

# Housing matters

National evidence relating to disabled children and their housing

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First published in Great Britain in November 2002 by

The Policy Press  
34 Tyndall's Park Road  
Bristol BS8 1PY  
UK

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E-mail [tpp-info@bristol.ac.uk](mailto:tpp-info@bristol.ac.uk)  
[www.policypress.org.uk](http://www.policypress.org.uk)

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Published for the Joseph Rowntree Foundation by The Policy Press

ISBN 1 86134 483 X

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The **Joseph Rowntree Foundation** has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of the Foundation.

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Cover design by Qube Design Associates, Bristol  
Printed in Great Britain by Hobbs the Printers Ltd, Southampton

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# Acknowledgements

This project was funded by the Joseph Rowntree Foundation. A number of people provided invaluable support and assistance to the project. We particularly wish to acknowledge the contributions of Roger Burrows, Teresa Frank, Dot Lawton, Julie Williams and members of the project's research advisory group. We would like to thank our research manager at the Joseph Rowntree Foundation, Alison Jarvis, for her support, enthusiasm and sensitivity to the conflicting deadlines we, as researchers, sometimes face.

The report presents what parents and practitioners have told us, in various ways, about housing and disabled children. We are aware that many of the people who took part in this project have pressured or difficult lives, yet they chose to be involved. We are very grateful for their time and contributions.

# Background

“Housing and education. Those are the things we wanted to get sorted. If you’ve got your home right you can cope.... Within 24 hours of being in this house it was like WOW! She was a different child.” (mother of Debbie, a nine-year-old severely disabled child)

## Introduction

In 1995 the Joseph Rowntree Foundation funded the first UK-based piece of research on housing, disabled children and their families. This qualitative piece of work revealed the significant impact that living in housing unsuitable for a disabled child’s needs can have on family members. The quote we used at the beginning of this chapter sums this up: our homes are fundamental to our well-being – they can make it better or make it worse. For disabled children and their families, living in an unsuitable home can affect parents’ mental and physical health and their needs for specialist support services. For the children, the impact is widespread, with a lack of spontaneity and variety in their home lives, and no, or limited opportunities, to develop independence and self-care skills. In addition, from the accounts of parents and professionals involved in this project, it seemed that the resources and systems currently in place to respond to the housing needs of disabled children and their families were woefully inadequate. A report of the project, entitled *Homes unfit for children: Housing, disabled children and their families*, was published in the late 1990s (Oldman and Beresford, 1998).

The Foundation was so persuaded by the findings of this project that it funded the researchers to carry out a series of regional ‘road-shows’ for staff

working in housing, social services and health authority departments. It also formed a planning group (the Housing and Disabled Children Promoting Positive Change Planning Group) whose remit was, in essence, to work towards identifying local and national solutions for the short, medium and long term. One of the first activities of this group was to canvas the opinions of key individuals through a 24-hour ‘national event’. The messages from participants at the roadshows and the national event were similar. All acknowledged that the housing needs of disabled children and their families are not being met. They identified the main barriers to meeting these needs to be: inadequate resources (both financial and in terms of good quality housing stock), lack of awareness among professionals of the housing needs of this particular population, and service fragmentation. Delegates to these events from housing, social services and health agencies worked together on these issues and identified some solutions or ways forward. These were brought together in the publication *Making homes fit for children: Working together to promote change in the lives of disabled children* (Beresford and Oldman, 2000).

Participants also thought that further research was needed in order to support and promote change. Specifically, quantitative, robust and nationally representative data was called for to complement the earlier qualitative work. The Foundation responded to this by commissioning such a piece of work, the culmination of which is this report.

## Other research

Since our first project in 1998, some new research has been published which has demonstrated the importance of paying attention to, and resolving,

the housing needs of disabled and older people (Bamford, 2000; Heywood, 2000). Neither study focused on disabled children although Heywood's sample did include some disabled children. Both studies found that housing adaptations can have a significant positive impact on the lives of disabled and older people.

Before adaptations, people described themselves with terms such as 'prisoner', 'smelly', 'degraded', 'depressed', 'ostracised', 'afraid', 'embarrassed', 'at screaming point' and 'very, very angry', to pick a few. After good adaptations had been done the key words were: 'freedom', 'independence', 'useful', 'confident' and 'proud. (Heywood, 2000)

The effectiveness of an adaptation, as with all services, is, however, dependent on the quality of the assessment process and service delivery. What both these pieces of research reiterate is the importance of paying attention to housing need. However, within the context of disabled children, almost nothing is known about the types of housing need experienced, and the extent to which these needs are met or unmet.

## The project

The aims of this project were:

- to ascertain the extent and nature of housing needs of disabled children and their families;
- to quantify current housing service delivery patterns to this group.

These aims of the study were met by three separate but related exercises:

- national needs mapping, and responses to unmet housing need, by means of a nationally representative survey of parents of severely disabled children (see Appendix A);
- a mapping of current funding and practice in terms of addressing the housing needs of disabled children and their families through telephone interviews with managers and practitioners working in housing and social services departments (see Appendix B).

Over 2,500 parents and over 100 practitioners in 43 housing authorities took part in the project. The survey of parents took place in the summer of 2000 and the work with practitioners in 2000 and 2001.

## Outline of the report

The following three chapters focus on reporting the findings from the national survey of parents. Chapter 2 presents background or contextual data about the families who took part in the survey, including the nature of the children's impairments, family and living circumstances. In Chapter 3 we present the findings about the nature and range of housing problems faced by families with a disabled child. The impact of the child's age, type of impairment, and socioeconomic factors on families' reports of their housing difficulties are also explored. Chapter 4 focuses on data concerning parents' responses to living in unsuitable housing. In Chapter 4 we report on parents' preferences for moving or adapting, and their experiences of these processes.

Chapter 5 moves on to look at what we found out about the supply issues: the second main aim of the project. We should note here, however, that efforts to collect data on current funding and practice were severely thwarted by a lack of strategic information management at a local level and the fact that what information there is is spread across a number of professionals. Although an important finding in itself, this does make for an analysis which lacks the detail and comprehensiveness originally hoped for.

In Chapter 6 we look at the research findings from a policy perspective. As with all applied research, the purpose of this project was to support and inform change. However, we know from our earlier work that the complexity of policy in this area is a key barrier to change. It is therefore important that any implications drawn from our findings are placed, or understood within the context of current policy (and potential future changes). Drawing on the evidence presented in this report, the final chapter, Chapter 7, proposes a framework around which to reconceptualise 'housing need', and suggests an agenda for change.



# The families and their living circumstances

It is common to find so-called background information about the characteristics of survey respondents consigned to appendices at the back of a research report. This, in the main, we have deliberately chosen not to do. We would argue that factors such as the nature of a child's impairment, family size, tenure and income are essential 'contextual' information which we need in order to fully understand the housing needs of disabled children and their families, and the implications for policy and practice which arise from that understanding.

## The children

Almost 3,000 disabled children and young people (up 18 years) were represented in the survey, with a relatively even spread across the age range, as is found in the national population of disabled children (see Appendix A). Boys and girls were equally represented. We asked parents to tell us about the types of impairment(s) that their child had (see Table 2.1).

**Table 2.1: Type of impairment (%)**

Type of impairment	
Learning	71
Communication	59
Behaviour	50
Posture and balance	46
Use of legs and feet	39
Continence	38
Serious long-term health problem	32
Use of arms	28
Sight	22
Hearing	18
<i>n=2,896 (missing = 45)</i>	

Note: sums to >100% as multiple response.

Given that this survey was concerned with children defined as 'severely disabled', it was not surprising to find that 9 out of 10 children had more than one impairment, and over half (56%) had four or more impairments. Children with only one impairment were most likely to either have a serious health condition or a hearing impairment. The majority of the sample had impairments which affected a number of activities or abilities. Seven out of 10 children were reported by their parents to have difficulties with learning. Over half of the children had communication difficulties, and problems with behaviour were reported for one in two children. Over a third of children had physical impairments, such as ability to use legs or feet and difficulties with posture and balance. A similar proportion had difficulties with continence. Around one in five children had sight and/or hearing impairments.

In addition, within the sample, just over 1 in 10 children were using at least one piece of *medical equipment* in order to maintain life or manage their healthcare needs. Equipment for enteral feeding, oxygen therapy and suction (of mucous) were the items most commonly being used. Whether or not medical equipment was being used in the home was strongly related to the child's age. A quarter of the children aged between 0 and 4 years were using medical equipment.

Recognising this multiplicity and range of impairment is key to fully understanding the scope and nature of housing difficulties which can be experienced by disabled children and their families. Later in the report we explore the association between type of impairment and areas of housing unsuitability.

**Table 2.2: Family size (%)**

Number of family members living at home	
2	9
3	23
4	35
5	20
6	9
7	4

### Family size

Family size is an important ‘background’ variable, as our earlier work showed the importance of family space in determining the suitability or unsuitability of housing (Oldman and Beresford, 1998). Four out of five families participating in the survey included two or more children, with 40% of families having three or more children. The average number of children living at home was 2.43; this is higher than the national average of 1.8 dependant children reported by the 1998 General Household Survey (ONS, 2000). In terms of total family size, the majority of families consisted of four or more members, with a third reporting five or more members (see Table 2.2). (It should be noted that any non-family members and members of the extended family living in the home are not included in this figure.)

### Family circumstances

Income and tenure play a key role both in terms of the presence of housing difficulties and the ways in which a family can respond to, or deal with, housing unsuitability (Oldman and Beresford, 1998).

#### Income

We asked parents to tell us their weekly take-home income (including earnings and benefits). The reported total weekly incomes of respondents are shown in Table 2.3, alongside national population data on total weekly incomes of families with dependant child(ren) collected by the 1998-99 Survey of English Housing.

**Table 2.3: Reported total weekly income (earnings and benefits) (%)**

	Current survey	Survey of English Housing 1998/99 <sup>a</sup>
Total weekly income		
<£100	5	14
£101-£150	23	9
£151-£200	19	11
£201-£250	19	8
£251-£300	12	11
£301-£350	7	6
£351-£400	5	9
£401-£450	4	6
£451-£500	3	5
£500 and over	3	20
	<i>n</i> =2,672	<i>n</i> =5,768

Note: <sup>a</sup> Analysis on families with dependant child(ren) only.

Fewer respondents in our survey reported incomes of less than £100 compared to the general population of families with a dependant child (5% as opposed to 14%). Receipt of benefits such as Disability Living Allowance (DLA) is likely to be the key factor in increasing many families’ incomes to over the £100/week threshold. However, the median weekly income for respondents in our survey was much lower (£151-£200) than for families in the general population (£251-£300). In addition, only 1 in 10 families in our survey had a total weekly income of over £400 compared to almost a third of families in the general population.

Comparative analyses of the incomes of families with and without a disabled child held on national datasets has shown that, in the 1990s, the household incomes of families with disabled children were much lower than the household incomes of equivalent families without disabled children (Gordon and Heslop, 1998). Furthermore, in summarising findings from the 1985 OPCS disability surveys on poverty and disability, Gordon and Heslop (1998) described families with a disabled child as “the poorest of the poor”. A number of factors are at play here. First, there is clear, and growing, research evidence of the association between social class and disability. For example, Gordon et al’s research evidence (2000a), on the basis of their re-analysis of the 1985 Office for Population Censuses and Surveys survey of disabled children, concluded there is “little doubt that ‘working

**Table 2.4: Distribution of sample by tenure (%)**

	Current survey	Survey of English Housing 1998/99
Homeowner: paying mortgage	39	62
Homeowner: mortgage paid	4	6
Rent from local authority	37	18
Rent from housing authority	12	6
Shared ownership	1	n/a
Rent from private landlord	5	8
Other	2	n/a
Total	n=2,919	n=5,768

Note: Analysis on families with dependant child(ren) only.

class' children have a higher risk of suffering from a disability than children from 'middle' or 'upper classes' (p 71). Second is the fact that meeting a disabled child's needs for care and support affects parents' capacities to earn (Beresford et al, 1996). Coupled with lower incomes, research has consistently shown that the 'extra costs' associated with bringing up a disabled child compared to a non-disabled child are considerable, with recent work suggesting a three-fold increase in costs (Dobson and Middleton, 1998).

Thus, while an over-representation of lower-income families was expected in this survey, given the source from which the sample was drawn (see Appendix A), we would argue that this sample is more representative of the majority

of families with a disabled child than might seem initially.

### Tenure

The distribution of the sample according to tenure is shown in Table 2.4. More families in this survey were renting their homes (54%) than were homeowners (43%). The main source of social housing was from local authorities, as opposed to housing associations. One in 20 families were renting their homes from a private landlord.

Table 2.4 also provides data on the tenure of families with dependant children found by the 1998/99 Survey of English Housing. This shows a considerable difference between patterns of tenure between families with a disabled child and the general population of families with a dependant child. The possible impact of different income profiles between families with a disabled child and families with non-disabled children on tenure patterns was therefore explored (see Table 2.5).

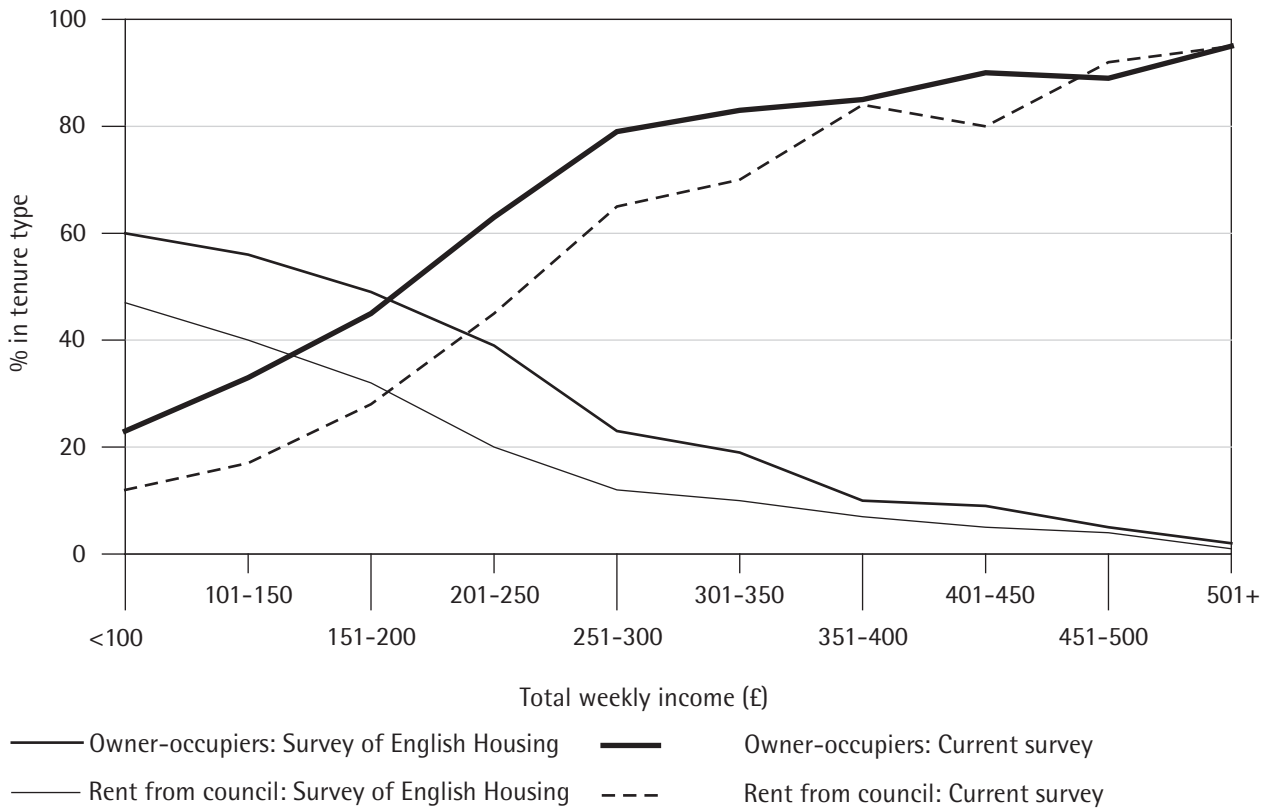
The data presented in Table 2.5 suggests that, even when possible differences in income are taken into account, the tenure patterns of families with a disabled child differ from families without a disabled child. In particular, except for families with total weekly incomes of over £450/week, home ownership is less likely among families with a disabled child compared to families with a non-disabled child(ren). Figure 2.1 shows the

**Table 2.5: The association between income and tenure: families with a disabled child and families with a dependant child in the general population (%)**

	Homeowners		Rent from council		Rent from housing authority		Rent from private landlord	
	Current survey	SEH	Current survey	SEH	Current survey	SEH	Current survey	SEH
<£100	12	23	60	47	19	17	8	13
£101-£150	17	33	56	40	18	17	9	10
£151-£200	28	45	49	32	17	10	7	13
£201-£250	45	63	39	20	11	7	5	10
£251-£300	65	79	23	12	8	3	4	6
£301-£350	70	83	19	10	7	1	4	6
£351-£400	84	85	10	7	4	2	2	6
£401-£450	80	90	9	5	6	1	5	4
£451-£500	92	89	5	4	3	1	-	6
£500 and over	95	95	2	1	-	0	3	4

Note: SEH = Survey of English Housing

**Figure 2.1: Association between income and tenure: families with a disabled child versus general population data**



impact of that discrepancy in home ownership on rates of renting council/local authority housing across income bands.

### Summary

This chapter has reported findings about the families who took part in the survey and their living circumstances.

- Most ‘severely disabled children’ have more than one impairment. These impairments affected different areas of the child’s life, including learning, communicating and physical abilities.
- One in 10 children in the sample were also using medical equipment in the home which was required for maintaining health or sustaining life.
- Families partaking in the survey had, on average, more children than families in the general population.

- In line with other research findings on income, the income levels of families with a disabled child(ren) was lower than families with non-disabled child(ren).
- The data suggests that families with a disabled child(ren) are more likely to be living in rented accommodation (particularly local authority housing) than families with a non-disabled child(ren) with a similar level of income.

These findings confirm what is already reported in the literature on the families with a disabled child and their living circumstances, and the impact of disability on tenure has been usefully further explored using comparative data from the Survey of English Housing. Overall these findings paint a picture of increased risk for deprivation. It is within this context children and families are facing and managing the extra difficulties and demands associated with the, often multiple, impairments which the child has.

# The problems with their homes

## Introduction

This chapter reports on the housing needs reported by respondents. The findings are divided into those which pertain to generic housing needs – housing condition and the local environment – and those which are generated by the child’s impairment and care needs.

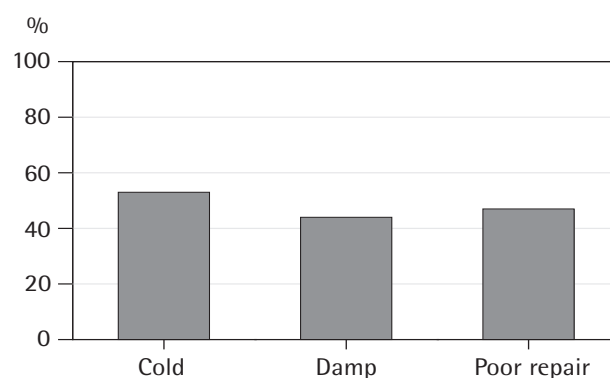
## Housing condition

Previous work on housing and disabled children (Oldman and Beresford, 1998) has revealed the impact not only of physical or structural factors within the home but has also highlighted the need to consider the impact of housing condition and the local environment in which families are living.

Four out of 10 respondents reported problems with cold, damp and/or poor repair. Of these families, one in two said that their home was cold, and just under half had problems with damp and/or poor repair (see Figure 3.1).

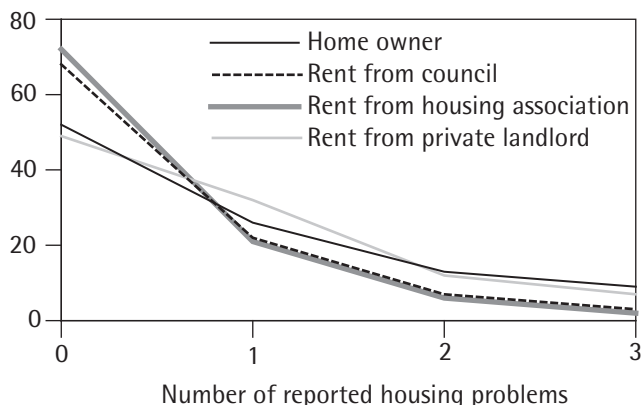
There is no available data on the general population against which we can make *direct* comparisons. However, we did compare our data with that of the Poverty and Social Exclusion Survey (Gordon et al, 2000b). Conducted in 1999, the Poverty and Social Exclusion Survey collected detailed data on various poverty indicators on a sample weighted towards those with low incomes (hence similar to our sample). Within the Survey sample, we looked at the data on respondents with dependant children ( $n=341$ ). Rates of reporting lack of adequate heating facilities were much lower than families in our survey. Eight per

**Figure 3.1: Prevalence of problems with housing conditions among families reporting poor housing condition**



cent of Survey families said they did not have adequate heating facilities, compared to 14% of families in our survey. Rates of reported problems with damp were more similar between the Poverty and Social Exclusion Survey and our sample: 11% of Poverty and Social Exclusion Survey families reported problems with damp, compared to 12% of families in our survey. These data suggest that families with a disabled child are more likely to be living in poor housing conditions than families with a similar economic profile but with non-disabled children. Given the known association between poverty and poor housing conditions, they confirm the notion that, overall, families with a disabled child are among the most disadvantaged groups. In addition, it is likely that the child’s impairment raises parents’ sensitivities to the suitability of the condition of their home.

**Figure 3.2: Number of problems with housing condition per family by tenure**



The frequency at which problems with housing condition was reported within the sample varied according to tenure (see Figure 3.2). Owner-occupier families and families renting from housing associations were more likely to report having no problems with the condition of their home compared to those renting from their council or from a private landlord. Similarly, a greater proportion of respondents in the latter two tenure groups reported problems with cold and damp and poor repair compared to owner-occupiers and those renting from housing associations.

### Difficulties with the local environment and community

We used a classification of aspects of the local environment/community from the Survey of English Housing to look at difficulties with the location in which families were living. Two thirds of families identified at least one problem with their local environment, with a third reporting three or more difficulties. The different features of the environment covered are shown in Table 3.1.

The most frequently reported problem was with crime: 4 out of 10 respondents stated that this was a problem in their local area. Vandalism and litter in the streets were reported as a local problem by a third of the sample, and problems with noise and dogs by a quarter of respondents. One in five families had problems with their neighbours. Over one in 10 non-white families reported racial harassment as a problem in the area in which they lived.

**Table 3.1: Reported problems with the local environment (%)**

Crime	39
Vandalism	32
Litter/rubbish in streets	32
Noise	27
Dogs	26
Problems with neighbours	20
Graffiti	19
Racial harassment	
- white families (n=2,545)	3
- non-white families (n=364)	12

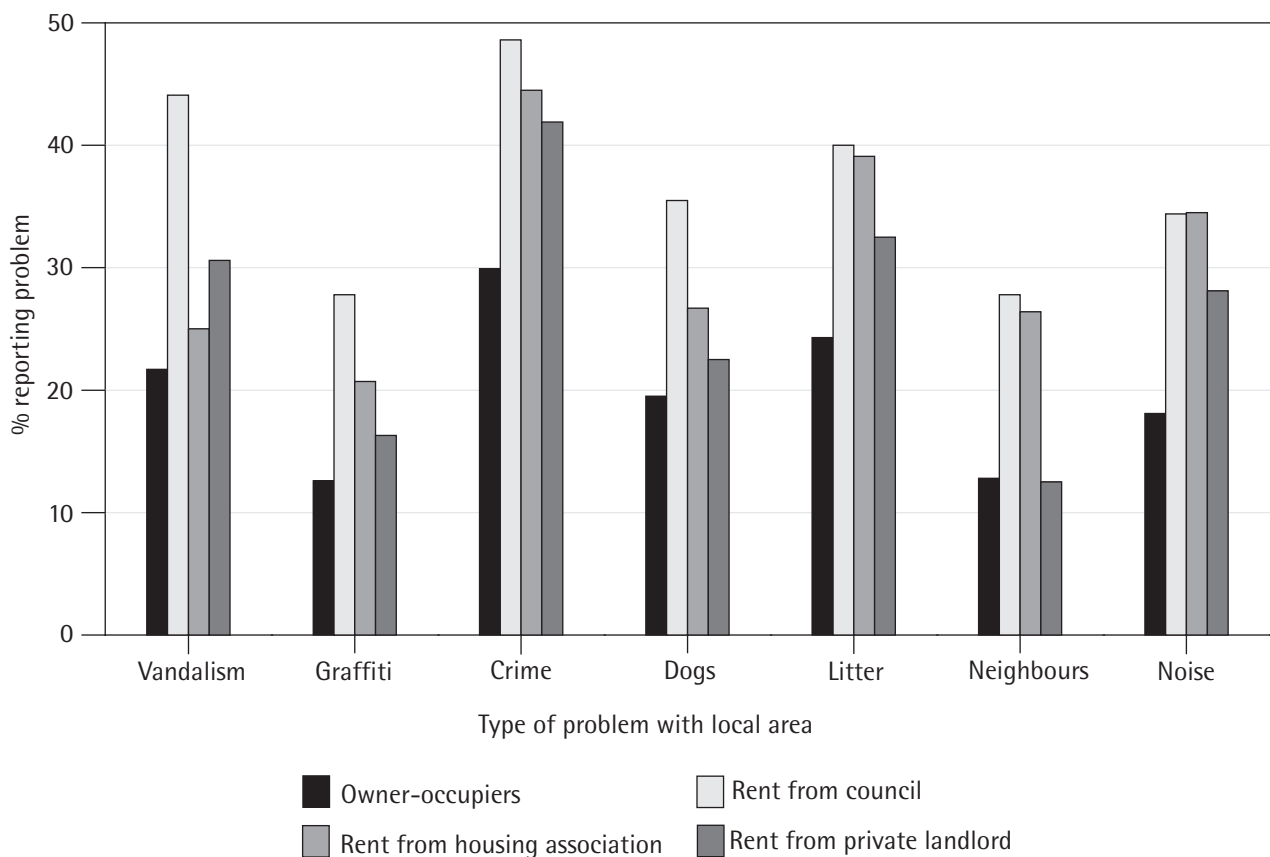
Whether or not families reported problems with their local area, and the number of problems they experienced, was associated with tenure (see Figure 3.3). Once again, owner-occupier families reported fewest difficulties with their local environment and those renting their homes from the local council had the greatest number of problems. It is interesting to note here that, in contrast to many of the other findings described in this report, this is one aspect of housing where families renting from a private landlord seem to fare better than those renting from the council or a housing association.

### Housing unsuitability: extent and range

In this section we turn to look at the extent and range of problems with housing which rendered homes unsuitable for disabled children and their families. Parents were asked to indicate the ways in which their homes were unsuitable for their disabled child and the rest of the family. Table 3.2 shows the extent to which each particular difficulty was experienced by the families taking part in this research.

The most frequently reported problem was the lack of space to store the child's equipment – almost 4 out of 10 parents stated this was a difficulty. Having only one toilet and/or bathroom was a problem for around a third of families. A quarter of families said that the lack of a downstairs toilet and/or bathroom made their home unsuitable. Issues of size and space also featured among the most frequently reported problems. Three out of 10 families said that their bathroom was too small. In addition, just under

Figure 3.3: Problems with the local environment by tenure



one in three families responded that they did not have enough bedrooms, and the fact that they only had one living room was a problem for a similar proportion of families.

### *The number of different problems reported by families*

Fourteen per cent of families reported that they did not experience any of the problems listed in Table 3.2. The remainder of families were living in homes that were, in at least one way, unsuitable for their child or them as carers of that child. Indeed, many families faced a number of problems: half of the families reported five or more different problems with their home. Of these families, one in three reported nine or more problems.

### **Aspects of housing unsuitability: identifying problem areas**

Following the preliminary analysis reported above, the various types of housing unsuitability

were then grouped into a series of *housing problem areas*. This was based on the findings from our earlier work on disabled children and housing unsuitability (Oldman and Beresford, 1998). Eleven *problem areas* emerged and are detailed below (see Table 3.3); the figures show the proportion of families reporting a difficulty in each problem area. We would suggest that these figures provide a rough estimate of the proportion of families with a severely disabled child experiencing difficulties with each of these areas of housing difficulty in England.

A lack of family space (that is, space to meet the needs of different family members, such as play, privacy, 'time out' and sleep) was the most frequently reported problem area. Over half of families said this was a problem. Difficulties with toileting and bathing due to small rooms or the lack of an additional bathroom/toilet or downstairs facilities were another common problem. One in five parents had unmet needs in terms of equipment to assist with lifting, toileting and bathing.

A lack of space for storing equipment was reported by just over a third of families and one

**Table 3.2: Proportion of families reporting types of housing unsuitability (%)**

Not enough space to store child's equipment	38
Only one toilet	34
Only one bathroom	30
Small bathroom	30
Stairs ( <i>n</i> =2,626 – families living in at least two-storey homes)	30
No downstairs toilet ( <i>n</i> =2,523 – families living in at least two-storey homes)	28
Not enough bedrooms	27
Only one living or family room	27
No downstairs bathroom ( <i>n</i> =2,523 – families living in at least two-storey homes)	26
Location of home is unsafe for child (eg busy roads)	25
Steps up to front/back door	24
No safe or suitable garden	22
Small kitchen	22
Cold	19
Small toilet	18
Neighbours unpleasant to child/other family members	16
Not enough space for child to use therapeutic/daily living equipment	16
Small living room(s)	16
Damp	15
No equipment to assist with lifting	14
No equipment to assist with bathing	14
Narrow doorways make use of wheelchair/walking frame impossible	11
Not enough space to carry out therapies	11
No equipment to assist with using the toilet	10
Narrow front/back doors	10
No facilities nearby	8
Steps between or into rooms	7
Inside of home unsafe in some way	3
Other	3

(*n*=2,941 unless stated)

in five families also said there was not enough space in their homes to carry out therapies and/or for their child to use the specialist equipment provided for them.

Just under 4 out of 10 parents (38%) reported that the location of the home (which includes features nearby such as busy roads making safety an issue, unpleasant neighbours and no nearby facilities) was a problem.

The figure for the number of families indicating safety was an issue inside the home is surprising,

**Table 3.3: Proportion of families reporting difficulties with each housing problem area (%)**

Family space (space to play, space apart from other family members)	55
'Functional rooms' (kitchen, toilet, bathroom) difficult to use due to size	42
Only one toilet and/or bathroom	41
Lack of space for storage of equipment	38
Location	38
Access around, and in and out of, the home	33
Lack of downstairs toilet and bathing facilities	33
Housing condition	27
Lack of space to use equipment and carry out therapies	21
Inadequate facilities to meet carer needs (re lifting, toileting and bathing)	21
Safety inside the home	3

and may reflect an inadequacy of the survey instrument. An alternative explanation is that dealing with some aspects of safety (such as door and window locks) are relatively inexpensive and may be something families had already addressed. (It is also important to remember that one in five families said they had no safe or suitable garden.)

### *Number of problem areas experienced by families*

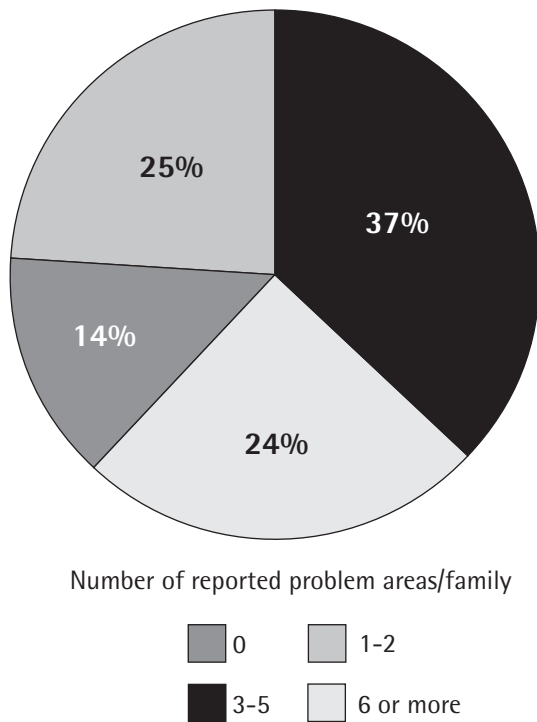
Three quarters of the families reported experiencing at least two problem areas, with one in four stating that there were six or more problem areas in their homes (see Figure 3.4).

### *Comparing with general population data*

While we are not able to make any direct comparisons in terms of reported problems with housing between our sample and with families with a dependant child(ren) in the general population, the 1998/99 Survey of English Housing collected data on respondents' satisfaction with a number of aspects of their accommodation including: overall satisfaction, layout of accommodation, number of rooms and size of rooms. Our analysis of the Survey of English Housing dataset (families with a dependant child[ren] only) found that almost 9 out of 10 respondents reported being either very or fairly satisfied with their accommodation. More than four out of five respondents were very or



**Figure 3.4: Number of housing problem areas per family**



fairly satisfied with the layout of their home and the size of rooms; furthermore, over three quarters were very or fairly satisfied with the number of rooms in their home. These figures, when compared with the data reported on types and number of problems with their home collected by our survey, suggest that families with a severely disabled child are experiencing far more difficulties with their housing than families with dependant children in general. Secondary analysis of the Poverty and Social Exclusion Survey (Gordon et al, 2000b) has allowed us to compare, at quite a crude level, our findings on reported lack of space against a population of similarly low-income families with non-disabled children. A third of families (33%) in the Survey reported shortage of space as a problem with their accommodation. This is further evidence that, even when income levels are accounted for, families with a disabled child are more likely to report difficulties with poor housing conditions and housing suitability compared to families with non-disabled dependant children.

**Figure 3.5: Factors associated with the number and/or types of problem areas experienced**

- income
- tenure
- age
- type of impairment
- ethnicity

### Factors associated with the areas of housing unsuitability experienced

Bivariate statistical tests were used to explore the association between the number and types of problem areas families experienced and demographic and impairment factors. A number of factors were found to be associated with the number and/or types of housing problems reported by families (see Figure 3.5).

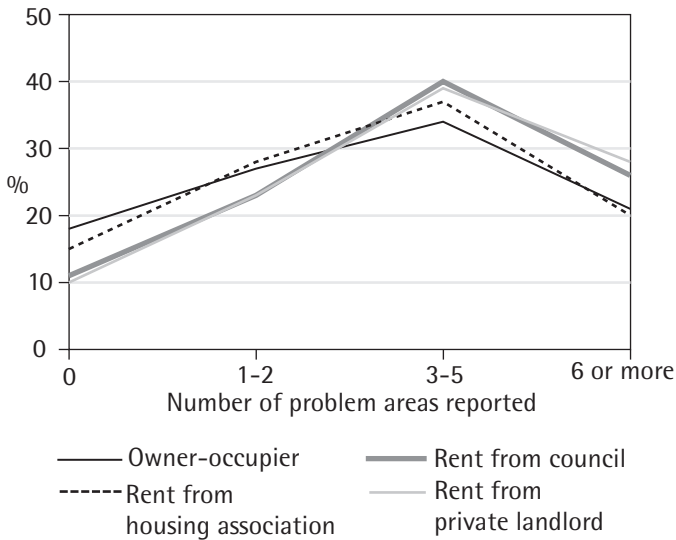
#### Income

A statistically significant effect of income on the total number of problem areas reported by parents was found between families on the lowest incomes (less than £250/week) with those in the highest income group (more than £350/week) ( $F(3,2668)=5.34 p\leq 0.001$ ). Table 3.4 shows the mean number of problem areas reported according to reported weekly take-home income and the maximum number of problem areas reported. Taken together, these findings make it clear that, while associated with income, difficulties with unsuitable housing are being experienced by families in the higher income ranges.

**Table 3.4: Mean number of housing problem areas by weekly take-home income**

Weekly income	Mean number of housing problem areas	Maximum number
<£150	3.8	11
£151-£250	3.8	11
£251-£350	3.4	10
£350+	2.9	10

**Figure 3.6: Association between tenure and number of problem areas reported**



square=41.98 df=9  $p \leq 0.001$ )<sup>1</sup>. Similarly, as Figure 3.6 shows, a greater proportion of the latter two tenure groups reported no problems with their housing.

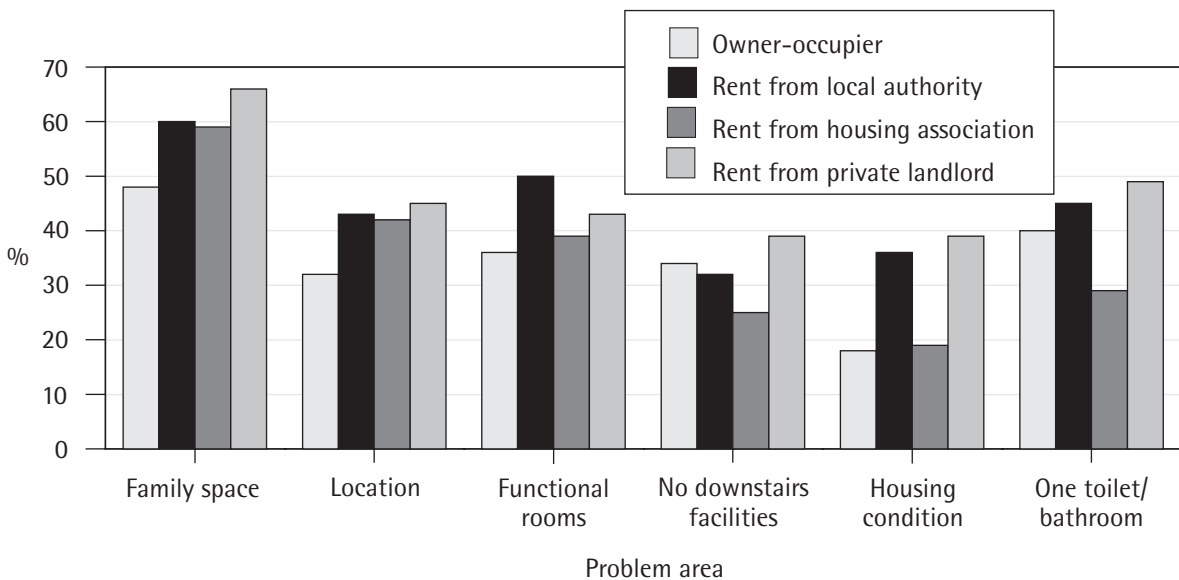
The specific differences between tenure groups underlying this overall difference are displayed in Figure 3.7. There were differences in the frequency at which 6 of the 11 problem areas were reported by the different tenure groups.

Owner-occupiers were least likely to report location and family space as a problem, while those renting from private landlords were most likely to experience this difficulty. It was among families renting from housing associations where a lack of downstairs, and/or a second, toilet/bathroom facilities was least frequently mentioned, with, again, those renting from private landlords most likely to report these sorts of problems. However, inadequate size of functional rooms (kitchen, bathroom, toilet) was most likely to be reported by families living in local authority housing, while owner-occupiers were least likely to experience this difficulty. Finally, housing condition was a far more common problem among those renting local council accommodation or from private landlords compared to the rest of the sample.

**Tenure**

Analysis of the data using bivariate statistical tests showed that a significantly greater proportion of families living in local authority housing or renting their home from a private landlord reported experiencing a lot of problem areas compared to owner-occupier families and those renting from housing associations (chi-

**Figure 3.7: Association between tenure and reported frequency of selected housing problem areas**



<sup>1</sup> The chi-square test is a test of association. Here we used chi-square to see if there was an association between tenure and the number of housing problem areas experienced. The 'p' value tells you the probability that an observed difference (in this case the number of housing problem areas experienced by families living in different tenures) has occurred 'by chance' or is a significant, 'real' association. Typically, to be viewed as a statistically significant effect, the 'p' value has to be at least 0.01. The 'p' value here suggests a strong association between the number of housing problem areas experienced and tenure.

## Age

The child's age was also significantly associated with the number of problem areas reported by parents (chi-square=64.70 df=12  $p \leq 0.001$ ).

Overall this appears to be a linear association with a decrease in the *number* of problem areas reported with an increase in the child's age. We tested to see whether this association was being affected by the over-representation of use of medical equipment in the youngest age group. However, this did not affect the overall pattern.

Differences were found in the association between age and *specific problem areas*. Difficulties with space for equipment storage, carrying out therapies, family space, safety and carers' needs in terms of lifting/handling were reported to a greater extent by parents of younger children. However, there were no clear patterns of association between age and difficulties with location, access around the home, size of functional rooms and lack of downstairs facilities. In addition, the likelihood that families would experience problems with housing condition and a lack of a second toilet/bathroom were not associated with the child's age.

Reasons for the observed decrease in the number of housing problems being reported as the age of

the child increases will include less reliance on parents for help with self-care activities, the fact that adaptations may have taken place, and equipment provided, and that, unlike under four-year-olds, the child is spending a proportion of the day in school. It is also important to note that the findings reported here are about *relative* changes. The issue of housing unsuitability is still very real for parents of older disabled children and young people. One in five parents of 16- to 18-year-old disabled young people in this survey were experiencing six or more problem areas with their housing. In addition, all we have been able to explore is the number of problem areas as opposed to their various impacts on the quality of life and well-being of family members.

## Type of impairment

As reported earlier, the majority of children represented in this study had multiple impairments. This made it impossible to look at the impact of a single impairment on each specific problem area of housing unsuitability. However, we have been able to look for patterns in the data in terms of the level of reporting of a particular problem area with the presence (but typically not exclusive presence) of a specific impairment. This is summarised in Table 3.5.

**Table 3.5: Type of impairment by problem area (%)**

Problem area	Type of impairment							Serious health problem
	Physical	Conti-nence	Visual	Hearing	Behaviour	Learning	Communi-cation	
Space of equipment storage	48	48	51	36	36	38	41	50
Safety inside	3	3	3	2	5	4	4	3
Space to use equipment and do therapies	31	29	26	20	15	20	22	29
Family space	58	58	58	55	59	56	58	59
Carer needs (lifting and handling)	34	30	32	19	17	21	23	29
Location	36	43	39	40	48	42	41	40
Access within and in and out of home	47	42	48	30	27	33	35	42
Size of functional rooms	45	48	44	43	43	43	45	48
Lack of downstairs toilet/ bathroom	38	38	36	28	33	33	35	37
House condition	25	26	27	30	30	27	27	31
Lack of second toilet/ bathroom	43	44	42	39	44	42	42	42

Each row of the table displays the proportion of children with each type of impairment whose parent reports a difficulty with that housing problem area. For example the top left-hand cell shows that 48% of children with a physical impairment reported a lack of space for storing equipment.

The key points to draw from the data displayed in Table 3.5 are as follows.

- Overall, these data suggest that some aspects/ areas of housing unsuitability are associated with particular types of impairment.
- The two different *sensory impairments* (hearing and sight) do not appear to generate similar difficulties in terms of housing unsuitability. One reason for this may be because, unlike hearing, sight impairments almost invariably co-occurred with physical and/or learning impairments.
- The nature of the child’s impairments did not appear to affect families’ reports of a lack of *family space*. This was a commonly reported issue for all types of family. Similarly, the *size of functional rooms* (kitchen, bathroom, toilet) did not appear to be linked to a particular impairment(s). Again it was frequently reported. *Housing condition* was another problem area that did not appear to be strongly associated with particular impairments.
- The presence of physical impairments and continence, learning and behavioural problems resulted in higher levels of reported need for *downstairs toilet and/or bathroom facilities or additional facilities* when compared to levels of reported need where hearing impairments were present.
- Reports of a *lack of space for storing equipment* was found most frequently in families where the child’s condition included a physical impairment, visual impairment, incontinence and/or the child had a serious health problem. These same impairments were also implicated in terms of *insufficient space to use specialist equipment or to carry out therapies*. We would suggest that the figures for children with visual impairments need to be treated with caution as this impairment typically co-occurred with at least one other impairment.
- Concerns about *safety* inside the home were most common where the child’s condition included behaviour, learning and/or communication difficulties.
- Problems with a *lack of equipment to manage lifting and handling* were, predictably, reported where there were physical impairments, continence problems, and serious health problems.
- The *location* of the family home was more frequently reported to be a problem when the child had certain impairments, particularly behavioural problems.
- Reports of difficulties with *access within, and in and out of, the home* were most common where one or more of the following impairments were present: physical impairment, visual impairment, continence problem and/or serious health problem. To some extent the finding for sight may be a result of the fact that, in this sample, sight impairments tended to co-occur with at least one other impairment.

**Table 3.6: Type of problem area by ethnicity: percentage of families reporting problems**

Problem area	Ethnic group			
	White	Black/African Caribbean	Indian	Pakistani and Bangladeshi
Space of equipment storage	19	27	31	31
Safety inside	3	6	3	3
Space to use equipment and do therapies	37	40	38	48
Family space	53	64	57	77
Carer needs (lifting and handling)	20	26	26	31
Location	38	39	28	38
Access within and in and out of home	32	21	38	36
Size of functional rooms	41	41	57	56
Lack of downstairs toilet/bathroom	32	24	32	40
House condition	24	31	37	45
Lack of second toilet/bathroom	40	41	50	58

## Ethnicity

Parents who described their origin as other than 'white' reported a greater number of problem areas compared to white families (chi-square=27.31 df=3  $p \leq 0.001$ ). A third of non-white families experienced three or more problem areas with their home compared to one in five white families.

The association between housing unsuitability and ethnicity is not just a question of white versus non-white. There were differences between ethnic groups in terms of the types of problem area they were likely to report (see Table 3.6).

Pakistani and Bangladeshi families were most likely to report needs in terms of *family space* (77% compared to 64% of Black/African Caribbean families and 57% of Indian families and 53% of white families); *a lack of a second toilet or bathroom* (58% compared to 50% of Indian families and 41% of Black/African Caribbean and 40% of white families); *poor housing conditions* (45% compared to 37% of Indian families, 31% of Black/African Caribbean families, and 24% of white families). Finally, concerns about *location* were least common among Indian families (28%, compared to 39% for other ethnic groups).

## Needs and priorities: an alternative data source

In the questionnaire we asked parents to tell us about the sorts of changes that were needed to make their homes more suitable for their child and themselves as carers of that child. An open-ended response format was used for this question and here we present our analysis of the first described change (although many parents listed numerous changes). This provides some idea of parents' priorities in terms of addressing the unsuitable aspects of their housing and offers an alternative approach to looking at their perceptions of their housing needs. Table 3.7 shows the types of desired changes parents told us about; they are listed in order of the frequency in which the changes were mentioned.

Issues of space featured strongly in the sorts of changes to their homes that parents wanted to carry out: an additional bedroom, increased living/communal space, a safe garden and space for the child to play, to use their specialist equipment and to have therapies. These represent the needs for space for the whole family: the child's needs for space for play and therapies; all family members' needs for

**Table 3.7: First 'change needed to the home' reported by parents (%)**

Additional bedroom (14% of whom stipulated ground floor)	14
Additional toilet (81% of whom stipulated ground floor)	12
Increased living/communal space	9
Garden – improve safety (fences and gates)	8
Improve general condition of house (eg heating, double glazing/new windows, damp, roof repairs, external doors replaced)	8
'Child' space (play, equipment, therapy)	8
Improved bathroom/toilet facilities (eg level access shower, electric toilet, hoists <i>not</i> minor equipment such as grab rails, bath instead of shower)	6
Internal access between rooms (door frames, internal steps, position of doors, change of flooring)	5
Additional bath/shower (62% of whom stipulated ground floor)	5
Ramps to external doors	5
Improve access to/use of garden	4
Access between floors (lift, stair lifts)	4
Increased size of toilet and/or bathroom	3
Small bathroom/toilet adaptations (rails and taps mainly; might be funded within an adaptation grant or within community equipment budget)	2
Rails to assist moving about	1
Safety (includes door and window locks, and safety glass)	1
Parking improvements (eg off-road, tarmac drive)	1
Changes to kitchen – improve safety or access/use by child	1
Other	3
( $n=1,532$ )	100

psychological space from each other; the need for privacy; and the need for uninterrupted sleep. Four out of 10 responses were concerned with improving or addressing these sorts of space needs.

Increasing or improving toilet and bathing facilities were other common areas of desired change. Just over one in four parents listed a change of this sort, and the need for downstairs facilities was stressed. Changes which assisted with the child being able to move about the home (changing internal features, installing lifts, rails and ramps) also featured. Fifteen per cent of responses concerned this issue. A further 4% listed improving access to, or the child's ability to use, the garden as a priority. Finally, improving general housing conditions was a priority for 1 in 12 families.

## Summary

In this chapter we have explored findings from the survey concerning the type and extent of the housing needs of families with a disabled child. First, data on housing quality or housing condition were reported. Second, findings about housing unsuitability were reported – here we looked at the features of the home environment which present difficulties to families in terms of either caring activities, promoting the disabled child's well-being and independence, and limiting the impact of the impairment(s) on other family members, such as siblings. Key findings arising from our analyses of the data are as follows:

- Families with a disabled child are almost twice as likely to report problems with inadequate heating in their homes compared to a similar population of families with non-disabled children.
- Comparisons with other data sets suggest that even when income levels are accounted for, families with a disabled child are more likely to report difficulties with poor housing conditions and housing suitability compared to families with non-disabled dependant children.
- Nine out of 10 respondents reported at least one difficulty with their housing which made it unsuitable for them as a family with a disabled child, and many families reported multiple problems.
- There were numerous ways in which home environments were unsuitable: lack of space, small size of rooms, difficult location, inadequate toileting/bathing facilities, poor housing, unsafe internal environment, access difficulties within and in and out of the home, and lack of equipment to assist with lifting and handling.
- Inside the home the most frequently reported area of difficulty was the lack of space. This included space for play, privacy or 'time out', equipment use and storage, and for carrying out therapies.
- Over a third of families also found the location of their home a problem. The most common reasons underlying difficulties with location were either the risks to the child's safety (for instance, being situated on a busy road) or difficulties with unpleasant neighbours.
- Comparisons with data on satisfaction with housing collected by the Survey of English Housing suggest that families with a disabled child experience far greater problems with their homes than families with non-disabled children.
- While level of income was associated with the number of housing problems reported, even among the middle/higher income groups an average of three different housing problems were reported.
- Parents from minority ethnic groups reported a greater number of housing problem areas compared to white families. In addition, the frequency at which the types of housing problems were reported differed between minority ethnic groups.
- A high level of housing unsuitability was reported across all tenure groups. However, overall, families renting their homes from private landlords and their local authority reported a greater number of problems.
- The age of the disabled child and type of impairment was associated with the ways in which a home was unsuitable for a family. However, some housing problem areas were not discriminated by age or type of impairment.

# Responding to unsuitable housing

## To move or adapt?

There are a number of options facing families living in unsuitable housing and our previous work has explored the reasons underpinning the choices families make (Oldman and Beresford, 1998). In essence, families can either find they cannot, or decide not to, do anything; adapt their current home; move to a more suitable home; or move to, and then adapt, a new home. A number of factors influence the decision made, including financial resources, availability of information and advice, access to services and feelings about current (and future) circumstances.

Half the parents said that, at the time of completing the survey questionnaire, they needed to change their housing in some way in order that it better suited the needs of their child and the rest of the family. Given the choice, more parents said they would prefer to move (57%) than to adapt their present home (43%).

## Factors affecting preference for moving or adapting

Tenure and the nature of the housing problem were both associated with parents' reported preferences to adapt or move. Figure 4.1 shows the association between tenure and parents' preferences in terms of how to deal with their unsuitable housing. Owner-occupiers were the only group where adapting the current home (56%) was preferred over moving (44%). For those renting their homes, moving was preferred by the majority and increasingly so among those renting from housing associations and private landlords. (With respect to the latter group, 16%

of respondents indicated that their landlord had prevented them from changing or adapting their home.) We know from our previous research that a number of factors will be at work here (including what parents believe their options to be). However, this finding does highlight the fact that moving is the preferred option for many parents.

Intuitively, a factor likely to influence parents' preferred way of dealing with a problem with their housing will be the ways in which the current home is unsuitable. This is, however, often a complex situation. Some of the ways in which a home can be unsuitable for a disabled child and their families cannot be solved by structural alterations and other adaptations. Families may be facing a cluster of problems – some of which might be better addressed by adapting while others would be resolved more effectively by moving.

We looked at the distribution of parents' preferences for adapting or for moving with respect to each housing problem area (see Table 4.1).

It is important when looking at these figures to bear in mind that, in the majority of cases, parents' preferences will have been based on the experience of facing more than one problem area. It is therefore essential not to 'over-interpret' or misinterpret this data. In addition it is important to bear in mind that we would have expected moving to appear as the preferred option given that, as reported above, overall this was the preferred option.

Despite this we would argue that these data suggest that for many of the housing problem areas there is no clear-cut distinction in terms of

Figure 4.1: Association between tenure and preferences to move or adapt



parents' preferences about how to address the problem. However, for certain housing problem areas there does appear to be a pattern in terms of a preference for moving. These are either where there is a need to increase the size or facilities of the home in order to have more space for equipment storage and/or use; an additional toilet/bathroom; or larger so-called functional rooms (kitchen, toilet, bathroom). In addition, not unsurprisingly, where *location* is one of the problem areas a family is facing, a greater number of respondents expressed a preference to move as opposed to adapting their current home.

## Assessment of housing need

### Methodological issues

Parents with a disabled child are in contact with numerous professionals from a number of different agencies, and many parents report considerable problems finding out about the organisation and provision of services (for example, Beresford et al, 1996; Mitchell and Sloper, 2001). It is therefore not surprising that researchers (and practitioners) have found it difficult to obtain an accurate picture from parents about the roles of the different professionals involved with their family and the assessments

Table 4.1: Type of problem area experienced by parents' preferred solution

Preferred solution	Type of problem area experienced					
	Equipment storage	Safety in home	Space for equipment and therapies	Family space	Carer needs: lifting and handling	Location
Adapt	41	48	41	47	47	32
Move	59	52	59	53	53	68

Preferred solution	Type of problem area experienced				
	Access in and around home	Size of functional rooms	Lack downstairs toilet/bathroom	Condition	No second toilet/bathroom
Adapt	47	41	46	37	42
Move	53	59	53	64	58



they have had. It is difficult, within the constraints of a large-scale postal survey, to identify ways of overcoming this difficulty. We sought to overcome this by asking parents whether they had had an assessment of their housing needs, to name the type of professional who carried out the assessment, and to describe the outcome of that assessment. We used responses to the two latter, subsidiary, questions to filter out any clearly erroneous responses to the question about whether or not the family had had an assessment of their housing needs. However, there still remains scope for some error in this data, particularly the possible confusion between an assessment for community equipment services and housing needs; both are typically carried out by an occupational therapist, and the boundaries between some adaptations and the provision of equipment can be rather blurred.

### Number of assessments

One in four respondents reported that an occupational therapist had assessed their and their child's housing needs. Typically, parents reported one of three possible outcomes to that assessment. Over a half reported changes/adaptations had been made to the home. Just under a third reported that nothing had happened following the assessment. A small proportion (7%) had moved, or were waiting to move within local authority or housing association housing. A few parents were in the assessment or adaptation process at the time of the survey.

The associations between the outcome of a housing need assessment and tenure are shown in Table 4.2.

The outcome of an assessment of housing need differed according to tenure. Changes or adaptations to the current home were most likely among owner-occupiers and least likely among those renting their homes from a housing association. However, the latter group were most likely to report they had been rehoused or were waiting to be rehoused. Around a third (rising to 4 out of 10 housing association tenants) of respondents reported that nothing had happened as a result of the assessment.

### Moving home

Of those families who had moved since their disabled child was born, almost two thirds said they had moved in order to live in a home that was more suited to their child's needs or their needs as a parent/carer of their child. Families who rented their homes were more likely to have moved in response to their housing needs compared to owner-occupier families – especially those renting from housing associations and those renting from private landlords. The data reported above suggests that decisions to move are, in the great majority of cases, made outside of any assessment process.

**Table 4.2: Outcome of housing need assessment**

Outcome	Tenure			Total (%)
	Owner-occupiers (%)	Rent from local authority (%)	Rent from housing authority (%)	
Changes/adaptations made to current home	60	51	39	54
Nothing changed or happened	30	27	43	31
Moved or waiting to move within local authority/housing authority	n/a	6	16	7
Still in assessment process	2	2	1	2
Still in adaptation process	4	6	–	4
Other	4	2	1	2
	n=343	n=246	n=86	n=693

Note: A very small sample size (n=18) means the figures for respondents renting from private landlords are not shown.

### Advice about moving

Indeed, 8 out of 10 families who had moved in response to their child’s needs or their needs as carers said they had done so without any professional advice. Where advice had been provided, this was most commonly from either an occupational therapist or a social worker.

### Barriers to moving

Respondents were asked whether, at the time of completing the questionnaire, they would like to move to more suitable housing but could not for some reason. Four out of 10 parents reported they were wanting to move but faced some barrier to achieving this. The barriers reported by parents included: financial reasons, the local authority or housing authority not accepting the family’s need for rehousing; a lack of, or waiting for, a suitable property to rent. Table 4.3 shows the association between the various barriers to moving and tenure.

Across tenure groups, different factors were at play in determining whether families were able to move in response to addressing their unmet housing needs. For owner-occupier families financial reasons were the dominant barrier to moving, being reported by almost 9 out of 10 respondents in that situation. A small proportion of owners-occupiers were seeking to change tenure by moving into a local authority or housing association property.

Among those renting their homes the picture in terms of the barriers to moving is quite similar. For some, the costs of moving or the prospects of

increased rent were a barrier – this is most frequently reported by those renting from private landlords. Some families had been unsuccessful in persuading their housing authority that they needed rehousing. In our analysis we did not find any factors, including type of impairment, that were associated with families being judged ineligible for rehousing. However, the most common reason for being unable to move given by those renting their homes was failure by their local authority or housing authority to offer them a home which was more suitable than the one in which they were currently living.

### Moving within social housing

Just under half of respondents who were renting their homes from a local authority or housing association had, *at some stage*, asked to be moved to a more suitable property. (This contrasts with the data reported above where we were asking about current moving intentions.) Of those, one in two had been rehoused. However, at the time of completing the questionnaire for the survey the remainder had still not moved. This was for one of three reasons: either the family was still waiting to move (70%); or they had been offered, but refused, a transfer (23%); or their request for a transfer had been refused (7%).

### Changing tenure

A small proportion of families (4%) had changed from being homeowner to renting their home from a council or housing association. We asked those families whether they were happy to have changed from being a homeowner to renting their

**Table 4.3: Barriers to moving and association with tenure (%)**

	Owner-occupier	Rent from local authority	Rent from housing authority	Rent from private landlord
Financial reasons	89	28	32	35
Local authority/housing authority do not accept need for rehousing	n/a	15	11	16
Local authority/housing authority have not offered a suitable property	8	40	39	36
Waiting for suitable local authority property to become available	3	17	18	13
	n=318	n=265	n=85	n=55

Note: Approximately a third of applicable parents chose not to complete this particular open-ended question. These data must therefore be treated with caution.

home. A greater proportion of families were unhappy about their change in tenure compared to those who were happy (see Figure 4.2). However, over a third of families who had moved tenure into social housing were happy with this change.

### Changing and adapting the home

Among families who reported that their housing needs had been assessed, the most common outcome (reported by over half of families) was changes or adaptations to the home (see Table 4.2).

The main source of local authority funding for house adaptations is the Disabled Facilities Grant (DFG). Families can seek help with all or part of the costs of adaptations to the home by applying for a DFG. This is a means-tested grant, and it is an application for a DFG which, typically, activates the process of assessing a family’s housing needs. Where families are renting their home from the local authority it is common practice not to follow the formal application, and families may not be aware of the source of

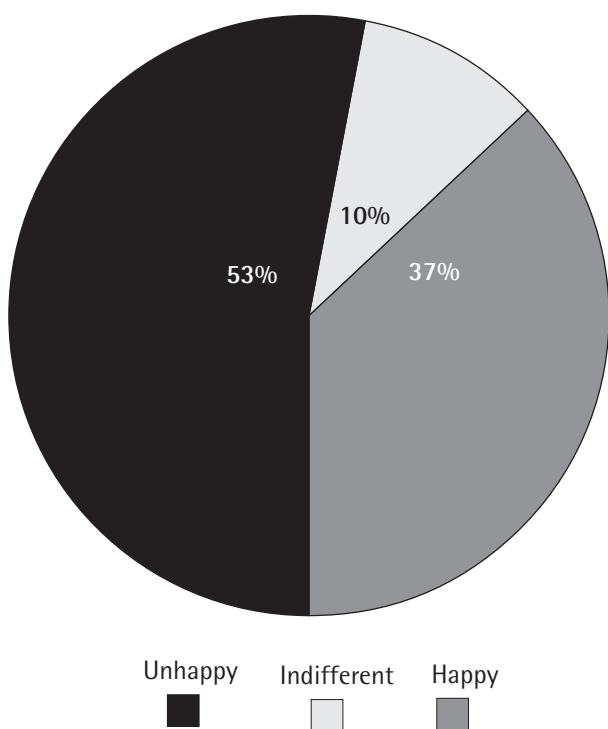
funding for any adaptations carried out to their property. However, owner-occupiers will have to undergo the formal and quite complex process of applying for a DFG.

### Awareness of the availability of local authority grants

Just over a third of parents were aware that families with a disabled child can apply to their local authority for help with meeting the costs of changing or adapting their home.

A number of factors were associated with levels of awareness of this potential source of funding. Families from minority ethnic groups, and families renting their homes, were less likely to know about this funding source. This latter finding is, in part, likely to be due to the different process by which local authority tenants have adaptations funded through a DFG (as described in the previous section). In addition, the type(s) of impairment the child had was associated with parents’ awareness. Those whose children were physically impaired were more likely to know about local authority adaptation grants compared to those whose child had no physical impairments. Finally, awareness increased with family income.

**Figure 4.2: Feelings about changing tenure: owner-occupier to renting local authority/housing authority property**



### Applying for financial assistance from the local authority

One in five respondents reported that they had asked their local authority for help with paying for changes or adaptations to their home. (A further 3% were in the process of making an application at the time of completing the survey questionnaire. Once again, as discussed earlier in this chapter, one needs to bear in mind the possibility of inaccuracies in parents’ reports here.)

Within our survey sample, 502 families (17%) said they had applied for *and completed* an application to their local authority for help with paying for the cost of adapting their home. This compares with a figure of 625 families who reported having asked their local authority for help with paying for adaptation costs. These figures support anecdotal evidence that a proportion of families ‘fall out’ of the DFG application process. The extent to which this is

happening cannot, however, be accurately ascertained as these figures are also likely to include families renting their homes from local authorities where the practice is to bypass the formalities of the DFG for their own tenants. Thus some families will have reported applying to their local authority for financial assistance, but will not have had to go through the DFG application process.

Respondents who stated they had withdrawn their application gave a variety of reasons, including the fact that the process was taking too long, was too bureaucratic, or they “didn’t like the system”. Others withdrew their applications when it became clear that they would be ineligible on grounds of their income.

### Outcome of completed applications

The outcomes for families who had *completed* the application process are detailed in Table 4.4. Given the different processes by which financial assistance is provided across tenures, we present the data from owner-occupiers and those renting their homes from their local authority separately.

Among owner-occupiers, a third had all the costs of an adaptation met by their local authority. However, a quarter of families failed in their application for a DFG and a further 1 in 10 families could not afford their assessed contribution to the cost of the adaptation. Just over one in four families who had applied for a DFG shared the costs of an adaptation with their local authority.

The picture for those renting their homes from a local authority shows that a similar proportion (to owner-occupying families) ‘failed’ in their application for financial assistance. However, a greater proportion of local authority renters had successfully applied for financial assistance with an adaptation compared to owner-occupiers. This reflects both the fact that levels of family income are likely to be lower among those renting their homes compared to owner-occupiers and the difference in funding practices used across tenures. The use of other non-DFG funding routes for local authority renters is evidenced by the very small proportion of families in this tenure being requested to share the costs of an adaptation.

We also asked these families to tell us how long their application took to be processed. (Response to this question was quite low – only 64% of eligible respondents – and we were asking parents to recall and estimate time, thus this data must be treated circumspectly.) For those who provided us with this information, just over 4 out of 10 said that they waited up to three months to hear the outcome of their application. A sixth of respondents had waited between three and six months, with a further one in five hearing the decision between 6 and 12 months after their application. One in 10 families had waited between one and two years, with a similar proportion reporting that they had waited between two and three years for their application to be processed.

**Table 4.4: Outcomes of completed applications for financial assistance from local authority for housing adaptations: owner-occupiers and local authority renters**

	Homeowners		Rent from local authority	
	n	%	n	%
Local authority met all the costs of the adaptation	103	34	89	63
Local authority would not meet any of the costs	76	25	44	31
Local authority met part of the costs and family paid remainder	84	28	4	3
Local authority offered to meet part of the costs but family could not afford their contribution	35	12	2	1
Local authority offered to rehouse	0	0	2	1
Received interest free loan from local authority (unclear whether local authority made a contribution)	3	<1	3	1
<b>Total</b>	<b>301</b>	<b>100</b>	<b>141</b>	<b>100</b>

### *Other sources of funding for adaptations to the home*

Just over 1 in 10 parents said they had received help with paying for the costs of adapting their home from members of their extended family (34%) or charitable organisations (66%).

### **Advice about changing or adapting outside the assessment process**

No family in the survey reported that they had received advice from an occupational therapist about changing or adapting their home outside of the assessment process.

- Awareness of the possibility of financial assistance from local authorities with the costs of housing adaptations was low. Only a third of families knew of this, and this figure was lower among families from minority ethnic groups.
- Only a third of owner-occupier families who had applied for a DFG had had the costs of adapting their home fully met by their local authority. A quarter of owner-occupiers' applications for a DFG were unsuccessful, with a further 1 in 10 families finding they were unable to afford their assessed contribution.
- The data suggest that professional advice and support to assist with changing or adapting their home is not offered outside the process of applying for and receiving financial assistance (for example, the DFG) from a local authority.

### **Summary**

In this chapter we have reported our findings on what families may do in response to living in unsuitable housing. Key findings are as follows:

- Among families expressing a desire to deal with their housing needs at the time of completing the survey, a greater proportion said they would prefer to move rather than adapt their current home.
- The way(s) in which a home is unsuitable for a disabled child and their family affect parents' preferences to dealing with the problem. Specifically, where the difficulty is caused by a lack of space, small-sized rooms and/or location, moving home (as opposed to adapting the existing home) is the preferred option.
- Tenure affected the sorts of barriers families faced when trying to move. Financial constraints were the dominant barrier for owner-occupier families. A lack of suitable properties was the most frequently reported problem for families in social housing.
- Decisions to move home in response to unsuitable housing are typically made without any professional advice or support.
- Only a minority of families believed they had had their housing needs (in terms of being a family with a disabled child) assessed.
- One in five families had applied for financial assistance from their local authority towards the costs of adapting their home.

# 5

## Current provision and funding practices

### Introduction

The first part of this report has been about the children and their families, and has been about needs. This chapter looks at the other side of the study: the work with providers from different agencies. The objective was to try and match, for each local authority in the study, data on needs and supply to get a feel for unmet need and the scale of resources that would be needed to address the situation. For the reasons described in Chapter 1, and as will become apparent through the course of this chapter, this did not work.

*Homes unfit for children* (Oldman and Beresford, 1998) and *Making homes fit for children* (Beresford and Oldman, 2000) identified three main reasons why the housing needs of disabled children and their families remain unmet. These were:

- service fragmentation;
- low levels of awareness of the central importance of housing and home;
- inadequate resources.

Unsurprisingly the 'supply fieldwork' for this study confirmed the early findings. It is important that the (limited) findings from the 'supply-side' of the fieldwork are understood in the context both of current policy and our previous research findings. Thus the format we have chosen for presenting the data is to organise the data around a series of themes, providing, where appropriate, background information followed by a report of relevant findings from this particular project.

In each of the 44 fieldwork sites (that is, housing authorities) we aimed to interview the following

professionals: officers with strategic and day-to-day responsibilities for adaptations in all tenures, housing allocation officers, occupational therapists and managers in charge of services for disabled children. In each authority this could involve up to six interviews and many more telephone calls 'tracking down' the right person.

### Fragmented responsibilities

Key to the difficulties in carrying out the supply-side fieldwork was the issue we know from previous work affects families and professionals alike: that is, service fragmentation.

Our previous research has shown that organisational structures, between and within local authorities, vary enormously, and this is confusing to families and professionals trying to chart a way through local government to get to a service. It should perhaps be no surprise that this same difficulty also confounds researchers trying to get a clear picture of resources devoted to providing services and meeting families' needs!

Typically, no single agency or department is willing to 'own' the issue of housing needs of disabled children and to be a figurehead or local champion. This is particularly critical given that our data has shown that such housing need has many manifestations. It may be an issue of poor condition or disrepair (bringing it perhaps within the remit of the private sector housing renewal team, or perhaps within the landlord function). It may be an issue of location, the external environment or space (perhaps requiring the input of the housing allocations sections of the authority or its partner providers). It may be that there are insufficient suitable properties in the

locality (bringing it within the remit of a housing policy team, and perhaps development sections of local housing associations). And it may be that an adaptation is required. Only then will there be a clearly defined role and responsibility to take the issues forward, albeit in a way that is likely to involve its own complex myriad of professional and technical inputs.

Of course, the complicated structure of housing functions would be less important if there were a 'guiding hand' available within social services departments. Here, authorities are increasingly adopting service teams focused on services for disabled children. However, of the 43 service managers involved in this study, only a handful had knowledge of, or expressed particular interest in, housing need: most said it was neither their area of jurisdiction nor expertise. In fact, as previous work has shown, it is occupational therapists who are often the key professional grouping involved in housing issues. However, their work is frequently focused narrowly on adaptations (rather than wider housing issues); they are themselves located in different teams depending on the organisational structure of the local authority; they are unlikely to have a clear route through which to communicate information to assist with strategic priorities/decisions; and they have long been in short supply.

This fragmentation of responsibilities made identifying suitable interviewees within the survey authorities a difficult task in itself, and this difficulty was compounded by the paucity of information available as the following section will show. Inevitably, because the focus of service response was hugely geared towards adaptation, this was the issue that yielded most data. Even here, however, there were very significant gaps.

## Assessing aggregate housing need

Housing departments have had, for many years, the mandatory requirement to assess the housing needs of their constituents. Housing needs surveys have been very popular; however, these have not focused very well on the needs of vulnerable groups. This should change with the advent of the new policy and funding regime *Supporting people* (DETR, 2001a). Increasingly the importance of low level preventative support services is being recognised and acted on.

Although *Supporting people* is intended for vulnerable adults it will help focus housing authorities' attention on locality needs assessment. However, it is not simply a question of mapping housing needs but communicating the findings to the social services authority and a comprehensive plan drawn up to address these needs. In shire counties this communication has been more difficult given the fact that each county will contain several non-unitary authorities. This is improving now. Needs assessment is not easy and more difficult in some areas, for example, rural settings (Oldman, 2002).

All the housing officers in the sample felt unable to comment whether resources for paying for adaptations were adequate. Annual budgets seemed historically determined and unconnected to any data on the overall needs of disabled children in the authority. The Audit Commission has consistently commented that resources should have a relationship with need, and that the need for adaptations falls far short of the supply, although budgets have increased each year. The delivery of adaptations locally is heavily influenced by a national framework which has had a part historically in ensuring that different tenures receive different treatments.

## Recognising and acting on housing need in individual needs assessment

*Homes unfit for children* noted that families did not know how to get a housing need noticed and consequently acted on. They also lacked the energy to get the ball rolling. What are needed are clear referral processes which are known to all who are likely to be in contact with such families.

Just one in four of the respondents in the parents' survey said they had had their housing needs assessed. (We have already noted that this may be an over-estimate as families may have confused an equipment and housing needs assessment, as both are conducted by occupational therapists.) Aside from that, a key finding reported in Chapter 4 was that in very few cases was housing need *successfully* dealt with. The findings from the fieldwork with practitioners offers an explanation for families' experiences.

### **Incorporation of housing into integrated needs assessment: an example of practice**

At the time of the study one local authority was piloting an integrated needs assessment form for disabled children which was being used by all agencies. There was a section on housing which looked at type of house, whether adapted, tenure, condition, heating and access. It also included space for open-ended comment. The form was filled in with the parents and everyone was invited to say what they thought about the home. If a housing need was identified then a copy of the form was sent to the disability equality officer in housing to plan appropriate action, which may be a referral to an occupational therapist to assess for an adaptation or it may result in a referral for rehousing. Families are also given a handbook about all the services in the city for disabled children.

In all the authorities social workers and occupational therapists were asked about individual needs assessment. Although around half said their forms asked about tenure and other housing circumstances, in only one authority did there seem to be any attempt to assess housing need in a general systematic way (see Figure 5.1).

Occupational therapists were often involved with families, not in terms of carrying out a holistic assessment of housing need, but rather for assessing equipment. Indeed a family may be involved with more than one occupational therapist. In terms of assessing housing need, referrals for *adaptations* typically came from health agencies or social workers and at this point the occupational therapist would be called in, but then for a specific assessment for *an adaptation*. Typically occupational therapists work in adult services: there were very few paediatric occupational therapists involved in the study.

Occupational therapists are in short supply and many worked part time. They often worked in areas which were not coterminous with the housing authorities in the sample. They also lacked status. A further problem was that they appeared to have little obligation to keep detailed and comprehensive information systems that could capture data for strategic purposes.

## **Adaptations: funding practice and procedures**

### *Public versus private sector ownership*

Funding practice and procedures varied between authorities, especially around the issue of tenure. In all but three of the 43 authorities participating in the research, adaptations for owner-occupiers,

the private rented sector and registered social landlord accommodation were funded by the Disabled Facilities Grant (DFG) and administered by a housing renewal team in a variety of sections and departments. Council adaptations were administered by the housing department and paid for out of the council's own resources in nearly all cases, although in 10 authorities the DFG process was applied. Very often the two departments, for the private sector and the public sector, had very little knowledge of each other's policies and procedures. It is confusing for people who are trying to find out how to have their housing needs met, and it raises issues of equity of treatment. One implication borne out by previous work, for example, is that council tenants are more likely to be required to move.

### *Record keeping and information management*

Interviewees were very helpful in trying to track down figures, but generally the information they came back with was unusable within a standard framework. Very few authorities were able to give any figures on the number of applicants from different tenures for adaptation, nor could they provide data about the success or otherwise of the application. Authorities often tried to come back with figures but these were usually not helpful. Client group is never recorded on information systems so it is not possible to compare work activity between the different groups. Few officers saw the need to record this piece of information although two non-unitary authorities had been asked by their social services department to break down their adaptation data by client group. Where it was impossible to obtain figures from housing officers, occupational therapists were approached. This was a more fruitful approach but occupational therapists do not record this information as a matter of course,



**Table 5.1: Data obtained from the authorities on adaptations for children (%)**

	Proportion of authorities able to supply previous year's information for all groups	Proportion of authorities able to supply previous year's information for disabled children
Number of DFGs	100	~75
Expenditure on DFGs	100	~75
Amount of applicant contributions	~50	<10
Number of council adaptations	100	~50
Expenditure on council adaptations	~75	~50
Number of schemes exceeding cost limit	100	~50
Number of applicants dropping out of process	~10	<10

and they often relied on their memories. The information was also piecemeal and did not correspond, as noted above, to local authority boundaries.

The paucity of information problem is illustrated in Table 5.1, which summarises what data was available.

Three out of four authorities could say with accuracy the number of DFGs for children which had been awarded and they could nearly always give total expenditure and/or budget for each tenure. These were the *only* pieces of information that were *routinely* available. It was not common practice to record information such as parental contributions, whether applications failed because the parents could not afford their share of the cost of a job, or how many adaptations exceeded £20,000.

Tables 5.2 and 5.3 opposite are illustrative of the sort of data that was available. They also offer examples of current levels of expenditure on adaptations for disabled children against overall levels of spending.

### Tenure

A number of officers were concerned about the issue of equity between tenures. This is a significant issue bearing in mind that disabled children are more likely to live in rented housing, and more likely to report a greater incidence of housing problems. In all areas participating in the research the budgets for council and private sector adaptations were roughly the same, but tenants were more likely to be required to move, particularly if the job was going to exceed a set amount.

**Table 5.2: Adaptation data for previous financial year for area A (metropolitan authority: population ~250,000)**

	Children	All groups
Number of DFGs:		
owner-occupiers	10	209
Number of council grants	16	Not available
Expenditure on DFGs	£44,276	£710,000
Council expenditure	£22,450	£754,000
Estimated number of severely disabled children living in area = ~1,500 <sup>a</sup>		

Note: <sup>a</sup>This figure is calculated from the number of children living in the area recorded on the Family Fund Trust database. This figure (in this case 756) is doubled given that conservative estimates of take-up of the Family Fund Trust is 50% of eligible families.

**Table 5.3: Adaptation data for previous financial year for area B (new, unitary authority: population ~100,000)**

	Children	All groups
Number of DFGs	6	32
Number of council grants	Not available	729
Expenditure on DFGs	£94,499	£373,000
Council expenditure	0	Not available
Estimated number of severely disabled children living in area = ~650		

### Use of discretionary DFG

Only five of the 43 authorities (that is, just over 10%) had ever used the discretionary element of the DFG for completing an expensive job or for helping parents out. Parental contributions were virtually unheard of in the council sector but thought to be quite common in the private sector.

Housing officers suspected that some parents did withdraw their applications once they had been notified of their contribution to the cost of the adaptation. Some housing officers suspected that financial reasons meant that some parents fall out of the 'DFG process' long before they themselves got involved.

### *Contribution of health authorities to funding*

In none of the health authorities (coterminous with the housing authorities in which the research was located) was funding available for either adaptations or moving home. This is despite health agencies' apparent interest in the links between poor housing and poor health. Without data on overall needs, however, no compelling case for additional resources can be made by social services to other agencies.

### *Comparison between children's and adults' adaptations*

It was the common view that children's adaptations were more costly than other adaptations but little data was obtained to substantiate this assertion. Questions were raised but not answered about the level of help that was offered. Some officers suggested that children missed out on the sort of help that older people get, such as the installation of bath and grab rails. (Data from a recently completed survey of community equipment needs [met and unmet] of disabled children [Beresford et al, 2001] supports that assertion.) Instead, children could be the beneficiaries of what one respondent called 'spectacular' adaptations for ground floor extensions. It was felt that there were some high profile cases where the need for change and modification to the house was obvious, but that many more cases were ignored or never got referred. Where there were data the average expenditure on children's adaptation was considerably higher than for other groups, but here again interpretation is not easy. Older people, for example, may be getting cheap responses to problems but these may not fully meet their needs.

## **Perceived extent of unmet need for adaptations**

For example, in all authorities of around 100,000 population interviewed as part of this study, total expenditure on adaptation rarely exceeded half a million. These resources appear barely adequate for the job in hand. However, the professionals we interviewed were unclear as to whether disabled children's needs for housing adaptations went unmet in their authority. Some felt that they were a high profile group and that resources would always be found because the adverse impact on the family if an adaptation were not done would be there for all to see.

## **The adaptations delivery process**

In none of the 43 authorities contacted were any of the procedures related to the assessment for and delivery of adaptations for a disabled child different from those used for other groups. It was felt, however, that most children's referrals do get a 'priority one' (the most urgent) and were, therefore, guaranteed to receive attention.

### *The assessment process*

A key issue was that the assessment process and form used for disabled children was no different from that used for other groups requiring some sort of housing adaptation, with the focus of attention on functional ability or impairment.

While written procedures may have been the same, it was apparent that occupational therapists and housing officers did see that the assessment process could be longer and more complex. In some cases attention was paid to the importance of play, the needs of other members of the family and the growing and changing needs of children. In areas with larger than average numbers of black and ethnic minority families, changes were made for both children and their grandparents. Key issues for both housing professionals and occupational therapists were real doubts about what was going to work and how long the adaptation would be useful to the child. It is often not known what course the impairment will take, and even when this is known, what more

will need to be done to accommodate change and growth.

In one authority a social worker described the assessment process as follows:

“We have an initial OT assessment which will concentrate on the presenting problem. But the OTs have to rely then on what is the presenting problems which may not be the whole story. With children they have to work through all the activities of daily living. So it’s a focus on improving independence or the caring abilities. The only reference to housing on the form is what the tenure is, size, locations of rooms, although they do try and have plans of the house to work through what would be the best thing to do. The OT will highlight to the adaptations officer if a house has an obvious problem with it or if the family bring up a problem with the OT.”

This approach to the assessment was very common. If families had no other access to housing structures or advice (and we can assume that many did not), the assessment would not have engaged with the needs, preferences and aspirations underlined by the findings of this study. In particular, it would not necessarily have picked up the central importance of space or the external environment, nor allowed for a full discussion of the pros and cons of moving as an option.

### *Issues of delay*

Delay is a commonly reported problem as far as adaptations are concerned, and here, as with every other part of this study, measurement, data and management information systems were problematic. Some of our 43 authorities would say that they were pleased with their efforts at addressing delay, but the key question was ‘When is the clock set to tick?’. Typically delay was measured in terms of how long *after* assessment the adaptation was completed. The biggest perceived bottleneck, however, was in waiting for an assessment although no data was provided to test this assertion. In most areas there was a severe shortage of the officers who carry out assessments. This seems to allow authorities to be very vague about the extent of the gap between demand and supply. Some authorities

would maintain that they kept up with demands, but they would not be passed applications unless there was some chance of them being dealt with that financial year. It was also asserted that children had less time to wait for assessments than adults.

### *Assessment of outcomes*

None of the participating authorities attempted to monitor the success, or otherwise, of an adaptation. Contact with the family was discontinued.

### **Providing an information and advice service**

Respondents seemed very unclear as to whether they provided any housing information or advice services to families separate to the adaptations delivery process. Thus families with a housing need that would not be resolved by an adaptation, as well as those who had unsuccessfully applied for a DFG (being turned down on financial grounds) are not able to access information or advice in relation to addressing their housing needs.

### **Deployment of housing stock**

In none of the authorities were the strategic housing needs of children considered with respect to the deployment of housing stock.

### *Management of vacant adapted properties*

Increasingly council stock has been severely depleted through Right to Buy policies. This has bitten more deeply in some areas than others, particularly in rural areas (Oldman, 2002). Housing departments have little room to manoeuvre when trying to offer a more suitable property. Despite the extreme shortage of good quality properties, these can stand vacant because the right family cannot be found in time. Around half of our authorities had no knowledge of what adapted properties they had, and some were trying to develop disability registers. One authority had instituted a pilot scheme whereby

every time a non-private sector property became vacant it was evaluated in terms of its potential for adaptation (in terms of improving physical access); each property is assigned to one of four categories: wheelchair standard, limited mobility, very limited, or not all adaptable.

Social services officers often reported their frustration with housing policies: housing officers need to keep voids to a minimum but some time was needed to match person with property. However, disability registers (located in housing authorities, and typically excluding disabled children) were reported to ease these joint working difficulties. In developing registers it has simply not occurred to housing officers that children have housing needs which could be met by moving.

### *Allocation policies*

One of the questions put to professionals concerned whether their housing allocation policies particularly picked up on or recognised the needs of disabled children. In one metropolitan authority extra points were awarded in the case of disabled children applying for housing. Typically, lettings procedures operated within very narrow definitions of housing need, based on the medical priority system focusing overly on inability (for example, to climb steps) rather than a more holistic, family and child-centred, approach.

### **Summary**

The data presented in this chapter is inevitably biased towards the data we were able to collect. Thus, while the funding of families to move, as opposed to adapting their current home, rehousing solutions, and the provision of an information and advice service were clearly important issues to parents (as revealed in their responses to the survey), they were not areas where we were able to collect data. This does not, however, diminish their importance.

A key finding from the fieldwork with practitioners and managers involved in meeting the housing needs of disabled children concerns the *lack* of data. This is apparent at a number of different levels:

- no data is routinely collected which could be used to inform projections of housing needs and demands on housing adaptation budgets and suitable properties;
- no authority could provide evidence on the extent to which supply matched (or mismatched) levels of housing need;
- there is no collection of information on the outcomes of an adaptation or a rehousing solution from the child's or family's perspective.

A second key finding concerns the lack of expertise and clarity of roles and responsibilities:

- typically, no single agency or department took overall responsibility for ensuring the housing needs of disabled children living in their authority were met;
- housing need is rarely (properly or fully) included in a needs assessment carried out under the auspices of the 1989 Children Act within the Framework for the Assessment of Children in Need and their Families;
- clearer lines of responsibility, and some small developments in terms of child-centred assessments, are found where the decision has been made to carry out an adaptation.

Furthermore, while hampered by scant and inadequate data, we would argue that the evidence presented in this and previous chapters points to significant under-resourcing in terms of meeting the housing needs of disabled children and their families. This applies not only to financial resources, but also staff resources – particularly occupational therapists.

Finally, disparities in funding practices, service provision and delivery between tenures have been revealed. Equity of treatment concerned officers, with families living in rented housing being required to move as opposed to having an adaptation to their current property.

# The study's policy implications

## Introduction

In this chapter we move on to consider the implications of the findings reported in the previous four chapters. In particular we focus on the policy implications. A strong message from our earlier work with practitioners and managers, about identifying ways of ensuring that the housing needs of disabled children are better met (Beresford and Oldman, 2000), was the need for policy-driven change, as opposed to relying on individual, idiosyncratic change at a local level. The issues of multi-agency involvement and financial resources mean that while local changes in both policy and practice can have an impact (and indeed a product of our earlier work was the sharing of solutions and good practice – Beresford and Oldman, 2000), the scale of the problem requires action at a higher level if the housing needs of disabled children receive the recognition and resources they so clearly require. Indeed, one of the key purposes of this project was to produce the national evidence to persuade the need for change and to inform that change.

We begin by discussing the inadequacies of the current legislative framework in terms of meeting the needs of disabled children. In particular we seek to illustrate the way that current policy has either contributed to the high levels of housing need reported by families with a disabled child or acts as a barrier to change. Next we consider the funding issues which the findings from this piece of research inevitably raise. Finally, we draw attention to issues related to housing stock and housing quality.

## An inadequate legislative framework

The nub of the problem concerning the general failure to meet the housing needs of disabled children is that there is no one single legislative framework for responding to the housing problems families have.

### *Children's legislation*

The key legislation applying to disabled children is the 1989 Children Act. Part III, Section 17 states that the local authority has a general duty to “safeguard and promote the welfare of children within their area who are in need” by providing a range of services appropriate to those children. Disabled children are defined by the Act as being a group in need. Schedule 2, Part I sets out the type of services that can be provided. The aim of these services should be to “minimise the effect on disabled children ... of their disabilities ... and give them the opportunity to lead lives as normal as possible”. The Act states that in some circumstances children will be helped by the provision of services to other members of their family.

Despite these very apparently wide powers, housing is largely ignored. It is not in any routine or systematic way part of individual needs assessment, although social services departments are required to work with other services to assess and provide for disabled children's needs. Assessments are intended to be comprehensive and holistic:

In conducting assessments and managing the care provided social services departments will need to ensure that all

necessary expertise is marshalled and that all those providing services are involved from both within and beyond the social service department. (1989 Children Act Guidance and Regulations, vol 6, p 9)

However, although concluding there was a great deal of room for improvement in the assessment process, the 1994 Social Services Inspectorate national inspection of services to disabled children and their families (Goodinge, 1998) did not mention housing once. One explanation for why inadequate attention has been paid to the disabling impact of children's domestic environments is the strong philosophy within the Children Act of 'children first, disabled after'. Although this social model approach to disability is to be welcomed, it has the effect of ignoring or diluting the effect on health and well-being of non-barrier-free housing (Oldman and Beresford, 2000).

This report is being written during the last months of the *Quality Protects* initiative: a five-year government initiative aimed at improving children's services. This initiative could have been an important banner under which to promote the housing needs of disabled children. Sadly, however, housing was not included as a sub-objective under which social services departments were expected to produce evidence of change or improvements in terms of services for disabled children. This contrasts with the significant attention given to what might equally be seen as a 'tangential issue' – namely, play and leisure services.

Thus, in terms of addressing the housing needs of disabled children, the legislation appears weak and nebulous. It is in marked contrast with the potentially powerful legislative framework for disabled adults encompassed in the 1986 Disabled Persons (Services, Consultation and Representation) Act and the 1990 NHS and Community Care Act.

### *Disability and carers' legislation*

Disability legislation, such as guidance on the Disabled Facilities Grant (DFG), does not manifest high levels of awareness of the importance of housing in children's lives. There do not appear to be any 'levers' within the recent disability legislation which could be used to

promote attention on, and resolution of, the housing needs of disabled children. To date attention has focused on 'public life': for instance, (physical) access to public places, public transport and community facilities, and equality of opportunity. An example here is the considerable amount of funding currently being given to schools to improve access for children with physical impairments. Equally pressing, we would argue, are the home lives of disabled children.

The 1970 Chronically Sick and Disabled Persons Act is a powerful piece of legislation which is based roughly on the social model of disability. However, it tends to get overlooked by authorities. Its other problem is that, like other legislation, it makes no mention of children.

Assessment of parents' housing needs could, in theory, be met through the 1995 Carers' Recognition and Services Act. This legislation gives social services departments a duty to assess a carer on request when an assessment is being made under Part 3 of the Children Act. The guidance makes clear that these assessments should be multi-agency, and housing is mentioned. However, research which has looked at the implementation of the Carers' Act points to the difficulties of achieving inter-agency assessments (Hepworth and Arksey, 2000). It could be that the recently implemented 2000 Carers and Disabled Children Act may increase the profile of parents' needs as carers. However, the Act does not come with additional resources and housing maintains its typically low profile in the accompanying guidance.

### *Housing legislation*

The housing policy environment only addresses the housing needs of disabled children tangentially and partially. It defines housing need almost entirely in terms of a legal requirement to modify or adapt a property. Yet the central message of this report is that housing need is very much broader than this. Families may live in unsuitable or poor quality housing. Families may want to move as opposed to adapt their current homes. Many disabled children have learning difficulties or behaviour problems which render their homes unsuitable. A suitable home may be rendered unsuitable by the location of that home – both in terms of a troublesome or unpleasant

local environment or its position in relation to formal services and informal support networks.

Housing authorities have a statutory duty to identify the housing needs of their populations. Although they do this they tend not to focus on children's needs. They need to work jointly with their social services departments to assess the needs of disabled children. Needs assessment is becoming central to housing policy with the advent of the new policy and funding regime for supported accommodation, *Supporting people*, coming in in April 2003. Although this programme will not fund children's services, it is an appropriate framework for needs analysis.

The present housing renovation system was introduced in the 1989 Local Government and Housing Act and subsequently modified by the 1996 Housing Grants, Construction and Regeneration Act. At the time of writing this legislation was in the process of being repealed. In March 2001 a consultative paper (DETR, 2001b) was issued which has made a number of quite radical proposals. One of the most welcome as far as the interests of this study is concerned is the suggestion that people should be helped with the cost of moving to another property when this is a better option than adapting their current home. However, the general drift of the proposed changes is to remove local authorities' detailed obligations and shift the burden of financial responsibility more onto the householder. The legislative system for home improvement offers no help to council tenants and yet much of the country's poor housing is in that sector. Resources for council house repair and improvement have to be found within local authority capital budgets. Nationally there is a serious backlog of council properties waiting for repair. It is to be hoped that new advice on adaptations (soon to be released) will be in the form of a joint publication from the Department of Health and the Office of the Deputy Prime Minister, as was common practice in the 1980s.

The residualisation of social housing over the last 20 years, including the massive sale of council housing through the Right to Buy programme, has led to very few opportunities for local authorities to find suitable housing for disabled people. However, stock transfer and close working with registered social landlords should mean that new development focuses more on housing which is suitable for disabled people. In addition, local

councils and developers need to work closely on the subject of space standards. In the 1960s social housing was built to very generous 'Parker Morris' space standards. Although there are now new design standards (for example Part M of Building Regulations and Joseph Rowntree Foundation Lifetime Homes), in space terms these come nowhere near 'Parker Morris'.

### *Service fragmentation: an inevitable result?*

A consequence of the current legislative system is service fragmentation. This study has found that the responsibility for meeting the housing needs of disabled children lies all over an authority, and in different authorities it can be located in different places. Where there has been a voluntary stock transfer it will go beyond statutory authorities. No one 'owns' the issue. Responsibility for mapping, assessing and planning housing needs for all groups lies somewhere within housing policy sections and somewhere in children's services within social services. Responsibility for easing physical access lies with different officers in different departments depending on the tenure of the applicant for adaptation, and responsibility for arranging a move to another property because it or their neighbourhood is unsuitable lies somewhere else all together. And at the moment, it seems that no one is acknowledging, let alone assuming responsibility for, the housing needs of children with learning or behavioural difficulties. The needs survey showed clearly that the problems people had with their houses and their environments are complex and manifold, and that responding to one aspect will not dramatically improve matters.

In addition, disabled children may not only need their housing modifying, they may also need equipment, and the two are complementary. Neither can properly work without the other but they are often assessed separately and delivered by different agencies and different professionals. Equipment traditionally has been supplied at no extra charge but there appears to be some evidence that authorities are beginning to impose charges for equipment. European legislation has had a drastic impact on adaptations budgets through the enactment of the 1992 Manual Handling Operations regulations which forbid care workers to lift. Housing workers complain that budgets are 'raided' for expensive fixed hoist

systems (Bull, 1998). The irony is, of course, that there is no corresponding requirement to protect informal carers, that is parents, from back and other injuries caused by lifting and handling. A further key issue is that care services will not be provided to homes where there is no lifting equipment.

There are clearly difficulties with community equipment provision, as highlighted by the Audit Commission's report (2000). More specifically, a survey carried out in 2001 showed high levels of unmet need among disabled children and their families for community equipment (Beresford et al, 2001). A consultation exercise with professionals carried out as part of that project highlighted the interdependency between community equipment and housing adaptations services. One participant stated:

It is obviously vital that equipment provision and any adaptations/work needed to make the equipment usable are seen as a whole, and that there are sufficient resources for both to be provided promptly and effectively. (Beresford et al, 2001, p 52)

The extent to which change and improvements in addressing housing needs can be achieved without, at the same time, paying attention to the crisis within community equipment services, is surely limited. A real opportunity exists for movement on this issue if the community equipment and housing adaptation services are scrutinised and included in the planned National Service Framework for Children, the preparatory work for which has just begun.

Finally, the increasing trend to merge housing and social services departments would appear to be a potentially positive step in resolving the issue of service fragmentation. However, there is little evidence that joint working has improved as a result.

## Funding structures: complexity and iniquity

### *Disabled Facilities Grants*

The main mechanism for funding adaptations is the DFG. The DFG is the only mandatory grant within the housing renewal system and can now

be given for items that benefit disabled children, such as safety. The main difficulty associated with the grant is that it is means-tested on the parents' income and no allowance is made for outgoings such as mortgages or the extra costs of disability. The result is that families, even those on just below average or average incomes, have to pay a large contribution to the cost of an adaptation and thus have to take out very expensive mortgages in order to afford a job, or, more usually, do without.

DFG resource distribution takes little notice of needs indicators. This has been highlighted in the Audit Commission's report on housing and community care which notes that there is a serious national shortfall in DFG resources (Audit Commission, 1998). The key policy message is that resource distribution should be linked to indicators of disability, such as prevalence data, at a local level.

Increasingly councils are using the DFG process to try and obtain financial contributions from council tenants whose incomes are above the limit for meeting all the costs of the work (Heywood, 1996). Council tenants are, in effect, paying for each other's adaptations. This is a key point which leads to inequity and should not be lost by the fact that some are now being taken down the DFG route and are consequently means tested. In the areas of our study council tenants often appear to have to move rather than have their houses adapted. A further problem which can confuse families is that the delivery of adaptations depends on the tenure of the applicant. A council tenant has to know that it is the housing department which they must first refer to, and the owner-occupier must know that they should apply to environmental health or the finance department, or an urban renewal section.

Families living in private rented housing can apply for DFGs, providing the landlord agrees, or the landlord can apply if the tenant does not have the contractual power or duty to undertake works to the home. Housing association tenants increasingly may be encouraged by their landlord to apply to their local authorities for DFGs. The Housing Corporation now excludes registered social landlords with more than £500,000 in their rent surplus funds from applying for its aids and adaptations budget. Increasingly more people will be affected by these restrictions as more and



more council housing stock is voluntarily transferred to not-for-profit companies.

### *Geographical variation*

The DFG ceiling of £20,000 (£24,000 in Wales) creates further problems, particularly in areas of the country where house prices and building costs are high. Discretionary DFG can be put alongside the mandatory grant, but in many authorities the former is not available. The law is quite clear that social services authorities retain powers to fund adaptations in circumstances where the job exceeds the limit, or the parents cannot afford their assessed contributions. Under the 1970 Chronically Sick and Disabled Persons Act social services are, as Bull puts it, the “default authority” (Bull, 1998). Social services usually loan the additional funding rather than grant it, but the means test is less stringent and ignores outgoings. They also will fund what is called ‘minor adaptations’, but the ceiling is usually very low.

### **Suitable housing: a search in vain?**

Some types of housing adaptation would not be necessary if domestic buildings were accessible. ‘Wheelchair’ housing, for example, constitutes a very small proportion of the social housing stock, and that which has been developed in the last 10 years or so is predominantly one-bedroom. The provision of accessible housing is likely to increase, albeit very slowly. There are currently three sets of housing standards which, to a greater or lesser extent, incorporate accessible features. These are Part M of the building regulations (requiring all domestic housing to be built to accessible standards from October 1999), Joseph Rowntree Lifetime Home Standards and The Housing Corporation Scheme Development Standards.

Some authorities are beginning to address the mismatch between the need for adaptation and their supply, which leads to such wasteful use of scarce resources. Due, in part, to years of inadequate investment in social housing, the supply of appropriate housing goes no way at all to meeting demand. As a result of years of Right to Buy policies, and the consequent reduction of a pool of suitable houses, authorities are forced to offer families properties on estates sometimes quite a distance from the family’s social networks.

These are rarely adapted with the needs of the child in mind, and families will often refuse offers. Also, when a property becomes available, despite the high levels of demand, a family cannot easily be found at that moment to move in, and the council loses rental income. Gradually, disability housing registers are being set up and maintained; these are both databases of need and supply. The better registers use the social model of disability for allocating properties (Shaw, 1999). However, at the moment these registers only tend to concern disabled adults and older people.

Allocation practices can contribute to meeting disabled families’ housing needs, but they rarely explicitly privilege this group. The Housing Green Paper *Quality and choice* (DETR, 2000) introduced a new approach to the issue of housing distribution. In recent years, in some parts of the country, it has been difficult to find tenants for some social housing. This phenomenon of low demand has led the government to stress the importance of choice in allocations. Such a change of direction needs to be applied to the housing needs of disabled children. If families had a greater choice about where to move, a more cost-effective use of stock would be achieved.

### **Summary**

In this chapter we have sought to provide explanations for the findings from the research in terms of the current legislative and policy context. In doing so we have highlighted areas where change is needed. In particular, the impact of an inadequate, messy and diverse legislative framework has been discussed and explored. The more specific issues of current funding structures and a depleting housing stock have also been considered.

### **Postscript**

The regulatory reform (Housing Assistance (England and Wales) Order 2002) came into force on 18 July 2002. This brings to an end the national framework for the provision of grants to improve private sector housing, and gives local authorities a new, broad discretionary power to provide assistance however they choose. Mandatory DFGs remain largely unchanged but discretionary DFGs also end under this legislation.

# 7

## Conclusions

### Introduction

We use this final chapter to outline a ‘way forward’ to better address the housing needs of disabled children and their families. The ideas and suggestions we present are grounded both in the research evidence we have presented in this report and the findings of other research. The central axis of our argument is that there needs to be a fundamental change in the way ‘housing need’ is conceptualised. In addition, this reconceptualisation needs to permeate all levels, areas, departments and authorities who, in some way, have a role or responsibility for the welfare and well-being of disabled children and their families.

### Reconceptualising housing need

Within this process of reconceptualisation, there are a number of facets that need redefining. These are discussed in this chapter and include:

- incorporating the social model of disability;
- adopting a child *and* family centred approach;
- highlighting the issue of space;
- embracing housing condition and location;
- redrawing the boundaries of housing unsuitability;
- expanding options for addressing housing need;
- recognising the tenure issue.

### *Incorporating the social model of disability*

Central to any reconceptualisation of housing need has to be a broadening of the ‘accepted’ definition of disability. At the moment the very

different housing needs of children with learning difficulties, those with socio-emotional and behavioural problems, and those with significant healthcare and nursing needs, are not acknowledged within policy, or by service providers. The focus is very much on physical disability and issues of access. Yet we know that among the population of severely disabled children, most will have more than one type of impairment or disability. Until this is recognised – in policy and accompanying guidance – the complete resolution of many disabled children’s housing needs has no chance of being attained. A greater acknowledgement of the social model of disability is needed (at all levels of policy and practice), with the focus being on identifying and removing barriers to independence and enabling disabled children access to the experiences and activities they want to have and to do.

### *Adopting a child- and family-centred approach*

We did come across some evidence that housing need assessments were beginning to include factors such as the need for play, and the housing needs – particularly space needs – of other family members. It is factors such as these that make the assessment of the housing needs of disabled children and their families different to other populations. It is essential that these pockets of good practice identified in this and previous work (Beresford and Oldman, 2000) become routine practice. Maybe if the term ‘domestic environment’, as opposed to housing, was used, then officers might be able to more clearly see the impact of housing and home on children, siblings and parents. Needs assessment should recognise that houses are homes where families live and interact together, and are not just ‘care locations’.

### *Highlighting the issue of space*

Official guidance on delivering adaptations has little to say about space, and yet lack of it was the single most difficult feature of families' lives. Space and domestic environment is now receiving overdue attention, and even the recent housing policy literature (for example, Heywood, 2000 has discussed its importance). Problems with space took many forms. The sheer size and range of equipment that children needed created problems. Adaptations can often make the problem worse by further limiting the available space. Kitchens and bathrooms were often too small. The lack of space was impeding progress with improvements in the child's condition: if the floor space was limited therapies cannot be undertaken. 'Time out' space is of crucial importance for non-disabled children *and* their parents, but inadequate bedrooms and other living space made this problematic.

### *Embracing housing condition and location*

Four out of 10 families reported problems with cold, damp and/or poor repair, and most families reported difficulties with the immediate location of their homes. These findings confirm and add to the conclusions of previous research. They reveal the importance of addressing not only the physical or structural limitations of a home but also the impact of poor housing conditions and poor environments and neighbourhoods (Murie, 1993; Oldman and Beresford, 2000).

Allen et al (2002) also remind us that we should not assume that more affluent families will not experience location problems. Living on a steep hill, living in an area not serviced by public transport, or being located away from support services are not income-related, but may render a 'suitable house' unsuitable. In addition, negative attitudes to disability are endemic across society and can be encountered anywhere.

### *Redrawing the boundaries of housing unsuitability*

The vast majority of the sample (9 out of 10) reported problems with their homes, half reported more than five problems, and one in three nine or more problems. We also know that most children represented in this survey (and as is the case for

the overall population of severely disabled children) had multiple impairments and had multiple housing needs. The 'site' of housing problems or housing unsuitability extended to all parts of the internal home environment, the external home environment – the garden and local neighbourhood – and the location of the home (with respect to support networks and services). In our analysis we identified 11 separate problem areas. Many of these are not routinely incorporated in a housing needs assessment:

- family space;
- difficulties with use of functional rooms, such as the kitchen, bathroom, toilet;
- only one toilet and/or bathroom;
- lack of space for storage of equipment;
- location;
- access around, and in and out of, the home;
- lack of downstairs toilet and bathing facilities;
- poor housing condition;
- lack of space to use equipment and carry out therapies;
- inadequate facilities to address carer needs in terms of lifting and handling;
- safety inside the home.

What this research has been able to do, for the first time, is to explore the association between impairment type and area of housing difficulty. We now know that some aspects of housing unsuitability are associated with particular types of impairment. For example, problems with safety and location were more frequently reported by families with a child with learning difficulties and/or behaviour problems. At the same time, our data also showed that children with learning difficulties and/or behaviour problems and their families (who are largely ignored within the current 'housing need' system) can experience the same sorts of problems with their housing as children with physical impairments – particularly in terms of the need for family space. Together this body of evidence calls into question current practice in terms of the groups of disabled children seen as 'eligible' for an assessment of their housing needs and assistance with addressing such needs. In addition, the types of problems particularly reported by families with a child with learning and/or behaviour problems also highlights the need to include moving as a recognised and supported (both in terms of finance and information and advice) option for families.

### *Expanding the options for addressing housing need*

Allen et al (2002) use the phrase ‘housing adjustments’ to encapsulate the activities which may take place in response to unsuitable housing. This is an interesting and potentially valuable approach in that it encourages a much wider consideration of the possibilities than is afforded by concepts such as ‘adaptations’ or ‘moving’. For disabled children, the term ‘adaptation’ typically brings to mind the so-called ‘spectacular adaptations’ such as ground floor extensions. Yet this excludes many of the changes to housing (big and small) that families say they need. In addition, the term ‘adjustments’ can include changes to address poor quality housing – a frequently reported problem among families with a disabled child. Finally, the option of moving can be included within the notion of ‘housing adjustment’.

### *Recognising the tenure issue*

Tenure is of enormous importance. It was quite apparent from the interviews with both housing and social services staff that this point was not recognised. The many needs assessment forms seen during the course of this study routinely collected information on the tenure of the family, yet this data is not used in any operational or strategic way. Tenure is key, not only because it indicates a lot of other information about families such as income and disability (Cooke and Lawton, 1985). To some extent, it also determines the sort of intervention that can be carried out. Although in overall terms families living in rented housing were in greater need than owner-occupiers, nevertheless, the latter did have acute needs and often were more hidden from official eyes.

## **An agenda for change**

As has been already discussed, there are three key reasons why the housing needs of disabled children and their families are not met: lack of money, lack of awareness, and service fragmentation. The following ‘agenda for change’ is suggested to address these factors.

- The need for the issue of meeting the housing needs of disabled children to be ‘owned’.

Social services is the most likely route through which families seek assistance and it is the agency responsible for carrying out a comprehensive assessment of need. Locating responsibility within the disabled children’s team would seem a sensible option, especially if the team contained occupational therapists, a practice currently operating in a small number of local authorities (Beresford and Oldman, 2000).

- The need for housing to be included in the assessment process and mechanisms set up to act on this. We have argued that within this assessment process the notion of housing need must be redefined.
- Specifically, housing needs to be broadened out and to be based on the social model of disability and, above all, to incorporate the importance of space in the lives of disabled children and their families.
- Furthermore, the assessment for meeting housing needs must be sensitive to different impairments and should include a discussion of the merits of adapting or moving.
- Funding levels need to be increased and their remit widened to reflect the proposed re-definition of housing need and the range of responses families may wish to take to address their housing needs.
- The needs of families for information and advice about possible options or solutions to addressing their housing needs remain largely unaddressed outside of the DFG process. The provision of information and advice needs to become an independent ‘prong’ of services offered, regardless of families’ utilisation of other aspect of services related to addressing housing need.
- The population’s housing needs must be mapped on a regular basis, capturing children’s development. This is necessary for informed planning and budgeting for a range of resources – financial, staff and housing. Access to the data collected would need to be shared with all departments involved in meeting the housing needs of disabled children and their families.
- Information systems need to be established which enable authorities to record the process of service delivery and the outcomes of a housing need ‘intervention’ and the availability of potentially suitable housing. There would need to be a shared database(s) given the range of professionals and departments potentially involved in meeting housing need.

- The fragmentation of the service delivery that is endemic in local authorities needs to be addressed: just one example is the way that community equipment is currently a separate service to housing adaptation services.
- Local authorities and registered social landlords should work closer together in order to achieve an expansion of the stock of more accessible housing with adequate space standards.
- Finally, solutions to the inequity between tenures – specifically, about availability of choice to move or adapt – should be explored and developed.

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# A

## Appendix A: The survey of parents

### Obtaining the sample

The sample of just under 5,000 families recruited to the study was drawn from the Family Fund Trust database. The sample covered 43 housing authorities in England and Wales. (For the purposes of the 'provider' side of the project, these comprised 33 authorities who had participated in a previous project [Beresford and Oldman, 2000] and supplemented by a further 10 areas, each of which had similar characteristics to one or more of the roadshow areas. Since the study areas covered all types of councils they differed significantly in size.)

The overall sampling frame was provided by extracting cases from the Family Fund Trust database which were recorded as being within relevant local authorities and where the disabled child was aged 0 to 18. Families were included only if they had either received help from the Family Fund Trust or had been turned down because of their economic circumstances. This selection criteria provided some guarantee that the child's disability was severe. The sampling frame was further refined using shortened postcodes for those housing authorities that were not uniquely defined by the Family Fund Trust local authority (social services) code – 27 out of the 43 areas. Some cases that appeared to overlap housing areas were subsequently allocated manually to the correct area. The size of the resulting sampling frame was 13,000 cases.

For three of the study areas, St Albans, Welwyn Hatfield and Rutland, numbers in the sampling frame were small, and so all 40 families within these areas were positively selected. In addition, families rejected on economic grounds were also all positively selected for the study, because it

was important to include as many families as possible with higher incomes. A further 460 study cases were positively selected for this reason. The remaining 4,500 study cases were selected at random from the sampling frame but stratified according to age, so that the final study sample had equal numbers in each of five age groups 0 to 4, 5 to 7, 8 to 11, 12 to 15 and 16 to 18.

The manual check of sample cases that appeared to overlap council boundaries was carried out after the sampling process in order to minimise the number of cases needing to be checked. As a result, nine of the sample cases proved to be outside the study areas altogether and had to be withdrawn, and the number of families resident in Oadby and Wigston Borough Council also proved to be smaller than was originally thought.

### The representativeness of the sample

The Family Fund Trust database is arguably the best national database of severely disabled children and their families. It represents over half of the population of all families with a severely disabled child in England. (Estimates of take-up suggest that between 60 and 70% of eligible families have applied to the Trust [Lawton and Quine, 1990].) While there is bias within the database toward lower-income families (a higher income cut-off is applied with families with household incomes of ~£20,000 being ineligible), this does not apply to the representativeness of the database in terms of conditions and impairments which result in children being severely disabled.



For this project, the disadvantage of the database is that it only concerns severely disabled children, as opposed to those with moderate or mild impairments. In terms of research, these two latter groups are very difficult to identify or access as many are unlikely to be in contact with social services and/or use specialist health provision. The scope of this project did not allow for a different set of sampling and recruitment procedures to be put in place in order that children with mild or moderate impairments could be included.

## The questionnaire

The questionnaire was informed by the findings of our previous research (Oldman and Beresford, 1998; Beresford and Oldman, 2000). Certain items in the questionnaire were drawn from national survey instruments (such as the Survey of English Housing and the General Household Survey).

The questionnaire included questions about family circumstances, family composition, the nature of the child's impairments, socioeconomic and demographic characteristics; areas of housing need and responses to dealing with unsuitable housing.

Wherever possible a fixed response format was used and pictures were used to increase the attractiveness of the questionnaire's appearance.

## The survey process

Two reminders were used to enhance the response rate. An information sheet about the project accompanied the questionnaire. Assistance with the questionnaire (through telephone interview) was offered, although take-up of this was extremely low (<5).

## Response rate

A total of 152 cases were withdrawn from the final sample size (new total = 4,839). The process of contacting these 152 families with the questionnaire yielded information that either

meant they were not eligible to take part in the survey (for example, their child no longer lived at home) or their child had died, or the family had moved and the questionnaire was undelivered. A total of 2,941 completed questionnaires were returned, which represents a response rate of 61%.

## Characteristics of the sample

A description of the sample, particularly the nature of the child's impairments, family composition and socioeconomic circumstances, can be found in Chapter 2. The following tables provide additional contextual information about the sample.

Over 12% of the sample were from minority ethnic groups. This is a pleasing level of response. The above-general population proportions of minority ethnic groups is to be expected.

**Table A1: Marital status of respondents**

	<i>n</i>	%
Married/living as married	1,988	68
Single	435	15
Separated/divorced	448	15
Widowed	47	2
Total	2,918	100

**Table A2: Ethnicity of respondents**

	<i>n</i>	Current survey %	General Household Survey 1998 (%)
White	2,555	87.5	93
Black African	36	1.2	1
Black Caribbean	37	1.3	
Chinese	9	0.3	–
Indian	69	2.4	2
Pakistani	74	2.5	2
Bangladeshi	76	2.6	
Mixed race	8	0.3	–
Other	56	1.9	(2)
Total	2,920	100	100

**Table A3: Ages of disabled children represented in the survey**

Years	<i>n</i>	%
0-4	631	22
5-7	570	20
8-11	590	21
12-15	503	18
16-18	554	19
Total	2,848	100

*The type and location of families' homes*

Two (or more) storey houses were by far the most common form of accommodation among the sample (see Table A4). Only 4% of the sample did not have ground floor access to their homes. In terms of gardens, 86% had a garden, while 4% had no access to any outside space.

**Table A4: Type of accommodation**

	<i>n</i>	%
Ground floor flat/maisonette	139	5
Flat/maisonette – not ground floor	103	4
House	2,523	86
Bungalow	143	5
Other	7	1
Total	2,916	100

**Table A5: Location**

	<i>n</i>	%
Country	120	4
Village	386	14
Town	1,016	36
Suburbs of city	729	25
Inner city	615	21
Total	2,866	100

# Appendix B:

## The supply-side fieldwork

It was felt that information on response to need was best obtained via telephone interviews. A semi-structured interview format was used, which covered the following areas:

- organisational processes for delivering adaptations;
- financial details about adaptations including parental contribution to the Disabled Facilities Grant (DFG);
- number of families helped and compared with the total volume of adaptations completed;
- interviews with occupational therapists focusing on the assessment of housing need, delivery and after-service;
- the effectiveness of intervention: moving versus adaptation;
- joint working;
- aggregate needs assessment.

The data collection process became a greater than expected task because of the number of different individuals involved, and the difficulty of tracking down the right person to talk to. In the event over 100 telephone contacts were made, but the benefits of process were relatively limited because answers were only available to a small number of questions. Because adaptations were invariably delivered on a tenure basis, some time was spent finding the relevant officers to talk to. The original aim of the study was to compare on an authority basis the degree of unmet need with the response to that need. It proved only possible to do this on a broad-brush basis. The professionals contacted in the course of the fieldwork are summarised in Table B.1.

**Table B1: Professionals contacted in the course of fieldwork on supply issues**

Job title	<i>n</i>
Service manager: disabled children	16
Housing officer with responsibility for adaptations in the private sector	35
Housing officer with responsibility for adaptations in the council sector	30
Occupational therapists	10
Housing policy officers	8