Money well spent

The effectiveness and value of housing adaptations

Frances Heywood

In conjunction with Christopher Lund, John Winfield
and officers from Bristol City Council, Cardiff County Council, Dudley Metropolitan
Borough Council, Eastbourne Borough Council, East Sussex County Council,
London Borough of Greenwich, Kirklees Metropolitan Borough Council,
Somerset County Council and South Somerset District Council

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1

Background and context

"After the adaptations, O my God it was wonderful. Could go up and downstairs. It was just the independence – keeping your independence. Not always asking other people and being dependent on them."

Introduction

People of all ages and in all tenures in England, Wales and Northern Ireland, who are disabled by unsuitable housing are entitled, subject to a means test, to mandatory grant aid to make adaptations to their homes. The items for which this help is available are listed in Appendix A.

This is the report of a research project designed to gather evidence on the effectiveness or otherwise of these housing adaptations – large and small – carried out at a cost to the public purse of over £220 million every year. The research was carried out in 1999-2000 by teams of professionals from seven local authority areas in England and Wales working in partnership with the research coordinator and with two disabled researchers. The findings are based on direct interviews with 104 recipients of major adaptations and 162 postal questionnaires returned by recipients of minor adaptations.

The purpose of the report is to present the evidence in a way which will be clear and helpful to specialist professionals and even more to non-specialist managers in housing, social services and health. The research shows what extraordinary power for good or ill lies in the hands of those who set and control adaptation policies and budgets. Good adaptations transform lives, improve health and keep people out of institutional care; bad adaptations are an opportunity lost: "money down the drain" as one recipient put it. The research also shows that although sometimes it is poor practice by professionals that prevents an adaptation from being fully effective, large-scale waste can often be the result of national or local authority policies. It is intended that the information offered here will help to inform both practice and policy audiences.

Housing and community care

For at least 25 years in England and Wales, policies of supporting frail older people and younger disabled people in their own homes rather than in hospitals or residential establishments have been gradually gaining ground. This general trend was crystallised in the public mind by the 1990 NHS and Community Care Act. The role of housing as an essential component of community care has also gradually been recognised. For most older and disabled people this does not mean specialised new provision but adaptations to their existing homes.

Expenditure on adaptations

In 1995, £221 million of public money was spent on the capital costs of adapting properties in all tenures in England and Wales in order to make them more suitable for their disabled occupants. This comprised £180 million from housing sources (housing revenue accounts, housing grants and Housing Corporation funding) and £41 million from social services budgets (Heywood with Smart, 1996).

No more up-to-date total is available because figures for social services spending and local authorities' expenditure on their own stock are not collected by government. Available figures confirm that spending on disabled facilities grants (DFG) has continued to rise. In 1999 it was £121 million in England (DETR, 2001a) and £20.8 million in Wales (National Assembly for Wales, 2000, Table 3.4), but the 1995 breakdown showed that expenditure on adaptations from housing revenue accounts was even higher than the DFG budget. In the registered social landlord (RSL) sector, The Housing Corporation's concern about growing outlay on adaptations has led to a succession of measures since 1996 to divert costs to individual associations.

Accepting that the 1995 estimate is likely to be a cautious one gives some indication of the importance of the cost of 'adaptations' as a public policy issue. If staff costs in all sectors are included, the annual outlay is, of course, considerably larger.

Growth in demand and growth in unit costs

The growing cost of adaptations is a reflection of both increasing numbers of requests and of the increasing costs of individual adaptations. Growth in numbers is above all a product of demography: 70% of all adaptations are for people aged over 60 (Pieda, 1996, para 5.7) and the growth in numbers of people aged over 85 is particularly significant. But other important factors are policy changes (care in the community, early hospital discharge) and medical advances which save more lives, young and old. Changing social attitudes and policies of care in the community may also be increasing the life expectancy of seriously disabled people. Finally, there are social and political factors contributing to demand. The disability movement has empowered disabled younger people living in parental homes or in residential institutions to ask for homes of their own, suitably adapted.

Unit costs of adaptations have risen partly because advances in technology have brought expensive sophisticated devices onto the market, and also because of legislation on lifting which has required the installation of tracking hoists, which tend to be very costly. The small size of recently-built housing will also be a factor, since it offers less scope for internal reorganisation. When all these things are taken together it becomes clear why adaptation costs are eating up available budgets.

Pressures on local authorities

In this situation of growing numerical demand and growing unit costs, local authorities are in a very difficult position. Government is committed to keeping down public expenditure, while local authorities have duties under both the 1970 Chronically Sick and Disabled Persons Act and the 1996 Housing Grants Construction and Regeneration Act to meet the adaptation needs of disabled people. In such a situation, it is essential to spend resources as wisely as possible, ensuring that what is provided represents value for money, is needed and is used. Adaptations to a disabled person's home that, for whatever reason, are not useful, represent a lost opportunity – depriving either that person or someone else of precious resources. But authorities are also under considerable local pressure to reduce waiting lists and completion times, which means processing as many applications as possible. Even with slightly increased staffing levels the growth in demand (6% increase in one year; DoH, 1997b, para 9) means that staff must work very hard just to keep abreast of referrals.

Policy imperatives

This spending is taking place in a context of government policies which continually emphasise the desirability of maintaining disabled people of all ages in their own homes and keeping them out of residential institutions. Moreover, a new, stronger emphasis has been given to the 'preventative' agenda.

In parallel, the social model of disability has emanated from the disability movement, with its central idea that, whereas people may have to live with the discomfort or difficulty of a physical impairment, they are avoidably 'disabled' by unsuitable environments: an issue of human rights and everyone's responsibility. The extension of Part M of the building regulations in 1999 (ensuring that all new homes in England and Wales will be built with a downstairs toilet, level access threshold and doors wide enough for a wheelchair to pass through) can be interpreted as the new model's first great triumph. It is arguably only a matter of time before a social model of ageing will begin to be more widely understood and make a similar impact on policy and practice.

The government has repeatedly emphasised and required policy makers to demonstrate the practice of consulting service users. This is core to Best Value and other government initiatives, and has gone beyond tokenism to a requirement for evidence of the impact of consultation. This links to the growing concern with evidence-based practice: measuring outcomes rather than inputs.

Thus many current policy trends – community care, joint working, user input, human rights, preventative investment and an emphasis on measuring outcomes and looking at effectiveness – have come together in this piece of work.

Aims of the research

The aims of the research were:

- to collect clear evidence on whether housing adaptations had improved the independence and quality of life of disabled people of all ages;
- to consider the evidence concerning poor quality or ineffective adaptations and to understand why these occur and how they may be prevented;
- to establish to what extent the provisions of the legislation on adaptations were being implemented;
- to test out a methodology that may be of value for future research of this type.

About the study

This was qualitative research into the subjective views of service users, backed up by evidence recorded on files and by the direct observations of interviewers. It was carried out systematically and on a large enough scale to produce some quantitative evidence about qualitative issues.

It comprised:

- a postal questionnaire of people whose homes had had 'minor' adaptations done (defined as quickly and easily fitted fixed alterations costing less than £500);
- an interview survey (face-to-face and telephone) of people who had had 'major' adaptations carried out to their homes.

The methodology was unusual in that most of the fieldwork was carried out by the professionals most closely involved in adaptation processes. Housing, environmental health and occupational therapy staff from seven local authorities across England and Wales conducted most of the work. Fifteen interviews (five each with children, adults under 60, and adults over 60) were sought in each area. They were carried out using a combination of structured and semi-structured formats, consistent for all areas. Disabled researchers and the research coordinator carried out additional interviews by telephone.

The surveys were intended to elicit why adaptations had been requested and then to discover how well the respondent felt their needs had been met. The main measure of 'effectiveness' was the degree to which the problems experienced by the respondent before adaptation were overcome by the adaptation, without the causing of new, equally or more serious problems, and without perceived waste.

Our stance was, and is, unashamedly user-centred. This does not, however, exclude consideration of effectiveness from service providers' points of view. Part of the argument that underpins the emphasis on consultation is that adopting a user-centred approach is an important way of avoiding waste, and that the interests of service users and service providers are not opposed but closely aligned. This research presents some evidence to that effect but readers must judge for themselves.

Further details of methodology – including sampling and response rates – can be found in Appendix C.

Structure of the report

This chapter has considered the background to the research, and outlined the approach adopted. Chapter 2 looks at the effectiveness of minor adaptations and Chapter 3 gives the core evidence about the good outcomes of major adaptations. Problems and disasters with major adaptations are described in Chapter 4, while Chapter 5 looks more analytically at the causes of waste, the costs and benefits of adaptations and ways of maximising effectiveness. Chapter 6 summarises the main findings of the research. It contains not only suggestions about changes to policy and practice that would increase the effectiveness of adaptation spending, but also an iteration of good policies which already exist but are not sufficiently known or implemented.

2

Minor adaptations, major triumphs: the effectiveness of minor adaptations

This chapter presents the results of the questionnaire survey into 'minor adaptations'. Of course, the distinction between 'major' and 'minor' is artificial, and there was, and still is, some blurring of the boundaries. But the two chief characteristics that were used in the definition – ease of fitting and cost under £500 – produced a body of replies that are coherent and distinctive from the more expensive, more disruptive and more intrusive major adaptations.

The evidence that follows is based on 162 replies, received from six of the seven authorities taking part. The questionnaire is reproduced in Appendix D.

Characteristics of respondents and properties

Most minor adaptations are given to older people and the random sampling that was used reflects this fact. The average age of respondents was 71; the median 75; the mode (most commonly occurring) 78. The oldest respondent was 98. No doubt related to this age profile, the ratio of female to male respondents was almost 3:1 (115 women, 42 men, 5 information not given), and the average household size was 1.9 persons, while the most common was 1. This is significant because when a person lives alone with no one to help out if something goes wrong, the importance of the adaptation is even greater. In a few cases a widow or widower of the original applicant filled in the form, saying that they were still finding the adaptation useful.

Many respondents left the ethnicity question blank but of those who chose to answer it, the overwhelming majority identified themselves as white British.

All tenures were represented in the sample (see Table 1). Properties included 24 bungalows, 23 flats, houses detached, semi detached, and terraced, one maisonette and one park home; they ranged from having one to five bedrooms with three-bedroom semi-detached houses being the most common.

Table 1: Minor adaptations: tenure of respondents

Owner-occupiers	Council tenants	Tenants of private landlords	Housing association tenants	Information not given
58%	27%	4%	4%	(6%)

Reasons for having adaptations

The question asking why alterations were needed to the respondent's home was open, and replies fell into two major camps: names of illnesses, or problems with the environment. These divisions neatly represent the medical and social models of disability (see Appendix B) – some people seeing their illness or impairment as the root of the problem, others focusing on a barrier in the home that needed to be overcome. Some people linked both types of answer. The words most commonly occurring in the replies were:

Bath	28
Stairs	26
Arthritis	24
Steps	15 (including several bungalow dwellers)
Fall	8
Toilet	7
Stroke	7
Safety	7

Seven of the eight respondents who mentioned risk of falling had already fallen. One had lost a leg as a result, three others had suffered broken bones (hip, wrist, shoulder). From the numbers later saying that they felt safer as a result of the adaptation, it is reasonable to surmise that fear of falling was also implied in the answers of many of those who listed difficulties with stairs and bathing as their reason for seeking adaptations.

Work done

The items that had been supplied to respondents are shown in Table 2.

Some of the items mentioned were too portable to be included under our agreed definition of 'adaptation' – these included the array of bath seats and bubbles, raised toilet seats, high chairs, chair raisers, bed levers and perching stools which are counted as 'equipment'. Other items were too large to count as 'minor' (eight walk-in showers, two stair-lifts, one through-floor lift and two hoists).

These factors illustrate unavoidable methodological problems. People who have had minor adaptations on one occasion may receive major adaptations at another time, and members of the public will not necessarily make a distinction between adaptation and equipment. There are advantages in considering equipment and adaptations together, as both the Audit Commission (2000) and the Department of Health (Qureshi et al, forthcoming) have done, but this research was confined to the impact of fixed alterations to housing.

Effectiveness

For each of the 11 possible objectives offered in the questionnaire, respondents were asked to indicate whether the adaptation helped, whether no help was needed or whether help was needed but the adaptations did not help. However, most respondents simply ticked the outcomes that had been achieved. The results are shown in Table 3.

Table 2: Work done

Adaptation item*	Number of respondents who had this item	(%) (n=162)
Grabrails	98	60
Stair-rails	69	43
External handrails	62	38
Ramps	19	12
Alterations to steps	10	6
Over bath shower	9	6
Heater or fan	6	4
Alterations to taps	5	3
Door entry system	5	3
Alterations to doors	4	2
Raised power sockets	4	2
Alterations to worktops	4	2
Long rail beside bath	3	2
Louder bell	2	1
Other†	26	16

* Some respondents had had more than one item.
† 'Other' items listed by respondents included flashing door lights, telephone lights and smoke detectors, and telephone amplifiers for people with hearing loss. In one case, there was a combination lock to allow emergency services and home help to enter. Another person had had numerous minor alterations in their kitchen.

Table 3: Outcomes of the minor adaptations

Objective achieved as consequence of the adaptation	Number ticking this item	% (n=162)
Feeling safer from risk of accidents	101	62
Taking a bath or shower	79	49
Using the toilet	63	39
Needing less help from others	59	36
Running your home generally	51	31
Being able to go out	39	24
Continuing with your interests	20	12
Preparing meals	13	8
Having a social life	13	8
Caring for someone else	5	3
Getting to work	2	1
Total number of positive effects	**445**	

This represents an average of 2.7 positive effects per person.

Health effects

Respondents were also specifically asked whether the adaptations had affected their health or peace of mind, with the options 'no effect', 'good effect', 'bad effect'. 145 people responded to this question, and their replies are shown in Table 4.

Thus while 22% of the 145 people who answered the question said there had been no effect on their health, a remarkable 77% said the adaptation had produced a good health outcome.

Table 4: Perceived effect on health of minor adaptations

Health consequence reported	Number ticking this response	% (n=145)
Bad effect	1	0.6
No effect	32	22
Good effect	112	77
Total	**145**	**100**

Note: 17 respondents did not answer this question.

Problems caused by adaptations

The researchers were aware at the start of the project that adaptations may be seen as intrusive and may cause problems as well as or instead of solving them. For example, the use of g-clamp external handrails has been described by service users in past research as ugly advertisements that the occupant of the property is disabled, thus increasing vulnerability to crime. There is also the problem of altering a home for one person without considering the impact on others who live there. It was therefore felt important to ask about negative impact, and the results of this are shown in Table 5.

Table 5: Perceived problems caused by adaptations

Response to question, 'Did the adaptation cause problems?'	Number	% (n=152)
Yes	10	7
No	142	93
Total	**152**	**100**

Note: 10 respondents did not answer this question.

Examination of the 10 instances in which adaptation was seen to create a problem revealed that two of these related to major adaptations that the respondents had received in addition to the minor ones (a shower depriving others of use of the bath, and a stair-lift making access upstairs for others difficult). Another related to an item of equipment (a perching stool), which took up too much room in a tiny kitchen. Three others were related to materials or workmanship in the fitting of grabrails; one related to changed circumstances (lowered kitchen units when the kitchen is now only used by non-disabled people); and one to the inadequacies of a re-allocated 'adapted property' where the handrails were wrongly positioned. Of the remaining two, one just wrote 'bathroom door', so it is not possible to know what the problem was; and one said 'huge electricity bills since heater put in bathroom'.

Quality of work apart, then, only one of these items – the cost of electricity – truly represents a problem caused by a minor adaptation properly supplied. Another – the handrails in the wrong place – also highlights the danger of using registers and re-allocations of 'adapted properties' if they are not accompanied by occupational therapy (OT) assessment and relevant changes being made.

The problems flagged up by the postal questionnaire, although small in number, are significant because they reflect in miniature the issues that are more common and serious with major adaptations. These include lack of space; changing needs; the problem of heating; poor communication, supervision, or quality of work; and bad effects on other family members. We will return to these issues in Chapter 4.

However, the overwhelming message from the survey is that minor adaptations are relatively problem-free: 93% of those who answered said there were no problems. Similarly high levels of satisfaction were found in response to the question 'Are you happy with the way the alterations look?', where 95% of 149 respondents answered 'yes'. Given that the appearance of minor adaptations has been highlighted as problematic by previous research, the findings of this survey suggest that standards have possibly risen and attention is now paid to these aesthetic issues.

'Waste' and 'value'

Because the research was interested in service users' views of value for money, as required in the implementation of Best Value, a question was included that asked, 'Was anything supplied or done at the time that you did not want?' This was followed by the subsidiary, 'If yes, has it since turned out to be useful?'

Just four out of 162 people said 'yes' to this question, but two of them then added that the occupational therapist had proved to be right and it had turned out to be useful. Later chapters will further explore the balancing act that has to be struck between looking ahead to what will be needed and the question of what people are able to accept. The conclusion from this question, however, is that there is very little waste in the sphere of minor adaptations.

Respondents were also asked if they would have spent the money in the same way, if they had been given it to undertake alterations themselves. 86% of the 138 responding answered 'yes'. The major issues for those who said 'no' was either quality of work or, most commonly, feeling that the bathing adaptation that had been supplied was not adequate to meet their needs.

This also showed itself in answers to the questions 'Was there anything you wanted that was not done?' to which 28 people said 'yes'. Most of these responses concerned bathing adaptations. This will be discussed later in the report, but it is worth noting that the OT partners in this research felt that their professional judgement is currently too often compromised in the matter of bathing. Inadequate budgets lead to requirements that they "go through a dance" of offering people inadequate solutions, such as equipment or rails that they anticipate will not properly meet needs. In the major adaptations survey we continue this theme when we discuss those who have fallen after being given such solutions. The minor adaptations questionnaire showed how thoroughly content people are with a simple handrail or two when this is all they need. The 15% of minor adaptation recipients who felt they needed more help with bathing deserve to be taken seriously, for they are part of a group who, in most other respects, are expressing modest expectations and high levels of satisfaction.

Summary of findings

The findings of the postal questionnaire constitute an overwhelming endorsement for the effectiveness of minor adaptations. These modest one-off interventions improve health and produce a range of good consequences for the users year in, year out. There are almost no negative side effects, no waste, and the majority of users consider the money well spent. In some cases, moreover, there are benefits to other people and this continues even after the original client has died.

It is difficult to think of many interventions of drugs, surgery or therapy that could produce comparable results.

The main lessons to be learned, apart from issues of quality of materials and workmanship, relate to:

1. **Prevention: Seven respondents had already had serious falls before the adaptations were fitted.**
2. **Bathing: Quite a number of people felt they still could not bathe safely, that the minor adaptation was a stop-gap when major adaptation was needed.**
3. **Changing needs: A number of people expressed surprise that no one had come back to check on their adaptation – and distress because they now needed more help.**

3

Major gains: the positive outcomes from major adaptations

Introduction

This key chapter contains further information to justify the title of the report: that money properly spent on adaptations is money well spent. It focuses on major adaptations, adding to the evidence concerning the effectiveness of minor adaptations given in Chapter 2. It is based on a total of 104 interviews carried out by the research team.

Overall rating: scores out of 10

At the end of most interviews (exceptions were interviews in the pilot study, and some telephone and face-to-face interviews where the question was omitted or recording was unclear), respondents were asked to give a score out of 10 in answer to the question 'How effective has the adaptation to your home been, weighing up the good and the bad?' This was introduced after the pilot, at the suggestion of the officers there, who saw that detailed criticism of particular points could mask overall feelings of satisfaction. Once the method was adopted, the interviewing officers were also required to agree a score for the adaptations. Table 6 shows the results.

These figures convey the overwhelmingly high levels of satisfaction expressed, despite all the problems. The scores given by service users were much the same whether the interviews were conducted by officers or carried out over the telephone by independent researchers, and were higher, on average, than the scores given by the officers themselves.

Instances where a low score (anything less than 9) was given and especially the low average scores for children's adaptations will be considered seriously in Chapter 4.

Money well spent?

Interviewees were also asked whether they would have spent the money in the same way if they had been given it to spend themselves. With various understandable qualifications about quality of builders or more work needed, 87.5% said 'yes'. As the question was taken seriously

Table 6: Scores out of 10 for the effectiveness of the adaptations

Age at time of adaptation	Average service user scores* for effectiveness of adaptation		Average scores* given by officers for same adaptations	
Adults 65 and over (n=26)	9.4	(range 5-10)	9.1	(range 8-10)
Adults 18-64 (n=21)	9.0	(range 2-10)	8.9	(range 6.5-10)
Children 0-17 (n=22)	8.3	(range 5-10)	7.8	(range 2-10)

*corrected to one decimal place.

and respondents considered what else they could have done with these large sums of money, the finding is significant of the value put on the adaptations. For 91 out of 104 interviewees, the money that had been spent had been mainly well spent. The exceptions are considered in Chapter 4.

To understand why people were so satisfied, it is necessary to understand the difficulties people faced before adaptation, and how the adaptation solved the problem. The rest of this chapter – set out in a series of objectives – puts flesh on the bones provided by the 'scores', through the words of those who gave interviews.

Objective 1: Having a bath or shower

The most common reasons for requesting adaptations are those relating to bathing. Every disabled person has a mandatory right to have an accessible bath or shower in their home (1996 Housing Grants, Construction and Regeneration Act; see Appendix A for details). Sadly this has sometimes been undermined by practices embedded in the individual, medicalised model of disability rather than in the social model (see Appendix B).

> "A major issue is that she cannot get into the bath and has been waiting four years for a shower. Was assessed in 1996 and told she was entitled but not a high priority because she is not incontinent. Last asked again two months ago."

Humiliation and embarrassment

Bathing, however, is a matter of immense importance to people's self-respect and confidence.

> "Effect of not having shower adaptation? Feels very depressed: feels she wants to cry. Doesn't feel clean; feels smelly all the time. Sometimes goes to father's house to have a shower. When she washes at home, can't wash her back – doesn't expect her children to wash her. It's awful when you think you smell, even though the family tells her she doesn't."

Parkes quotes Florence Nightingale as saying that a nurse leaving a patient unwashed was interfering injuriously with the healing process "as effectively as if she were to give the patient poison" (1993, p 18). Parkes' own work is significant for the evidence she collects about the importance bathing has had throughout their lives to people who are now older. In 1993 she interviewed 60 people of an average age of 80. She discovered that, despite the absence of plumbed-in baths in their childhood homes, the weekly bath (tin tub at home or visit to the public baths) had always been an important ritual and had been associated with spiritual and physical health.

Our research showed acute embarrassment at having to be washed by someone else adding to distress at being unable to bathe properly.

> "She was suffering terribly loss of dignity, loss of independence. She hated being seen naked. 'Don't want to be on show like someone at Madame Tussaud's: keep your bits to yourself'."

Other people described the discomfort and difficulties of the alternatives.

> "I find when I've had a bed-bath it takes so much out of me by the time I'm dried and dressed – I'm so exhausted I have probably lost two or three hours."

> "Bathing was a nightmare. The occupational therapist supplied a board across the bath to sit on but it was not much good. Only way she could get bath was to visit her daughter who had a sunken bath she could get into. This mattered because the physiotherapist had told her that water would relieve the pain – which it does."

Positive outcomes

The evidence about what was achieved by bath or shower adaptations was overwhelming. The interviews showed how the adaptations restored confidence, dignity and self-respect, promoted independence and reduced stress. They offered relief to those whose condition benefited from a good soak or the sprinkling of a shower, with the additional liberating effect of water play for children. They also reduced accidents and the need for assistance.

Box 1: Effectiveness of bathing adaptations

> "She thought the shower was fantastic, it was nice and big and that suited her. She could sit down in the chair, turn it on and use the shower by herself. She enjoyed no longer needing help to wash, even if you're old, you don't like, do you? She enjoyed being able to shower any time she wanted to. She had a nice little heater to keep her bathroom warm enough. Her bathroom was big enough for her to have plenty of room to change it."

> "Now things are in it gives her a lot more independence. She can bath on her own and she feels the benefit of a soak in the warm bath."

> "It has made a big difference really, especially the shower, as it had been hard to lift him into the bath and he had kept slipping and had whacked his head in the bath. He loves the water anyway."

Objective 2: Using the toilet

If problems of feeling smelly are hard to discuss, the issue of actual incontinence or the need for help using a toilet is an even more unmentionable issue. The need to reach a toilet and the problems connected to this can cause agony – physical and mental. If the bathroom and only toilet are upstairs, people who are confined downstairs will have a problem.

> "Climbing stairs become a terrible problem – could only go up with help and come down on one hip. Desperate because toilet upstairs – would hang on as long as possible – only go upstairs three or four times a day."

> "For the mother the crunch came when she couldn't lift her daughter into the house and the child nearly wet herself in the wheelchair. The child was in a lot of pain and very angry at everyone, including her parents."

Some physical conditions mean that people may need to spend many hours at a time in the toilet, during which times, if there is only one toilet, it is inaccessible to the rest of the family. If the only toilet is located in the bathroom, the problem is even worse. The evidence collected also shows people's horror and embarrassment at having to be helped, having to use commodes, and how lack of a toilet can cause isolation and social exclusion for the individual and even the whole family.

> "In the morning she has to wait for a carer to lift her bodily onto the toilet. Has to be lifted on and wiped. So degrading."

> "It was about two-and-a-half years between the time of the accident and the date adaptations were completed. In that time it was really terrible. People would come to visit and he was embarrassed. The commode was in the kitchen and sometimes the smell was terrible – had to spray deodorant everywhere."

> "We have a lot of children and grandchildren visiting which wasn't good – I had to ask a neighbour to come in and empty the commode."

Box 2: Effectiveness of toilet adaptations

> "Wonderful. Can go to the toilet whenever she wants."

> "The new toilet arrangements [Clos-o-mat] changed our relationship as previously it was difficult." [Husband had previously assisted client with personal hygiene]

> "Client is less stressed about the possibility of needing to use the toilet more frequently when taking diuretics. 'I'm so independent now. I have more peace of mind through having had the adaptations done.' She felt it was a bonus that she had smart ground-floor toilet facilities for visitors to use too!"

> "It is better for our sons if they have friends visiting etc." "It is only since we have had it that we have realised how much of a struggle it was before." "More independence for son – regarding coming in and out and use of the toilet."

> "The first time I was able to flush the toilet, I cried."

Positive outcomes

People's joy and relief at being supplied with an adaptation that enabled the use of a proper toilet was immense. The toilet adaptations improved relationships between partners and above all ended humiliation and social isolation.

Objective 3: Overcoming the barrier of stairs

Small, narrow staircases are a very British institution. For people with reduced mobility they offer pain and struggle on the one hand and the risk of falling on the other.

> "Getting upstairs was an agonising process. She would do it one foot at a time, her husband supporting her bottom while she pulled herself up step by step. It took 15 minutes to climb the stairs, and reduced her to tears every night. She endured that for two-and-a-half years."

The staircase constitutes an insuperable barrier for wheelchair users and is a source of extra risk to parents to carry their disabled children up and down (Oldman and Beresford have recorded the difficulties [1998, p 23] and this research reinforces their findings).

> "Their daughter was getting heavier to carry and the stairs were very awkward with two turns in them. The parents have slipped themselves on the stairs, so carrying her up to the toilet and bed was getting increasingly dangerous."

Stairs tend to stand between bedrooms, bathroom and toilet on the one floor and kitchen, living room and garden on the other, with devastating consequences, especially with regard to the toilet. The research showed how both children and adults could be isolated upstairs or confined downstairs. Evidence from older people in particular in this study begs the question of how many old people crawl up and down the stairs of their home in pain every day, not knowing help is available.

> "She had had one knee done and was in a terrible state, it was taking her half an hour at a time to get upstairs, it was like a nightmare."

> "When he was in hospital they had asked him how he was managing at home and he had told them he was going upstairs on all fours. He had been doing that for two to three years before that. They had never asked for anything, but were told they could apply. They had not known that beforehand."

It is only when you pause to think what it must be like to take half an hour to climb a staircase that the joy of people who have received a suitable adaptation becomes fully comprehensible.

Positive outcomes

Remedies for those who are disabled by stairs vary according to circumstances. For some a stair-lift is all that is needed; other people require the provision of downstairs facilities or full en-suite extension. It may be that both a through-floor vertical lift and an extension are needed (see the example in Box 3).

Stair-lifts can be very slow (as the cartoon at the front shows) and they are not suitable for all disabled people. In many cases, however, and for the ordinary business of having access to the whole home, they can be very useful, as Box 3 shows. Through-floor lifts are more problematic, as Chapter 4 will discuss, but can still, if there is enough space overall, be valuable and valued.

Reading the views expressed in Box 3, it is possible to understand why so many people used the term 'godsend' to describe a stair-lift: "no longer a prisoner"; no longer "enduring nightly pain" (from the process of getting upstairs to bed). No wonder one man told the interviewers he would never describe it as "*just* a stair-lift" and that he wanted to give it 12 out of 10.

Box 3: Effectiveness of lifts

"The stair-lift has been 'an absolute godsend'. What used to take 15 minutes now takes one. She is no longer trapped up or downstairs and no longer endures the nightly pain."

"The ability to gain access to the whole house is wonderful. No longer a prisoner."

"Client would give a score of 12 out of 10 if he could, but had to be content with 10! He could only describe the stair-lift as a 'godsend' and would never describe it as '*just* a stair-lift'."

"The vertical lift was a godsend and the downstairs toilet and sink meant it was easier and quicker to use, however many times the child needed to use them."

In those cases where downstairs facilities were needed and provided, the evidence of the good achieved is equally strong, and some examples are given in Box 4.

Box 4: Effectiveness of downstairs facilities

"Child gets little warning when he needs to urinate so having an easily accessible WC on the ground floor is a great bonus and it gives the child more dignity and reduces embarrassment – especially if there are visitors in the house. It is also helping with educating bowel habits."

"It has helped the mother who needs to use the toilet frequently and urgently because of her diabetes."

"For mother? Wonderful – just to walk in off the kitchen with daughter rather than get her upstairs. Has made life much easier. Good effects on health – less stress and strain – she used to get to screaming point."

Both the stair-lifts and the downstairs facilities dramatically reduced the danger of falling on the stairs, too, as many respondents pointed out.

Objective 4: Having sufficient space

Many of the officers from the higher-cost areas covered in this study felt that the maximum grant of £20,000 was no longer adequate, particularly when an extension was needed. (One manager advising the project said that the housing boom in the South East in 2000 had led builders to quote prices of around £35,000.) It is because extensions are expensive that it is especially important to understand why they are necessary and what they achieve.

In cases where the disabled person – old or young – needed constant care throughout the day, giving them a bedroom and facilities on the ground floor made this job more sustainable and countered isolation. An extension was usually necessary to provide what was needed without destroying family life. Several families interviewed had taken an older relative into their home in order to look after them and needed more room. For families with a disabled child, the need for more space is the one consistent, persistent, unrelenting reality. There is a sense, in reading the interviews, of the extension giving the type of relief experienced when you have been travelling with three well-built people in the back of a small saloon car and at last one gets out.

This is the significance of "plenty of storage for medical supplies"; being "able to escape to her own private room"; "more space in the rest of the house"; "it has improved our lives and his!" (see Box 5). The value of providing something that allows older children to have a place of their own (with facilities on hand, eliminating embarrassing interludes) is shown in the improvements parents saw in their children: "It has made such a difference".

Positive outcomes

Chapter 4 will show the terrible waste that can occur if a necessary extension is not provided at all, or is provided but is not big enough or not heated. This makes it all the more important to look at the evidence from this research concerning the good outcomes of extensions properly provided.

The extensions referred to in Box 5 varied from something just big enough to house a ground floor shower and WC to the provision of double bedroom with en suite facilities.

Box 5: Effectiveness of extensions

Extension for families including a disabled child

> "One of the grants officers had suggested an extension for Richard with sliding-door access into his own extension. 'Score 10 out of 10, because it has made such a difference – it's improved our lives and his. If it had all been done at once it would have been 12 out of 10!'"
>
> "Large side extension, bedroom, bathroom with plenty of storage for medical supplies was built. The final scheme has helped everyone in the family. It is safer for carer and, because Jason has his own area in the house, there is some privacy provided for other children. The total dependence level of Jason does not allow for much social development irrespective of what scheme was provided but the benefits for the other children are significant as there is more space in the rest of the house."

Extension for an adult

> "The adaptations for his grandmother have made a big difference to her as she appreciated being able to escape to her own private room. Central heating had been put in throughout, in every room."

Objective 5: Warmth

In 1998, 89% of all British homes had central heating (DETR, 2000; the source showed that whereas 91% of owner-occupiers and RSL tenants had central heating, only 87% of council tenants and 77% of private tenants did). Unfortunately, among the minority who did not have central heating were a disproportionate number of older people and families with a disabled member, as these are the groups with, on average, lower incomes and worse housing conditions, even though they are also the groups who most need warm homes:

> "They applied because it used to be freezing; they just had a gas fire in the two rooms downstairs and had used a calor gas fire in the bedroom which had smelt awful. It had been damp upstairs and the draughts were dreadful. They had sat in rooms with the doors closed and draught excluders by the doors. Their health had suffered and he had been chesty and had colds all the time." [Man with Parkinson's disease]

In some cases the cold caused pain or was potentially life threatening:

> "Before the adaptation, sitting, walking, any movement caused pain. The cold temperature increased the pain, he needed to wrap up in a sleeping bag to keep warm."
>
> "I had a heart transplant. They came and did a visit from [the hospital] and said the house was too cold for me."

Chris Lund, one of the disabled researchers, explained how important it is for some conditions that the *whole* home be warm, so that if a fit or other crisis occurs, it is not made worse by cold experienced in the process of transfer to a place suitable for recovery. This was borne out by evidence from respondents about the good effects of heating adaptations, as Box 6 suggests.

Positive outcomes

Chapter 4 will show that some major adaptations were rendered void or severely weakened by the lack of adequate heating. The benefits when it was provided, however, were remarkable. Not only does the warmth reduce pain and lessen the problems of damp, it also enables people to use more of the space in their homes.

Warmth: a low-cost way of increasing space

As space is one of the housing provisions most needed by wheelchair users, and one of the most expensive and difficult to provide through adaptation, it is worth noting that heating is a way of at least maximising the use of any space there is. In a number of participating authorities, after the research the officers followed up the interviews by encouraging participants to apply for new Home Energy Efficiency Scheme (HEES) grants, which is a valuable addition to adaptation resources.

Box 6 shows what warmth achieved.

Box 6: Effectiveness of central heating

> "It's been wonderful. The general warmth was the main benefit for all the family and the damp is less of a problem now."
>
> "Effect of the central heating? Great difference. They have a big living room which gets very cold, not much sun. Has a gas fire as well as the radiator. Now wife's legs and hands, knees and ankles don't ache so much – nor the spine. Also much better for husband. He explained that the effect of the tablets for angina is to make you feel cold. Now he doesn't feel cold for so long, especially in the morning when he takes the tablets. Can walk around the house without feeling cold and doesn't have to get down to press the button to light the gas fire, which wife can't do because of arthritis."
>
> "The older daughter tends to spend more time up in her room now that it is warm."
>
> "He no longer needs to sleep in his sleeping bag and the pain is reduced."
>
> "He can now go into a warm bedroom rather than wait for it to heat up and he doesn't have to lie out on the sofa in the warm living room anymore, as the bedroom is always warm. His wife had had to creep around when he was in the living room on the sofa. He can be incontinent when he has a major fit so it was also important to have a constant supply of hot water."

Objective 6: Preventing accidents and improving health

In this study, 40% of recipients of major adaptations had either already fallen or were in fear of falling or other accidental injury.

> "There was originally a bath with floor to ceiling pole and a bath stool, but she had had three falls...."
>
> "The mother had already fallen down the stairs whilst carrying her child."
>
> "The child had no sense of danger and was also epileptic, so his problems could potentially be fatal if he climbed out of a window and fell, and he was at risk of drowning in the bath."

Positive outcomes

In nearly all cases where falling or fear of falling had been a problem, the adaptation removed this danger (the exceptions were when the details were not quite right: see Chapter 4).

As far as the physical health of applicants was concerned, the most dramatic finding was from a man with epilepsy whose consultant had recommended central heating. The result was that the number of major fits halved and, although he suffered more frequent minor fits, he was clear that the health gain to him was a wonderful outcome. Less dramatic but still important were general feelings of greater well-being or direct benefits resulting from having access to a warm bath or shower and a more comfortable and suitable home.

Box 7: Physical health gains and the prevention of accidents

"Physical health and stress and pain? With the stair-lift this is all so much better. And the shower with a seat in; I couldn't stand in the shower, as I got dizzy when I shut my eyes."

"They had originally been referred for heating for the two children who had asthma because the asthma had tended to get worse in the winter. They had noticed some improvement in the children's health chest-wise, especially their younger daughter."

"He said that the number of major fits he has a week has gone down by 50% since the heating was put in."

"Both Mum and girls had problems telling what temperature the old shower had been. The girls had complained it was too cold when it had actually been hot. New shower is set to the right number and left, so that's safer."

"His is kept very clean to minimise the risk of infections for him, and when he has an infection he uses only that toilet to protect the rest of the family."

"Makes a lot of difference. He feels long-time better because he can have a shower. Feels much fresher when the water sprinkles over. The warm water makes a lot of difference."

Box 8: Aspects of improved well-being

"Believes she wouldn't be alive without the adaptations – for psychological rather than physical reasons. Hated having to ask for help and her life was existing, not living."

"Having an easily accessible WC on the ground floor is a great bonus and it gives the child more dignity and reduces embarrassment, especially if there are visitors in the house."

"It has made a big difference to her life. The first-floor WC in the bedroom is good. Life is easier as a mother. Much more independent. She can take the 'Hoover' and ironing up in the lift and be self-contained on the first floor if necessary. Morale has been uplifted."

"She is now able to use the kitchen whereas before it was impossible. There is now much more space so it is wheelchair accessible."

"He feels safer and is now completely independent in the bathroom. It was wonderful not to need assistance."

"She's more social and in with the family. Biggest aim in mother's life is for this daughter to be accepted socially."

"He wouldn't be at home with his family without it. We wouldn't be as happy as we are without it. It has definitely transformed both our lives."

These physical benefits to the applicants must be also linked to the health benefits to carers – considered below – and to the equally important issue of mental well-being.

Objective 7: Improving well-being and combating depression

Evidence already given has indicated the mental strain, stress and depression endured by people needing and awaiting adaptations. Living in fear of accidents was one factor, feeling imprisoned another. However, perhaps more important still was what people said about loss of dignity and feelings of uselessness and helplessness: having a commode in their living room, feeling smelly all the time, being dependent. One parent said her child had stopped asking for things – a serious sign of withdrawal.

> "He had been getting into the habit, before the stair-lift and access were done, that he wouldn't ask for things. He would say he was bored but did not like to ask his parents for something if he had asked for something previously, he would rather go without. He would rather do nothing than ask for something."

Positive outcomes after adaptation

Box 8 gives some examples of what was achieved in overlapping areas of dignity, confidence, social inclusion and feelings of independence.

Self-respect and dignity

Many of the comments relating to dignity are related to the relief at being able to use a toilet independently (Clos-o-mats are mentioned several times), or no longer having to be seen naked. Parents said that they were conscious of the need to respect the dignity of growing children. But people's self respect was enhanced in other ways, too: "it makes you feel good being able to do things for yourself"; it helps to feel "still a bit useful". Evidence was also given about the importance of the appearance of the work: as with the couple who felt it was very good for their disabled son that the results did not look like a 'disabled facility'. This echoed evidence in the Royal Commission on Long Term Care (1999, vol 2, pp 325-46), which said that supporting technology needs to be desirable in a mainstream way to be psychologically beneficial to older people. It is interesting too, that one carer stated that it was helpful to *her* that her husband had "got his dignity back".

Growing confidence

Although confidence is important to all age groups, it seemed particularly important to parents, who saw how the confidence adaptations gave opened vistas of development and opportunities to flourish for their children.

Social inclusion and family life

It was interesting and pleasing to see the different ways in which good adaptations could bring disabled family members back into family life; from making it possible for the family to watch TV together to enabling a child, formerly often confined upstairs, to be less 'ostracised'. For children, it often meant the chance of friends visiting or of being able to go into the street to play for the first time in their lives. The comments convey by implication the isolation and restriction that existed for many children before they received adaptations. The point about appearance not creating difference and exclusion is picked up too, "I'm proud of it and happy for my friends to go in there". For older people as well, those who had previously felt like 'prisoners' were now able to get out and go on visits, while the independence given to the disabled partner in a couple allowed a partner who had formerly also been trapped at home to go out.

Independence conferred or restored

Independence is clearly one of the most important and most common issues addressed by adaptations (see Clark et al, 1996, for a discussion of its importance to older people). Although there was no direct question about it, 46% of those interviewed chose to say that improved independence (either restored or achieved for the first time) was one of the outcomes of adaptations. The independence of a disabled person also benefits care-givers and statutory services, and if someone is happier because they feel less frustrated, everyone will gain.

However, the issue has its complexities. Disabled people have made it clear that 'independence' does not necessarily mean people struggling to perform every routine task for themselves but rather maximising people's freedom to act for themselves in whatever ways are important to them.

The comments on independence from adults show not only people feeling better about themselves but also the practical benefits to families when disabled parents were able to undertake some household tasks. When people say they are much happier and that their morale has been uplifted these are good signs in regard to mental health.

For children, independence is linked by the evidence to development and will therefore affect the whole of the child's future life.

Box 9: Well-being in children

"Parents said they were 'ecstatic' with the difference in their child: 'he is a different person, much more confident and independent', 'he would not be the lad he is now without it', 'has helped him grow up'."

"The child is much more confident and in control. Having the space for her friends to come has made a big difference especially as some are also disabled."

"The big benefit to him is that he can be more independent going in and out of the bedroom – he shuffles on his bottom in and out to pick the videos he wants to watch (before he would have been stuck upstairs – and only able to indicate what he wanted by moaning). Now he comes into the kitchen with his mother – pulls the pots and pans out and generally explores in the way all children do."

"You couldn't say for certain whether this has affected his development [child, now seven], because he is also getting older – but at recent yearly review they were very pleased – he'd come on a great deal. Previously he was upstairs and a bit more ostracised."

"He has some friends around here and he likes to go outside when they are playing football and rugby (an especial favourite). Before the porch and path were there he had not been able to get out there alone. Now he can take himself out whenever he wants to."

"He said he was still pleased with it all two years on, 'It looks brilliant and I am proud of it and happy for my friends to go in there' (boy, age 12)."

All these issues – dignity, confidence, social inclusion and independence – contribute to a person's sense of self-worth and hence to their mental health and well-being.

Objective 8: Help for care-givers

Here again the problems were both mental and physical. Living in unsuitable accommodation causes stress on all members of a family, as the mother said who described herself as "getting to screaming point" before the adaptations for her child were fitted.

Lifting and carrying: the strains on family

In their study for the Office of Population Censuses Surveys, Meltzer, Smyth and Robus (1989) found that over one third of those caring for disabled children felt their health had been adversely affected by caring (cited in Bennett, 1994, p 21), and back problems are a common difficulty.

It is often assumed that EU regulations on lifting do not apply to family members, although, because social services departments have a duty of care to carers, this assumption is open to challenge (see Clements, 2000). In the meantime, however, this research has shown clearly that many family members are putting their health at risk or suffering actual short- or long-term injury through lifting or carrying their children or other relatives, because of the lack of suitable facilities. Actual carrying is mainly restricted to parents.

> "He had been nearly five years old and his Mum was pregnant with his younger sister and had been carrying him upstairs to bed. Mother had noticed her shoulder blades had been hurting after lifting Mark."
>
> "His mother has had back problems and had to have an emergency operation after lifting him in the toilet one day. She has seen X-rays of her spine which have convinced her that she cannot risk further damage by trying to help him in these areas."
>
> "Carrying 12-year-old daughter a growing problem as she was getting bigger – as years go on back cannot cope. Husband has already damaged his [back] by carrying her and had to have hospital treatment. Mother feels odd twinge – not enough to go to doctor."

Other carers, often not young themselves, are also at risk, however:

> "Mr E couldn't lift his legs over into the bath. He also found it difficult to get downstairs in the night to go to the toilet and he was having to do this three to four times a night. They did get a commode to help, but it was a lot of work for Mrs E who wasn't in the best of health herself. Mrs E often had to help her husband with bathing which was hard as he was a big man. Also carrying the commode pan up and down stairs was hard."

Positive outcomes for care-givers

The reciprocity of support and interdependence of family members is something that emerged time and time again in interviews. If the family is helped the disabled person benefits; if the disabled person is helped the family benefits. (And if families are supported, the care they are giving will not break under the strain and the state and wider community will benefit.)

The evidence in Box 10 gives just a few examples of the positive outcomes from adaptations for family members in addition to the disabled person. These include physical relief (especially with regard to back strain), reduction of stress, gains for siblings and generally greater happiness within families. The comment from a boy that he is glad he no longer holds up his parents and brothers because he has his own bathroom shows how important it is to understand the interconnectedness of individual and family well-being.

Payne's small research study showed how the installation of bathing adaptations for children reduced the incidence of soft tissue injury to parents (Payne, 1998, p 32). This research also produced reports of reduced strain on backs. This is a subject with major financial implications, as a damaged back can cost the state dearly in medical treatment and lost employment.

Box 10: Positive outcomes for carers and other family members

"It took a lot of worry off the wife. She used to worry a lot. Now she can put him on the lift and know he will be safe."

"Both parents have back problems so there has been a noticeable improvement due to the reduction in lifting/handling for bathing particularly as child is quite heavy."

"The child said when he is in the shower he can do it all himself, whereas he was definitely struggling before when he had to use the bath. Everything is a lot quicker and it has made a big difference to him. Having his own bathroom means he does not hold up his parents and brother."

"The adaptations have enabled greater interaction between the children have allowed us [the parents] to keep an eye on *all* the children and have brought a warmth to the house."

"Benefits of adaptations: the final scheme has helped everyone in the family. It is safer for the carer and because Jason has his own area in the house there is some privacy provided for other children."

"For siblings? – Rest of the family? Sister thinks it's wonderful. All family has shower together – younger sister feels included. (The whole of our life revolves around older daughter.) Money well spent? Definitely. Can't imagine life without these adaptations. Can't think of anything we wanted extra or different."

Objective 9: Preventing admission to care

For those who are disabled by their unsuitable housing, but would prefer not to go into residential care, adaptations can be the lifeline that makes all the difference. For others, ‘preventative’ adaptations that protect them from breaking a hip or becoming ill through cold and damp will also mean the ability to stay in their own homes. Almost 1 in 10 (6 out of 70) of the adults interviewed listed the specific achievement for the adaptation of preventing admission to care.

Box 11 gives some details. One person had been brought out of residential care and in four of the other five cases it was felt that, without the adaptations, admission would have been inevitable.

Box 11: Avoiding care

> “Their grandmother had originally been in a home but she had not settled there so they decided to have her live with them.”
>
> “We could not have carried on without them. Husband would have had to go into a home. He wouldn't be at home with his family without it.”
>
> “If these had not been done, could not have gone on caring for mother at home. Before – when she was in a bedroom upstairs – it was dreadful. The living room was smelly – mother had a catheter but in her confusion pulled it out. Had to keep squirting air fresheners. Embarrassing for son, who hadn't realised what it would be like. Now mother sits in her own room and is perfectly happy. Watches TV, sometimes goes in the garden. Goes to daycare four days a week. Wears pads. Major incontinence problem is at night – but it's much easier for daughter to deal with now. Family have own space and privacy.”

Conclusion

Evidence given in the chapter has shown how those who had received adaptations felt many objectives had been met because of the adaptations. Carers felt more supported, the health of disabled people and other family members improved, social isolation was overcome, and children began to flourish and develop in ways which would enhance their educational and life-course chances.

For individuals there were the simple benefits of such things as being able to go in and out, take a bath, keep warm, look after their families and live with dignity in their homes.

It is clear from these interviews that the power of major adaptations to transform lives is even greater and more dramatic than that of the smaller adaptations. When major adaptations are good, they are very, very good:

> **“I bless it every day.”**
>
> **“Who wouldn’t be pleased and I don’t care who knows.”**
>
> **“Money well spent? Definitely. Can’t imagine life without these adaptations. Can’t think of anything we wanted extra or different.”**

4

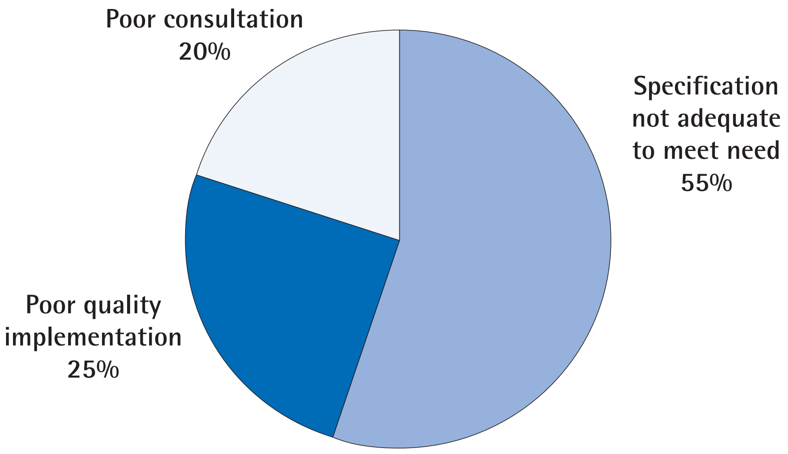
Major pains: problems and disasters with major adaptations

Evidence of good outcomes was the major finding of this research. There were also, however, some serious problems common enough to appear endemic in the system as it is at present, and some downright disasters.

The officers who carried out the research felt that people were so grateful to have had any help at all that they were inclined to understate the defects, even when work was patently unsatisfactory. However, whenever someone who had given an interview gave a score less than 10 out of 10, they were encouraged to explain their reasons. Figure 1 shows the principal findings and Table 7 provides a more detailed breakdown.

The rest of this chapter will give detailed evidence to illustrate these issues that reduced the effectiveness of adaptations. Underlying causes of the problems, above all the issue of inadequate specification which means that some adaptations are virtually doomed from the start, will be pursued more analytically in Chapter 5.

Figure 1: Principal causes of ineffective adaptations



Note: Based on 80 causes given by 44 respondents

Table 7: Reasons for scores under 10 for effectiveness

1. Processes of consultation and communication prior to specification	
Not what was asked for	6
Not adequately consulted	3
Not listened to	2
Consultation process itself unsatisfactory	2
End result not what person expected	2
Not adequately consulted about detail	1
Total	**16**
2. Poor quality implementation	
Poor quality building in general	14
Remedies poor when problems arose	2
Poor quality shower installation	2
Specification not followed	1
Adaptation not functioning properly	1
Total	**20**
3. Specification not adequate to meet need	
Access provision unsatisfactory (from front, rear or both)	11
Adaptation too small/no provision for child's growth	10
Detrimental to rest of family	7
Too cold and/or damp	6
Independence still not quite attained	4
Adaptation hard to use	4
No access to kitchen	1
Total	**43**

Notes: Based on 79 causes given by 44 respondents; 44 respondents out of 69 face-to-face interviewees gave one or more reasons for their adaptation not being wholly effective. The other 25 had no complaints. Those who had problems mainly listed one principal cause, but some gave more than one, up to a maximum of four in one case.

Bad workmanship and professional failure

A number of adaptations were spoilt by bad workmanship:

> "The builder was hopeless; he measured the floor wrong so that the flooring was cut too small, he put the wrong drain in so that the waste water from came back up through the drain in the floor when the toilet was flushed. He had to take up the floor to redo the drain but then measured the floor incorrectly again."

Poor quality professional supervision was another, connected problem. This applied to all tenures:

> "New flat roof has leaked and door-frame fell off. The workmanship was poor and not properly overseen by council surveyor."

> "The architect agent had not overseen the work properly. The grant had been paid to him to distribute to the contractors, which he had failed to do. The couple had recently been upset to receive a letter from one of the suppliers threatening court action if they did not pay the £7,000 which was still outstanding. They were

> concerned that this may affect their credit rating and had meant the supplier would not offer them a maintenance contract for the equipment. They had to take out a separate insurance on the lift, as the supplier would not even give them a quote due to the mix up with the payment. They paid £100 per year, plus parts."

Also, once things had gone wrong, it was commonly very hard to get them put right:

> "The council paid the builders although the work was not finished. Then it was really difficult to get the builders back."

> "Difficult to contact council. All you get is music playing and then put to a different place and more music playing."

Specification details not right ('more a disaster from start to finish')

Many of the problems listed were not to do with workmanship but with the details of what was done, either because of the initial specification or because what was installed was not what had been specified. Either way, the difficulties could be pretty serious. This was especially common in the case of showers.

> "Shower: is very grateful to have it but there are problems because it is not big enough. There is not enough room for the seat under the shower as respondent doesn't want to wash her hair when she has a shower (has a hairdresser who comes for that). Result is, although was meant to be able to sit, has to stand. Has to go very gingerly so as not to fall, and has to catch hold of the rail they've put in, but gets tangled up in the curtains. Has to be very, very careful when turning because of poor balance.
>
> If the shower had been just a little bit longer, would have been able to sit down. Wasn't given any choice or taken to see or try out."

> "The shower, unfortunately has not been a success. More a disaster from start to finish. The builders brought the wrong one – not the model she'd chosen. She protested, but they had already ripped out the bath so instead of replacing the model they spent a week trying to modify it. Man from council came but when she said the shower was too small he said it was what had been ordered. When later she told the occupational therapist, the occupational therapist agreed it was not the right model (which had had an oblong base, not square). Problem is it is too small; respondent keeps hitting her arms and elbows on the grabrails. It's better than nothing, but not good."

The shower being too small was a common problem and potentially both painful and dangerous, especially for people with arthritis. If no seat was provided, there was a danger of falling. Some controls were out of reach, some could not be read by older people in a steamy atmosphere without their glasses, and there was a risk of scalding. Unsuitable screens meant carers getting completely soaked, unless they took a shower too. Sometimes there was a step up or down which could not be managed without help. One wheelchair user was provided with a shower that could not be accessed in her wheelchair. The noise of the pump necessary for some upstairs showers was also a problem, causing major complaints from neighbours. In several cases, there was no handrail, or nowhere to put soap or shampoo. In other cases, the room with the shower in was too cold to use at all in winter. The showers were sometimes also very awkward to clean, especially for a disabled person.

As far as level access showers are concerned, professionals say that design has improved greatly in recent years and should prevent some of the difficulties experienced by the people in the interviews. But these difficulties stand as an example of how important the *details* are in all adaptations (and explain why second-hand adaptations need to be regarded warily unless an assessment is done to ensure the details are right).

There were other types of adaptation where details undermined effectiveness.

> "No light-switch near his bed for night time, so if he needs to get up at night he's in pitch dark. Has to shout for help at night (baby alarm had to be switched off as he plays music all night to shut out other more disruptive noises such as rain on the extension's flat roof)."

> "Window controls difficult to manage, making ventilation awkward to control."

> "The intercom is in the hall and it takes time to get there. Sometimes people go before I can get there."

Omissions

Also important are those things that were needed but were left out:

> "The only disappointment is that I cannot move the basin independently (it can be adjusted, but only manually). If I had been living alone, I would have been given an electric one."

> "She likes to cook, but cannot reach the kitchen cupboards."

> "He still needs help when he is brought by the school bus. His Dad has to be at home at 3.30pm every day to help him over the step. He gets frustrated by not being able to do these things by himself."

> "Access to play in the garden was recognised by the occupational therapist but did not happen due to cost constraints. They were told only about two weeks before the works started. This was very disappointing to the little girl and her mother."

Adaptations not meeting children's needs

At 8.3, the average score out of 10 given by respondents for adaptations for children was the lowest of the three age groups, and the professionals gave only 7.8. The examples show how sometimes there is no ideal solution, particularly when insufficient space is the problem.

> "First effects were not good. He didn't want to be on his own in a bedroom downstairs. The change was noticed at school and he went down. He's ok now – older and more knowing. And his other brother sometimes sleeps downstairs with him."

> "Harry does not like to be out there on his own. He feels vulnerable in his bedroom at the back of the house."

It is not surprising that a young disabled child does not want to sleep alone downstairs when the rest of the family is upstairs – but sometimes the extension is the only way to provide what is needed. If this is the case, however, it has to be big enough:

> "He needs someone with him at night, which was not really considered when the adaptation was being done. The problem with the lack of space in the bedroom will get worse, as they will be getting a hospital bed which is wider than his present bed, and he will need equipment to help him breath as well."

One officer commented that after the research they will never again specify a single-bed sized extension, understanding now the need always to have more room, including room for another person to sleep.

If a child's extension bedroom is likely to be a place where they spend much of their lives, it has to be adequate to fulfil that role, but often was not. In one example, a family described how their son's bed was placed in the front room during his frequent periods of bed-rest, while the displaced furniture was stored in his bedroom. This common upheaval was necessary because the room provided for him was too isolated from the family living room.

Lack of access to outdoor play space was raised many times:

> "There is nowhere to play. He has drop-knee fits so can only play in his own room. His room when it is done is to be his safe area." [Officers felt this 8-year-old should also have had a safe play area outside.]

The lack of access to outdoor play space was a cause of severe disappointment to many respondents. An adaptation disappointment is not the same as a one-off event that one can get over – it is something that has to be lived with day in day out – a continual source of regret or frustration.

It was also unusual for provision to be made for the disabled child to have access to the family kitchen:

> "Kerry will never be able to use the kitchen due to size and lack of turning space."

Lack of storage was another key issue. The fact that a disabled child cannot have a special bike at home because there is no room to store it seems especially harsh:

> "They have had a lot of equipment to store for her including a plinth, parallel bars, two wheelchairs and the bathmaster. She has also got a big three-wheeler bike, which they had to send into school because it had been too awkward to store at home. They were also waiting for a proper chair for her. Space was obviously quite a concern and they had applied to have a shed for storage but found that the Family Fund did not fund sheds."

There is one more point to be made specifically about adaptations for families with a disabled child, and that is to remember those who are cut off from any help at all by the current test of resources. From work elsewhere (Keep and Clarkson, 1994; Oldman and Beresford, 1998; Beresford and Oldman, 2000) we know this will include families suffering all the difficulties described in Chapter 3 and without *any* hope of help until the rules are changed and budgets increased, or until social services authorities are able to help more.

Insufficient space because of adaptation

One family was given a through-floor lift out of a living room and into the biggest bedroom instead of an extension. The pressure on this mother is clearly terrible, and explains why extensions are provided.

> "I've had to move from the front bedroom with the lift in so the girls can sleep in there, they need more space now they are older. I sleep in the back bedroom, which means I can't open the door properly with the double bed in. He sleeps in the small bedroom, which the wheelchair won't fit in. There is not enough space for us all, especially upstairs. The bathroom has a hoist but its very difficult as there is not enough space. There is no storage space for all his equipment, his incontinence pads are downstairs under the stairs, that's were the wheelchair has to go as well."

Loss of space caused by adaptation could also be a problem for disabled adults. This was particularly the case with stair-lifts and through-floor lifts, which took up space in small hallways or intruded into rooms. Several people expressed regret at losing a pantry or other storage space if this was converted into a shower. But space is more commonly an issue where there is a disabled child, partly because the dwelling is likely to have more people living in it.

Disasters

Officers from several authorities discovered adaptations that had gone disastrously wrong.

> "As the boy grew, it became increasingly difficult to lift him. Bedroom wasn't big enough to use the manual hoist. Applied for electric hoist but there was a two-year wait. Terrible in that time trying to cope with changing him: it was so awkward. In the end, wife injured her shoulder and was admitted to hospital. She was in four days, and son was taken into respite. Electric hoist has now been fitted. Whole adaptation is too small. No thought given to the fact that a child grows up. In his bedroom there is room for wardrobe, bed, table and hoist and nothing else. Has to have his computer in the kitchen: can't get into the bedroom. Ramp at the back is too steep – dangerous: footplates catch on it. Also there is no entrance at the back to give fire escape. Waiting for action on this but it may be two years."

In this case, the adaptation was doomed from the time the size of the extension was decided, for the anxiety, injury and need for respite care all followed from this. The next example also resulted from initial specification: an extension without adequate insulation and heating for a very frail child.

> "The adaptation has probably had a detrimental effect on child's health due to the bedroom extension being cold in winter months – child has a weak chest and has to use inhalers. He had pneumonia last October and was very ill in hospital for five weeks. Mother very worried about the effect of cold and damp on him – states that in very cold weather 'you can see your breath in the air'."

The mother, who has four other children, has to get up through the night in cold weather to check that this child is covered and warm.

Elsewhere, a couple who were provided with a double-bedroom extension heated with a single radiator tried valiantly to use it. Even with the addition of a convector heater, the room was 'like an ice box!'. After three winters the family admitted defeat and the disabled husband returned to sleeping on a sofa while his wife slept upstairs. The £13,000 spent on the adaptation was effectively wasted, for which the husband apologised, explaining they "couldn't use it just in the summer even, because of the difficulty of moving the furniture". He gave a score of 4 saying it would be 10 if the heating could be sorted out.

In another case, lack of heating was a problem but not the major one. The officers gave a score of 5 out of 10, commenting: "Through-floor lift was not used. Tracking hoists were not positioned so they could be used. Shower area very limited space. Bathroom lacked heating". This represents a very expensive mistake, as a through-floor lift and tracking hoists are both extremely costly items. In this case, the officers reported that the tracking hoists could not have been used because they were incorrectly positioned, but the lift was not used because (as the rest of the interview explained) it was not what was wanted.

One example, which concerned a person who had had a serious accident, was especially disturbing:

> "When the lift was put in – the last thing that was done – she was able at last to go upstairs. Everything was wrong – even the wash basin. She went to use the shower and could not get in (it is not big enough for her wheelchair, so she has to transfer to a commode on wheels and be pushed in; even then she can't get in unaided) as it has a lip all round it. Has now forgotten everything she learnt in hospital because hasn't been able to put it to use.
>
> Back-door ramp is dangerous. She tried to use it and fell out of the wheelchair. Gradient too steep – like going over a cliff. Builders destroyed the lawn and patio – left it all like a tip.
>
> Whole scenario of being in wheelchair has contributed to depression, so it's not easy to separate out how much caused by these 'adaptations'. Is in hell now – like prisoner in own home. Don't trust anyone and can't be bothered to get up. Terrified at what may happen to her husband because of his angina. And the adaptations are not just not right – they are dangerous.
>
> The money (£35,000) has been totally thrown down the drain. Whoever's money it was it has been totally and utterly wasted (and all the cost of rehab wasted too)."

This sad story illustrates a system that had broken down, possibly in the turmoil of a reorganisation. Action has been taken by the relevant authorities to remedy this last case and some of the other individual problems but, regrettably, there is not normally any swift remedy for people with legitimate complaints, however serious, nor budget to put right what has gone wrong. People may not only face another long wait (up to two or three years), but may also feel unable to endure the disruption of more building work.

Conclusion

This chapter has contained examples of some problematic and some disastrous adaptations. Both must be balanced against the greater number of positive outcomes, but give cause for concern, because they represent lost opportunities and wasted resources.

In the next chapter we will look at the lessons to be learned from the research about the causes of this kind of waste and ways to prevent it.

5

Maximising effectiveness for major adaptations

Any public sector manager who learns that £20,000 has been spent within her or his service to little purpose, or has even done harm, will be concerned about the waste and lost opportunity. What has this research shown to be the most common causes of 'waste' in adaptation spending, and how can it be prevented?

The causes of waste

Inadequate or compromised assessment or specification

Assessment is the foundation on which all adaptations rest. Figure 1 (page 22) showed how the most common reason for unhappiness with adaptations related to the original assessment and specification. If problems of consultation, which are very closely related, are added in, the assessment-related problems outnumber those caused by implementation by three to one. These are cases that were 'doomed from the start' in that what was specified was never going to meet needs adequately.

There are two streams to this problem. Sometimes professionals do not use their practice interpretation skills well enough. In other cases, 'institutional' bad assessment or specification is caused by the pressures put on occupational therapists to compromise their professional judgement in order to meet other criteria.

Shortcomings in 'practice interpretation'

Insufficient attention to detail: Examples of this all too common problem were given in Chapter 4. Failure to get the details right causes much waste because, if you are disabled, the usefulness of a bar can be completely destroyed by its being six inches in the wrong place. The frustration of a too-high shelf or a shower switch that could not be reached was all the greater for having been preventable.

Failure to consult adequately: Consultation with service users is one of the four 'C's of Best Value. This is for hard-headed reasons, rather than sentimental ones and the evidence in this research bears this out. 'Consultation' in the local government context sometimes means general consultation with user groups on broad issues of policy and practice. In the context of major adaptations, the evidence suggests it must also mean direct consultation with every individual client at the time of assessment.

Omitting to use the client's expertise: There are two sources of expertise needed to make an effective adaptation. One is that of the professionals who know about disabling conditions in general and know what can be provided; the other is the expertise of the disabled person and family members who help to care for them, who know the unique factors about that individual. What is needed is a pooling of this expertise. Planning major adaptations without adequate consultation is akin to supplying a wedding dress without measuring the bride or asking her for her preferences.

The evidence from users on good and bad practice will speak for itself. The message to managers of adaptation services (OT, environmental health or housing) is to ask them to connect assessment to consultation and to consider the costs and consequences of skimped consultation (skimped assessment), as presented in this research.

> "The shower was not at all what was expected. She still couldn't shower properly due to pain and discomfort. People should show clients the designs. And make sure that they go into every detail."

> "Alternatives were not really discussed in terms of choices of equipment, adaptations or moving. Opportunity not given to see walk-in shower in advance of work even though we had reservations about it."

In this second case, the officers found that the walk-in shower was not used at all. Other aspects of the adaptation were fine, but failure to hear the 'reservations' about the walk-in shower, or to spend more time explaining or showing what was planned, meant a wasted item fitted. A number of people felt that their own expertise with regard to their own or their child's disability was not heeded, so that the adaptations were much less effective than they might have been. The contrast with those who did feel consulted is striking.

> "They told her what they were going to do and discussed it. She requested that the electrical installations were put inside a cupboard and they did it."

> "They picked the colour of the floor and saw the plans and were consulted. There were two estimates and they were told they could have the higher of the two if they wanted to pay the difference."

The value of home improvement agencies in giving advocacy and support was also recorded several times:

> "Once Care and Repair got involved it was brilliant. The surveyor personalised the plans, wanted to maintain the character of the house, made it look less clinical, more personal."

Failure to understand and assess psychological needs: It is not just functional needs – to be able to bathe or get up the stairs – that have to be met, but the needs of the whole person, including need for self-respect, dignity and a sense of pride in the home. In fact, for the disabled person, the meeting of physical needs may come way below the meeting of emotional needs.

Moreover, for some at least, the first step of accepting the need for adaptation is itself extraordinarily difficult and painful:

> "I had been advised by the hospital some time previously to apply for a stair-lift but refused to accept I needed one at that time."

> "They wanted to consider her long-term needs. Mrs H said that this was hard, as she didn't really want to think about the possibility of things that she would not be able to do in the future."

The views expressed above tie in with what is known about the bad effects of being made to feel helpless (Seligman, c1975). Adaptations may eventually aid independence as defined by service users, but initially accepting the need for them may seriously undermine that precious commodity. When people are in need of adaptations, what they have lost is a major aspect of their home. The officers should therefore be thinking, 'Can we adapt in a way that gives the home back?', or at least asking the person to say what aspect is most important.

Professionals know that people will be at different points along the spectrum of coping. Some of those interviewed made comments such as 'ugly but functional' – indicating that they had come to terms with what was necessary to give them the independence they craved. Others were not ready, and forcing the wrong adaptations on them clearly did harm. The evidence of this is the low 'scores' and patent unhappiness of those who had been given intrusive, ugly adaptations that violated their home, constantly reinforced the dependency of the disabled person and reduced the chance of privacy of all family members.

The expensive and almost unused through-floor lifts were an example of this: "I did not want the step lift or the through-floor lift". So, too, was the "concrete pad monstrosity" supplied to one person instead of a ramp, or the area left "like a tip" where once there had been a beautiful garden and patio.

Officers in some of these cases, while noting the low scores (and giving very low scores themselves) wrote that the adaptation 'met the need' and ticked the box in the research pro forma that asked whether the psychological need was being met. But an adaptation that is hated and barely, if ever, used, is not 'meeting the need' and the money spent on it is wasted. That this is avoidable waste is shown by the many contrasting examples. Best adaptations can preserve or even add a new dimension to the home.

> "The adaptation has really enhanced the house. They didn't feel it looked like a 'disabled facility' that would be off putting to people. This point was also particularly important for their son."
>
> "Her friends have seen the lift and think it's cool."

Policy-driven problems of compromised assessment and specification

Compromised assessment and specification was more common and more wasteful on a large scale when it was driven by over-rigid policies outside the remit of individual officers. Examples were as follows.

Failure to recognise the need for warmth: Chapter 4 contains examples of adaptations being wholly nullified by inadequate heating. This information adds to that already known about the extreme importance of warmth in making shower adaptations effective (Payne, 1998). Yet restrictions on heating provision were often the result of local policies.

One authority in the study had a rule, 'night storage heaters only' in all circumstances (the policy has since changed). In another area, the social services policy was for officers never to specify central heating unless challenged. Another authority had a policy of 'no gas' – even though mains existed in the street. The resultant choice for one user was, officers said, "between frozen and de-frost".

Failure to recognise the need for space: The failure to recognise space considerations manifested itself most commonly in the provision of too-small extensions – especially in the provision of extensions for children that were not capable of being altered as they grew or as their needs changed. No room for a parent to sleep beside a terminally ill child, no room for a hoist, no room for a computer or for a friend in a wheelchair to come in to play, no room even for a bedside light. Problems like these were common and widespread – all stemming from pressure to keep adaptation costs to a minimum.

The guidance on DFGs in DoE Circular 17/96 states that the adaptation will not be considered to have met its purpose if the burden on the carer is not significantly reduced (DoE, 1996, Annex 1, para 49). Adaptations that are too small fall into this category. The case given in Chapter 4 (p 26) shows the tangible costs to the public purse of an inadequately sized extension. In this example, there was no room for a manual hoist so the carer ended up spending four days in hospital with an injured shoulder while the child had to be taken into respite care.

Lack of space was felt even more acutely where a through-floor lift was provided instead of an extension and actually reduced the total available floor space. One authority spent £21,000 and £17,000 respectively on two adaptations of this type that:

- achieved almost no improvement for either the child or the family;
- increased overcrowding; and
- reduced the value of the council-owned properties.

The families – one of four people, one of five, both in three-bedroom properties – scored 5 out of 10 and 7 out of 10 respectively for their adaptations, in an area where the most common score was 10. The officers gave scores of 6 and 5. In the second case, where there were two children in wheelchairs, the officers concluded that the lift was not used.

The terrible overcrowding experienced by the family in the first case *after* and *because of* the adaptation is described under the heading 'Insufficient space after adaptation' in Chapter 4.

It seems clear that the decision in these cases not to provide an extension meant that the money spent was spent without any useful outcome, and was in fact even harmful. An important contrast is the case of a parent in a different authority who, coming up against similar pressure to accept a lift, "insisted on an extension, as the importance of this was stressed by other families in the same position that she knew about". The total spent on this extension scheme, including the applicant's contribution of £3,309, was £23,309. This was only £2,100 more than the cost of the through-floor lift scheme but secured an effectiveness score of 10 out of 10 rather than 5 out of 10. There was reduced stress on the carer and reduced strain in the family.

Persistence of 'Poor Law' thinking?: It appears that these cases of the reluctance to provide extensions are not just about money. Through-floor lifts can be excellent, but they are expensive, so why are they being provided when not wanted? Perhaps the cause is the product of a deep-seated tradition in Britain of not supplying through the public purse anything that is intrinsically attractive, for fear of fraudulent applications. 'Extensions' and gas central heating are things that everyone aspires to and should therefore not be offered if something less desirable could be substituted. This can be traced in an unbroken line back to the 'Poor Law' reforms of 1834 and is not replicated in continental Europe. It is a tradition that is worth challenging because, while it appears to protect public money, it may be causing waste.

Both mothers in the contrasting cases described above were aware that their child's life might be short and that there would be a question about the longer-term use of the money. The mother with the extension was not very concerned about the future, saying, when asked, only that she supposed it wouldn't be difficult to move if they ever had to, and that the value of the house had probably increased. The mother with the through-floor lift showed her understanding of the pressure on council properties and her anger at the wastefulness and short-sightedness of what had happened when she said:

> "If I'd had the extension and if anything had happened to him I would have moved, but now I will not move. They will have to take all this out."

Persistence of medicalised model: The individual (medicalised) model of disability (see Appendix B) is still widely in evidence in social services and other authorities' definitions of need (including the VAT rules). The 1970 Chronically Sick and Disabled Persons' Act, rather than the 1996 Housing Grants, Construction and Regeneration Act, tends to be followed in matters of assessment. The later Act asserts the rights of disabled people more specifically and lies more within the social model of disability. Within the individual model, people (especially older people) are liable to be told that they do not qualify for a bathing adaptation unless they have a 'medical' need, and other very ordinary human requirements are liable to be dismissed as 'wants, not needs'. The persistence of the medicalised individual model may be mainly a defence against a shortage of resources, but it may also be a habit of thought that should now be reconsidered.

Failure to recognise cultural diversity: Officers who saw a family where the teenage grandsons helped to care for their grandfather by helping him to have a shower were impressed. The corollary of such family care in Asian families (among others), however, is a general need for enough space to lead the normal life of an extended family culture. This expects as a norm to have large family gatherings in the home, to plan ahead to have room for married children to live for a while, and to offer prolonged hospitality to visiting relatives. This is often the reason why people have chosen to live in older homes with larger rooms and with at least two living rooms, and why it is not appropriate to imply that they are being unreasonable when they seek to keep this space.

> "The couple did not feel that they had really been listened to. While the adaptations had been for their father, the house was for all the family and they had to consider what their family needed both then and in the future."

Understanding cultural differences is hard because it requires an understanding of where the issue fits into a whole, coherent but sometimes different outlook on life.

Tendency to forget the needs of the whole family, including carers: This relates closely to the issue of cultural diversity.

> In determining the needs of the disabled person, consideration should be given to the particular household group in which the disabled occupant resides so that any adaptations being contemplated do not cause strain on the household which may lead to breakdown of the present care arrangements. For instance, a relevant factor might be the continued privacy of the disabled person or carer following the completion of works. (DoE, 1996, Annex 1, para 48)

The inclusion of this provision in the guidance to the DFG legislation shows the common sense of those who drafted it. But it also highlights the gap that too often exists between government guidance and policy implementation.

Other causes of waste

Inadequate ongoing consultation and supervision during the work

The case cited in Chapter 4 in which the respondent felt that £35,000 had been utterly wasted (p 27) represents all the other cases where there was inadequate liaison between occupational therapists, housing officers and builders, and no system for regular consultation with the client during the work. The woman was paralysed, a wheelchair user, and present in the house, but the builders continued installing adaptations suitable only for an ambulant person.

This was an extreme example, but not unique. Occupational therapists must be allowed time to re-visit their clients at the crucial stages when work is in progress. Leaving out such check-up visits because there are long waits for first assessment is more risky than efficient. By contrast, one very satisfied client described how the occupational therapist came back when the housing officer came, and came again when the builders were about to start work. The client said, "she didn't know what she would have done without the occupational therapist, who was wonderful and still is". Staying Put/Care and Repair Agencies were also mentioned, for their consistent and long-term support and availability when needed. Surveyors can judge the quality of building work but, unless very experienced cannot know whether what is being installed is suitable. This is why time for liaison and communication between the professionals and with the client must be built into the strategic planning of adaptation services.

Delay

This research was focused on outcomes rather than processes, but the impact of the long waits for assessment and implementation were found to be having serious effects on outcomes. There were assessments that were 18 months out of date – accidents and hospitalisation happened during this waiting time and other conditions, including mental health worsened. Habits of dependency became established in children and were hard to unlearn and crucial opportunities for independence and development were lost.

Inadequate resources to do the job

Inadequate staffing levels and capital budgets: Many of the practices or problems listed above may be fostered in all areas by inadequate staffing ratios and inadequate funding. When budgets and staff levels are too low overall the result is delay with all its costly consequences. Where too few professional staff are employed, there will be reduced quality assessment and inadequate supervision of the expensive work in hand. Inadequate budgets result in rigid rules that lead to inappropriate and wasteful adaptations.

Grant limit too low: The grant limit of £20,000 in England, £24,000 in Wales, was said by participating officers to be purchasing less and less, and affecting specification. It was especially leading to downsizing of adaptations for children in order to come within budget. They reported that the limit was now so tight that the only way builders could get their estimates within it was to cut corners with poor quality materials and workmanship. Waste is also caused when the problem is overcome by giving a second grant, as enlarging a space is more costly than providing it in the first place.

Occupational therapists say their specification is affected by budgets and the grant limit because social services might be required to 'top up' if the need has been assessed and the housing authority is unable to afford to fund the work. They were afraid to discuss what was really needed with clients for fear of raising expectations. There was also a reluctance to bring in specialist therapists (for example, for children or sensory impairment) because they would say what was actually needed. In all these ways the grant limit contributes to the type of waste caused by inadequate provision found in this research.

Officers discussing this issue were also aware that a raising of the grant limit carries the risk that builders will simply raise their charges in line with the new limit. One solution to this might be a removal of the limit, in line with the situation between September 1990 and April 1993 where there was no limit, or making it much higher, as in the period April 1993-January 1994 when the limit was £50,000. As earlier work has shown (Heywood with Smart, 1996, Chapter 12), at this time there was not a vast increase in extravagant spending.

This evidence is still important in considering the true impact of grant ceilings. Could it be that such limits cause more waste than they prevent?

Lack of adaptation-related subsidy for council tenants: Adaptations for owner-occupiers and RSL tenants who go through the DFG system attract a subsidy of 60% from central government in England (the system in Wales is different). Adaptations to council properties get no subsidy directly related to the costs of the adaptations carried out, and there is no ring-fenced budget for adaptations as there is for private sector housing in England. Instead, expenditure must come from the same budget that would pay for schemes of modernising and improvements for all tenants. Whatever the ins and outs of the arguments for this, the effect on local authorities is that many try to keep the cost limits of adaptations to their own stock even lower than the DFG limit. A limit of £12,000 was set in one area in the study. If the work was to cost more, the family were required to move, but the evidence from this research was that such moves had been neither cheap nor effective. As it is, the different rules mean that ineffective, inadequately sized and inadequately heated adaptations are more likely in council housing than in the private sector.

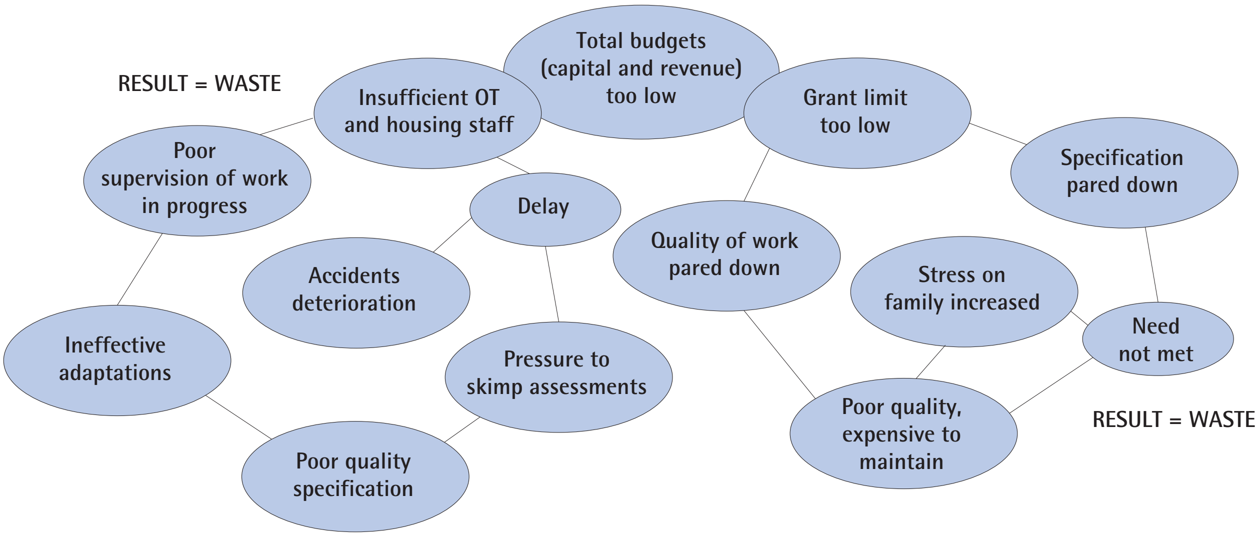
Pressure of 'lowest quote' culture: There were a number of examples in which careful assessment and specification was undermined by the policy of accepting the lowest quote. This led to stair-lifts being fitted which did not meet the person's needs as specified (for example, did not have a seat that turned as required).

The Test of Resources for DFG: At present the Test of Resources for DFG means that some families are unable to secure adaptations at all. Officers were concerned that in some cases where families were unable to pay their assessed contributions, they were being left without help or advice from social services, even though the adaptation was badly needed. The preventative, developmental and educational benefits of adaptations, as demonstrated in this research, are therefore lost, while health and social security costs are likely to result.

Problems with moving as an option: It is often said that if adaptations are expensive moving will be a better option. The evidence of this research challenges that assumption, at least in the case of families. In two cases, council tenants had been moved into a property deemed more suitable by professionals and had then had adaptations. In both cases this proved a costly and disastrous failure. The minimal gains in space did not outweigh the disadvantages of an unsuitable location. Both families gave very low scores and one needed to move again. The problem is that social landlords are unlikely to own properties *in the right location* for the family's needs that are *significantly more suitable*, that is, with the generous space standards that are really needed. Some RSLs have a fine track record in custom-building suitable properties for families with a disabled member, and some local authorities have made good use of this willingness, but the process is slow and location is critical.

For owners, the problem is different. Some might want to move but not be able to afford it – first because moving itself costs many thousands of pounds and, second, because families are likely to need bigger, and therefore more expensive housing. If the grant available for adaptation could be used to assist a move where this would achieve a better outcome, this could provide better value for money. The government's proposal to make this possible is therefore to be greatly welcomed. In a consultation paper of March 2001 (DETR, 2001b), it is suggested that local authorities should have the power to use discretionary grants to help people with the cost of buying another property when this is a better option than adapting their own home.

Figure 2: The cycles of skimping



Conclusion on causes of waste

The research has shown how, in the matter of waste, one thing can lead to another. This is summarised in Figure 2, which shows how a shortage of resources leads to skimped assessments and policies which impede professional judgement, causing poor assessments that lead in turn to money wastefully spent.

Shortage of resources, however, is not the only issue, for, in matters of consultation and assessment, there are changes in policies and habits of thinking that could, without extra expenditure, quickly lead to some more effective adaptations.

Calculating value for money in adaptations

This section outlines the information the research has produced so far and suggests some different ways of considering this important issue.

Table 8 represents the figures for 67 major adaptations in six local authorities. Information was not always available. One authority did not supply this information and data were not available for the telephone interviews.

Who pays?

Although it was not possible to obtain financial information for all the cases of major adaptation in this research, we do have information from the files from six authorities for a total of 67 major adaptations. The capital costs of supplying these adaptations varied from £800 to £45,968; the average being £9,657 and the median £5,890. Table 8 gives a breakdown of the sources of funding. This shows that 96.7% of the costs were funded from the public purse. The largest contribution by far, 95.9%, was from housing sources. About a quarter of all the costs were borne by housing revenue accounts with no direct subsidy relating to adaptation. Social services departments contributed only one top-up grant (of £5,189) in these 67 cases. (There were also two social services loans, totalling £10,471 but these will be repaid, so only the lost interest would ultimately be a cost.) Four of these 67 cases were housing association tenants, but there was no record of funding from The Housing Corporation or any RSL.

Householders and social services departments will both have incurred additional costs in terms of maintenance contracts for lifts (in the order of £100-£150 per year). Social services will also have paid for a proportion of minor adaptations, but we did not collect this information on this occasion.

Table 8: Costs and funding sources of major adaptations in this study

Source of funding	Number of cases using this source*	Total spent from this source (£)	% of all spending
Mandatory DFG	48	404,225	} 71.9
Discretionary DFG, Wales†	8	71,782	
Discretionary DFG, England‡	1	49	–
Householders' contributions to DFG	19	12,527	1.9
Social services top-up	1	5,189	0.8
Housing revenue account	16	158,506	24.0
Housing Corporation/RSL funding§	0	0	0
Householder payments for extras	6	10,046	1.5
All sources	67	662,324	100.0

* More than one source may have been used for one adaptation, so totals are more than 67.

† Through a quirk of the grant system, discretionary DFG was used instead of mandatory DFG in the Welsh cases.

‡ This figure of £49 is not a misprint!

§ Four of these 67 cases (5.9%) were housing association properties at the time the adaptation was done.

Perhaps the most startling figure in this table is the solitary discretionary grant for England of £49.

Who benefits?

Table 9 shows some of the beneficiaries of adaptations. The benefits to individuals and their families are the most immediate, but the qualitative evidence given in preceding chapters has indicated how social services and health providers also benefit from reduced demand (less need for care, less onerous or risky work for professional carers, less accidents, less likelihood of depression). One woman was specifically

Table 9: Beneficiaries of adaptations

Individuals	Improved dignity, privacy, independence, health (physical and mental), social inclusion Opportunities for education and employment
Family carers	Reduced physical and mental strain More freedom and peace of mind
Other family members	Improved social inclusion Improved educational chances
Health providers	Fewer accidents to treat Fewer hospital admissions Reduced costs of drugs and GP time for depression and physical illnesses
Social care providers	Fewer demands on carers – either reduced hours or reduced risk of injury to carers Prevention of admission to residential care
Department of Social Security	Prevention of injuries leading to short- or long-term sickness and unemployment benefits for carers Increased likelihood of employment for disabled people – and for carers when disabled people are made more independent

enabled by the adaptations to continue working, although, strangely, adaptations to enable a person to work are still only 'discretionary'.

Measuring costs and benefits

This research produced a number of examples of tangible (but not quantifiable) costs to the health service of failure to provide adaptations (broken limbs, injured backs, pneumonia, hospital admissions) and qualitative evidence of improved health – physical and mental – following adaptation.

It was noted earlier that, because once an adaptation is installed it may be in service a long time, this should be built into the cost/benefit equation. For example, evidence was collected in the interviews about whether the adaptation had reduced the burden of care. This will have principally affected family members, but also relates to professionals. It is now understood that one of the most economical ways of reducing the burden on the public purse is to give timely support to unpaid carers. A total of 39 respondents said this was an outcome in their case. A filter for these particular cases applied to the database showed that the adaptations had been in place for an average of 3.57 years (2,227 weeks) and had cost an average of £10,569. If this is broken down into weeks it amounts to an average of £4.74 a week to reduce the burden of care on either a family carer or on paid carers, which is less than the cost of providing one hour's care. The adaptation will probably have also conferred other benefits – but just in terms of helping with lifting, carrying and strain this added value for time helps to put large capital costs into perspective. If prevention of admission to residential care were considered, the same technique could be used.

In a similar way, just as simple handrails were found to be benefiting widows and friends even after the original recipient died, so major adaptations may benefit more than one person in a household and thus give added value. In our sample there were 13 cases in which the adaptation was benefiting an extra disabled person, and the average time the adpatation had already been in use was 2.7 years. At an average cost of £10,861, this equates to a cost of £6.40 per week for a single person, but only £3.20 per week if the second beneficiary is taken into account.

The value of the stock

There has been a tendency to regard improved property value as something to be avoided in adaptation. A new approach would be to regard the housing stock (whoever owns it) as a national asset and take the view that if money is to be spent on a property it would be viewed all the more positively if it enhanced its value. (This is akin to deciding that it is a good thing rather than a bad thing if an adaptation benefits the whole family.) Positive encouragement to make adaptations as attractive and home-enhancing as possible would help improve the value of these large-scale capital investments.

Costing options

In the 'Option Appraisal' or 'Most Satisfactory Course of Action' systems used by housing and environmental health officers, it is normal to consider and cost a range of options. This is, of course, also represented in the 'challenge' part of Best Value.

When someone is disabled by their housing the options are:

- do nothing
- adapt the existing home
- move home
- move home and adapt.

So far, the costs of 'doing nothing' and of 'adapting the existing home' have been considered, but not the comparative costs and benefits of moving or moving and adaptation.

Moving as an option

As indicated above, there were cases in this research in which the property was so completely unsuitable and difficult to adapt that, although thousands of pounds were spent, little was achieved. Some owners indicated that they would like to have moved but could not afford to. Moreover, for families with children, what would usually be needed is help to buy a home with *more space*, which would normally mean somewhere more expensive.

At present, the idea of helping a family to increase the value of their equity by buying a bigger house might seem strange to controllers of public expenditure. But, in an option appraisal, if the choice were spending £20,000 on adaptations with little benefit, or spending £20,000 on enabling a move to somewhere more suitable, with benefits to all parties, the rational choice would be to fund the move. In this context, the proposals to allow local authorities to give discretionary grants to help families to move when the owner and the authority agree that this would make more sense are very encouraging (see p 33 and DETR, 2001b).

In considering the value for money of offering grant money for 'move' or 'move and adapt' options, the following points need to be borne in mind.

- Moving is in itself expensive: with surveying and conveyancing costs as well as the costs of removal, it is likely to cost owner-occupiers at least £4,000-£5,000. Moving between rented properties is less expensive, but still has costs attached for both landlords and tenants.
- For all people, location is likely to be the most important factor in housing. The people in this study were no different. The benefits of a move must therefore be carefully weighed against costs in terms of lost support, lost convenience and so on.
- The concept of an 'adapted' home is a misleading one, as the solitary 'harmful effect' respondent in the minor adaptations research showed. Even if a property with good access is made available, costs will need to be allowed for necessary changes and additions appropriate to individual needs.

Conclusion on value for money

The benefits to individuals and families of the money spent on adaptations have been indicated by the evidence of the whole research project, especially the evidence in Chapter 3. To turn this into a cost benefit analysis, accurate information on costs of hospital stays, drug prescriptions, residential care and long-term sickness/ employment benefits would be required.

Techniques of adding in allowances for the long-term benefits (or costs where appropriate) of alterations to housing would be appropriate. At the moment, there are no proper ways of considering options other than adaptation because the funding is not available. With better techniques and more flexible funding, it might be possible to ensure that any adaptation carried out is truly the most beneficial option from the viewpoint of the family or individual, and the most sensible use of money.

Conclusion on maximising effectiveness

Because assessment is so crucial to adaptation effectiveness, much of this chapter has been concerned with analysing the causes of poor assessment and the types of adaptations that are doomed from the moment the specification is made. Although these causes may sometimes be a matter of professional failing (failure to listen, insufficient attention to detail) they are much more likely to be institutional and structural. Within the current arrangements, these structural causes include inadequate funding and staffing levels, confused legislation and the pressures of performance targets relating to outputs, rather than outcomes. Philosophical issues, such as the persistence of medical models of need, are also influential in limiting effective practice. To maximise effectiveness, the good practice found in much of this research must be encouraged.

From a broader perspective, it will do no harm to the cause of adaptations if the costs and benefits of adaptation services are more clearly worked out, so that a proper share of funding from the budgets for preventative healthcare may be sought.

6

Money well spent: conclusions and recommendations

This final chapter sums up the findings of the research and, in making recommendations, sets out to incorporate and attempt to synthesise the views of all parties involved – from the youngest child who gave an interview to the most experienced members of the Advisory Group.

The question that the research set out to answer initially was: 'Is what is spent on adaptations "money well spent"?' Are the adaptations effective in achieving what they set out to achieve? Can the benefits be demonstrated? Can they be quantified? Is what is done good value for money or could the same benefits be achieved in another, less expensive way? It also set out to examine cases where adaptations had failed or only partly succeeded and to discover the reasons why.

A major problem in presenting the findings has been balance. Inevitably, much of the detail of research such as this will be focused on the problems and the reasons for them, as these are the areas where full understanding is needed in order to achieve change. However, the overwhelming finding of the research was of positive outcomes. A debt of gratitude is owed to the officers in the pilot study who suggested the need to ask people to give a score out of 10 to capture their overall judgement of the value of what had been done. Without this, the balance between good outcomes achieved and detailed points for improvement could not have been known or shown.

Good outcomes

The postal survey revealed that minor adaptations are a highly effective use of money. They reduced the help needed from others, enabled people to prepare meals, take a bath and use the toilet, and in all these things were felt to have prevented accidents. They had a positive effect on the health of 77% of those interviewed and a negative effect on only 1 person out of 145 (the recycled adaptation). Minor adaptations helped 5 people in the sample to care for someone else and 2 to be able to work. They also helped social inclusion by enabling people to get out and to enjoy a social life. There was almost no waste. A total of 86% of those sampled said that they would have spent the money in the same way, and even for the remainder, the main problem was that what had been done was not enough.

The good outcomes of major adaptations were even more dramatic. Quotations capture some of the general feelings:

> "Having the adaptation done had helped his health and enabled him to definitely live longer."

> "Believes she wouldn't be alive without the adaptations – for psychological rather than physical reasons."

> "Wonderful, can't praise it enough, the results far exceeded our expectations, cannot thank you all enough."

> "The stair-lift and shower were better than sliced bread, both marvellous things and they couldn't manage without them."

The proportion of replies of this kind is indicated by average scores of 9.2 out of 10 for adults (the average for children was 8.2). Health gains, confidence, self-respect, increased independence and reduced strain on care-givers were all described by numerous respondents.

Bad or less good outcomes

If some adaptations are so effective, why are others not so? In the case of minor adaptations, the most common problem arose when people needed a proper walk-in shower but were offered cheaper substitutes. This was the product of pressures on budgets, combined with some apparent problems with regard to social services authorities' awareness of the DFG legislation (see below). For major adaptations, the highest satisfaction levels tended to be with the more straightforward, least disruptive items, notably stair-lifts. In other cases the needs that were being met were more complex and the constraints of the housing sometimes meant that no totally satisfactory solution was possible. Sadly, this was also true in cases where those interviewed had moved to what was intended to be a more suitable house.

Recipients of major adaptations may have suffered the shock of a terrible accident or be slowly coming to terms with having a seriously disabled child. It will therefore matter whether the adaptation becomes a daily reminder of their pain and loss, or a positive intervention that restores their lives and gives them back a home that they can feel proud of. Adults and children alike are often living with constant pain. They may also have a deteriorating or fluctuating condition so that the adaptations are effectively aimed at a moving target. Parents may be living with the possibility of the child's death always hanging over them and several parents interviewed talked of what would happen to the adaptations "if something happens to ...". The more complex the situation, the more difficult a task it clearly is to make sure the adaptation is right. Not only is the specification more difficult, but the need for communication between everyone from client to builder is greater, with greater chances of things going wrong at every stage. If inadequate funding, delay and the fettering of professional judgement by local policies are added into the equation, it is not surprising that some major adaptations are very, very bad.

Legislative compliance

- The research found that environmental health/grants officers and occupational therapists were often effectively working to different legislation. The former were implementing the mandatory provisions of the 1996 Housing Grants, Construction and Regeneration Act (see Appendix A) and accompanying guidance. In some social services departments, however, managers laid down guidance for occupational therapists based only on the 1970 Chronically Sick and Disabled Persons' Act. This is why we found respondents who could not take a bath or shower but had been told that they would not be a priority for adaptation, or would not even be assessed, because they were not in medical need. There is nothing in the 1996 legislation about an applicant needing medical justification for wanting to have a bath!
- In every face-to-face interview, officers checked compliance with the detailed provisions of the 1996 Act. Their findings were that certain items of the mandatory provision were quite often omitted. These included (besides the common bathing issues) heating, caring for someone else, access to the kitchen and items to do with sensory impairment. Right of access to the garden (included in the definition of 'building' in the 1996 Act) was another item regularly omitted, and a major cause of distress.
- They also noted an overwhelming reluctance, when circumstances were exceptional, to realise that this was an appropriate time to use the discretionary powers of the 1996 Act. The fact that there was just one solitary discretionary grant of £49 in the whole sample of six English authorities bears out the officers' impression.
- There was also little sign of compliance with the time-scales for approving grants laid down in the Housing Grants, Construction and Regeneration Act.
- Housing association and other RSL tenants were felt to be losing out badly because of the current legislative confusion on responsibility for funding.

Policy and practice implications of the findings

Good policies and practice to be preserved

Before considering changes needed, stock should be taken of what were the good factors that enabled high satisfaction levels from many respondents, even when the adaptation was nine years old and very out of date. These included:

- the existence of a mandatory DFG;
- the recognition by government since 1997 of the importance of warmth and existence of new HEES grants and other assistance;
- support by government for home improvement agencies (including Care and Repair and Staying Put) that help people to manage the process and secure what was needed;
- growing emphasis by government on user involvement in all policy areas;
- the new building regulations, which will make adaptations of homes built in the 21st century cheaper and easier;
- the skills of OT and housing professionals in assessing, specifying and securing beneficial adaptations;
- the good cooperation that existed between these two professions in all the areas where the research was carried out;
- good relationships with builders, including in one area an arrangement for builders to take part in training on adaptations issues.

Good policies that need to be better used

- The maximum time limit of six months for responding to an application for a DFG would be an excellent policy if it were honestly implemented and included the wait for assessment.
- The existence of a social services top-up grant. Although social services have a duty to meet assessed need when the housing authority or the applicant are unable to do so, only some authorities are accepting this responsibility.
- Social services authorities also have a responsibility to family carers, which includes concern for the risks they suffer in lifting those they look after, but this duty was also not much implemented.
- The existence of discretionary DFG (the policy is of little value if it is not matched with funding).
- Support for the social model of disability.
- A growing interest in health and social services authorities in preventing accidents and admissions to hospitals and residential homes. Shortage of capital to fund adaptations was beginning to block beds in one area at least and had become a strategic health issue.
- Opportunities for Primary Care Groups or Trusts to put funding into adaptation services under the preventative agenda.

Local policy issues affecting the effectiveness of adaptations

- Local policies are sometimes so drawn up that they penalise certain tenure groups and render adaptations less effective in those tenures.
- Delays are so harmful they have to be reduced, but not at the expense of the quality of assessment. Local policies therefore need to consider what staffing levels are needed to prevent waste by delay, bad assessment and poor supervision. This means staffing ratios must rise, which has implications for training and recruitment as well as the revenue budgets of employing authorities.
- In considering Best Value purchases of items such as stair-lifts and showers, or heating systems, it would be helpful if issues wider than the purchase price could be taken into account. These could include suitability and safety for the whole household, pre- and after-sales services, ease of cleaning for the householder and likely annual maintenance and running costs, including easy and mainstream availability of parts.
- There could also be a decision to look particularly favourably on proposals that would increase the attractiveness and value of a property, rather than reducing it.
- Processes and budgets to rectify things when they have gone wrong are needed. Systems are wholly unsatisfactory at present.
- Systems are also needed for giving OT advice about moving to families, including owner-occupiers, so that they do not move from one unsuitable property to another. This is not a service normally offered and families who are put off by the Test of Resources may be barred much too early from such help.
- There is a lack of information or publicity and no systematic seeking out of those who need adaptations. Many of those interviewed found out about the possibility of adaptation by chance or only after an accident.
- Assessment of need for adaptations needs to be done at a local level in accordance with all the legislation, including the Housing Grants, Construction and Regeneration Act, the Chronically Sick and Disabled Persons' Act, the Carers' Act, the Children Act and Quality Protects.
- In the interests of keeping down adaptation costs in the future, local authorities need to ensure that the implementation of Part M of the building regulations in respect of all new domestic dwellings is being properly carried out in their area.

Local practice issues

Better information for senior managers and elected members

It is essential for effective policies that senior managers and councillors understand the main issues of adaptation as well as they understand, for example, the principles of stock maintenance or of child protection. The understanding of senior managers is a key to the prevention of waste and it needs to be as well informed as possible.

Counselling a necessary part of assessment

When there are problems of prognosis and disclosure, families need counselling and support, not just assessment. It is vital to the outcome of the adaptation that the occupational therapists have sufficient time to give this help.

Longer-term view needed in specification, including provision for growth in children

This applies to adults and children, but the failure to allow for children's growth was a particularly widespread problem. This longer-term view would not mean providing for a four-year-old who was still walking everything she might need as a teenage wheelchair user, but it would mean allowing for sufficient space. The long-term plan might well be for planned incremental changes (see overleaf).

Incremental adaptations

It is important for children and adults that it becomes easy and normal for adaptations to be given in stages as people need or are ready for them, without facing another 2- to 3-year wait each time. This was a major message from the officers and was reiterated by service users:

> "The child's needs change but the building can't change. Look at temporary changes."
>
> "It would have been better to have had temporary changes and adapt as the child grew up."

Better ways of communicating choices

Better ways of showing people what adaptations will look like are needed, as are better ways of communicating between officers and builders. Service users repeatedly made this point in the interviews:

> "More and ongoing consultation: show people what things are going to look like; let them try them, give them choices, give them the chance of paying the difference in cost and having the preferred option."
>
> "It would help if the proposed adaptations could be tried prior to installation. Everybody is different and what suits one would not suit another."

Provision of heating

This may be a policy rather than a practice issue, but it must be included – above all in bathrooms and bedrooms – as it is crucial to the effectiveness of adaptations.

Better shower specification

The necessity for attention to minute details was shown in the research to be especially important in relation to showers.

Checking work at all the crucial stages

This was another point where service users reinforced the officers' views.

Training for professionals

The issue of the training of the relevant professionals as a way of improving effectiveness was discussed at length with the research partners at a joint meeting. There is an ongoing shortage of occupational therapists who choose to specialise in housing and community services rather than hospital work, but it was the view of the partners and the Advisory Group that the OT syllabus at undergraduate level was already overloaded and that the best plan was in-service training. The universal view was that it should be joint training with housing officers. It was felt that the research itself had been a highly effective training mechanism. This might be replicated widely and regularly by having small programmes of user consultation, possibly as part of Best Value.

Social services budgets for OT training were minimal, and did not in any way reflect the high costs of adaptations, the cost of mistakes made because therapists were not sufficiently skilled in plan reading or the good investment training was likely to be.

Training for builders in the installation of new adaptation products would also reduce waste.

There needs to be, within social services, a whole new philosophy of aiming to tailor adaptations to individual needs, albeit within the realities of a limited budget. Maybe there should be training courses specifically on this topic. This is especially important for the smaller adaptations (say up to £5,000). There is a tendency to think that if it is not big, it does not matter so much, and the standard approach will do, but this is where real savings could be made.

National policy issues

Extension of subsidy to end discrimination against council tenants

An extension of the direct subsidy arrangements to include council properties and the creation of a ring-fenced budget could remove the inequality that currently exists in such policies as lower grant limits in council housing.

Change to, or removal of, grant limit

The current grant ceiling has remained the same since 1996 and its purchasing power has gone down year by year. The limit needs to be raised substantially to something more realistic, or removed altogether. Such change will require an increase in budgets, but not as much as might appear – doubling the maximum grant limit will not double adaptation expenditure! This is because the costs of the great majority of adaptations under DFGs do not come anywhere near the grant limit, and will not be affected. It will, however, enable the major adaptations to become cost effective. The research has shown that the grant limit – designed to save money – has, in practice, led to wasted spending and to cost implications for both health and social services.

More resources needed

The delays between needing and obtaining adaptations, that were found to be so harmful and wasteful, were not caused just by a shortage of assessment staff. In some areas, there was insufficient capital funding and recently announced increases for 2000-03 are inadequate to meet needs.

Money from health authorities to be sought

It would be highly appropriate for some of the extra money to come from health commissioner sources. In one of the partner authorities a Primary Care Group was already paying for an extra adaptation assessment officer, and all the Welsh health authorities are putting money into Care and Repair agencies on the basis of their role in both preventing admission and assisting discharge.

Introduction of 'move and adapt' grant

The proposals made by government in the DETR consultation paper of March 2001 (DETR, 2001b) to allow local authorities to give discretionary grants to help disabled people to move when their home is unsuitable for adaptation will, if adopted, greatly augment the possibility of the best use of public resources. This grant might be needed to help with the purchase price of a larger property, as well as with the costs of moving and any adaptations necessary in the new property. It would be necessary for the family and the officers to work out the division of the funding between purchase, moving and adaptation that achieved the best outcome and value for money.

It would also help if owners could commission alterations to new housing as it is being built (at present grants cannot be given until the house is owned, so for intending owner-occupiers it has to be built unsuitable and then expensively altered).

The only worrying factor affecting the proposal is the evidence from this research that only a total of £49 was spent on discretionary grants in England out of 37 randomly selected cases that were funded through DFG. Failure to use discretionary grants in exceptional cases was one of the criticisms officers made of normal practice in most authorities.

Quality as a factor in tendering or choice of contractor

As one user put it: “It is not necessarily the cheapest quote that is the best job”. Guidance from government about ways of judging quality (long-term running and maintenance costs might be an issue that could be taken into account) would help to achieve better value. The roles of the Audit Commission and Housing Inspectorate in helping to promote practice that achieves effective outcomes for users are clearly crucial.

Clarification of responsibilities

There is a need to clarify more realistically the division of responsibilities between housing departments, social services departments and The Housing Corporation. (The Housing Corporation’s decision in 1996 to drastically reduce its adaptations budget has had most serious consequences for RSL tenants, who now face long waits while housing, social services and the landlord dispute responsibility.)

Legislation or guidance re needs of children

There is urgent need for guidance (and/or legislation) that addresses the adaptation needs of children and young people. It should recognise the difference in 'play' for adults (implication: something frivolous and optional) and 'play' for children, which is an activity that is central to their development and well-being. Principles of equal opportunity to give them rights to have play space, social space, access to garden and kitchen on a par with non-disabled children need to be established. The rights and needs of siblings should also be included.

Minimum space standards

For all wheelchair users, minimum space standards, taking into account storage and circulation needs as well as issues of access should be laid down.

Challenge to government: those who benefit are not those who pay

The major problem in considering value for money in adaptations is illustrated in Table 8 (p 35). Of all public expenditure on the capital costs of adaptations, in this research 96% came from housing sources, while the financial benefits are experienced almost entirely elsewhere by social services, health providers and the DSS.

Government has recognised this type of issue in general in its preventative agenda, but needs to take it further. Suitable housing needs to be part of strategic thinking in a whole range of arenas, and money from other sources needs to be diverted or added to existing resources.

More information needed

If developers are to be encouraged to build more homes that would be suitable for households where someone is disabled, information on levels and types of need will be essential. The work currently underway to establish levels of housing need for disabled children, supported by the Joseph Rowntree Foundation, will be important in providing this link.

Need for government sponsored development

At present, technical research is left to the manufacturers of adaptation equipment. It might prove a good long-term investment if government were to sponsor a competition for better, more attractive and cheaper solutions to some of the most common adaptation needs.

Conclusion to the research

For those who have any responsibility for adaptations, the findings of this research offer encouragement and affirmation.

Before adaptations, people described themselves with terms such as ‘a prisoner’, ‘smelly’, ‘degraded’, ‘depressed’, ‘ostracised’, ‘afraid’, ‘embarrassed’, ‘at screaming point’ and ‘very, very angry’, to pick just a few. After good adaptations had been done the key words were: ‘freedom’, ‘independence’, ‘useful’, ‘confident’ and ‘proud’, interspersed with descriptions of the adaptation as ‘wonderful’, ‘brilliant’, ‘a godsend’ and ‘warm’.

Most of the 266 people who took part had found their health and well-being improved, their dignity and independence restored.

The research found widespread evidence that housing adaptations deliver many of the government’s key objectives: keeping people out of hospital, reducing strain on carers and need for outside help, preventing accidents, improving educational chances, improving health and reducing social exclusion.

Knowing what good adaptations achieve makes the waste involved in bad adaptations all the more regrettable. The research found that the most common cause of a failed adaptation lay in the original specification, and that this was most likely when assessment was constrained by rigid rules. Sometimes, often even, restrictions on capital budgets were the underlying cause, but lack of time for assessment could also be an important factor.

All the way through this research, the same points emerged: the need for better communication; the vital importance of listening; the need for tendering systems that take quality into account and a generous-spirited whole approach that buries the traditions of the Poor Law once and for all. Adaptation work is for a person or a family and is about their home. Although the individuals who took part in this research were very different, the picture that emerged was a whole and consistent one.

It is encouraging to consider the number of policy initiatives into which this issue fits: Prevention Grants from *Modernising social services* (DoH, 1998a); *Our healthier nation* targets (DoH, 1998b); Quality Protects; Best Value; the whole interest in effective practice and the new requirement on local authorities in the 2000 Local Government Act to address issues of well-being. If adaptation grants to enable disabled people to work were made mandatory, instead of discretionary (and therefore usually refused), this would fit well with government’s general policies on employment.

The research findings challenge some previous assumptions.

- It is common to say that adaptations cannot meet people’s expectations, but the officers found that people’s expectations were in general too low rather than too high.
- Money may be saved by re-using adaptations, but this is no use if the adaptations are not appropriate for the new user.
- Moving is not an easy or cheap option, and may not result in good value for money. On the other hand, it may be the option that could produce the best outcomes and should be facilitated when this is the case.
- Obliging people to have things they do not like, or about which they have reservations, may result in wholly wasted expenditure.
- Economising on heat is likely to render the whole adaptation unusable.
- Economising on space may cost the public purse dear in health or social services outlay.
- Economising on assessment and ongoing contact caused the most expensive waste in the whole project: enough to employ an occupational therapist for a whole year.
- Having an upper grant limit may not be the best way to ensure wise public spending.

The promised increase in resources for adaptations is welcome but may well not be sufficient. What it is hoped that this research has demonstrated is that if extra money is put in and wisely used, it will be – from everybody’s point of view – ‘Money well spent’.

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Appendix A: The provisions of the mandatory disabled facilities grant

As laid out in the 1996 Housing Grants, Construction and Regeneration Act, Part 1, Chapter 1, Section 23 (1).

23 (1) The purposes for which an application for a disabled facilities grant must be approved, subject to the provisions of this Chapter, are the following:

(a) facilitating access by the disabled occupant to and from the dwelling or the building in which the dwelling or, as the case may be, flat is situated;

(b) making the dwelling or building safe for the disabled occupant and other persons residing with him;

(c) facilitating access by the disabled occupant to a room used or usable as the principal family room;

(d) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room used or usable for sleeping;

(e) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a lavatory, or facilitating the use by the disabled occupant of such a facility;

(f) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a bath or shower (or both), or facilitating the use by the disabled occupant of such a facility;

(g) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a washhand basin, or facilitating the use by the disabled occupant of such a facility;

(h) facilitating the preparation and cooking of food by the disabled occupant;

(i) improving any heating system in the dwelling to meet the need of the disabled occupant, or if there is no existing heating system in the dwelling or any such system is unsuitable for use by the disabled occupant, providing a heating system to meet his needs;

(j) facilitating the use by the disabled occupant of a source of power, light or heat by altering the position of one or more means of access to or control of that source or by providing additional means of control;

(k) facilitating access and movement by the disabled occupant around the dwelling in order to enable him to care for a person who is normally resident in the dwelling and is in need of such care;

(l) such other purposes as may be specified by order of the Secretary of State.

Appendix B: 'Models of disability': brief explanation

In the last quarter of the 20th century the concept evolved, from within the disability movement, of a 'social model' of disability that demonstrated the extent to which disability was socially constructed:

> In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. (UPIAS, 1976, p 14, cited in Oliver, 1996, p 33, see also the table on p 34 that clarifies the key characteristics of the social and individual models)

The starting point of the social model is a distinction between impairment and disability. A person may be impaired following an accident and may need to use a wheelchair to move about, but it is society that *disables* that person by building (or continuing to tolerate) an environment where doors are too narrow and steps create insuperable barriers. By altering attitudes and the environment, society has it in its power to remove the disablement. Car drivers, for example, would be seriously disabled if the nation had not accepted responsibility for their needs and spent many billions of pounds creating access for them.

The contrasting model is one that sees the 'problem' of impairment as being the responsibility of the individual, a view that is reinforced by a medicalised, 'personal tragedy' approach to the issue. Within this individual model, professional 'experts' assess individuals and decide what will be done to solve what is seen as the individual's problem.

C

Appendix C: Methodology and definitions

This appendix supplements the information in Chapter 1.

General approach

The underlying idea behind all three questionnaires – postal, telephone and face-to-face – was the same. They were intended to elicit why adaptations had been asked for and then to discover how well the respondent felt their needs had been met. This matches OT models that ask service users to define their goals and then to assess how well they feel they are achieving the goals: 'enabling people to achieve their valued activities'.

Time-scale

The pilot study was carried out between April and August 1999. The other authorities undertook their research between October 1999 and September 2000.

What each research team did

Selecting and contacting the sample was a major part of the task for every team, and much help was given by other officers in the local authorities.

Personalised letters, including details of the actual work done, were sent to the sample names for both major (face-to-face and telephone) and minor adaptations.

Minor adaptations

The returned postal questionnaires on minor adaptations were anonymous, but provision was made for any respondent with an adaptation problem to raise that separately with the authority.

Major adaptations

Telephone: Once consent had been obtained, officers passed on contact details, but no other information, to the research coordinator and these interviews remained anonymous.

Face-to-face: For the face-to-face interviews on major adaptations, the initial letter was usually followed up with a telephone call to check willingness and arrange an interview appointment. Once agreement was given, an outline of the questions to be asked was sent in advance. After this, each team of officers:

- conducted a semi-structured interview, usually beginning by being shown the adaptations (see Appendix E for a topic guide) and, at the end, asked the respondent to give a score out of 10 for the effectiveness of the adaptation overall; in a few cases an additional separate interview was conducted with a child;
- went through, in consultation with the respondent, a set checklist based on the legislative provision for adaptations to see whether it had been fully implemented;
- conferred together privately after the interview, recording their own views of the adaptation and also agreeing their own score out of 10 for its effectiveness;

- used the files to fill in another set form seeking any significant background detail and factual information about waiting times, costs of work, contributions, details of other grants, problems and negotiations;
- wrote up the replies to the semi-structured interview, including, as requested, one key verbatim quote wherever possible;
- in many cases, sent the written-up interview to the respondent to allow the respondent to amend or correct as appropriate;
- passed on all the pro formas and written-up interviews to the research coordinator.

Once the interviews were complete, a debriefing meeting between partner officers and the research coordinator was held. There has also been a post-research meeting where officers from all but one of the participating authorities met together, reported and discussed their experiences and findings and made many constructive proposals.

Sampling

Securing a sample that was truly random was considered vital to the research and a set of guidelines was given to each team. The sample was to be stratified over time (completion dates from January 1992-December 1998) and cover a range of tenures, geographical areas within the authority, and racial/ethnic groups as appropriate to the area, as well as the specified age ranges.

Sampling problems

In most authorities, sampling proved a major problem and was extremely time consuming, revealing what is probably a nation-wide information problem.

In general, social services keep records by name, housing authorities by address only, and matching or linking was very hard. Files going back as far as 1992 are extremely unlikely to be on a database, so hard files had to be used, and were unlikely to be all in one place. One authority found that its shiny new database contained hardly any data. In one two-tier authority, some housing authorities were unwilling to allow access to their files for the research, while in one unitary authority the social services department was similarly uncooperative.

Final response rates

Face-to-face

The full, planned number of interviews was achieved in most authorities. The hardest interviews to secure were those with parents of disabled children, and we do not have a full number of these. A total of 84 face-to-face interviews were completed.

Telephone

Five out of seven authorities produced either four or five telephone respondents: a total of 20 were completed. Again, finding a case in which the adaptation was for a child was sometimes impossible.

Postal

A total of 162 completed questionnaires were returned from six authorities in England and Wales, an average of 27 out of 50 from each (minimum 20, maximum 30). Despite efforts to check that individuals were still living, there were inevitably some returned marked 'deceased'. In a few cases a surviving widow or widower filled in the form, saying that they were still finding the adaptation useful.

Validity of the research findings

The importance of this detail about the sample and response rates is a concern that we cannot be sure that those who agreed to interviews were statistically representative of the users of adaptations as a whole. We can only say that responses came from a great variety of people; ranged from the ecstatically pleased to the deeply dissatisfied and included a few people who were not using the adaptations – a group we thought might be especially likely not to reply. In one authority, the refusal rate was minimal and the sample reliably random. There was no great noticeable difference in the replies from this authority.

Definitions used in this research

Adaptation: Any permanent or fixed alteration to a home designed to make it more suitable for the disabled occupant and their family. The research did not cover items of equipment that are not fixed, such as seats across the bath, chair raisers, perching stools and bedraisers. Respondents did not necessarily make this distinction, however, so such items were quite often mentioned under 'other' in the postal questionnaire responses.

Minor adaptations: Fixed alterations which were easily fitted (that is, within one day) and which cost under £500. Typical examples are handrails and grabrails, but the specific items covered are given in Chapter 2.

Major adaptations: Adaptations that combined more serious disruption to the householder for their installation and cost more than £500. Cost was the major deciding factor between minor and major, so items such as stair-lifts, which were easily fixed but expensive, were classed as major. Typical major adaptations were bathroom conversions (usually providing a level-access shower); heating installations; extensions to provide ground-floor bedroom, bathroom or both; stair- and through-floor lifts; the installation of a downstairs toilet; often in combination with door widening and the installation of ramps and possibly kitchen alterations.

Effective: Achieving the desired end. The degree to which the problems experienced by the respondent *before* adaptation were overcome *by the* adaptation, without causing new, equally or more serious problems, and without perceived waste, was, in this research, the main measure of effectiveness.

Appendix D: Postal questionnaire on housing alterations

1. **Whose idea was it to make alterations to your home?**

My/our own ☐ My doctor's ☐ An occupational therapist's ☐
A social worker's ☐ Son or daughter's ☐ Can't remember ☐
Other (please specify) ....

2. **Why were they needed?**

3. **What alterations were made?**

Grabrails ☐
Second handrail up the stairs ☐
Ramp to front or back door ☐
Raised or lowered worktops ☐
Outside handrail ☐
Other (please describe)

Over-bath shower ☐
Louder door bell ☐
Altered tap fittings ☐
Heater or fan ☐

4. **Were you offered any choices about what was done?** Yes ☐ No ☐

5. **On a scale of 1-5, how fully do you feel you were involved in deciding what you needed and what would be done? (please circle)**

Not involved		Partially involved		Fully involved
1	2	3	4	5

6. **Have the alterations been helpful to you (please tick all that apply)**

	Yes, the alterations helped	Help was needed, but the alterations made no difference	No help needed
Running your home generally			
Getting to work			
Continuing with your interests			
Being able to go out			
Preparing meals			
Taking a bath or shower			
Using the toilet			
Feeling safer (from risk of accidents)			
Caring for someone else			
Having a social life			
Needing less help from others			

7. Are you happy with the way the alterations look? Yes ☐ No ☐

8. Has having these items in your home affected your health or peace of mind in any way?

No effect ☐ Good effect ☐ Bad effect ☐

9. Have the alterations caused you or anyone else in your home any problems?

No ☐ Yes ☐

If yes please explain.

10. a) Was anything supplied or done that at the time you didn't want?

Yes ☐ No ☐

b) If yes, has it since turned out to be useful?

Yes ☐ No ☐

11. Was there anything you wanted that was *not* done?

No ☐ Yes ☐

If yes, please describe.

12. If you had been given the money to undertake alterations, would you have done the same things?

Yes ☐ No ☐

If no, please explain.

13. Any other comments?

14. And about yourself (or selves) ...

Male ☐ Female ☐ Age(s) ☐

Number in household, including yourself (selves)? ☐

Type of property (such as, '3-bed semi' or '1-bed bungalow')? Please describe.

Tenure? Council tenant ☐ Tenant of private landlord ☐
Housing association tenant ☐ Homeowner ☐

15. And what ethnic group would you say you belong to?

PLEASE RETURN THIS QUESTIONNAIRE IN THE PRE-PAID ENVELOPE PROVIDED

THANK YOU FOR YOUR TIME AND ASSISTANCE IN THIS SURVEY

Appendix E: Topic guide for interviews on major adaptations

Interviews with disabled adults (any age 18+)

(There was an adapted version of this for use where the disabled person was a child, and a simplified version for use in telephone interviews.)

Preliminaries

(i) If either or both of the interviewing team were involved in the original work, check that the person is happy to talk to you.

(ii) Check how long the person can give you and explain they can call a halt (for a break or completely) at any time.

Outline questions

Ask the main question and allow plenty of time for the person to respond. Only use the prompts if person has really stopped talking and if they haven't touched on the topic.

1. Can you tell us first what exactly was done to your home? (if the person offers to show you – fine!)

Prompts: How much were you consulted?
Did you understand in advance what things would look like?
Did you pay to have extras?
Were there things done that you didn't want?
Or things you wanted that were not done?

2. What caused you to apply originally?

Prompts: Why needed?
What person wanted to do and couldn't do?
Issues of discomfort/pain?
Whose idea it was?
How much help did you require to do various things?

3. What options were you given?

Prompts: Moving instead of adapting?
Different adaptations?
Chance to see alternatives?

4. What do you think of the results? (What difference have the adaptations made to you?)

Prompts: End result matching expectations?
Pain/discomfort?
Need for assistance?
Speed of doing things?
Ability to cook?
Ability to bathe?
Employment?
Ability to care for someone?
Ability to enjoy a social life?
Ability to be spontaneous?

Prompts re problems:
Have there been any difficulties of maintenance?
Are there aspects you don't like or that have caused problems?
Extra costs? (eg, electricity, effect of paying contribution)
What do you think of the way the adaptations look?

5. Have the adaptations had any effect good or bad, on other members of the family/people who help you (ask as appropriate)?

Prompts: Reducing time spent on care?
Reducing risk of injury?
Reducing stress?
Depriving family of space?

6. Has your ability to move home if and when you want to been restricted because you have had this work done?

7. On reflection, if you had been in control of the money, would you have spent it in the same way?

Prompts: Did you think of moving as an alternative?
Are there other things you needed?

8. Is there anything else you would like to say, that might help us give a better service in the future?

9. Finally, taking everything into account that you've said and weighing up the good and the bad, would you give a score out of 10 for how effective the adaptation to your home has been from your point of view?

10	Perfect
9	
8	
7	
6	
5	Just about okay
4	
3	
2	
1	
0	No good at all

(Ask the person to look at the chart and circle a score. If they say the adaptation was effective when done but is not so effective now, ask them to give two scores. If the score is less than 10, check briefly with them what they feel would need to happen to make things better.)

Practical details

Male Female

Age

Number in household (details if there are children)

Type of dwelling, number of bedrooms

Ethnic group

Appendix F: Impact of the research

It was anticipated from the start of this research project that, because it was being undertaken by local officers, action at a local level might follow from the research and this has in fact happened.

Direct action to help respondents

Following the research, action was taken in all participating authorities to put right problems that were discovered, including the very serious ones, or re-refer those where new needs had arisen. In one area, 30% of those who responded to the postal questionnaire requested a reassessment. In several other areas, particular attention was paid to improving heating where that was deficient through the use of new HEES grants. (These steps illustrate the relevance of the officers' recommendations that the adaptation process in general needs to be more open-ended and incremental, to respond to changing needs.)

Changes in local policies and organisation

Steps were also taken in some of the authorities to change organisation or policy with a view to preventing reoccurrence of waste.

- One authority had reorganised so that a specific occupational therapist was attached to each housing office, to deal with all private sector adaptations other than those for children. This was to improve coordination between housing and social services and was felt at the time of reporting to be working well.
- The same area had produced a booklet on 'joint approaches to adaptations' designed to speed up the processes. They planned to audit the outcomes after 12 months, and publish if the results were useful.
- Another authority had made a decision to have occupational therapists dedicated specifically to adaptations and to involve them in both pre-contract and completion meetings.
- Elsewhere, the research is to be presented by participating officers to a wider audience as part of planning to improve services in that area.
- A senior environmental health officer involved in the research was hoping to be able to influence strategic planning and policies on new-build in his authority, in light of the research. This was particularly in response to the lack of suitable properties to buy or rent, which left families and authorities in the area with no choice other than adaptation, however unsuitable the property.
- Another senior environmental health officer has negotiated with the architects in his authority to turn around adaptation-related work in five days that used to be held up for several months.
- It was hoped that local authority officers responsible for the designs of adaptations in one area would be interested in the information from the research.

Effects on practice

From making joint visits for the research, professionals had learnt a lot from each other. The occupational therapists had learnt more about structural items like roofs and drains; the housing and environmental health officers improved their understanding of the medical background to what was needed. This experience gave one housing officer the confidence to re-refer a case in which he had been asked to fit one item but noticed the householder struggling with other things.

Conclusion on the value of the methodology

I believe that both the immediate benefits to service users and the long-term effect on policy and practice have demonstrated the value of a methodology which allows professionals the time to consider the outcomes of their work in consultation with the service users and in reflection with other colleagues. This also proved a very encouraging experience to officers who normally hear only of problems and not about the positive things that their work achieves.