is worth dwelling on the concept of ‘domiciliary services’. In the UK domiciliary services have traditionally been the preserve of elderly people, people who had acquired their housing earlier in life. Faced with increasing physical or mental frailty, many choose to remain in their own home (rather than go into residential care), with services (ranging from home care to nursing services) being brought in to help sustain them in that choice. The promotion of domiciliary services for elderly people has been a feature of Government policy for well over a decade. By and large the general principle is not questioned, principally because people already have their own homes. This is generally not true for people with learning disabilities no longer living in their family home. In most instances services will have to create a combined ‘housing and support’ option. In structural terms this might not be that different to the service used by the disabled elderly person down the street, yet many agencies have found the concept of supported living far harder to both grasp and accept. It is fair to say that supported living, like many relatively new ideas, is more talked about than done.

This chapter attempts to describe the origins of supported living, outline the ‘principles’ of supported living that have been articulated by its supporters, and to review the evidence relating to its implementation.

THE ORIGINS OF SUPPORTED LIVING

To describe supported living as an entirely new idea is misleading. People have been doing things that would fit within the framework of supported living for some time (see, for example, ideas about ‘lifesharing’ - Tyne and Morris, 1990). However, the numbers of such arrangements were tiny. In the UK, the use of supported living as a clearly defined term emerged after the publication of two short reports by Peter Kinsella in 1993 (Kinsella 1993a and 1993b). Kinsella had just returned from a year in the US where he had witnessed some of the newer developments in Wisconsin.

The ideas articulated by Kinsella and by other writers on supported living appeared to strike a chord with many people in both the US and the UK. By and large they were people who had supported the development of the so called ‘ordinary life’ services described in the previous chapter. However, there was increasing frustration at the failure of such services to live up to the notion of an ordinary life. At the same time, expectations of what an ordinary life might involve had also risen. The assumption that life in a group home could necessarily be ‘ordinary’ was coming under fire, partly at least as a reflection of the idea of ‘independent living’ developed by the wider disability movement (see for example, Morris, 1993).

\[11\] Of course there are individuals who inherit property.
The result was a comprehensive critique of the way that services had developed (see for example, Kinsella, 1993b; O’Brien, 1991). This included concerns that services typically:

* provide an environment that is physically home-like, but which offer a lifestyle which is still very substantially different from the experience of most citizens. People are living in homes that belong to organisations, not to the individuals using the service, and this has a substantial impact on the way they work.

* preclude the opportunity for people with learning disabilities to choose with whom they live. In too many instances they end up sharing with people they do not like or whom they even fear.

* offer little security of tenure. People are moved, not because they want to move, but because they do not ‘fit’ the service.

* continue to be controlling, with few opportunities for individuals to be autonomous.

* leave most people socially isolated. The location and design of services generally fail to take into account the existing links with family, friends and community, and then compound the problem by failing to help either maintain or develop new relationships.

* show little sign of individual planning in their design of services. Most people have to fit within standardised levels of resourcing and practices that reflect organisational concerns rather than the needs and aspirations or individuals.

* are not comprehensive. Individuals are excluded from particular options because services are insufficiently flexible to accommodate their specific needs.

In effect, far from supporting the principles of an ‘ordinary life’, it is argued that all too often services act to maintain exclusion.

There are some clear parallels with the concerns expressed by researchers in the previous chapter. However, the emphasis is rather different. Rather than focusing primarily on staff practice, these criticisms are concerned with the wider policy context. Implicitly, there is an assumption that, in part at least, the problems stem from the way that services are developed, organised, funded, regulated and managed. In this context it is therefore perhaps not surprising that supported living represents a radical attempt to change the structure of services.

A DEFINITION

As a defined concept, supported living is most clearly identified with the US and the UK, although we were able to find examples in a range of other countries including Ireland (Hennessy, undated), Holland (Van Gennep, 1997a and b), Canada (Roeher Institute, 1996) and Sweden (Ericsson, 1996).
There is now a wealth of material that defines the principles of supported living and reflects on the experiences of trying to put it into practice in a wider framework which is still at best neutral and at worst hostile (for example, some of the original texts include O’Brien, 1991; O’Brien 1993; O’Brien and O’Brien 1994; Smull and Danehey, 1994; Racino and Taylor, 1993; Kinsella, 1993a). The definition we use here is effectively a composite summary of these different sources.

Supported living is primarily about enabling people with learning disabilities to be actively engaged citizens through:

* supporting them to live in their own homes (owned or rented by them)
* enabling them to participate in their communities (for example through working if they wish).

There are effectively four distinct ‘planks’ underpinning supported living:

* **person centred planning**
  Services should be designed and developed around the needs and aspirations of individuals. By definition this means developing a ‘technology’ for both developing a comprehensive view of what the needs and aspirations are, and also translating them into concrete arrangements.

* **individualised support**
  Supports are attached to individuals, not to buildings.

* **bridge building (community development)**
  Individualised support is only part of the story. There will also need to be community development work to open up a range of opportunities, including housing, work and community participation.

* **systems change**
  Many of the original advocates of supported living argued that the wider service system would have to be adapted to make supported living possible.

In terms of the specific focus of this report (housing and support services) supported living has meant:

* **opening up a full range of housing options**
  Choice is not limited by the existing pattern of services. People should be enabled to access a much wider range of both physical properties and living arrangements.

* **designing services around community**
  People’s community of origin, and their links with family and friends should be a starting point in terms of services design. In this context location becomes critical. Far too many people have to move to where traditional services are located. Supported living represents an attempt to halt the process of their exclusion from many communities. There has also been a lot of emphasis on trying to ‘build’ new
community links around isolated individuals; supported living has therefore become closely linked with ideas like circles of support (Wertheimer, 1995).

* **ensuring people can choose with whom they live**
Some people in supported living arrangements live alone. Others share with friends with learning disabilities or non-disabled people (options ranging from ‘support tenants’ to full blown ‘lifesharing’).

* **contractual separation of housing and support**
Fundamentally, supported living represented a rejection of the idea that people’s choice of home should be determined primarily by their support needs. For this reason, the separation of housing and support was critical in philosophical terms. In the UK it was also important for practical reasons: the appropriate separation of housing and support is critical in ensuring that such arrangements do not fall within the scope of registration and inspection.12 While this involved moving outside the established regulatory framework, the separation of housing and support provided opportunities for adding in new ‘checks and balances’. The flexibility of the arrangements means that if something goes wrong it is easier to reconfigure the service (the support provider can be changed without forcing the individual to move, and vice versa).

* **people have the security and status of being tenants or owners**
One of the paradoxes of residential care is that a system for vulnerable people actually leaves them with fewer rights and less security. Having the status of tenant or owner provides an additional degree of protection.

* **nobody should be seen as ‘too disabled’ to live in their own home**
As Felce (1999) has pointed out, the greater people’s needs for support are, the more they are likely to live in ‘pathologically’ defined groups, excluded from all but a limited range of options. Where people do not fit into existing service patterns they are likely to be moved or rejected by service providers as being too difficult to accommodate. On the other hand supported living works on the principle of adapting support to the person involved. For people who are very challenging to services this is always going to be difficult, but from the start the argument was that supported living should be comprehensive, that nobody should be excluded from these individualised options. Indeed, it could be argued that the more complex an individual’s needs are, the more they are likely to gain from individually designed supports (see for example, SSI 1996).

* **people should have as much control as possible over the services they use**
To live in one’s own home is to be in control of the major decisions about what happens within it. As far as is possible, people should be determining their own lifestyles. We explore some of the ways this has been operationalised in chapter 5.

As should be apparent by now, supported living is an ambitious and complex set of ideas on which to base services; in the best sense of the word it is idealistic. This has two consequences. Firstly, there is some scepticism as to whether such an approach is viable, both in terms of practicality (we look at the evidence later) and affordability, and some questioning

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12 See Simons and Ward, 1997 for a fuller discussion of this issue.
of whether, even if implemented, supported living would necessarily deliver the kind of improvements in services its supporters hope for (see Hatton, 1996).

Secondly, the message gets simplified and distorted in the process of transmission, with some confusion about what supported living is - and is not (see Simons and Ward, 1997). Some aspects of supported living tend to be de-emphasised. For example, in the UK there has been relatively little discussion of the wider systems change needed for making supported living more than a marginal activity (Simons, 1998a), while other aspects are seized upon, for example the separation of housing and support. On the whole, this is not surprising. However, at this point it is worth emphasising some points.

Supported living is:

* **not a single model**
  There will be many different kinds of arrangements (Klein, 1998), designed for different circumstances, and with different strengths and weaknesses. Supported living represents a way of thinking about services not a precise set of instructions (Kinsella, 1993a).

* **more than simply deregistering group homes and giving the tenants a tenancy**
  These steps may be appropriate in certain circumstances, but it is not supported living, simply an unregistered group home.

* **not a magic wand that will instantly resolve all problems**
  For example, the implementation of supported living services will not resolve the dilemma involved when people do things that are a danger to themselves or others. There will still be a need for skilled professional intervention (Howard, 1996).

**EVIDENCE FOR THE VIABILITY OF SUPPORTED LIVING**

Most of the earlier material on supported living was primarily focused around case studies, descriptions of particular service organisations or individual arrangements (see, for example, Bradley, et al, 1994; Taylor et al, 1991; Racino et al, 1993; Fitton et al, 1995; Simons and Ward, 1997 and Wertheimer, 1998). This material has undoubted value; it has helped to show how the principles can be articulated in practice, and demonstrates that, in some circumstances at least, it is possible to create opportunities that fit the supported living framework and which, taken at face value, represent high quality, reliable support systems for a range of individuals (Simons and Ward, 1997). Of course this leaves the critical question of how easy it would be to generalise these approaches. These options may work for particular individuals, but is it feasible to implement these ideas on a grander scale? In addition the essential qualitative nature of this data has not convinced some sceptics.

It is only recently that more formal evaluations of supported living have started to appear. For example, in Oregon, Howe and colleagues (1998) carried out a study of the supported living

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13 As Collins (1996) points out there is some degree of separation in many residential care arrangements, with the property being provided by a social landlord, and the support provided by a separate not-for-profit organisation. This has led some organisations to claim they are doing 'supported living' within the framework of residential care (Simons and Ward, 1997).
arrangements for 20 individuals chosen at random from amongst users of supported living services who were then matched with individuals in ‘more traditional residential services’. The researchers were able to distinguish between the two sets of services in terms of some of the features that fitted the supported living principles (as the authors comment this was not something that could necessarily be taken for granted), including being an owner/renter, choice of housemate (if any), involvement in the development of support arrangements, and greater autonomy. However, for some of the other criteria examined (for example, use of natural supports, choice of location) there was no significant difference between the services. People in supported living settings lived with fewer people; the average was actually less than one housemate, compared to nearly six in more traditional services. Finally, there was some evidence of differences in staff practice. In the supported living arrangements there was said to be more emphasis on support and supervision and less on providing instruction and training.\textsuperscript{14}

At the same time, the people in supported living arrangements were also more likely to have access to a more extensive range\textsuperscript{15} of community based activities than the people in traditional settings. Further, there was some evidence of extended social networks; the supported living participants tended to undertake the activities with a wider range of people.

This information, coupled with data on costs (see chapter 8) led the authors to conclude that:

\begin{quote}
The present data ... suggest that Oregon’s policy decision to establish supported living options is a cost-neutral strategy for improving some important aspects of lifestyle quality for its citizens with disabilities.
\end{quote}

Van Gennep (1997a) briefly outlines the result of a small supported living initiative in Rotterdam, primarily designed for people with moderate learning disability. Overall, he describes it as a success for nine of the 12 participants, and a ‘moderate success’ for the remaining three, with all the individuals being sustained in their own homes during the period of the study and being largely satisfied with the arrangements. It is worth noting that all three for whom the services was judged to be only a moderate success were said to have very limited social networks, and two of these individuals also had difficult relationships with partners.

Lakin, Hayden and Burwell (1996) provide a summary on the impact of a Medicaid Community Supported Living Arrangements (CSLA) Programme. This was a special demonstration programme established over a five year period, designed to enable states (eight in all) to explore reforms of their Medicaid funding rules for community based services, including various supported living arrangements and family support services. Part of the problem had been Medicaid eligibility criteria that precluded people who did not need ‘active treatment’. One of the aims of the CSLA programme was therefore to enable states to

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\textsuperscript{14}This last finding is a little difficult to interpret in a UK context, and probably relates to the regulatory requirement for ICF/MRs to provide formal ‘treatment’ programmes. In principle, there is no reason why supported living arrangements should not be helping people to develop a range of competencies.
\textsuperscript{15}This was in terms of absolute number of activities, in the different types of activities, and in the extent these activities matched preferences.
\end{flushright}
provide a more comprehensive service. Therefore many of the CLSA participants were younger and less disabled than the typical user of long-term services.

The report by Lakin and his colleagues is primarily about the structural implications of the CLSA programme (see chapter 8). There had been some local monitoring of outcomes and these clearly informed the report. However, there is no specific outcome data in the report, although it does give some indications of both the success of the programme and problems encountered.

For example, the report mentions that the experiences of the CLSA programme resulted in a more generalised expansion of supported living services in six of the eight states. Two thirds of CLSA participants were able to live in their own homes, either alone or with a housemate (only 1% of participants ended up sharing with more than three people). The use of both paid and non-paid non-disabled housemates was common, along with some examples of the creative use of people like neighbours in ‘natural’ support roles.

On the other hand there were some problems. The lack of employment opportunities was said to be one of the greatest sources of dissatisfaction with less than half the participants in some form of work. Social isolation continued to be a problem for many CSLA participants. This was particularly the case for people who had previously been living in group homes or who had moved from their community of origin:

... it is easier to maintain social networks and relationships than to create them anew.

Further, few staff were well trained or well supported in developing or promoting social inclusion.

Developing appropriate quality assurance and monitoring programmes proved to be a considerable challenge, in particular managing a balance between providing sufficient oversight without imposing licensing conditions that frustrated the aims of services.

Many of the problems were said to stem from the financial limitations of the CLSA system. The lack of access to work reflected the continuing problems with funding vocational activities using Medicaid. Similarly, many of the case managers involved in the CSLA programme lacked experience of supported living and person centred planning and had large caseloads; the lack of funding for more intensive care management was cited as one of the limiting factors.

One of the earlier UK evaluations involved the South Warwickshire Accommodation Project, which informally reported a range of positive outcomes for the 21 participants (Ryburn and Wellstead 1997), based on interviews with the individuals, their support workers and their families. However, they also recognised a number of problems. Some people were lonely, and still relatively isolated. The authors of the report concluded that it had been easier to tackle housing issues than to tackle the wider issues of lifestyle and community. There had been some concerns about the possibility of vulnerable people being exploited, although it is not clear that anything actually happened. Also, there had been some conflict between the participants and the families about standards of hygiene in some of the homes; the report comments on the difficulty of:
Finally, the UK Department of Health commissioned a large scale comparative study of a range of service options including village communities (see next chapter), hospital campuses and ‘dispersed housing’. This latter category included examples of both supported living and community based staffed houses/group homes. This study is likely to make a significant contribution to our knowledge about a number of options. However, to date only limited preliminary data is available (Emerson et al., 1999b). Luckily this does at least provide some initial comparisons between supported living and the other forms of community based services.

The study collected data on 281 individuals chosen at random from 10 services provided by 10 different agencies, all of whom were considered to represent exemplary practice. Although only one of these agencies focused solely on supported living, another five provided a mixture of both group homes and supported living. As a result, the researchers were able to collect data on 63 people who had access to a service that was both labelled as supported living and which met basic selection criteria (for example, the arrangement was not registered as a residential care home and there were not more than three co-residents). Of the remaining participants in the study, 55 were living in small group homes (1-3 people), with 152 in larger homes (4-6 people). It is worth noting that the researchers found some inconsistency in the labelling of services. For example, 20 people said to be living in supported living were excluded either on the grounds that their home was registered, or that there were more than three co-residents!

The supported living arrangements appear to be associated with some positive advantages over the group homes. For example, they:

* were much more likely to provide users with a tenancy agreement, although somewhat alarmingly this was true of only just over two thirds of the sample
* tended to deliver more intensive staffing than the alternatives
* had better internal procedures for allocating staff support on the basis of the needs of tenants
* showed evidence of greater choice for tenants overall, and in particular over the question of where and with whom they lived
* enabled people to participate in a greater number of community based activities.
* were more likely to have ensured that tenants had a recent hearing check.

However, on many of the variables examined, there were no differences between supported living and the group homes. Indeed, there were some instances where supported living appeared to be associated with some disadvantages. These included:

* tenants were likely to have fewer hours of scheduled activity during the day
tenants were more likely to have had their house vandalised (17% compared to between 5% and 7% for the group homes

supported living arrangements appeared to offer poorer implementation of ‘habilitative’ procedures (for example, they were less likely to have a designated key worker, an individual plan, and internal procedures for assessment and teaching were said to be weaker).

Some of the findings are a little difficult to interpret (for example person centred planning appear to be relatively rare in all settings)¹⁶ and to complicate matters there appeared to be instances where supported living and arrangements and small group homes both outperformed the larger settings (for example, offering larger social networks, and less ‘depersonalised’ regimes). Small group homes also appeared to offer less perceived risk of abuse by co-residents than the larger settings.

**IMPLICATIONS**

Although the available evidence is still rather thin, supported living appears to do relatively well when subject to formal evaluation. On the basis of the information available, supported living can claim to be a practical as well as a principled option, one that has a legitimate claim to be a key part in any commissioning strategy.

However, it is also clear that its implementation poses a number of challenges to services. While supported living might offer a framework for helping people with learning disabilities maintain their existing connections and relationships, it is clearly no panacea; it does not necessarily appear to lead to people being active participants in their communities. Indeed, on reflection it may well be naive to expect a housing and support service to achieve that. Finding ways to help people achieve a full community life may well require an additional range of services requiring a different range of skills. Not least, access to the workplace is likely to play an important role in any such strategy (for further discussion of these issues see Felce et al, 1998a; Myers et al, 1998).

Similarly, further thought clearly needs to be given to minimising risks and offering appropriate protection to vulnerable people without limiting their opportunities (this would appear to be true of all settings), a point we return to in chapter 6.

Further, as it was implemented, supported living often fell short of the principles we outlined earlier. As Emerson at al (1999b) comment, there is some evidence of ‘dilution’ of the concept in practice, although they add that this has also been a feature of more traditional services; some degree of distortion and confusion is inevitable. This was an issue that has concerned many of the founders of the supported living movement. There has been an emphasis on the need for a ‘thoughtful’ and reflective approach to developing and designing services (see O’Brien and O’Brien, 1992; O’Brienet al, 1995 and O’Brien et al, 1998).

Person centred planning is a particular case in point. The idea of individualised planning has been at the forefront of discussions about services for many years. There were considerable

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¹⁶ Publication of the final report may help put some of these findings in context.
hopes that individualised planning, by focusing on specific goals for services would provide a framework which would help services become both more responsive to the individuals and more focused on ensuring positive outcomes for recipients of the service. However, there has been increasing frustration at the limitations of individualised planning (Greasley, 1995). Indeed, a very recent US study found that individual ‘habilitative’ planning within services appeared to make no difference whatsoever in terms of outcomes achieved (Stancliffe, Hayden and Lakin, 1999). Person centred planning was designed quite specifically to overcome limitations of most existing individualised planning systems, by evolving a process which would put the individual at the centre of services design (see O’Brien and Lovett, 1992; Small and Harrison, 1992 and Mount, 1994; while Sanderson et al, 1998, provide a comprehensive UK text on the subject). Needless to say this does not fit with the way that traditional services are developed. Despite all the rhetoric to the contrary, it is hard to conceive how a service based on group homes could be anything other than buildings-led. The scope for reversing the process (finding the individuals, and then obtaining the housing that suits them) is inevitably limited, unless there is a radical re-think.

As a result there are inevitable tensions between the requirements of organisations and the demands of person centred planning (Mount, 1994; O’Brien, O’Brien and Mount, 1997; Holburn and Vietze, 1998). Reconciling those tensions is going to be critical if person centred planning is to play the role for which it was intended, and if high quality supported living is to become more of a mainstream option. Person centred planning is slow and labour intensive. Some investment in developing the skills and systems required is needed to make the approach work for anything other than a tiny number of people.

It is also worth emphasising that the causal link between inputs and outcomes is, to say the least, complex. It is simply naive to assume that implementing some structural change to services (for example, separation of housing and support, the use of tenancies) will in themselves necessarily lead to the hoped for result. In the words of David Felce (1999):

Realising or even approximating such aspirations is likely to require an operational sophistication which goes beyond that which mere structural reform brings about.

Similarly, on the basis of experience in North West England, Howard (1996) concluded that where supported living arrangements had worked best for people with more complex needs they not only reflected a sustained commitment to individuals but also combined:

* skilled personal assistance

* clear identification of risk behaviours, and strategies to appropriately manage such risk (including therapeutic interventions to help the individual develop alternative skills; procedures for handling crisis situations, and continuous evaluation and fine-tuning of supports)

* the ability to mobilise additional problem solving resources and skilled assistance at short notice.

It is worth recalling the end of the previous chapter, where there was also evidence that the implementation of ‘active support’ procedures can make an impact on the quality of support
provided to people, particularly those with the greatest needs for assistance. There is a danger that the refinement of the management of staffed housing and the development of supported living will somehow be seen as alternative strategies. Yet there is scope for synthesising what, in the UK at least, have been two quite distinct strands of thought. Certainly on the basis of what we already know there is a risk that:

* supported living services will be focused on housing and other structural issues without paying sufficient attention to how paid staff are trained and deployed. People in supported living arrangements will still need competent, reliable support.

* the impact of ‘active support’ procedures may well be limited or frustrated without due attention to the wider organisation and reform of the services.

Services have come along way in the last two decades. However, improving the reliability of existing services, whilst at the same time exploring and refining developments like supported living and active support, will be a challenging agenda.
CHAPTER 5: LOW PROFILE OPTIONS

This chapter stands more or less as a corrective to chapters three and four. For example, if we had simply relied on material from the systematic search of journals, it would not have existed; these are service options which, for various reasons, do not feature much in the literature. In each case we opted to include some material already known to us simply to ensure they do at least feature in this report. Perhaps inevitably, this chapter almost exclusively relates to the UK.

LOW SUPPORT SERVICES

The financial pressures on UK local authority spending has been a significant feature of the late 1980s and the 1990s. This has led many to introduce a system of explicit eligibility criteria to aid with the ‘prioritisation’ of community services, and then to subsequently tighten those criteria (see Simons, 1998b). Somewhat scandalously there is no published information about what form those eligibility criteria take, nor is there any indication of how many people have been subsequently excluded from community care services as a result.

Of course some people with learning disabilities have always lived with little or no support from specialist services (Edgerton 1967; Flynn, 1989). However, there is some tangential evidence that the number of people in this situation is increasing (Russell et al, 1996), including people who would have been able to get support in the past. Where individuals who have previously managed run into a crisis, it can mean an expensive and difficult move into some form of residential service. As a result there is an increasing interest in ‘preventative’ services (Audit Commission, 1998). By definition these will have to be cost-effective ‘low support’ options designed to help people remain independent.

By and large, there has been little consideration of low support options for people with learning disabilities. Home care services appear not to be particularly helpful, and while some supported living arrangements can, in theory, incorporate very low levels of support, there are relatively few examples.

There are of course a few exceptions, including the services provided by the organisation KeyRing, the subject of a recent evaluation by Simons (1998b). KeyRing is specifically targeted at people with learning disabilities who might generally be seen as low priority by social services departments; people whose needs for assistance is either relatively low or intermittent, but who do require some support to maintain a tenancy.

KeyRing is based on the idea of ‘living support networks’. The organisation negotiates with local housing agencies to ensure access for people with learning disabilities to housing within a defined neighbourhood. As suitable accommodation becomes available, KeyRing assists people with learning disabilities to move in until a dispersed network of up to nine individuals is established. The first accommodation to become available is offered rent free to someone recruited from the local community in exchange for a commitment of between 10 to 12 hours a week of support to the other members of the network. Additional management and supervision of the network is provided by KeyRing staff. There is considerable emphasis on mutual support by tenants, with the formation of a tenants group.
The aim is to provide low key, unobtrusive support to help people maintain their tenancies. In general it seems to be successful in this, and is popular amongst those who use its service. The arrangement is not without its challenges: a significant feature of the support offered by KeyRing is in helping tenants manage their relationships with the wider community.

The advantage for commissioners is that KeyRing networks represent a very affordable option. Simons concluded that if more than three (out of nine) tenants in the network move out of residential care, then the network is likely to be self-financing.

A strategy which relies largely on residential care will inevitably exclude some people who need support, but for whom the costs of a residential care place cannot be justified. Effectively, registration of a residential care home imposes a minimum level of service and therefore of costs; in 1997 residential care home fees typically started at around £250 per week per person (Laing and Buisson, 1997). As we suggest in chapter 8, low support options have a potentially valuable role in underpinning more intensive services and ensuring that the system is both more affordable and more comprehensive.

ADULT PLACEMENTS

There is actually a long history of adults with learning disabilities being placed with substitute families. For example, Ramon (1996) cites a large scale Belgian scheme dating from early in this century.

In the UK, family-based services for adults have typically been associated with short-term breaks (see Beckford and Robinson, 1993). However, some adults do live with a substitute family long-term. It is worth distinguishing between situations where the person with learning disabilities lives as a member of the household (adult placements) and living separately within the same building and receiving support from the on-site landlord (supported lodgings). For example, Cambridge et al (1994) found 6% of people resettled from hospital in adult placements, with a further 1% in supported lodgings. In Northern Ireland there were no adult placements recorded, but around 3% of ex-hospital residents were in supported lodgings. Shifting the focus onto more general social services populations, Watson (1996) found 5% of people with learning disabilities in adult placements, and according to Dagnan (1994) 54% of social services departments had an adult placement scheme. Though it is clear ‘adult fostering’ is known in the US (Dagnan, 1997), we found no data about their general prevalence.

On the basis of interviews with users and carers in both short and long-term schemes, Robinson and Simons (1996) concluded that the chance to participate in family life was very much an aspiration for some people with learning disabilities, and in general, people living in adult placement schemes preferred them to their previous experiences of care. Nevertheless, a minority of placements were not without problems (there were some examples of rather restrictive practices), and the authors question just how integrated some individuals were within the family setting. A similar point is made by Dagnan (1997).

Both Dagnan (1994) and Robinson and Simons (1996) report some stresses for carers in adult placements. Although there was reported satisfaction in seeing users of the service gain
independence or skills, the role of being a full time carer could be a demanding one (especially when the recipient has more complex needs) and some carers found the pressure from commissioners to become more ‘business like’ undermined their commitment to the projects. Robinson and Simons also found the inclusion of adult placements within the scope of the Registered Homes Act had not been helpful. Whilst the authors recognise that careful recruitment, training, and matching of carers with prospective users is important, along with continued supervision and support, the increased regulation at best simply duplicated the checks and systems built into the better adult placement schemes and at worst hindered further development.

Adult placement schemes would appear to have a valuable place in a range of service options. However, further thought needs to be given to an appropriate regulatory framework and to mechanisms for ensuring the quality of the arrangements.

**VILLAGE COMMUNITIES**

Village communities - sometimes called intentional communities (Grover, 1995) - are probably one of the more international forms of residential support (for reasons that should become apparent we hesitate to use the word service), with examples in many European countries, in North America and South Africa, and in a range of many developing countries. Yet it is equally the case that in a country like the UK the actual numbers of people living in such communities is relatively small (Grover 1995).

The archetypal village community would probably be thought of as something along the lines of Botton, the Camphill community in Yorkshire. Here around 400 people live together in small ‘family based’ groupings, with both disabled and some non-disabled people sharing a household. Everyone involved in the community is involved in a range of productive activities (there is a bakery, and an organic farm) with all goods held in common; none of the members of the community receives a wage, all income is held in common.

In this sense Botton certain has many of the distinctive characteristics of an intentional community. It is neither obligated family care, nor (by and large) a professionalised care service. There is a large emphasis on inter-dependence; disabled and non-disabled people sharing each others’ lives. There is often a very distinct arrangement in terms of money. Finally, such communities tend to reflect very distinct vision; for example, the Camphill movement is based on theosophical theories of Rudolf Steiner.

On the basis of a visit to a large village community, the Mental Health Commission of Inquiry, whilst recognising some positive attempts to make the community more outward looking, also expressed some reservations about the arrangements. Given the obvious parallels between some of the larger village communities and the self-contained long stay institutions, it would be easy to place intentional communities at the institutional end of a linear spectrum. However, things are a little more complicated than that would imply. To begin with, the large rural idyll is a stereotype; both Camphill and L’Arche (the two organisations most closely associated with village communities) are actually involved in a range of other options, including small housing based in urban areas. Indeed, the idea of intentional communities shades off into options that would be more closely associated with supported living, including
housing co-operatives (see the next chapter) and ‘lifesharing’ (see for example, Lutifiyya (1991).

Village communities have been the source of some considerable controversy in the UK. This is partly because they have been the focus of considerable lobbying by RESCARE, a parent based organisation, which has argued for the conversion of some of the old-long stay hospital sites into village communities (Segal, 1990; Cox and Pearson, 1995). These arguments appear to be partly driven by fears and concerns about community care arrangements, and partly by a belief that minimising the costs of services for people with learning disabilities would leave them less vulnerable to financial pressures; there is an assumption that village communities would offer considerable economies of scale. In fact there is little evidence that this would be the case (DoH/PSSRU, 1996). Further, it is far from obvious that it would be possible to recreate an intentional community (as in the form evolved by Camphill) in an ex-hospital site. There are inevitable fears that what would emerge would inevitably be closer to the old long-stay hospital than a village community (MHF, 1996).

There is actually remarkably little information about how village communities actually work in practice (as opposed to in theory). However, this situation is likely to change with the forthcoming publication of the study by the Hester Adrian Research Centre referred to in previous chapters. This will include a direct comparison of larger intentional communities, arrangements based on hospital campuses (effectively the option advocated by RESCARE), and dispersed housing. It would therefore seem sensible to wait for the findings from this study to emerge before drawing any definitive conclusions, although, as we implied earlier, it is difficult to see how it would be possible to create intentional communities (in the full meaning of the word) as a matter of public policy. Indeed, by their very nature, intentional communities of all forms pose a considerable challenge to formal systems. As both Grover (1995) and Racino (1995) comment, they fit very uncomfortably into the existing commissioning and regulatory frameworks for services. Clearly, it would be a pity if the wider service system failed to accommodate options that may have some inherent value. Further thought needs to be given to this.

**SERVICES TO FAMILIES**

The rest of this report is about housing and support services. Yet the entire system is effectively dependent on the fact that many adults with learning disabilities live in the family home well into adulthood. A comprehensive review of the literature on supports to families with a disabled member is outside the scope of this report (for a more comprehensive discussion of the issues in the particular context of the All Wales Strategy, see Felce et al, 1998a). However, we did wish to draw attention to the point that a truly comprehensive strategy for housing and support services would need to take into account a range of issues, including in-home support and short-term break services designed to ease pressure on carers and to improve the quality of life for adults with learning disabilities (Cotterill et al, 1997; Robinson, 1994); assistance with long-term planning and the transition for individuals into services (Bigby, 1996; Prosser, 1997); and advice on a range of matters (including the management of inheritances, a matter likely to be critical where significant amounts of money or property are being passed on).
Services need to be geared to a much more sophisticated understanding of the dynamics of informal caring, and to recognise and respond to the experiences and aspirations of carers (not least for opportunities to work: Bigby, 1997; Todd and Shearn, 1996; Grant, Ramcharan, and McGrath, 1998). In the UK the 1995 Carers (Recognition and Services) Act gave carers the right to seek an assessment of their own needs as carers, but the implementation of this Act remains patchy (SSI, 1998). Any strategy will also need to take account of the National Strategy for Carers (DoH, 1999).

In comparison to some parts of the US, where there is increasing recognition of the critical role played by families (Braddock and Hemp, 1997; Braddock, in press), family services in the UK seem relatively sparse and underdeveloped, often not extending much beyond a minimal amount of respite provision. Of particular interest are the examples from both the US and Canada of the use of cash payments to families (Lakin, 1999), enabling them to buy in support how and when they need it. This is a subject that would warrant further exploration.
CHAPTER 6: REGULATION AND PROTECTION

*It is no longer acceptable for those involved in services to believe that ‘it could never happen here’. They must realise that ‘it can happen here’ and unless something is done ‘it will happen here’.*

(ARC/NAPSAC, 1993)

The history of learning disability services is a history of good intentions that have gone wrong (or at least not worked out as intended). At the same time, most people with learning disabilities are vulnerable in some way, and indeed some are very vulnerable. Therefore when things go wrong, they can go disastrously wrong. By their very nature, residential or housing and support services have an important role in helping people to stay safe.

It is a reasonable starting assumption that, no matter how well designed, no type of service will be immune from disasters. Whether through misunderstanding, carelessness, bad design, misfortune, or even deliberate intent, people with learning disabilities will end up badly served, neglected or even abused. However, it is an equally reasonable premise that commissioners and providers of services can, and should, take steps both to minimise the risk of things going wrong, and to respond effectively and appropriately to such events if and when they happen. However, while the specific scandals are relatively well documented (the recent Longcare enquiry is a case in point - see Churchill, 1998), there is little apparent consensus (or indeed evidence) about how to provide effective protection; as Kelly (1997) argues, despite the acknowledged problem with abuse in service settings, there is relatively little systematic research on the subject. With the exception of a paper on the patterns of abuse in large US institutions (McCartney and Campbell, 1998) we were able to find no journal articles that explored the subject with a specific focus on residential care or housing and support services.

There is some material that deals in general terms with the issue of sexual abuse (see for example, Brown et al, 1995; McCarthy and Thompson, 1997)\(^\text{17}\). McCarthy and Thompson (1996) argue that services have unwittingly ‘designed in’ the danger of such abuse. Amongst other things they highlight the lack of empowerment and advocacy, the lack of single sex provision for those who choose it, the lack of appropriate services for people with learning disabilities who are themselves abusers (see Hill-Tout et al, 1998, for an example), the complex attitudes of staff towards sexual matters, the tolerance of poor or potentially abusive practices, and the failure to deal appropriately with abuse when it is identified.

We were also aware of more generalised material about violence and abuse (Sobsey, 1994) and crime and victimisation (Williams, 1995) in relation to people with learning disabilities. Both these highlight the failure of wider structures like the criminal justice system to respond to the needs of people with learning disabilities. However, other important areas (for example, financial abuse - see Bewley, 1997) have, relatively speaking, been ignored.

\(^{17}\) A training pack by McCarthy and Thompson, 1998, provides an extensive resource list as well as being of value in its own right.
It is important not to underestimate the salience of the issue of safety for people with learning disabilities. One of the authors helps facilitate a small group of people with learning disabilities who are part of an Advisory Group to the UK Department of Health. Most of the group have had experiences of abusive behaviour of one kind or another. When asked to make a presentation about what they wanted from services, the group included ‘being safe and secure’ high up the list. However, they were also clear that while ‘keeping people safe’ was important for services, they were also equally clear that this should not be done in ways that ‘stop you doing things’. In the past, their experiences of ‘being protected’ had all too often meant being denied important opportunities to be part of their wider community. At the same time, this rather paternalistic approach to protection does not appear to be effective. Equally, however, once people with learning disabilities take more control over their lives, they will inevitably want to do things that may have inherent risks (Simons, 1998b). Dealing with this balance is difficult for services. However, before we go further, it is worth adding that simplistic assumptions (that the ‘community’ is inherently riskier than more ‘protected settings’; that supported living arrangements will be relatively safe from abuse because of the progressive ethos of supported living providers) should be abandoned. As Hilary Brown (1996) comments:

The debate is often framed in terms of empowerment versus protection, but actually people need both ...

Effectively, there are three broad strategies that service systems use to ensure that services provide a degree of protection: internal quality assurance systems, external regulation, and contracting, contract compliance and monitoring by the commissioners of services.

* Internal quality assurance systems
Not surprisingly, there is a widespread assumption that better quality services will be the best form of protection for people. Issues like management and leadership, and staff training will all make an important contribution to prevention. There is actually a substantial volume of material on this subject (more than we can conceivably cover in this report) covering a range of approaches to the promotion of ‘quality’ within organisations from those imported from business (like Total Quality Management - Goddard et al. 1995) right through to the use of ‘story telling’ within the supported movement (see O’Brien and O’Brien, 1992), taking in on the way, accreditation, quality action groups, PASS and PASSING evaluations, and so on (see, for example, Millner et al, 1991; Joyce and Close, 1997; Pilling and Watson, 1995; Flece and Perry, 1997).

* External regulation
Both the UK and the US are characterised by a complex system of external oversight of service providers. In the UK residential care homes are subject to a regime of registration (demonstration of adherence to pre-defined criteria) and inspection (a combination of

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18 Hendey and Pascall (1998) argue that lack of appropriate protection can undermine independent living.

19 The UK reader might find some of the US material that is readily available on the internet of interest, including Polister et al (1998) and Bradley et al, 1996.
announced and unannounced visits by local authority inspectors). Registration is required when board (accommodation and food) is provided along with ‘personal care’. There is actually no clear legal definition of ‘personal care’. Intimate ‘touching’ assistance would certainly be included, but some interpretations would stretch the concept to include various forms of counselling. The 1994 Homes Act provides the legislative framework, although each local authority Inspection Unit (meant to operate at ‘arms length’ from the operational management and commissioning of services) has a role in interpreting and implementing the legislation locally. The Act originally only included large homes (homes with fewer than four people were excluded). However, the 1991 Registered Homes Amendment Act extended the scope of the legislation to all homes that met the criteria (it is possible to have a one-person registered home!). People who live in their own home are not included within the scope of the Act; not least, the requirement for unhindered access by inspectors would not be compatible with the right of tenants to have sole access to their home.

Registered homes are public spaces. They therefore also have to conform to other requirements that govern such legal entities, including fire and public health legislation.

In the US, Intermediate Care Facilities (ICF/MR’s) are subject to a broadly similar (though generally more prescriptive) licensing system. The Home and Community Based (HCBS) Waiver system allows states to forego some of the more restrictive requirements of the ICF/MR system, but still provides a high degree of formal regulation.

There are some differences between the US and the UK system for regulating what is effectively residential care. In the US the regulation is bound up with funding. If services do not utilise these two Medicaid funding systems then they are not subject to the rules, though states which are using other public money to pay for services are likely to impose their own local licensing requirements. In the UK all services providing residential care are required to register, regardless of the funding source. Further, in the US the ICF/MR system was introduced as an attempt to force an improvement in conditions in the old long-stay institutions. From its outset, it was intended to raise standards by forcing providers to meet what were then deemed to be requirements of a good service (both in terms of the physical environment and care practice) at the time. The system also provided access to some resources to enable providers to meet these standards. In contrast, in the UK regulation is focused more on policing a set of minimum standards (Brammer, 1995). Although inspection units do have a role in promoting better standards, there are limits to the extent that this can be pursued through the formal regulatory process. As Day et al (1996) note, there were concerns that a system which continually demanded improvements of services would necessarily raise costs.

* contracting, contract compliance and monitoring by the commissioners of services

Domiciliary services are not currently subject to any statutory regulation in the UK. That is not to say they are unregulated. Most local authorities have ‘approved provider lists’, and usually require any service provide using public money, to conform to some basic requirements. Commissioners can also specify additional standards in any contract they have with providers. There is an expectation that commissioners will directly monitor any services

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See Biggs, 1996 for a discussion of the location of inspection units within local authorities.
provided (this might include carrying out surveys of recipients’ views) and ensure that contractual conditions are adhered to (see for example, Miles, 1998). However, there are frequent complaints about the absence of monitoring on the part of commissioners (Mansell, 1996) and there is little evidence that most authorities have a system approach to monitoring domiciliary services (SSI 1995).

PROBLEMS WITH REGULATORY STRUCTURES

There has been some discussion about the impact of existing systems, particularly regulation and licensing. These systems clearly help to winnow out some of the more manifestly inappropriate services. However, there is little evidence that these rather bureaucratic structures have acted as a catalyst for improving services:

... the general consensus\textsuperscript{21} was that regulation and oversight ... has not led to quality.

(Allard, 1996)

Commentators are increasingly questioning the negative ‘side effects’ of such systems including the way they:

* **are partial, inconsistent and arbitrary**
  Both in the UK and the US there are statutory systems of regulation that are required for some services, but variable and voluntary regulation for others (Diesfeld, 1996). There has been little attention to the boundaries between these different systems, with very arbitrary and inconsistent interpretations (see for example, Robinson and Simons, 1996; Audit Commission 1998).

* **fail to regulate for diversity**
  In the UK in particular, the system of Inspection and Regulation is largely geared to concerns about large scale residential care for the elderly. Only in Wales is there any requirement that inspection protocols make any specific reference to services for people with learning disabilities (they are meant to reflect the aims of the All Wales Strategy).

* **stifle innovation**
  The regulatory structures have been one of the factors limiting the development of supported living arrangements in both the UK (Simons, 1998a) and the US. In the UK the regulatory system assumes there is a clear divide between domiciliary services and residential care (the 1996 Burgner Report is a case in point). In practice, supported living services occupy a grey area in between.

* **promote dependency and isolation**
  The connection between regulation and rights is weak. As we have already noted, people in residential care will have fewer tenancy rights (and consequently less security of tenure) than people living in their own home with an assured tenancy. There is little, if any, emphasis in regulation on self-determination and empowerment. Taken alongside the culture of compliance

\textsuperscript{21} The whole of the 1992 June issue of Mental Retardation (Vol 3. No 1) is devoted to papers from a symposium on this subject.
in many services, there is a case for arguing that the current regulatory structures may leave individuals more, rather than less, vulnerable.

* have unfortunate side-effects

The interaction of regulatory status, funding streams and benefits systems means that people in more regulated systems typically have lower disposable incomes (Simons 1998a), with little opportunity to change this situation by working. As the Canadian Roeher Institute (1996) has pointed out, because people with learning disabilities are seen as vulnerable they are effectively ‘excluded’ from mainstream. However, one effect of this is to reinforce their poverty:

Poverty is both a consequence of disadvantage, and a contributor to marginalisation.
(Roeher, 1996)

Further, as we have already indicated, most people with learning disabilities living in services are socially isolated. While this may not be a direct function of regulatory status, the general context in which such services operate certainly do not assist in addressing such social isolation.

It has to be emphasised that this is not an argument for complete de-regulation. There is certainly the need for further research into the factors that leave people vulnerable. However, in the meantime, it is possible to begin thinking in terms of what a more appropriate regulatory framework might look like. This is particularly true in the UK where there are likely to be substantial changes to the system in the near future (see chapter 10).

According to Simons (1998c) a reformed system could:

* pay more attention to rights
The need for regulatory protection should not require people to forego housing choice, nor should it be contingent on reduced civil rights. The system needs to recognise and articulate a right for all people with learning disabilities to live in their own home if they so wish, and for them to have maximum possible security of tenure in whatever setting.

* recognise diversity
Regulation should reflect the diversity of services, with regulatory frameworks that are appropriate to the aims of the service, and proportionate to risk and vulnerability.

* regulate in partnership
The key players in protection are people with learning disabilities themselves, and their families and other people who care ‘about’ them. A key part of any strategy would therefore be to ensure that people with learning disabilities have the knowledge and tools to protect both themselves and each other. For example, training in being safe ought to be available to all vulnerable people (see Singer 1996, for example). Similarly there is scope for vastly improved complaints procedures, particularly in independent sector supported housing services (see Simons, 1997b). Similarly, while family and other community members are sometimes a source of risk, they are more often an important source of protection and oversight (see for example, O’Brien, O’Brien and Schwartz, 1990). Any regulatory system should be geared to the aim of both minimising social isolation and ensuring that families, advocates and other informal supporters are actively engaged with the regulatory system. Finally, people who use
services, along with families and advocates need to be engaged in formal monitoring and evaluation processes (for examples, see Simons, 1999; Polister et al, 1998).

* should involve a whole system approach
Regulation should encompass the role of commissioners (ensuring that they are accountable for developing effective direct monitoring of the services they purchase on behalf of people with learning disabilities) as well as providers of services, with clear expectations that a range of systems will be introduced including improved complaints procedures (Simons, 1997b) and appropriate procedures for identifying and managing risk (Manthorpe, et al, 1997) along with regular independent auditing and evaluation which focuses clearly on measures of outcome (Bradley et al, 1996; Nocon and Qureshi, 1996).

Finally, the issue of protection (as opposed to merely regulation) needs to be a ‘whole community’ issue. Many other statutory agencies have a role to play, including the police and the criminal justice system. In discussing this report Philippa Russell (personal communication) described the situation in two adjacent local authorities. In one, the residents of a group home who had experienced some harassment from local youths were told by the police to ‘stay indoors’. However, in the second authority, a young man who had just moved into a supported living arrangement and who was having similar problems, received a very different response. The police provided him with a personal alarm, and also liaised with the local authorities to ensure that the Housing Department took up the matter with the parents of the youngsters causing the problem. If necessary, the housing department was prepared to use its powers to evict the offending families unless they ensured that their children complied with the requirement that the harassment of the man with learning disabilities should cease.
CHAPTER 7: WHO IS THE BOSS HERE?
THE ISSUE OF SELF-DETERMINATION

While it is important to note the general tendency towards greater autonomy, independence, and choice associated with life in smaller community homes, community living by no means assures universal or sufficient self-determination outcomes for all.
(Lakin, 1999)

In chapter 4 we noted that one of the aims of supported living was to give people much more control over their lives. This is an area that has seen significant developments over the last few years, and we have therefore opted to include a brief chapter focusing specifically on the subject. In the UK these developments have been somewhat fragmented. However, in the US there has been a rather more coherent programme of development, under the general heading of ‘self-determination’ (see box below).

The Robert Wood Johnson Foundation
self-determination programme

One of the factors that has helped shape the development of the self-determination agenda in the US has been the grants distributed by the Robert Wood Johnson Foundation. This has involved a five million dollar programme designed to help states convert their service systems in ways which promote self-determination. In addition grants have been made to a variety of organisations (including People First and The Arc) to enable them to support and assist with these changes. Information about this programme is available from the Robert Wood Johnson Foundation web site (see Appendix 2), while a brief description of each project (along with contact details) is included in Reinventing Quality (Polister et al, 1998), also available on the web from the Research and Training Centre on Community Living (part of the Institute for Community Integration web site).

Although each programme reflects local developments, there are some factors in common. For example, the ‘O Wau Ke Alaka i’ (this translates as ‘I am the leader’) programme from Hawaii is fairly typical. Here the state is planning to:

* develop person centred planning
* introduce participant management of resources (see ‘participant driven supports’ below)
* develop support brokers to assist to individuals and families to have more control over their supports
* pool existing budgets as part of a managed care programme
* restructure state and provider administrative and regulatory systems to facilitate the development of individualised services
* develop a quality assurance system based on individual outcomes.
A number of the programmes specially target groups who have been poorly served in the past (in particular people from minority ethnic groups). This reflects a hope that more flexible, individualised services, over which individuals and their families have more control, will suit these groups in ways which more traditional services have not.

The link between self-determination and ‘managed care’ (effectively a system for controlling costs - see chapter 8) is another common feature.

Conroy and Yuskauskas (1996)\textsuperscript{22} reported on preliminary data from an evaluation of the Monadnock self-determination project in New Hampshire. This found:

* significantly increased control for participants on 12 out of 26 measures (with a significant drop in control on just one measure)
* significant gains in perceived quality of life on 8 out of 9 measures
* a significant decrease in challenging behaviour, a significant increase in a measure of productive behaviour, with no discernible change in adaptive behaviour
* a decline in costs of between 12\% and 16\%.

What follows is by no means an exhaustive list of the relevant initiatives (either in the UK or the US). However, it does include some indication of the range of options and issues currently being explored. These would include: the development of collective advocacy and the evolution of the role of People Groups; the introduction of participant driven supports; the use of information, advice and technical assistance to enable people with learning disabilities and their families to make use of ‘participant driven’ resources; the development of home ownership options; housing co-operatives; tenants participation; and participation in the strategic development and commissioning of services.

**COLLECTIVE ADVOCACY**

The development of self-advocacy - and in particular the People First movement - has been one of the most striking feature of the 1990s. Independent People First have sprung up across both the UK and the US, and the self-advocacy movement as a whole has become both more organised and influential. Such groups have an increasingly important role to play in shaping services.

Inevitably, People First groups have become interested in housing issues. For example, London People First have carried out a number of evaluations of housing and support services, including *Outside, but not inside ... yet* (Etherington et al, 1994). Many of their recommendations echo the findings from chapters three and four. For example, they felt that the group homes and adult placements they looked at were good options, and there should be more opportunities for people to have these kinds of choices. However, they also felt there

\textsuperscript{22} Available on the web at http://www.state.nh.us/sdp/pubs/indeval.html.
was clearly room for improvement. Their recommendations are extensive, and include their belief that services should do ‘much more’ to help people make friends, do more to help people have more contact with their families, do more to help people learn things by going to college, help people work out and handle problems on the street, and to involve people in things like training staff and evaluating services.

Self-determination itself is also a central issue for self-advocates. For example, New Hampshire People First have developed the ‘Who Decides?’ survey, designed to help explore the extent to which services provide opportunities to develop self-determination (see Polister et al, 1998). Similarly, Swindon People First recently obtained funding to help them develop a ‘direct payment’ scheme (see participant driven supports below) targeted specifically at people with learning disabilities (see Holman and Bewley, 1999).

There have been a number of efforts to help self-advocates develop their knowledge and leadership skills, including the Self-advocate Leadership Network (they have a training pack for self-advocates on participant driven supports)\textsuperscript{23} and Partners in Policymaking courses\textsuperscript{24} (targeted at both disabled people and families with young disabled children).

\textbf{PARTICIPANT DRIVEN SUPPORTS}

The idea of participant driven supports is a critical plank of the developments both in the UK and the US. Essentially it involves a variety of mechanisms for enabling individuals (and, particularly in the US, their families and other supporters) to have direct control of the service they use. Although the specific arrangements used vary considerably (see for, for example, Polister et al, 1998) they revolve around two key concepts:

\begin{itemize}
  \item \textbf{individualised funding}\textsuperscript{25}
    The resources needed to enable an individual to use a service are identified and collated into a budget. He or she has at least some say in where and how this is spent. The situations range from where the budget remains under the control of professionals, right through to situations where cash is passed over to the individuals to spend on appropriate services (what in the UK would be called ‘direct payments’). People with learning disabilities are specifically included in the scope of the enabling legislation that permits local authorities to make direct payments. However, so far relatively few people have been able to take up this opportunity (see Holman and Bewley, 1999).
  \item \textbf{flexible, personal assistance}
    Once an individual has some control over resources, they can use them to either purchase suitable support from an existing provider, or they can be involved (to
\end{itemize}

\textsuperscript{23} see Self-Advocate Leadership Network (1998); details are available on the Human Services Research Centre web site.

\textsuperscript{24} First established in Minnesota (see Polister et al, 1998) but which is now also offered in the UK (see Simons, 1999).

\textsuperscript{25} Those interested in keeping abreast of issues relating to individualised funding will find a web site devoted to the issues at http://www.members.home.net/bsalisbury/. 

65
varying degrees) in the direct employment of ‘personal assistants’. This latter arrangement inevitably gives those involved a large degree of direct control over how and when the support is provided. Such models are widely used by physically disabled people, and despite some inevitable complications, they have proved very popular (see for example Kestenbaum, 1992). A key aim of most self-determination initiatives is to open up these opportunities to people with learning disabilities (see next point).

**SUPPORT, ADVICE AND INFORMATION**

For people to make more informed choices about housing and support options, they will first of all need information, not just about what is available, but what is possible. There have been a number of UK based initiatives to try and ensure that people with learning disabilities get to hear about some of the new ideas and developments, including the video pack produced by Values Into Action (Holman, 1998), and the *Plain Facts* series, which provides accessible summaries of research supported by the Joseph Rowntree Foundation (Townsley and Gyde, 1997).

However, this is very much a starting point. People who want to take more control over their services will need varying degrees of support and assistance. This may potentially come from a number of sources, including:

* **Centres for Independent Living (CILs) or Self-Operated Personal Assistant Schemes (SOPAS)**
  Peer support from other disabled people has been a key feature of the wider development of the independent living movement. Both in North America and in the UK there has been a big growth in organisations run by disabled people which provide advice and support to those who wish to employ their own personal assistants. Some people with learning disabilities have found such schemes hard to access (see Simons and Ward, 1997; Holman and Bewley, 1999) since they are typically assessed as needing more support to manage their personal assistance than such schemes have traditionally offered. However, the Arizona self-determination initiative, targeted specifically at people with developmental disabilities (and part of the Robert Wood Johnson Foundation Programme) will involve a major programme led by the local CIL.

* **Independent service brokerage**
  Independent service brokers provide assistance to people who want to develop their own person centred plan, and then design and implement a package of services. There is considerable stress on the importance of brokers being independent of services, thereby avoiding the conflict of interest inherent for care managers who have to be both facilitators and gatekeepers. Although there has been considerable interest in the idea of service brokerage (see Dowson, 1995; Roeher Institute, 1993; Brandon, 1994; MacKinnon, 1995) its implementation in the UK has been limited (Holman and Bewley, 1999).

* **Individual trusts and ‘micro-boards’**
  Given the limited opportunities for people with learning disabilities to access the kinds of assistance listed above, there has inevitably been attempts to explore other ways of organising such supports. These have tended to involve formalising the informal assistance of friends and family in ways that ensure a degree of accountability and safeguards for both the individuals involved and the wider system. For example, Holman and Bewley (1999) mention both the
Independent living Trusts (UK) and ‘Micro-boards’ (Canada). These developments are likely to be particularly critical for ensuring that people with more complex needs are not left out (see box below).

**Exclusion and incapacity**

Simons (1998a) warns of the danger of ‘exclusion by incapacity’. In many instances access to particular kinds of arrangements are subject to some form of test of the individual’s capacity to enter into a legal contract (this is the case with direct payments and is particularly likely to be an issue with house purchase). There is a risk that some of the people who stand to gain most from more flexible, individualised solutions will be left out because of an assumption that models of service which reflect a self-determination agenda are for people with legal capacity (see Holman and Bewley for their discussion of these issues in relation to direct payments).

Yet the aim of the self-determination movement is to be inclusive, the opportunities should also extend to people with ‘severe disabilities’ (Wehmeyer, 1998; Brown et al, 1998; and Bambara et al, 1998). People who are not currently judged to have legal capacity have to rely on the various forms of ‘substitute’ decision making. However, there is criticism on both sides of the Atlantic about the way these systems operate, including the concern that they are invoked too quickly (capacity is interpreted as an all or nothing issue), and for the lack of accountability of the substitute decision makers (see Bewley, 1997; Herr, 1995). This has led to calls for a switch to a framework based on ‘assisted’ decision making (see Bewley, 1998; Simons, 1998a). Inevitably, assisted decision making would not preclude others from having to make decisions on behalf of people who lack understanding of the relevant issues, it would place an onus on those taking decisions to maximise the participation of the person with learning disabilities in any decision making process, and to demonstrate that the decision was in accord with what is known about the vulnerable individual’s wishes or feelings.

**HOME OWNERSHIP**

As we indicated in chapter 1 home ownership programmes have been initiated in both the UK and the US. This subject could have fitted into any one of a number of chapters (not least the one on costs), yet because people who own their own home tend to have more control over it than those who rent, we have chosen to include it here.

There is widespread assumption that people with learning disabilities will not be able to achieve home ownership because of reliance on social security benefits. Therefore, although some might conceivably inherit property (itself an important opportunity which needs to be successfully managed) the chance to buy a home will be beyond most. Home ownership is certainly not likely to quickly become a major option for people with learning disabilities. However, the basic assumption is demonstrably wrong; it is possible for people with learning disabilities to use benefit income to buy a property.

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26 Herr points to the Swedish system of rights as one example of a framework that would promote self-determination whilst also protecting the interests of vulnerable people.
For example, in the UK, King (1996) has demonstrated how Income Support contributions can be used by disabled people to cover the interest on a mortgage. Similarly, in the US the National Home of Your Own Alliance (see Klein and Black, 1995; TAC/CCD, 1996; TAC/CCD, 1998a) have shown that home ownership can be affordable using SSI payments (see chapter 8 for a very brief outline of SSI). Indeed, providing (and this tends to be a fairly significant qualification, see King 1996) everyone involved can be convinced that the rules allow it, benefit can provide a sufficiently reliable source of income for at least some mortgage lenders to advance the loans required.

Within the overall framework of home ownership, there are usually a number of options which will be more or less feasible depending on the circumstances of the individuals involved. In the UK these might include shared or joint ownership (King 1996). However, whichever option is selected a number of problems will have to be solved. These include:

* enabling individuals to find the necessary equity to provide deposits and/or cover the costs of purchasing. Options have included loans or gifts from families, sleeping equity, second soft or ‘forgivable’ loans, or even the delightfully named ‘sweaty equity’ (contributing to the value of the building by directly repairing or renovating it)

* covering the costs of maintaining the building. In the UK the use of different forms of shared ownership (involving the continued involvement of social housing providers - see King, 1996) have provided a useful framework for managing this issue. In the US, the emphasis has been on organising various forms of financial planning.

Home ownership typically requires access to considerable technical knowledge. In the US technical assistance is provided by the Home of Your Own Alliance, while in the UK some assistance is available in England from the Housing Options Advisory Service (a Scottish equivalent has recently been established). Both these organisations have useful web sites, the addresses for which are included in Appendix 2.

Considerable cross agency collaboration is required to make these options work, and as even the advocates of home ownership acknowledge, the complexity of issues means that they will not be suitable for everyone:

... *staff must be mindful not to substitute their own advocacy or enthusiasm for the motivation of the prospective buyer.*

(TAC/CCD, 1996)

Nonetheless, as a solution for particular situations, home ownership for people with learning disabilities has a potentially critical role to play, and should be part of any comprehensive housing and support strategy.

**Housing Co-operatives**

Individual home ownership is just one way of gaining direct control over housing. Other options might include collective ownership or management through a housing co-operative
TENANT PARTICIPATION: INVOLVEMENT IN FRONT LINE SERVICES

One of the roles of the Housing Corporation (in England), Tai Cymru (in Wales) and Scottish Homes is to promote tenant participation; people who live in mainstream social housing are likely to be offered a variety of opportunities to influence the management of the housing in which they live. Unfortunately, there was little evidence that these opportunities were being extended to people in supported housing. The result has been a stream of initiatives designed to open up these opportunities to a range of hitherto marginalised groups, including people with learning disabilities (see Keeble, 1996; Simons, 1997b; Dowson et al, 1998; VIA Direct Video Group, 1996).

For people who live in supported housing the issues about participation and control will also extend into the way support providers work. Many of the wider mechanisms for enabling people to become involved in shaping service organisations would apply equally well in the context of housing and support (Simons, 1998e), including participation in selecting staff (Townsley et al, 1997) and in delivering training (NIACE and Change, 1998).

User-led services for people with learning disabilities are rare, although Simons (1995b) describes one housing project in South West England which grew out of an ‘interest group’ for people with learning disabilities. People with learning disabilities made up over half the management committee, and two were employed as part of the project team.

INVOLVEMENT AND PARTICIPATION IN STRATEGIC DECISION MAKING

Finally, as Agosta et al (1998) comment, there needs to be substantial change at a systems level to facilitate the further development of a self-determination agenda. This is more likely to happen when individuals and families are involved to a greater extent in strategic decision making. For example, Simons (1999) describes examples of participation of people with learning disabilities in the commissioning and purchasing of services in the UK, including an enhanced role in both planning and monitoring of services.

Many of the developments described in this chapter and chapter 4 will require greater access to mainstream housing options by people with learning disabilities. If this is to happen then some strategic recognition of their housing needs will be required.

In both the UK and the US there are processes which require local communities to identify their housing needs and to develop agreed priorities for new developments as a condition of receiving funding from central government. For example, in England the Housing Corporation requires local strategic housing authorities to develop Housing Improvement Plans (HIPS). In the US, the equivalent agencies have to produce a ‘Consolidated Plan’, setting out the housing strategy for the community. In neither country is there a guarantee that the needs of people with learning disabilities will be recognised in such plans. However, in the case of the Consolidated Plan the process specifies minimum levels of citizen participation, and some
commentators have argued that at least this provides a focus for advocacy and lobbying by disabled people and their allies (TAC/CCD, 1997).
CHAPTER 8: THE BILL PLEASE:
COSTS, FUNDING SYSTEMS, PRICE AND INCOME

INTRODUCTION

In the process of scanning the US literature we came across several variations of an aphorism to effect that the budget is policy stripped of its ‘warm words’. Quite clearly costs (and the availability of resources to meet those costs) will have an important impact on determining service patterns. However, we also argue in this chapter that global costs are only part of the story. We would add that the complex funding systems used in both the US and the UK add further complications and distortions, and that having some sense of how they work adds to our understanding of services. Indeed, we would suggest that it is price (and particularly who pays out of which budget) rather than costs which are more important in determining behaviour. Finally, if we are examining financial issues, then the level of disposable income received by the person using the service should not be forgotten.

COSTS

What determines the cost of residential/housing and support services for people with learning disabilities? An important question, but one that we cannot answer definitively. However, there are some fairly important indicators. Two factors appear to be a function of increased costs:

* need for assistance
  Given the perversity of some of the findings outlined below, it is perhaps comforting (if reasonably predictable) to find that in general services for people with a greater degree of impairment costs more (Shiell et al, 1992; Felce, 1996), particularly those for people who also have challenging behaviour. In general, this relationship is most apparent at a global level; once services are examined in more detail the relationship between costs and the characteristics of service users becomes more confused (see for example, Felce et al, 1998b). On the whole, costs reflect the level of staffing provided, so the decisions about the way staff are deployed will have a major bearing on costs. As Felce (1996) points out, the link between the needs of residents and the determination of staffing practice is often weak. This point is echoed in the US (see Stancliffe and Lakin, 1998) where the regulatory regime (specifically, the use of the ICF/MR regime) appears to impose costs that mask the link with the needs of those using the service.

* the type of provider
  In the UK the voluntary and private sector services tend to be less expensive than the services provided directly by the local authority and the NHS (Shiell et al, 1992). Similar patterns emerge in the US where services provided by the states tend to be markedly more expensive than those provided by private sector providers (Stancliffe and Lakin, 1998).

At the same time there are three sets of findings that might well strike some as counter-intuitive:
* cost is a poor predictor of quality
Most of the studies have found little, if any, link between the cost of the service provided and measures of quality (Cambridge, 1997; Hatton and Emerson, 1996; Beecham et al, 1997; Felce et al, 1998b)

* there is little evidence of economies of scale
It is often assumed that larger group homes will offer economies of scale: within community settings there is almost no evidence of this (Raynes et al, 1994; Hatton and Emerson, 1996; Felce 1996; Stancliffe and Lakin, 1998), though there is concern that ‘micro-services’ might of necessity be more expensive (Raynes at al, 1994 - see the comments below on the cost of supported living).

* the variation within models is probably as great as between models
There is considerable variation in cost within all the different service models, including small staffed houses and group homes (Felce, 1996; Hatton and Emerson, 1996), a factor which undoubtedly serves to confuse the overall picture.

There is some divergence between the UK and the US in the comparative differences between institutional and community settings. In the UK, a number of studies have found the staffed housing/group approach has proved to be more expensive than the long-stay hospital (Cambridge, 1997; Hatton and Emerson, 1996; Felce et al, 1998a), although Beecham et al (1997) found that this was not the case in Northern Ireland and there have been other exceptions to this general rule (Allen and Lowe, 1995; Donnelly et al, 1994; Hatton et al, 1995). Felce (1996) concluded that any differences could be more than justified by the better quality of services in community settings. However in the US, institutional costs have tended to be higher than community based alternatives (Stancliffe and Lakin, 1998; Lakin, 1999; Mansell, 1996), possibly reflecting greater pressures to improve institutional conditions prior to closure (it is worth recalling the active role the courts have played in the US). This appears to be the case even when people with severe disabilities and challenging behaviour are involved (Knobbe et al, 1995).

Most of the studies on cost have focused on the relative costs of staffed houses/group homes. It is far from clear to what extent these findings could be generalised to supported living arrangements. Simons and Ward (1997) report very entrenched beliefs that such individualised services would necessarily be very costly:

>This is a sequinned dress where a woolly jumper would do!

If the approach to funding supported living is the same as that used for residential care services, then this risks becoming a self-fulfilling prophecy. As Felce (1996) comments:

>Unless there is a departure from traditional arrangements, as in the use of natural supports or of shared living arrangements, there are clear inflationary pressures.

However, the point about supported living is that it is meant to be about using resources differently. In the UK, the absence of any formal evaluation had meant this has been more a case of speculation than substance. As a result, advocates of these arrangements have been
forced to rely primarily on a limited number of case studies which show that, in certain circumstances, supported living can actually be cheaper than residential care (see Simons and Ward, 1997; Ryan, 1998). These typically involved innovative funding packages (for example shared-ownership), the use of ‘natural supports’ (like non-disabled support tenants’) or a combination of both.

The South Warwickshire Accommodation Project (Ryburn and Wellstead, 1997) kept a record of the extent of support hours over a period of three years during which 21 people moved into a variety of supported living arrangements. At the point of the move, the support hours needed by these individuals ranged from under 4 to 168 hours per week, with an average of 47. Over time the average support hours declined steadily (for example, a year after the move the average number of hours a week was down to 22). Simply taking into account the costs of these support hours, the average cost for the group as a whole was said to be initially well under the average for local residential care, and falling further as the support hours fell. The authors comment that the declining number of support hours enabled the team to support a great range of needs, and also meant there was enough flexibility to raise the level of support to any individuals who experienced any form of crisis.

There is rather more substantial evidence from the US, where there has been a rather longer-standing experience of supported living. Gary Smith has summarised the findings from demonstration programmes in a number of states (1990 and 1994). He found, as with almost every other form of service, wide variation in the costs of supported living. However, the average costs of supported living arrangements were well below the average for ICF/MRs. Smith cautioned against drawing too many conclusions from this, since it was probably a function of the fact that people with fewer needs tend to find it easier to access supported living. He argued that the experience of Colorado presented a more realistic picture; here a similar ‘case-mix’ of people were using both supported living and ICF/MRs and the average costs were broadly similar.

Smith attributes the relative affordability of supported living to:

* its flexibility, allowing much more efficient use of resources
* more effective use of non-professional resources
* not sharing some of the ‘clinical treatment’ assumptions built into the ICF/MR system.

The finding that, on average, supported living services can be contained within a similar budget to staffed houses/group homes is replicated by the study in Oregon involving 20 matched pairs (Howe et al, 1998). As before, costs within each varied enormously, both within service type and between the matched individuals. However, there was no significant difference between the average public support costs for supported living and the more traditional residential services.

Others have pointed to the possibility of the cost reductions involved in the use of ‘participant driven supports’. The combination of direct payments and personal assistance has been a very cost-effective option for people with physical disabilities in both the UK (Zarb and Nadash, 1994) and Canada (Roeher Institute, 1997a and 1997b). Again the flexibility of these arrangements, coupled with reduced overheads (effectively disabled people and their supporters tend to take much more responsibility for making these arrangements work) mean they can be anything up to 30% cheaper than the equivalent services. Simons and Ward
(1997) pointed to the significance of these findings, whilst cautioning that people with learning disabilities using similar models are likely to need more assistance in managing these types of arrangements, with consequentially fewer savings over more traditional forms of service. Indeed, we noted in the previous chapter that Conroy and Yuskauskas (1996) found cost reductions of between 12% and 16% in their evaluation of the Monadnock self-determination project (see also Shumway, 1998).

As a counter-balance, both Simons and Ward (1997) and Smith (1990 and 1994) point to the probability of increased ‘design’ costs; developing intensive supported living arrangements is likely to require some investment in more intensive care management and/or service brokerage.

Finally, the major UK study carried out by Emerson and his colleagues (1999) attempted to comprehensively cost the different services involved. As we indicated earlier, at the time of writing, only preliminary data is available for the comparison of supported living with other forms of dispersed housing. Raw and adjusted accommodation costs tended to be higher in supported living than group homes, but the reverse was true of non-accommodation costs. As a result there were no significant differences in total costs.

The sheer variation in costs suggests there are many factors at play here. One possible source of such variation is the complex systems used to fund services in both the US and the UK. The following section therefore provides an outline of their main features.

**FUNDING SYSTEMS**

The service funding systems in both the US and the UK are both very complex. What follows is inevitably a rather simplistic picture. For almost any rule, there are always important exceptions. Indeed, the opportunity to exploit loopholes and anomalies has often been one of the factors assisting in innovation. However, equally, the rigidity of the mainstream funding patterns has also served to ensure such innovation remains relatively marginal. In order to try and present as coherent an account as possible we have chosen to describe the situation in the US and the UK separately.

**The US**

The primary source of funding for learning disability services is the Medicaid system. Our description of the system draws heavily on the comprehensive collection of data and analysis provided by Braddock and his colleagues (1998). Originally conceived as a mechanism for providing basic health care for people on low incomes, Medicaid now has three distinct strands: health insurance for low income individuals, long term care for elderly and disabled people, and a specialised programme for people with developmental disabilities or a mental health needs. Here we are primarily concerned with the last of these, which accounts for over 70% of the total public funding for developmental disabilities long-term care services, although it also only currently represents about 10% of the total Medicaid budget (down from a high of 13% during most of the 1980s).

Medicaid is effectively a federal/state partnership. Within the framework of the state’s Medicaid Plan, the US Government reimburses the state for a proportion of the dollars spent.
The rate of reimbursement depends on the relative wealth of the state; for those with the highest per capita income the federal exchequer picks up half the bill. At the other extreme Mississippi (the poorest of the states) contributes just $21 out every $100 spent on services.

The Medicaid system is effectively divided into two separate programmes. These are:

* **The Intermediate Care Facility/Mental Retardation (ICF/MR) programme**
  This source of funding is primarily used to cover the costs of the larger residential settings (usually with more than 16 people) although some states have also opted to use it for smaller group homes. The use of ICF/MR funding is conditional on a complex and rigid system of licensing.

* **The Home and Community Based Service Waiver (HCBS) System**
  In the early 1980s there was increasing recognition by Congress that the ICF/MR system had its limitations. The result was the creation of The Home and Community Based Service Waiver (HCBS) System intended to provide funding for smaller community based services without imposing the full range of ICF/MR requirements (hence the term ‘waiver’).

At first, use of the HCBS was very limited, but it has become increasingly popular, and the balance between the two funding systems is shifting fast. In 1995, for the first time, there were more waiver participants than ICF/MR residents. However, in terms of total volume, spending on the ICF/MRs still exceeds that on the HCBS waiver system (just under $6B compared to just under $4B), reflecting the higher costs in ICF/MRs (often said to be a function of the rigidity of the licensing requirements).
It is worth adding that the HCBS system is not generally expected to cover board (housing and food costs); it is primarily concerned with the staffing costs. We cover the issue of the costs of board in the section on housing.

As might be expected from the data in chapter 2, there is considerable variation from state to state in the expenditure on services for people with developmental disabilities. Interestingly Braddock et al (1998b) found that some of the more obvious characteristics of the states (size and wealth) were actually poor predictors of spending levels. In their analysis they found that three quite different variables (early commitment to implementing civil rights legislation, strength of local ‘consumer advocacy’27 and evidence of local leadership28) could account for almost 60% of the variation.

Overall, expenditure on Medicaid both at federal and state levels has risen steadily (Braddock, 1998). This has inevitably led to pressures to contain expenditure, primarily through the introduction of various managed care plans. From the perspective of the non-specialist UK reader, managed care is a baffling subject. At the same time it appears to be the subject of a vast amount of information (see for example, Braddock, 1998; Smith and Ashbaugh, 1995). Based on the mechanisms developed by the US health insurance industry, it involves a shift away from a fee-for service system, towards one based on capitation premiums (a fixed amount per person) typically paid to an intermediary agency which then organises the various services for the individual. The significant feature is the degree of ‘risk sharing’ involved. If services prove to be less expensive than the capitation fee, then the intermediary agency makes a profit, if they are more expensive then they may bear at least some of the loss.

Managed care has its advocates, not least because it does sometime appear as a framework for more flexible and rational use of resources (Smith and Asbaugh 1995), and there are often links between managed care and the use of ‘participant driven’ supports described in the chapter on self-determination (for example, see Agosta et al, 1998). Nevertheless there is also some concern about the appropriateness of some managed care arrangements (Braddock, 1998), with many organisations reserving their position on managed care (see for example CHP, 1996; Arc, 1995).

The UK

Like the US, the spending pattern in the UK is vary varied, though by no means as easy to discover. This is partly because there is a lack of easily accessed data, and partly because the system is so fragmented. For example, in their analysis of spending (Jones and Wright, 1996) point out that even as late as 1993, the NHS continued to provide a majority of the funding for learning disability services (55% compared to 45% for local authority social services). When the two sources of funding were combined, the per capita spending varied by more than a factor of 2, with no obvious linkage in spending in the two sectors.

27 As measured by the size of local ARC membership lists - ARC is broadly the US equivalent of MENCAP in the UK.

28 The proxy measure used here was the extent to which politicians had been able to lever in federal HCBS waiver monies by assigning matching funding.
Although it might not be so apparent, the UK system also largely relies on a partnership of central/local government funding. Prior to the early 1990s the cost of most ‘residential care’ for people who could not afford it themselves was met through the social security system paid by central government. Aside from creating strong incentives for moving people into residential care (this mainly affected elderly people who needed assistance), it was impossible to control costs; effectively entry into the system was determined by eligibility criteria not the size of the budget (which was rising fast).

The implementation of the 1990 NHS and Community Care Act saw some radical changes. Central Government shifted most of the responsibility for paying for residential care to local government social services departments. This increase in responsibility by a parallel shift in resources, broadly matched the levels of social security expenditure at the time of the transfer. However, there is now an important difference. Unlike the previous system, local authority budgets are capped and largely discretionary.

The changes were not quite complete. Most individuals with learning disability will still be eligible for some social security payments including a specific residential care allowance. Indeed, people who were in residential care prior to 1993 have ‘preserved rights’ to enhanced social security payments at the original rates. However, the residential care system effectively acts as a charging framework. Local authorities will recoup most of those benefits leaving the individual with a very small disposable income. Despite this, the costs of residential care inevitably exceed the benefits available and represent a considerable cost to local authorities. As with the ICF/MR system in the US, there is no distinction in residential care between the so called ‘hotel’ costs and the costs of care; they are bundled up together in a single package.

Local authorities are also responsible for funding the support costs for people in unregistered group homes or their own home, though just as with the HCBS waiver system, not housing or food costs; as we explain later, these are met through a rather more diverse range of benefits.

There is some direct central government funding to help with the personal assistance costs of people living in their own home: known as the Independent Living Fund (ILF). Right from its conception ILF awards were in the form of cash, which could be used by recipients to either pay for services or to directly employ personal assistants. The ILF has been very important in developing wider ideas about independent living in the UK (see for example, Kestenbaum 1992 and 1996) and certainly has been used by people with learning disabilities. However, the sheer success of the scheme (demand for ILF funding hugely exceeded expectations) led the previous administration to change the rules in 1995. The current ILF scheme is subject to a curious catch 22: only severely disabled people are eligible for it and yet the combination of ILF award and a mandatory social services contribution of £200 is limited to a maximum of £500 per week, effectively excluding many people with learning disabilities (either they are not seen as sufficiently disabled, or their support costs exceed the limits). It is possible to get around the limit by combining funding from health authorities within the package. However, this mechanism is not widely known about or used, and indeed in some areas there would be no local mechanisms in place to allow it to happen. As a result, the take-up of the ILF by people with learning disabilities is very uneven and localised.

To complicate matters, the National Health Service (funded directly by central government) still has a continuing role in the provision of residential services (and indeed in some cases, domiciliary support). As we indicated there are still some people in long-stay hospitals
provided by NHS Trusts. In some areas, as hospitals close, funding is transferred from the NHS to local authorities as part of hospital reprovision strategies. However, in other areas local health authorities have commissioned community based services from NHS Trusts. Since NHS care has to be free at the point of delivery, people in NHS provision will not face the same charging regimes as those in residential care purchased on their behalf by local authorities.

In the UK there is no direct equivalent to managed care for people with learning disabilities. Nevertheless cost containment is very much on the agenda of most service commissioners. This is typically achieved by a combination of relatively short-term strategies, including unilaterally dictating fees (more or less regardless of the actual costs of providers), the use of so called net-cost policies (supported living arrangements will only be funded if, for the given individual, they cost the authority less than the residential care), and developing more and more rigorous eligibility criteria (effectively more stringent gatekeeping). The exclusion of some people from services is particularly perverse in view of the general failure to develop effective low support services (Simons, 1998b). These could help ease the pressure on more intensive services and help to prevent expensive admissions when individuals who are unsupported experience some sort of crisis (Audit Commission, 1998).

**HOUSING AND FOOD COSTS**

As we have already suggested, both in residential care and ICF/MRs, the support people get is inextricably bound up with the place they live, and the funding systems reflect that. However, in other forms of provision (notably supported living), there has been a conscious attempt to decouple ‘housing’ and ‘support’ and this is inevitably reflected in the funding systems. In particular, there is an implicit assumption that the way the people will pay for these costs will be less ‘special’ and more ‘typical’ (for example, reflecting the systems used by other people on low incomes).

As before we outline the system in the UK and US separately, this time starting with the UK.

**The UK**

Sources of funding can be divided up into four distinct strands:

* income maintenance benefits

These are essentially designed to provide people with basic income to pay for essentials like food and clothes. People with learning disabilities are particularly likely to be eligible for a combination of two benefits, the Severe Disablement Allowance, and Income Support (which will typically include various supplements for which disabled people are eligible). The UK, like most European countries has a social security system based on a social insurance/contributory principle. Unfortunately, for people with learning disabilities, this effectively discriminates against people who have never been economically active (see Simons, 1998a, for a more detailed discussion). One (of the many) effects of this is to leave people with learning disabilities subject to a particularly ferocious means test. Basically they lose benefit £ for £ if their income increases beyond a notional £15. This creates very powerful financial incentives against taking up more than a limited amount of paid work, which in turn
is likely to be one of the factors making supported employment less cost-effective in the UK compared to the US (see Beyer et al, 1997; Simons, 1998a). People remain eligible for most of these benefits regardless of where they are living.

* disability benefits

Disabled people in the UK are able to access an additional social security benefit designed to compensate for the additional cost of disability, the Disability Living Allowance (DLA). This is divided into the ‘care’ component (three levels) and the mobility component (two levels). People living in residential care are not eligible for the DLA care component; indeed DLA has been an important factor in promoting independent living in the UK. It is not means tested (although see the caveat later), and can be claimed by people in work.

* Housing and Community Tax Benefit

In the UK people with low incomes (specifically at income support level) are eligible for direct subsidies which can cover all rent and local property taxes. Housing Benefit is not available to people in residential care, or those who own their own home; people have to be renting their home to be eligible for it. Housing Benefit can, in some circumstances, cover not only rent but the additional costs of intensive housing management and accommodation related support. Although Housing Benefit is administered by local authorities, most expenditure is reimbursed by central government. Housing Benefit is based on eligibility criteria, not (as yet) a fixed budget. It is means tested, with a relatively steep taper. Once an individual’s income rises above Income Support levels, the corresponding reductions in Housing and Community Tax Benefits can leave him or her with net gains of as little as 15p for every £1 earned. Although the poverty trap is not quite as acute as for people in residential care, people relying on Housing Benefit also face considerable financial disincentives from taking more than a minimal amount of paid work (Simons, 1998a).

Of course, the very things that make it attractive for people with learning disabilities make it a focus of concern for central government. The Housing Benefit budget has risen markedly over the last decade, and has promoted a number of initiatives to limit its growth. In certain circumstances the amount of housing benefit can be capped. The ‘worst case’ scenario would be someone who wanted to live in a larger property (perhaps to accommodate a support tenant), rented from a private sector landlord, in an area of high housing costs. The risk here is that people with learning disabilities may effectively be excluded from particular communities. Complications have arisen in terms of the additional service charges that might be included in rents (see Simons 1998a), and this is an area of policy currently under review (see concluding chapter). Fundamentally, the availability of Housing Benefit is one of the important incentives for commissioners considering alternatives to residential care. This is often seen in negative terms (so called ‘cost-shunting’). Certainly, there has been some abuse of the system. There has been considerable interest in ‘de-registering’ group homes (often under the somewhat misleading label of supported living) primarily to take advantage of Housing Benefit. Similarly, in some instances service charges have been artificially inflated to absorb as many of the ‘care’ costs (notionally the responsibility of the local authority commissioner) as possible. On the other hand, Housing Benefit is likely to play a critical role in developing a range of housing opportunities for people with learning disabilities (what has been called the ‘economics of citizenship’). Forcing people with learning disabilities to use residential care (as has certainly been the case in some areas where local authorities have
insisted on registering all supported living arrangements) is to deny people the right to access a source of income that non-disabled people in the same financial situation can access without question.

* Housing subsidies

The last two decades have seen dramatic shifts in housing policy in the UK away from ‘bricks and mortar’ subsidies, towards the use of ‘market rents’ and the compensation of individuals with low incomes (Housing Benefit). There is some low rent council (local authority) housing still available (though nothing like the scale of provision there once was) and there is some central government funding for the development of housing distributed through the Housing Corporation (England), Tai Cymru (Wales) and Scottish Homes. This funding involves a capital subsidy available to social registered landlords (the Housing Association Grant - HAG) designed to provide help develop affordable housing. A relatively small proportion of HAG is allocated to a special needs programme specifically for the development of supported housing (and here the term supported housing would encompass the full range of provision from residential care to people renting their own home) to people with ‘special needs’ and with some revenue subsidy (Special Needs Management Allowance - SNMA) to housing providers to help towards the additional costs of providing more intensive housing management. The main problem is that the resources available are dwarfed by the potential demand. For example, it has been suggested that the Housing Corporation programme allocation for people with learning disabilities contains sufficient capital to generate about 400 ‘bed spaces’ per year (New Era Housing Association, 1996) whereas the number actually needed has been estimated at around 5,000 per year (Watson and Harker, 1993). Clearly, relying on ‘special needs’ funding systems alone will simply not generate the level of provision required; opening up mainstream housing options to people with learning disabilities is going to be a critical part of the strategy. However, there are other Housing Corporation programmes (for example, promoting low cost home ownership) which until recently have been ignored by the learning disability services (King 1996).

**The US**

In some ways the US system has a direct set of parallels for each of the UK components described earlier. However, there is one fundamental difference; there is no direct equivalent to Housing Benefit, available as of right, and covering all the main costs of renting.

Essentially, people with learning disabilities renting (or indeed owning) their own homes would be expected to cover their costs through their income support benefits (SSI). This is regularly cited in the US literature as being $494 per month in 1998, and represents the equivalent of about 60% of the federal minimum wage level. In some states SSI is enhanced

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29 Just 10% of HAG went into the special needs programme in the 1994/5 financial year, according to Jones and Wright (1996). Of this slightly over 12% went to people with learning disabilities alongside the many other groups. In other words only just over 1% of HAG was specifically targeted at people with learning disabilities.

30 In Scotland SNMA is replaced by the Special Needs Allowance Package (SNAP).

31 Approximately £310 per month assuming an exchange rate of $1.60/£.

32 In 1998 this was $5.15, or about £3.20 per hour.
by a local supplement. However, in only three states does this provide a level of income even approaching the level of the minimum wage, and 30 states offer no such additional assistance.

According to Edgar et al (1998) the US Department of Housing considers anyone spending more than 50% of their income on housing to have a severe ‘rent burden’ and to have ‘worst case housing needs’. Broadly, the system is geared to an assumption that no more than 30% is ideal. Part of the problem faced by disabled people in the US is that housing costs have outstripped SSI levels. Indeed, using the official fair rent established for each housing area, Edger and colleagues have calculated that a disabled person wanting to rent a basic one bedroom apartment will pay on average 69% of his or her monthly SSI income. Indeed they claim there is not a single housing market area in the US where disabled people could rent a modest apartment and keep to the 30% guideline if they have to rely on SSI alone. As a result, the authors of the study argue that there is an acute housing crisis for disabled people in the US:

At this income level it is not surprising that several million people with disabilities cannot afford their own place to live.

There is some subsidised housing available, but this appears to have been increasingly designated as ‘elderly only’ housing. Therefore, disabled people are likely to have to rely on one of two federal programmes:

* **Section 811 funding**
  Designed to help non-profit organisations create affordable housing for disabled individuals (in very broad terms the equivalent of HAG and SNMA or SNAP in the UK) through offering subsidies towards the construction, acquisition, renovation, and operating costs of a range of options from small group homes to supported living (see TAC/CCD, 1999). However, competition for the limited Section 811 funding is ‘extremely competitive’. Further, this limited pot is shrinking: the 1999 budget allocation represents only 50% of the 1995 funding levels.

* **Section 8 certificates and vouchers**
  Section 8 funding is a system for subsidising the rents of individuals with a disability (or families with a disabled member) to enable them to rent the property that suits them. It is means tested: to be eligible the household must have income that is at, or below, the 50% of the US median (this will be about twice the level of SSI. If accepted onto the programme, the tenant will pay a limited percentage of his or her income (usually about 30%) as rent, with the balance of any housing costs being paid to the landlord through the Section 8 programme.

Section 8 has some positive advantages over Housing Benefit. For example, tenants can stay on Section 8 funding until 30% of their income is equivalent to the full rent (avoiding the steep poverty trap inherent in HB). However, it has some inherent disadvantages.

There is no absolute right to Section 8. For example, individuals may be denied access to the programme if they, or a member of their household, have been involved in recent drug related activity. Even more critically, Section 8 funding is finite and capped. Although TAC/CCD (1998c) estimate there are now something like 1.4 million Section 8 certificates or vouchers in
circulation, the demand far outstrips supply. As a result there are extensive Section 8 waiting lists, which in some instances have actually been closed because of the pressure of numbers.

Quite clearly, paying for housing in the US is a much more uncertain process. This is one possible explanation for the relatively slow growth of supported living in the US. For example, states were unable to spend all of the funding that was allocated to them as part of the experimental Medicaid Community Supported Living Programme (Lakin, Hayden and Burwell, 1996). This was partly because planning on an individual basis took longer than expected, but an evaluation of the programme also found that many participants had difficulty finding suitable housing, both because of their limited income, but also because of the lack of decent affordable housing in some communities (there were examples of people holding section 8 certificates but not being able to find a suitable home).

**PRICES**

As the preceding section has hopefully made clear, whoever is responsible for commissioning services for people with learning disabilities is likely to face a number of challenges. Aside from the complexity of the system, any commissioner is likely to be experiencing a combination of budget constraints and considerable demand. Further, whatever service they elect to purchase, it will depend to some degree on marshalling resources acquired from quite different systems over which the commissioner will have little control; systems which will often be working to different priorities and assumptions.

Further, in the case of the UK at least, the commissioner is unlikely to have any idea of the true cost of the service (Cambridge, 1997), or much clear information about the quality. Nor indeed, is there any pressure to be concerned about costs; the main aim of any commissioner is likely to be to protect the budget for which he or she is responsible. The issue of preserved rights illustrates this point. As we noticed earlier, people in residential care prior to 1993 are entitled to enhanced social security contributions towards the cost of their services. These contributions effectively represent an additional central government subsidy for the placement. People who move out of residential care lose their entitlement to enhanced benefits. There is, therefore, a marked disincentive for commissioners to co-operate with any move into supported living for these individuals. There is anecdotal evidence that the issue of preserved rights is becoming an increasingly important barrier, more or less regardless of the wider financial implications (Simons, 1998a).

However, the difficulties are not confined to preserved rights. For example, Simons (1998a) has suggested that the combination of the Income Support Residential Care Allowance with the limitations on access to the ILF and the considerable variation in residential care fees, creates a very inconsistent and frequently perverse set of financial incentives, sometimes tipping in favour of residential care even when an individual is capable of living independently with relatively little support.

In making important strategic decisions, commissioners in the UK will typically have to rely on a combination of informal information, status, trust and reputation as a basis for assessing the relative cost-effectiveness of services (Mannion and Smith, 1997). Without relevant data to counteract them, the kind of unfounded assumptions about costs mentioned earlier (that large services will deliver economies of scale, that supported living arrangements will only be
feasible for people who require little support) are likely to be both prevalent and unchallenged. In this context rationalist assumptions about the efficient deployment of resources are unlikely to hold.

**THE ISSUE OF INCOME**

One of the striking features of the research is the almost complete absence of data on the disposable income of people with learning disabilities. By and large they tend to be cash poor (Davis et al, 1993), even if the material surroundings in which they live (the group home) may be of a perfectly adequate standard. Yet the lack of decent disposable income is likely to be at least one of the factors that limit people’s access to community based activities (and therefore the opportunities to develop a wide network of relationships). As Simons (1998a) comments:

> What price ‘an ordinary life’ on £14.20?  

In this context it is worth noting that one of the arguments in favour of supported living is that it offers greater opportunities to maximise the disposable income of the individuals involved. For example, in his study of adult placements, Griffiths (1995) found that people in unregistered settings were, in terms of spending money, markedly better off (though by no means well-off). Simons and Ward (1997) make a similar point in discussing examples of supported living packages.

However, some caution is needed here. As we suggested earlier, one of the effects of the residential care framework was to act as a particularly rigorous charging system; local authorities may well also charge for domiciliary care services. This is likely to reflect local policies, with wide variation in terms of both the rates that are charged, and the services involved. For example, both Kestenbaum and Carva (1998) and MENCAP (1999) found increasing evidence that local authorities were including Disability Living Allowance and Income Support (meant to provide a basic minimum level of income) when assessing capacity to pay for services like personal assistance, domiciliary care and day services. These policies varied considerably from area to area, leaving some disabled people subject to arbitrary and unjustifiable limitations on their income.

**SUMMARY AND IMPLICATIONS**

In summary, the findings outlined here suggest that, in terms of broad costs, small staffed houses/group homes and supported living style arrangements are both financially feasible, and there is little evidence that a return to larger settings will present any cost savings, at least not without significant compromises on the quality of the service provided.

However, the funding system in both the US and the UK have a number of distinct disadvantages in common (Hemp et al, 1998; Simons, 1998a). These include:

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33 This is the amount of personal spending money that someone living in residential care is likely to have each week, once their food and accommodation costs are taken into account. In many instances they will be expected to save a significant proportion of this for the costs of clothes and holidays.
* **a pro-institutional bias**
Both the ICF/MR and the system for funding residential care provide ‘perverse incentives’ in favour of institutional rather than supported living style arrangements. Few of the funding systems seemed to be geared around the notions of citizenship and inclusion.

* **excessive rigidity**
The systems are primarily geared to the status quo, and often hinder innovation and change.

* **primarily geared to political and organisational concerns**
Rather than delivering to individuals the resources they need to lead decent lives, the systems appear to be primarily geared to a combination of essentially bureaucratic aims including managing costs and maintaining the financial viability of service providers.

* **are inefficient**
Despite the emphasis on controlling budgets, the systems are not flexible enough to promote the efficient use of resources.

The net result is a system that is neither justifiable nor sustainable. Taking into account the evidence of the existing and projected shortfalls in the volume of services, there is probably a need for further investment (see Felce, 1999). However, almost by definition, we also have to ‘do more with less’; there will have to be a much more efficient use of existing resources. Certainly, the wide variation in existing costs and the lack of a clear link with quality suggest that this might actually be possible. Some commentators (for example, Smull and Danehay, 1994; Simons, 1997; Simons 1998d) have argued that more flexible approaches, like supported living have an important strategic contribution to make here. However, there is also need for a substantial rethink of the way services are resourced, and the way these resources are deployed. At a macro level, there will need to be a review of the financial incentives for commissioners to make better use of resources. At a more micro level, commissioners intending to develop a comprehensive, affordable array of services will have to:

* **use a whole system approach**
The management of costs needs to be done on the basis of a strategic approach which recognises that while some costs can be reduced others will also need to rise if people are going to get the service they need (Smith, 1994; Howard, 1996).

* **lever in additional resources**
The special needs funding system is inadequate to the task. The role of services needs to be reframed in terms of enabling people with learning disabilities to access the resources they need for a decent life through their rights as citizens. In practical terms this will include maximising access to a much wider range of housing (including low cost home ownership), along with funding (the ILF, Housing Benefit, and other individual benefits are obvious targets).

* **draw in and complement natural supports**
The use of ideas like support tenants needs to be developed and extended.
* **ensure support is organised and targeted as flexibly as possible**
  Staffing needs to reflect needs for assistance and activities, rather than the standard application of rotas. Situations where individuals have more support than they need will have to be rectified. Rather than staffing arrangements being fixed, they will need to be adjusted as the needs for assistance rise or fall, and situations where individuals are either receiving too little or too much support will have to be rectified.

* **develop more extensive low support options**
  A basic low cost core service could help ease the pressure on more intensive services.

* **make better use of ‘assistive technology’**
  Some basic ‘assistive technology (adapted phones, alarm systems, etc) could help reduce reliance on expensive 24 hour staffed support (Lakin 1999).

* **maximise individual income**
  Ensuring that individuals have the resources to participate economically in the wider community needs to be part of any wider strategy for ensuring inclusion.

* **develop competence and autonomy, and promote effective ‘participant driven supports’**
  Ideas like direct payments and personal assistance have a potential role to play in reducing overheads.

Central government will have a significant role to play, not just in ensuring that wider policy developments are consistent with these aims, but by providing technical assistance and supporting further research to ensure that more coherent approaches to resourcing services are developed, evaluated and disseminated.
CHAPTER 9: HOUSING AND SUPPORT SERVICES ORGANISED AROUND WORK: THE CASE OF FRANCE AND GERMANY

INTRODUCTION

So far in this report, we have included very little material from central or southern Europe. As we suggested in chapter 1, we had reason to believe that services are organised in ways that differ significantly from the UK. Notably, many of the residential services are run by organisations whose primary focus is various forms of sheltered work. We had managed to access a limited amount of material, which, given the circumstances, we felt was worth including. Therefore, in this chapter we briefly set out to describe the situation in two countries: France and Germany. It is worth adding that, from the brief description by Carnaby (1997 and 1998), services in Milan would appear to have some similar features.

FRANCE

This part of the chapter is based on a fieldwork visit to France carried out by colleagues from the Norah Fry Research Centre and the University of West of England (Pannell, Simons and Macadam, 1998).

The primary focus of the study was a comparison of employment services in France and the UK, although one aim was to also see if access to work opened up other opportunities including mainstream housing.

The main form of employment opportunities for people with learning disabilities in France is the Centre d’Aide par le Travail (the CATs – literally centres for help through employment). In terms of their role in the French system they are analogous to the UK day centre; a majority of people with learning disabilities will use one (they serve over 80,000 people, most of whom are people with learning disabilities). However, unlike the average day centre, the emphasis in the CATs is firmly on work. The individual CATs vary both within and between different regions of France. However, in general terms they involve a combination of sheltered workshops and what would be increasingly called social firms, with a small amount of supported employment being added to the mix. So, for example, one of the CATs visited consisted of:

* a contract gardening team
* a combined market garden/snail farm
* a bakery unit
* the village baker’s shop and a mobile shop
* two packaging workshops.

CATs are semi-commercial enterprises, and they pay workers wages. However, these are rarely enough to live on, and so are supplemented by a benefit paid by central government through the CAT wage packet (the nearest equivalent would be the Disabled Person’s Tax Credit (formerly the Disabled Person’s Working Allowance). People also receive disability benefits. The three sources of income combine to give them a total income similar to the
French minimum wage (the SMIC), significantly above the French equivalent of Income Support. It should be noted that the CAT’s workers have the status of ‘travailleur handicapé’; they do not have full workers’ rights.

In the UK there is generally a divide between ‘day’ and ‘residential services’. The CATs often span this gap; over half the CATs provide housing and support services as well as employment. The form this takes varies from CAT to CAT, but will typically involve both hotel accommodation and supported tenancies. To take the example of the CAT described earlier, it offered a hostel and a floating support service.

The use of ‘ordinary’ social or private rented housing is extensive; according to a 1993 survey (Insertion et Travail Adapté) 21% of CAT workers lived in ordinary tenancies in the community, with 38% living in hostels, and 42% with their families. Some people living in apartments do share with other CATs workers (usually between two to four people), but most prefer individual studios or bedsits. Although the pattern was not perhaps as clear cut as in Germany (see below), people with higher support needs are more likely to be in the hostels. It is worth remembering that the latest estimate of the number of people living in their own tenancies in the UK was as low as 8%. The figures are not directly comparable, but they do suggest that significantly more people in France have the opportunity to live in their own home, even if this is restricted to more able people. Again, it is worth adding that although in principle supported living arrangements are meant to be for anybody, in both the UK and the US the practice has been rather different; in general it is also the more able people who have been given this opportunity.

People who live in the CAT hostels have to pay board and lodging, and are left only with pocket money, as in the UK residential care system. In contrast the people in supported tenancies tend to have a larger disposable income. They are entitled to Allotment de Logement (the French equivalent of housing benefit) to help cover the rent. This is means tested, and because of their earnings most CATs workers will not get the maximum. Nevertheless, taken in combination with the other sources of income, workers were still left with a disposable income of around £100 per week (1996/7 figure) even after housing costs have been paid. It would be an oversimplification to say that the income provided by the CATs is a sole factor in opening up this wider range of housing opportunities. Nevertheless, the increased income is part of the whole package of financial assistance.

The services provided by CATs are funded by a combination of commercial activities and national government funding. Access to CATs is determined by a complex assessment by a Government organization (COTOREP). This is a large scale process (600,000 assessments a year), geared to placing people into four crude categories, designed to reflect the individual’s potential productive capacity. People with very severe learning disabilities would typically be seen as incapable of work, and would therefore not be allocated to a CAT. Instead, they are likely to be recommended for a specialist home (Maison d’Accueil Spécialisée - which resembles a UK nursing home), or a Foyer Occupationnel, which is a hostel or day centre with occupational therapy but not work.

The CATs have some very distinct disadvantages. The work is often segregated or semi-segregated. As a result relatively few CAT workers were said to have friends outside the CAT. The system is very bureaucratic and rigid, and excludes more severely disabled people.
However, it does provide a more successful link between housing and work, a link that is missing in the UK.

**GERMANY**

The following section is based on three documents:

- a set of notes in English produced by Bunderesvereinigung Lebenshilfe (Lebenshilfe 1994)\(^{34}\), which outlines their recommendations for the future pattern of services, produced in 1994;

- a report of a survey of services carried by Lebenshilfe (1996). This contained details of the responses from 500 members of their organization (62% of the total);

- an accessible booklet for people with learning disabilities describing the kinds of options that are possible (Gobel, 1998).

It is worth noting that the services provided by Lebenshilfe seem to be among the better provision. Thus, as we note below, there are likely to be some difference between what we describe here and the norm in Germany.

As with many services in the UK Lebenshilfe appear to have been keen to reform their services. Further, they emphasised that the wishes of people with learning disabilities (and their parents) have been an important pressure for reform.

Many of the same issues found in the UK literature were also reflected in the Lebenshilfe publications. For example, their plans stated that:

... small, distinct living groups satisfy the interests of people with mental handicap and this must be recognised.

They added that the aim of their recommendations is to help people with learning disabilities to live ‘normally’ within society, and as a result they intend to focus largely on smaller settings (‘as a natural neighbour in a residential area), although they also acknowledged that:

larger living facilities still prevail in practice.

The actual average size of Lebenshilfe homes at the time was (excluding individual flats) nearly 17 people (and over 23 in the former East Germany).

Lebenshilfe describe two different financing systems. These are:

- **residential integration assistance financed through the Federal Social Assistance Act’s nursing allowance**

\(^{34}\) Lebenshilfe are, in broad terms, the German equivalent of MENCAP.
This broadly corresponds to the UK residential care framework, in that the fee is negotiated between the service provider and the regional authority responsible for social assistance. The person has to commit their benefit income to pay for care and is just left with pocket money, which can only be increased by a small amount of earned income. Within this framework Lebenshilfe say it is possible to provide the following range of services:

- **group living homes.** These are the equivalent of hostels, although there is usually much greater emphasis on people living in smaller groups (not more than six to eight people, though six to eleven is common in other services). Lebenshilfe suggest there should be a maximum of three groups within the wider unit, which would give a notional maximum of 24 residents. It is clear that it is not unusual to have units that are larger than this (one with 100 residents was mentioned)

- **group flats,** with not more than 6 residents

- **individual flats or flats for couples**

- **parent-child flats, for people with learning disabilities who have children.**

**Social Assistance benefits**

These include a rent subsidy and supplementary benefits to pay for care staff. There is a standard rate, plus extra amounts for very specific needs, which have to be applied for in some detail (a cause of frustration). In general this system is used to finance the arrangements for people who want to live in their own flats; what Lebenshilfe refer to as ‘outside services’ and which would appear to broadly correspond to supported living. However, just as in the UK, it is not always easy for people who want to live in their own home:

*I it is a pity, but the legal right to non-residential care is not yet sufficiently assured.*

It seems that the local agencies administering the Social Assistance will sometimes only accept ‘shared living groups’.

It would also appear that the people living in their own flats have to be largely independent, as the levels of support will be relatively low. Indeed there appears to be an implicit assumption that people with greater needs will be in the group living homes. For example, the information for self advocates indicates there will be less support in the group flats than in the group living homes.

As with both the UK and the US there is an apparent shortfall in services (the survey found over 5,000 people on waiting lists, not far off the total number of people using the services surveyed). Lebenshilfe also estimated there were around 19,000 people ‘wrongly placed’ in psychiatric institutions in Germany, and catering for this population was one of Lebenshilfe’s priorities.

Just over two-thirds of people in Lebenshilfe accommodation have their own room, with most of the rest sharing with one other person. This is said to compare well with a national average of just 38% with their own room. There is also some evidence of self-advocacy emerging, with 62% of lebenshilfe homes having residents’ councils.
The survey recognizes a number of concerns, some of which would be familiar to a UK audience, including:

* a low ratio of staff to resident (1:12)
* the lack of flexible work patterns
* insufficient ‘therapy support’ for some residents
* a lack of leisure activities
* the danger of social isolation.

Note that a lack of ‘non-leisure’ activity is not seen as a problem. One of the features that would make Lebenshilfe provision stand out in the UK is the proportion of people with structured activities during the day (94% according to the survey, with most in sheltered workshops). Spending at least part of the day in a work-like setting is seen as part of having a ‘normalising’ experience. Indeed, it would appear that most people move into Lebenshilfe accommodation after having been in a Lebenshilfe workshop.

Again this leaves the question of what happens to people who are not part of the workshop system. As in France, they would appear to be with their families or in institutions. This was an issue that Lebenshilfe was just beginning to address, with some discussion of developing homes for people who, it was felt, would not fit into the workshop.

**Implications**

In both France and Germany, there was a strong emphasis on ‘inclusion’ through work; through making a productive contribution to the community (even if it was in relatively segregated settings). The service system has therefore primarily revolved around employment services, with access to some housing and support options being a secondary function. This has some positive effects. In France the additional income from work has been one of the factors that has helped a wider number of people access their own home. It makes a positive link between home and work. These systems have their obvious disadvantages, particularly for those seen as not able to work; they are likely to be limited to a very narrow range of choices.

In the UK the situation is almost the diametric opposite to that in France. If you are a person with learning disabilities, the kind of place you live in (or more particularly, funding system used) is a significant determinant of whether work is a viable option. The combination of charging (in residential care) and a steep Housing Benefit taper (in tenancies), along with the interactions with the disability benefit system, acts as a strong disincentive to take more than a minimal amount of paid work (Simons, 1998a). The people who stand to gain most from supported employment initiatives are those living in the family home. Indeed, in the short term the failure to either adjust the social security system to the minimum wage, or to provide any accommodation within the minimum wage system for people who are not very productive, is likely to produce further complications.

This situation is fundamentally unhealthy. People should not be largely excluded from the workplace because of the needs for a housing and support service. Given that people with learning disabilities are one of the poorest groups, the lack of an opportunity to supplement
their income through work is singularly unhelpful. Work might have a useful role in helping people open up their social networks, yet the current framework effectively minimises that possibility. Finally, it also means that we use resources in inefficient ways. Although the US system shares some of the limitations of the UK’s, the disincentives are not as strong. As a result people with learning disabilities are likely to work both longer hours and gain more in earned income. This in turn means that supported employment is considerably more cost effective in the US than in the UK (see Beyer, et al, 1997).

Although the disadvantages of the French and German systems would appear to outweigh their advantages, they stand as a useful reminder that work is an important issue. People should not have to choose between full-time work or housing and support. Working out how to flexibly combine both sets of opportunities should be a major policy objective.
Chapter 10: Concluding thoughts

On the basis of the material reviewed in the preceding chapters, services for people with learning disabilities appear to have many strengths. They have continued to build on earlier developments, and have demonstrated a capacity to innovate. Nevertheless, they also have considerable collective weaknesses. The quality of such services is far from assured. There are not enough services for all those who might need them. In some areas (participation in the wider community is a prime example) aspirations far outstrip capacity to deliver the goods. Most people still do not live in arrangements that correspond to the models we know work best. The net effect is that people with learning disabilities still experience exclusion and discrimination. This situation is neither justifiable nor sustainable. Progress has been real, but it has only gone so far. There is a need for further reform.

Fortunately, there are some grounds for optimism. On the basis of the evidence from this review it is possible to map out what a ‘modernised’ service for people with learning disabilities might look like. For example, it would:

- be based on the principles of citizenship and civil rights. Access to a wide range of mainstream housing options would be a key plank
- be comprehensive, providing equitable access for all the different communities, and ranging from low support options right through to very intensive services for people with the most complex needs
- draw on a synthesis of the supported living models and developments like ‘active’ support
- be based on person-centred planning, along with community development strategies to open up a wider range of opportunities
- take the issue of self-determination seriously, with increased access to ‘participant driven’ supports for individuals and families who want these options
- use resources efficiently, and flexibly, with levels of support reflecting the needs of people who use the service, not organisational needs or arbitrary regulatory requirements
- involve regulatory reform, coupled with a comprehensive commissioning strategy
- require the creation of a coherent funding base which included appropriate incentives for commissioners to develop housing and support options (rather than focus exclusively on residential care)
- be complemented by a range of other services (including employment, continuing education and supported leisure services) which operate in a coordinated way towards collective aims.
THE INEVITABILITY OF CHANGE

On the basis of this analysis momentum for change needs to be maintained or even developed. In the UK, at least, there are signs that the general environment may favour change. Indeed, it would appear that some degree of change is inevitable. The current Government has already initiated, or is in the process of considering, a whole raft of policy reforms designed to ‘modernise’ social services. These include:

- **The White Paper ‘Modernising Social Services’**
  The White Paper places considerable emphasis on promoting independence. It also recognises the need for preventive services and the potential significance of work as a focus for tackling exclusion and dependence, highlighting the role of social services departments in making the New Deal for disabled people work. It specifically announced an intention to:
  - reform regulation by establishing independent Commissioners for care standards, and extending regulation to domiciliary services
  - extend the scope of direct payments

- **The Best Value Initiative**
  If it works, the Best Value framework will provide a pressure for the more rational use of resources coupled with attention to the views of people who use the service. Certainly some of the developments we described earlier in this report could fit well within a Best Value approach, although there is a risk that it could simply be a set of crude mechanisms for cost containment. The emphasis on benchmarking between authorities will certainly highlight the inequalities of current provision, although without clear targets the effect might leave authorities who have invested in learning disability services vulnerable to pressures to cut expenditure, rather than exposing under-investment to critical scrutiny.

- **Supporting People**
  This discussion paper, produced as part of the inter-department review on supported housing, proposes that a number of current streams of funding (including the residential care allowance, the Special Needs Management Allowance, and the additional support charges covered by Housing Benefit) should be consolidated into a single budget. This would then be passed to local authorities, who would have a corporate responsibility for commissioning a range of services designed to complement and enhance community care.

- **The Royal Commission on long term care**
  The Royal Commission was charged with the task of making recommendations for the future funding and charging arrangements for ‘continuing care’. This Commission has inevitably focused primarily on the situation of elderly people faced with the prospect of paying for residential care. However, by definition, its findings are likely to have important implications for people with learning disabilities who, more than any other group, are likely to be users of

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35 As we indicated in chapter 1 there is a completely separate Scottish White Paper (see Scottish Office, 1998a. There is also a pre-existing document called Modernising community care: an action plan (Scottish Office, 1998), although the latter is not primarily concerned with disability services. Both are available on the Scottish Executive web site (see Appendix 2).

36 Amongst other differences, we could find no reference to direct payments in the Scottish version.
residential care before the age of 65. The recommendations made by the Commission include
the proposal that all ‘personal care’ should be free. This would have some obvious
advantages, although aside from the problem of defining where personal care begins and ends,
there are dangers it might introduce a line of cleavage between services that provide personal
care and those that do not. We understand that the Government has not yet accepted the
Commission’s recommendations and will consult further. However, some way of resolving
the current tensions will be needed, so some change is bound to emerge from this process.

• **The New Deal for disabled people**
The development of the New Deal for disabled people puts employment issues squarely on the
agenda (where indeed they should be). Some of the employment initiatives that have involved
people with learning disabilities (particularly supported employment, but also the development
of some social firm initiatives) have been relatively successful, but they remain marginalised
within the wider employment services (see Simons, 1998a). The New Deal represents an
opportunity to change that. However, if such opportunities are to be optimised for people
with learning disabilities, then there will need to be a re-think about the unhelpful links
between work, income, and housing and support services.

• **The implementation of the Disability Rights Commission**
As we suggested in chapter 1, the effective exclusion of people with learning disabilities from
a range of mainstream housing options is a matter of discrimination. This introduction of the
Disability Rights Commission is bound to focus attention on the issue of civil rights for
disabled people, which in turn could have profound implications for services that have not,
hitherto, been organised around these principles.

Taken together, and implemented in full, these policies would imply a degree of change that
would be as radical and thoroughgoing (if not more so) than the 1993 community care
reforms. Such extensive change would represent both opportunity and risk for people
with learning disabilities.

In terms of opportunity, these wider policy reforms might provide a framework for addressing
the problems that learning disability services need to solve before wholesale change could be
achieved. For the first time, the direction in which learning disability services has been moving
is largely in accord with the wider Government agenda, particularly the concern about social
exclusion and citizenship. Given how rarely this happens, this is not a chance to be wasted.
Further there are some resources targeted on ‘modernisation’; if a due proportion were to be
targeted on services for people with learning disabilities, it would certainly help with the
process of reconfiguration. Of course, even in the most optimistic scenario significant change
will not happen overnight. We will continue to have the historical legacy of services for the
foreseeable future. An enthusiasm for new forms of service provision should never preclude
efforts to improve the quality of more traditional services, nor should it be an excuse for
throwing assorted babies out with the bath water. There are dangers of change being
implemented thoughtlessly. The lessons from previous generations of services need to be
absorbed and applied to new developments, which in turn should be looked at carefully and
critically. Similarly, the development of a more genuinely inclusive service strategy need not
preclude the chance for some individuals or families to choose rather different options.

However, while the overall direction of reform might appear to be favorable, the devil is likely
to be in the detail. Wider social policy change is rarely, if ever, driven by the concerns of
people with learning disabilities (the example of the Royal Commission on long-term care, with only one chapter devoted to ‘younger disabled people’ is an obvious case in point). Major change represents a particular risk of unintended side effects for people with learning disabilities. One of the more obvious pitfalls includes a reformed regulatory system that fails to accommodate the development of intensive domiciliary services. There is also the danger that services for people with learning disabilities will not be seen as a sufficiently high priority for modernisation resources.

Further, the different elements within these reforms are likely to interact in ways that will be difficult to predict. Therefore, there is a strong case for the systematic piloting of these reforms, building in careful evaluation. Some of the proposed changes in *Supporting People* would be an obvious starting point.

Given the complexity of the changes that are both needed, and which are more or less inevitable, there is a strong case for finding a mechanism for ensuring a clearer focus on issues relating to people with learning disabilities within government. For example, there have been calls for a new national statement of policy for learning disability services (Felce, 1999), equivalent in scope to the 1971 White Paper for England and Wales, and including updated principles, a stocktaking of provision, lessons from research, recommended service design criteria and norms for provision. Not least, as Felce argues, this could:

> … provide a safeguard against the potential for manipulation of demand which is inherent in the care assessment system.

Equally, given the advent of devolution, one possibility would be to revisit the idea of the national strategies. As we suggested in chapter 2, the experience of the All Wales Strategy offer both positive lessons about the advantages of such an approach, and advance warning of some of the potential pitfalls which might be avoided a second time around. Certainly, if services for Scottish citizens with learning disabilities are going to be as good as they could be, some kind of coordination of policy and resources will be vital. In the context of the current review of learning disability services in Scotland, it would be a very opportune time to consider the equivalent of an All Scotland Strategy for the new millennium.
APPENDIX 1: SEARCH STRATEGY

Given the limited time available we used a very pragmatic strategy for seeking out material to include in this review, effectively combining both formal and informal search methods. For example we:

* returned to material cited in previous publications
* carried out a hand search of the specialist library of material held at the Norah Fry Research Centre, focusing primarily on material published since 1995. This included the main UK learning disability journals
* contacted a network of experts in the learning disability field, including significant numbers of individuals from North America and Europe
* carried out formal searches of the following on-line data bases:
  - BE1 The British Education Index on Bath Information and Data Services (BIDS Education)
  - IBSS The International Bibliography of the Social Sciences
  - Ingenta Ingenta Journals Bibliographic details
  - BIDS ISI The Bath Information and Data Services Science Citation Index
  - IBSS on BIDS The Bath Information and Data Services Institute for Scientific Information Incorporated Social Sciences Citation Index
  - Applied Social Sciences Index and Abstracts
  - Cochrane database of systematic reviews
  - Sociological Abstracts
  - PsychLit

As has been our previous experience, the key words used to categorise items that relate to people with learning disability are at best inconsistent, and at worst irrelevant. Specific terms (like group homes, supported living, staff housing, and so on) produced few hits; even sometimes failing to identify relevant items that we knew existed. More generic terms like ‘housing’ produce many more hits, but few are relevant. Having tried a range of search terms, and cross-cataloguing the results, we generally fell back on broad terms like learning disability (see list below), working through the inevitably large number of hits by hand. Some care had to be taken, since searches using learning disability (as opposed to learning disabilities) would produce quite different results, often with only partial overlap (for example, on one particular database the latter resulted in 532 hits, but just 277 with the former).

The search terms used (in combination) included:

learning disability/disabilities
learning difficulty/difficulties
intellectual disability/disabilities
developmental disability/disabilities
mental retardation
supported living
group homes
residential care
residential services
community care
community facilities
housing
village communities

We also made an extensive search of the world wide web. We list some of the sites discovered in Appendix 2, where we also note similar problems with index systems. On the whole, using links between sites provided more productive than relying on search engines.
APPENDIX 2

USEFUL WEB SITES

We visited a large number of web sites in the course of producing this report. We have included below a list of the more useful/more accessible sites, grouped by country. This is not by any means an exhaustive list, and in the very nature of the web, it will soon be out of date. Nevertheless, we felt it would be useful to provide these details, for the following reasons:

* In the main body of the report we cite material that was down-loaded from the web. In general, we have simply listed this material in the bibliography as having been ‘published’ by the originating organisation. However, using the list below it should enable those wishing to access this material to find the relevant web site. We have chosen this approach (rather than citing the exact web page with each reference) on the grounds that organisations frequently re-organise their web pages. However, moves for ‘home’ pages are rather less common.

* The web is likely to become an increasingly important source of information for both policy makers, practitioners and researchers. Many of the sites we list below will be important sources, both now and in the future.

* Many of the sites we point to are valuable not just because of the information they hold, but also because they are a gateway to further information. For example, the American Association of Affiliated University Programs for Persons with Developmental Disabilities web site includes details of the research and development centres in each of the states. Indeed, most sites will have ‘links’ pages, which will provide valuable pointers.

There is a significant down-side to the web. It is possible to spend a lot of time searching for information without necessarily having much to show for it at the end. Because of the poor indexing of much information, using some of the search engines either produces very little, or unmanageably large numbers of sites. There is little control over the material posted on the web, so some caution needs to be exercised in evaluating this material; it will not be like a journal article that has been subject to critical peer review. However, allowing for these difficulties, we believe to ignore the web would be a mistake. We hope, therefore, that the following list of sites will provide a useful starting point for would-be surfers.
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