

Housing and disabled children

Round-up
Reviewing the evidence

June 2008

In recent years the issue of housing and disabled children has moved up the policy agenda, and there are currently opportunities for change at both the national and local policy level. This round-up provides an overview of what is known about the housing circumstances of disabled children and their families.

Key points

- Families with a disabled child are more likely to be renting their homes than families with non-disabled children. Whilst there has been an increase in the proportion of families as a whole being home-owners, the proportion of families with a disabled child becoming home-owners has remained the same.
- Families with a disabled child are less likely to be living in a decent home compared to families with a non-disabled child. Those with a disabled child are 50 per cent more likely than other families to live in overcrowded accommodation, to rate their home as being in a poor state of repair, and to report problems with wiring, draughts and damp in the child's bedroom.
- Compared to other groups of disabled people, disabled children requiring specifically adapted homes are the least likely to be living in suitable accommodation.
- The great majority of families with disabled children report that their homes are unsuitable for their child's needs and the associated needs of other family members. Often the home is unsuitable in a number of ways,
- All disabled children and their families, not just children with physical disabilities, are likely to experience difficulties with their housing.
- The sorts of problems with housing most frequently reported by families include lack of family space, and lack of space for storing and using therapeutic equipment. Other common problems are difficulties with location and unsuitable or inaccessible kitchens, toilets and bathrooms.
- Moving, as opposed to adapting the current home, is the preferred option for dealing with unsuitable housing for around half of families.
- Disabled children and young people spend more time at home than non-disabled children, but there is evidence to suggest that their homes are the most restrictive environments in which they spend their time.
- Improvements in families' housing situation can lead to increased independence, more confidence and greater self-reliance among disabled children. However, families can experience significant difficulties accessing support and services to help them address the problems with their housing.
- Living in unsuitable housing has been found to be associated with increased levels of parental stress. Parents describe the negative impact living in unsuitable housing has on their child's well-being and development as well as on their own, and their other children's, physical and emotional well-being.

The research

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Introduction

The past decade has seen an increase in the evidence base on housing and disabled children, which has in turn contributed to greater awareness of this issue among practitioners working in housing and children's services. The issue has also moved up the policy agenda, with government reporting that more needs to be done to improve the housing situation of families with disabled children (Department of Health, 2004; Cabinet Office, 2005). On-going policy developments within children's services and housing may provide further opportunities for change at a policy level, and the implementation of those policies locally offers the chance for local services to reconsider the way they currently meet the housing needs of families with disabled children living in their area (Beresford, 2006).

“Housing is paramount to the well-being of children. It is ridiculous that it isn’t considered a priority.” (Housing officer)(Beresford and Oldman, 2000)

This round-up provides an overview of what is currently known about the housing circumstances of disabled children and their families. Published government statistics, secondary analysis of government surveys, and primary quantitative and qualitative research are used to review the following topics:

- the prevalence of childhood disability;
- tenure;
- house condition;
- satisfaction with housing;
- housing suitability;
- types and incidence of housing needs;
- the impact of unsuitable housing on families’ lives;
- dealing with unsuitable housing, and outcomes of that process.

The prevalence of childhood disability

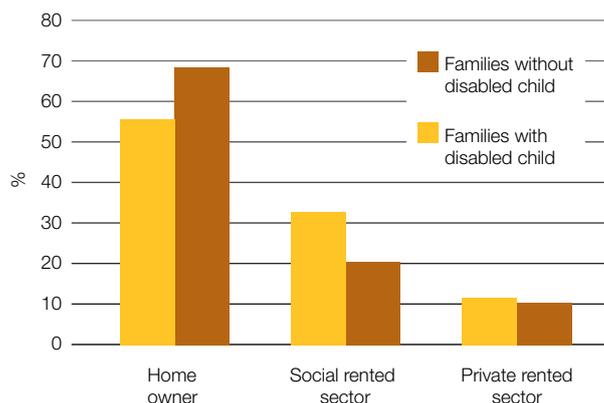
Over the years different figures or estimates of the prevalence of childhood disability have been reported, ranging from 3 per cent to 16 per cent of children. This variance is essentially due to the definition of disability used within a particular study. Figures from the 2001 Census show that 4.1 per cent (n=9,854,841) of all 0-to15-year-olds had a ‘limiting long-term illness, health problem or disability’. There is a query, however, over whether people include learning difficulties and other non-physical impairments when responding to that question. Emerson and Hatton’s (2005) secondary analysis of the 2004 Family and Children Study (FACS) used the presence of one of three indicators¹, which included learning difficulties more explicitly, and reported a prevalence rate of 10 per cent (n=~1.2 million) among children under 17 years living in Britain.

For ease of reading, this summary will use the phrase ‘disabled child’ to encompass the range of definitions used, though the reader should bear in mind the possible weaknesses or omissions in the way disability has been defined by a piece of research.

Tenure

Across national datasets, there is consistent evidence that families with a disabled child are more likely to be renting their homes than families with non-disabled children (Census, 2001, English House Conditions Survey (EHCS), 2003-2004). Figures from the 2001 Census showed 69 per cent of families with non-disabled children were home-owners compared with 56 per cent of families with a disabled child (Figure 1).

Figure 1 Tenure among families with and without a disabled child



Emerson and Hatton’s secondary analysis of the FACS produced similar figures, with families with a disabled child being significantly more likely than families with non-disabled children to be social renters (36 per cent vs. 20 per cent) and significantly less likely to be home-owners than families with non-disabled children (55 per cent vs. 72 per cent). Comparison with data published in the mid-1980s (Cooke and Lawton, 1985) suggests that, whilst there has been an increase in the proportion of families as a whole being home-owners, a similar picture is not found for families with disabled children. In 1980, in a nationally representative sample, 53 per cent of families with a disabled child were home-owners, a figure very similar to the current one.

Data on families with very severely disabled children suggests that these families are even more likely to be renting their homes. Beresford and Oldman’s survey of just under 3,000 families with a severely disabled child (2002) found just 43 per cent were home-owners while 54 per cent rented. Thus, for this group, a greater proportion are renting their homes than are home-owners. It should be noted that the sample used for this research is biased towards low income families and thus is not fully representative of all families. At the same time, the strong association between low income and disability is well-established (Gordon and Heslop, 1998; Gordon *et al.*, 2000a).

Although very small proportions, Emerson and Hatton (2005) also found that families with a disabled child were significantly more likely to have lived in temporary accommodation in the previous year compared to families with non-disabled children (2 per cent vs. 1 per cent).

The overall picture painted by these figures is that the basic housing profile of families with disabled children is different to those of families without disabled children. In addition, there is evidence to suggest that families with disabled children have not experienced the same changes in housing ownership experienced by families as a whole.

The housing situation: data from generic surveys

Datasets from government surveys can also provide information on housing condition and suitability of housing. However, this information is limited because generic tools of suitability and housing quality are used. These do not, therefore, collect information on aspects of housing need or suitability that are specific to childhood disability, nor do they reflect the need for more exacting standards of some aspects of housing quality (for example, thermal comfort, overcrowding) to be applied in order to reflect the needs of disabled children and their families.

Housing condition

However, starting with these data sources, our own secondary analysis of the 2003–2004 EHCS found that families with a disabled child are less likely to be living in a ‘decent home’² compared to families with a non-disabled child (71.6 per cent vs. 76.2 per cent).

More detailed information on housing condition is provided by Emerson and Hatton’s (2005) secondary analysis of the 2002 FACS (see Table 1).

On all indicators of housing condition (except for the presence of central heating), families with a disabled child were significantly more likely to report problems with the condition of their homes. In particular, they were twice as likely to report difficulties with keeping the house and/or child’s bedroom warm. In addition, these families were 50 per cent more likely than other families to live in overcrowded accommodation, to rate their home as being in a poor state of repair and to report problems with pests, wiring, draughts and damp in the child’s bedroom.

“I wash every day but my machine no longer works properly and I can’t dry my washing. I have one gas fire to heat the whole house. The house is very cold and damp and I have got black mould on the walls. I have no carpet as I had to throw it away as the damp ruined it.” (Beresford, 1996)

A more subjective measure of housing condition is found in the EHCS question on respondents’ satisfaction with the state of repair of their home. Here, our analysis revealed lower levels of satisfaction among families with disabled children compared to families with non-disabled children (see Table 2).

Table 1: Comparison of housing condition reported by families with a disabled child and families without a disabled child

	Families with child at risk of disability (%) ^a	Families without child at risk of disability (%)	Odds ratio and level of statistical significance (%)
No central heating	9	8	1.09
Not warm enough in winter	10	5	2.02***
Cannot keep child’s bedroom warm	8	4	2.02***
Cannot keep warm due to cost	4	2	2.11***
Overall poor state of repair	11	7	1.76***
Problems with damp/mould/condensation	26	20	1.38***
Problems with pests (insects/rats)	7	5	1.67***
Problems with wiring	9	6	1.57***
Problems with plumbing	10	7	1.39**
Problems with rot/decay	10	8	1.39**
Problems with drafts	16	12	1.50***
Damp in child’s bedroom	11	8	1.52***

Notes:

a The phrase ‘risk of disability’ is used by Emerson and Hatton because their analyses were based on the social model of disability which argues that the presence of certain intellectual or physical characteristics are likely (given the nature of the society) to result in children and families being made disabled in a wide range of contexts.

* p<0.05; ** p<0.01; *** p<0.001

(Emerson and Hatton, 2005, p 14)

Table 2: Satisfaction with current state of repair of home

Level of satisfaction	Households with a disabled dependent child (%)	Households with a non-disabled dependent child (%)
Very satisfied	17	27
Fairly satisfied	42	48
Neither satisfied nor dissatisfied	11	7
Slightly dissatisfied	15	12
Very dissatisfied	15	6
<i>Total</i>	<i>100</i>	<i>100</i>
<i>Weighted N.</i>	<i>840,601</i>	<i>5,624,929</i>

Overcrowding

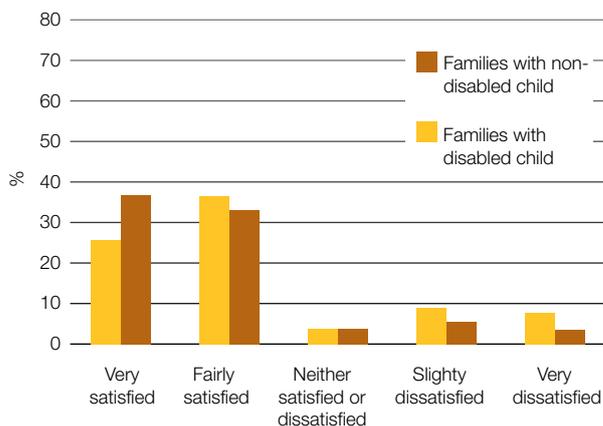
Our secondary analysis of the 2001 census found that more families with a disabled child were under-accommodated³ compared to families with non-disabled children (12 per cent vs. 10 per cent), and more families with non-disabled children (67 per cent) were living in homes with at least one more room than they required compared to families with disabled children (61 per cent). The FACS figures on overcrowding also show families with a disabled child are disadvantaged on this housing indicator, and are significantly more likely to have insufficient bedrooms compared to families with non-disabled children (16 per cent vs. 9 per cent) (Emerson and Hatton, 2005). A study conducted twenty years earlier reported a similar situation (17 per cent vs. 8.5 per cent) (Cooke and Lawton, 1985), suggesting there has been little progress on this issue in the intervening years.

“Because Richard needs a lot of attention at night it is very disturbing for his three brothers having to share a bedroom with him. My husband often ends up sleeping on the settee downstairs so that Richard can sleep with me. I also find it hard work carrying Richard up and down to the toilet which all eight of us share.” (Beresford, 1996)

Satisfaction with housing

The 2003–2004 ECHS asked participants for an overall rating of their satisfaction with their home. Families with a disabled child were twice as likely to report being very dissatisfied with their home compared to families with non-disabled children. Similarly, just a third reported being very satisfied compared to almost a half of families with non-disabled children (see Figure 2).

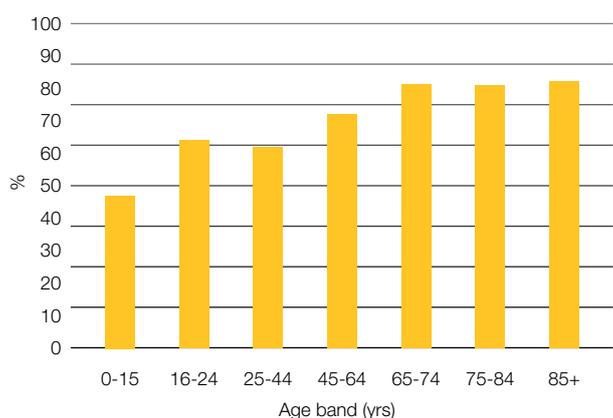
Figure 2: Comparison of satisfaction with housing between families with a disabled child and families with non-disabled children



Suitability of housing for children requiring specially adapted accommodation

The Survey of English Housing provides annual data on the housing situations of 20,000 households. It asks whether there is someone in the household with a long-standing illness, disability or infirmity and, if so, if they require specially adapted accommodation. Of those requiring specially adapted accommodation, it then asks if the accommodation is suitable. Data from the 2005/06 survey (Department of Communities and Local Government, 2007) shows that, across all age groups, children (aged 0–15 years) are the group least likely to be living in suitable accommodation (see Figure 3).

Figure 3: Suitability of accommodation for persons requiring specially adapted accommodation due to illness or disability



Less than half of disabled children (47 per cent) who require specially adapted homes are living in suitable accommodation; this compares with just over 80 per cent of people aged 65 or more, more than 70 per cent of those aged 45-64, and around 60 per cent of those aged 16-44. Looking back over findings from earlier surveys (2000/01 onwards) shows that there has been no improvement in this figure over that period (Department of Communities and Local Government, 2007).

Housing needs: data from research with families with disabled children

Research that has specifically looked at housing needs among disabled children and their families has typically either taken the approach of studying children with a particular condition(s) or has focused on a sub-population, namely severely disabled children.

National evidence

A key source of evidence on the housing needs and experiences of families with a severely disabled child comes from a survey of almost 3,000 families living in England and Wales conducted in 2000 (Beresford and Oldman, 2002). Housing difficulties experienced by these families clustered into eleven problem area (see Table 3).

A key finding is the range of ways in which a home can be unsuitable for a family with a disabled child. This finding challenges the stereotypical view of housing need being an access issue. Instead, the dominant theme from the data was space.

Three different problem areas were concerned with space. Lack of family space was the most frequently reported problem (55 per cent).

Table 3: The nature and extent of housing problems experienced by families with a disabled child

Problem area	Proportion of families reporting difficulties (%)
Family space (space to play, space apart from other family members)	55
'Functional rooms' (kitchen, toilet, bathroom) difficult to use	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/or bathing facilities	33
Housing condition	27
Lack of space to use equipment and carry out therapies	21
Inadequate facilities to meet carer needs (e.g. lifting, toileting, bathing)	21
Safety inside the home	3

“We need two houses. One for him and one for us.” (Oldman and Beresford, 1998)

“My perfect home if I could design it...it would have a large family room, if it's trashed it doesn't matter. And then a large kitchen, a large dining room and a conservatory. It would have a big garden and be child proof. Things would be out of the way. Covers on the sockets, windows not too low.” (Oldman and Beresford, 1998)

In addition, almost four out of ten families reported insufficient space for storing equipment and one in five said there was not enough space in their home to use equipment (for example, standing frames) and to carry out therapies. Comparison of these figures with data collected by the Poverty and Social Exclusion Survey (Gordon *et al.*, 2000b) suggests that families with a severely disabled child are much more likely to report problems with lack of space than families in similar economic circumstances but with non-disabled children.

The other most common problems were that 'functional rooms' (kitchen, toilet, bathroom) were unsuitable, either for parents as they cared for their child and/or for the children to use themselves, and the home had only one toilet and/or bathroom.

Over a third of families reported difficulties with the location of their home. This could be due to the location being unsafe for the child (for example, by a busy road), difficulties with neighbours, and/or the lack of local facilities or services.

“My son is beaten up by neighbourhood children because of the way he is.” (Chamba *et al.*, 1999)

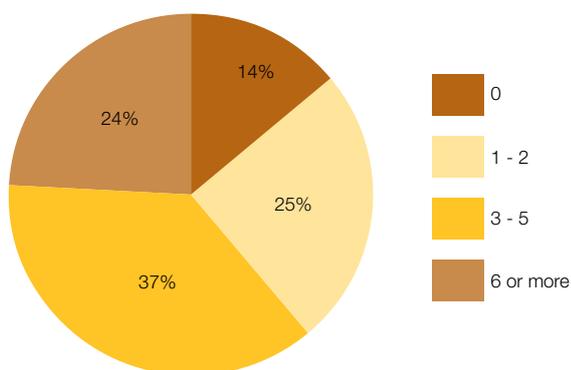
One in three families had problems with access within or in and out of the home, and a similar proportion found the lack of a downstairs toilet/bathroom presented problems.

“If he messes his nappy I have to carry him upstairs to the bathroom. As I have no shower I have to try holding him up with one hand then throwing jugs of water over him with the other hand. Therefore a downstairs bathroom with a shower would be very helpful.” (Beresford, 1996)

Over a quarter said the condition of their home made it unsuitable for their child. One in five families indicated their home lacked adaptations/equipment to support them as they cared for their child. Finally, a small number of families reported their homes were unsafe for their child.

The majority of families (86 per cent) were living in homes where there were difficulties with at least one of these problem areas, and a quarter of families were experiencing difficulties with six or more different problems (see Figure 4).

Figure 4: Number of housing problem areas reported by families



No home is perfect and some inadequacies can be lived with without having any significant impact on its occupants. This survey did not collect information on the severity of the problems being reported and a proxy indicator is therefore needed. The number of respondents reporting that they needed to change their housing in some way so that it better suited the needs of their child and the rest of their family can be

used in this way. Half of parents stated this was the case, suggesting that, for many families, their housing difficulties were impacting on their lives in such a way that some action needed to be taken.

Social factors affecting levels and types of housing need

Further analysis of this dataset revealed that families with the lowest incomes experienced a greater number of difficulties with their housing compared to higher income families. However, even higher income families reported an average of three different problems with their homes. Similarly, whilst families across all tenures reported housing difficulties, renting from a local authority or private landlord was associated with families experiencing more housing difficulties compared to those renting from housing associations or home owners.

In line with earlier research, which found that black and minority ethnic families reported a greater number of difficulties with their housing (Chamba *et al.*, 1999), ethnicity was also found to be associated with the number of problems reported. In addition, there were differences between ethnic groups in the types of problems they were likely to be experiencing. Pakistani and Bangladeshi families appear to be particularly vulnerable to unmet housing need and living in poor housing conditions and, again, this corroborates findings from Chamba *et al.*'s (1999) earlier survey of over 2,500 families with a disabled child from black and minority ethnic groups.

The relationship between the type of impairment and housing unsuitability

A crucial finding from this research, and supporting qualitative evidence (Oldman and Beresford, 1998), was that all families with a disabled child are likely to experience housing difficulties, regardless of the nature of their impairment. This reiterates once more that housing need is not simply about physical impairment and access issues. In addition, analysis of the data identified that some housing difficulties are universally experienced, whereas others are more likely to be experienced by children with certain sorts of impairments (see Figure 5).

Families' preferred responses to unsuitable housing

The national survey (Beresford and Oldman, 2002) again provides information about how families respond to unsuitable housing. Here the survey found that more parents would prefer to move (57 per cent) than to adapt their present home (43 per cent). Tenure and the nature of the housing problem were associated with parents' preferences. Home-owners were the only tenure group where the majority expressed a preference

for adapting over moving. Not surprisingly, families reporting that the location of their home was unsuitable were more likely to prefer to move. In addition the need for larger rooms, more storage space and an additional toilet/bathroom were all associated with a preference for moving as opposed to adapting their current property.

These findings shed light on the complexity of meeting the housing needs of families with a disabled child, especially as most families report more than one type of problem with their current home. Adapting may resolve some issues but leave other difficulties unaddressed. Similarly, moving may resolve issues of space and location, for example, but not necessarily other housing needs.

The impact of unsuitable housing on families' lives

The impact on children's lives

Disabled children and young people spend more time at home than non-disabled children (for example, Mulderij, 1996; Howard, 1996; Beresford *et al.*, 2006) increasing even further the importance of the home environment to this group of children. There is evidence to suggest, however, that disabled children's homes are the most restrictive environments in which they spend time (Oldman and Beresford, 1998).

“When I’m at school I go round in ma [sic] wheelchair, and when I’m at home I just sit in a seat.” (Hannah, 9, very limited mobility) (Oldman and Beresford, 1998)

Research with disabled children about their homes is very limited, and to date has only explored the experiences of children with physical or sensory impairments. Beresford and Oldman (1998) found that children wanted to be able to access all parts of their home, including the garden. However, living in unsuitable housing restricted their play or leisure experiences, primarily because it restricted their ability to move about the house independently and safely. Their inability to move about spontaneously, or without expending considerable effort, meant they had little control over where, or with whom, they spent their time at home. Unsuitable housing also impinged on their ability to develop self-care skills, such as cooking, and also meant that they needed their parents to help them with bathing and using the toilet, which they would not have needed if they were in suitable housing.

“I would prefer my mum and dad not to help us [sic] in the toilet 'cos I'm getting older, it's nerve wracking and stuff. Even though it's me mum and dad I still don't like it...when I tell my friends they think I'm sick or something...I usually 'go' about four or five times a day. I try to keep it in a bit

Figure 5: Associations between impairments and housing problem experienced

Not associated with a particular impairment

- Family space
- Difficulty using functional rooms
- Housing condition

Associated with a physical impairment and/or serious health problem

- Lack of space to use equipment or carry out therapies
- Lack of space for storing equipment
- Lack of facilities to assist parent with lifting and handling
- Access within, and in and out of, home

Associated with behaviour and/or learning difficulties

- Safety inside the home
- Location

longer 'cos it's hard getting up the stairs.” (Laura, 13, limited mobility). (Oldman and Beresford, 1998)

Heywood (2004) also reports children being bored, and feeling helpless and overly dependent as a result of living in housing which did not accommodate their needs. Parents have also expressed these concerns for their children (Heywood, 2004; Oldman and Beresford, 1998).

“I want to wash the pots. Amy [sister] comes and washes them or Zoe [sister]. And I get frustrated 'cos I've never washed the pots yet.” (Kate, 8, visual impairment) (Oldman and Beresford, 1998)

The children participating in Oldman and Beresford's survey (1998) were, typically, acutely aware of their environments. They tended to dislike cluttered rooms which made moving about difficult, and those who were walking but vulnerable to falling disliked rooms which had furniture with sharp corners or with hard floors. When asked about their 'ideal home', all the children mentioned having more space within the house and having a garden.

Parents also report risks of physical harm to their child associated with living in unsuitable housing. These included children falling in the bath or shower, having accidents in the kitchen, and the pain experienced whilst being lifted awkwardly by their parents (Heywood, 2004). Oldman and Beresford (1998) heard of similar

experiences from parents participating in their research and, in addition, children being accidentally knocked and bruised because of the difficulties of lifting and moving in a small space and difficulties with access, and injuries caused by children breaking windows. Furthermore, where a lack of space limited the use of equipment or carrying out therapies, parents believed this had an impact on the development or maintenance of their child's physical abilities.

A final impact of unsuitable housing on children reported by research is that it can prevent babies and children being discharged home following birth or significant and traumatic injury, resulting in very prolonged stays in hospital (Noyes, 2002).

The impact on parents

The physical and psychological consequences for parents of having and caring for a disabled child in an environment that is not suitable for the child's or parent's needs have been identified by research.

In terms of the impact on physical health, parents report back injuries, injuries sustained when falling on the stairs whilst carrying their child and interrupted sleep caused by having to share a bedroom with the disabled child (Oldman and Beresford, 1998; Heywood, 2004).

"There [are] 18 steps. Well you think about it...3 stone 11 pounds. When I get to the top I am knackered. I'm not Arnold Schwarzenegger, I'm not. I am getting older and older. I love my 'baby'. I want to keep her. I'm concerned about my back." (Oldman and Beresford, 1998)

Qualitative research with parents also reveals the psychological strain of living in unsuitable housing. In particular, overcrowded living space and the lack of space for different family members to have time out from each other could be a significant source of stress, especially where the child had learning and/or behavioural problems. Trying to deal with unsuitable housing was also identified as a stressor in itself.

Evidence from quantitative research supports the notion of an association between living in unsuitable housing and levels of stress in mothers. Bradshaw's study of over 300 mothers caring for a severely disabled child found that, while mothers' level of stress was not significantly associated with objective measures of basic housing amenities, mothers who felt their house was unsuitable because of the child had significantly higher scores on a measure of stress compared to those who thought their house was suitable (Bradshaw and Lawton, 1978). More recently, in a long-term study of families with a child with Down's syndrome, adequacy of housing was found to be significantly associated with levels of stress and perceived satisfaction with life among mothers (Sloper *et al.*, 1991).

The impact on siblings

When parents are interviewed about the impact of unsuitable housing on their lives, they also typically mention the way it can impact on siblings (Oldman and Beresford, 1998). In particular, where a sibling shared a bedroom with the disabled child, parents talked about siblings experiencing disturbed sleep and also, where the disabled child had behavioural problems, a lack of a private space for 'time out' and to store valued possessions which could not be accessed by their disabled sibling.

Experiences of dealing with unsuitable housing

"Housing and education. Those are the things we wanted to get sorted. If you've got your home right you can cope. This house is like a cocoon. It doesn't matter what's coming to us now." (Oldman and Beresford, 1998)

Research on families' experiences of trying to resolve their housing difficulties through moving or adapting is limited. Access to information on meeting housing needs and housing services is an issue raised by parents as a barrier to them being able to resolve their housing difficulties (Oldman and Beresford, 1998; Beresford and Oldman, 2000).

"It's a do-it-yourself club." (Oldman and Beresford, 1998)

"The housing – you're just left." (Oldman and Beresford, 1998)

Families from minority ethnic groups and low income families are less likely to know about housing services and sources of funding (Beresford and Oldman, 2002). Other researchers have found that difficulties with accessing information and communication are a reason for low service take-up among black and minority ethnic families (Chamba *et al.*, 1998; Russell, 2003). Fazil *et al.*'s (2002) depth work with Pakistani and Bangladeshi families corroborates this. Families participating in this study reported housing to be a particularly difficult service to identify and make contact with. Similarly, low income families have been identified in previous research as being least likely to know about services (Beresford, 1995).

"We have been in refuges and temporary homes, have moved five time and found on the last move that we were put in unsuitable property. Seven months on we are still waiting for the work to be carried out. I have had to fight every step of the way for help and information." (Chamba *et al.*, 1999)

Another group identified as being less likely to know about housing support were families with children with learning or behavioural difficulties (as opposed to physical impairments).

There is evidence that, unless the local authority is funding or part-funding an adaptation through the Disabled Facilities Grant (DFG), then families do not or cannot access advice and information about addressing their housing needs (Oldman and Beresford, 1998; Beresford and Oldman, 2000; Beresford and Oldman, 2002). However, only a minority of families receive a DFG and therefore have access to expert advice (Beresford and Oldman, 2002).

Beresford and Oldman (2002) report that one in four families participating in their survey said an occupational therapist had assessed their housing needs⁴. Overall, the most common outcome was changes or adaptations to the current home (54 per cent), though a third report nothing had changed or happened as a result of the assessment. Families renting their homes from a housing association were most likely to report this outcome.

Parents and practitioners report significant difficulties with the adaptations delivery process (Oldman and Beresford, 1998; Beresford and Oldman, 2000; Beresford and Oldman, 2002; Townsley *et al.*, 2003). This included delays in the application and assessment process, assessments not taking account of the changing (developmental) needs of the child, assessments not accounting for child-specific needs or the needs of other family members and disagreements, usually driven by funding constraints, between parents and professionals about the best solution. A lack of coordination between services also contributed to families' difficulties negotiating the system.

Outcomes of improving families' housing situation

A couple of studies have looked at the outcomes of adaptations for children and other family members. Improvements or changes experienced by children reported by parents included increased independence, more confidence and greater self-reliance (Oldman and Beresford, 1998; Heywood, 2004). Payne's small-scale evaluation of bathing and showering adaptations found that all children and young people experienced a positive change. For some it was improved independence, and for others greater participation in self-care and more play (Payne 1998). Children also express pleasure at the improvements to their homes (Oldman and Beresford, 1998; Heywood, 2004).

"I love my [specially adapted] sink! Because if it weren't for my sink I wouldn't be able to get myself a drink, I wouldn't be able to do my teeth, and I wouldn't be able to wash my hands or anything like that." (Danielle, 8, wheelchair user). (Oldman and Beresford, 1998)

"Within 24 hours of being in this house, it was like WOW! She was a different child. Her confidence increased overnight. I can't describe to you the difference in Debbie." (Oldman and Beresford, 1998)

Parents can also recognise the benefits of an adaptation in terms of easing the process of caring for their child through a reduction in the physical demands and/or emotional strain (Oldman and Beresford, 1998; Heywood, 2004). However, poor-quality workmanship and/or equipment and even greater constraints on space caused by the adaptation can reduce its benefits.

Whilst adapting and moving may result in some positive outcomes being achieved, it is not the case that adapting or moving means all housing needs are addressed. Families who have moved to a more suitable home for their child still report problems with their home (Chamba *et al.*, 1999). The picture appears to be similar for families who have made adaptations. Oldman and Beresford's (1998) survey of 200 families found that only one in five of those who had adapted reported all their housing needs were now met. Indeed, a fifth of families were still living in homes which were unsuitable in multiple ways. As already noted, some types of housing problem (for example, location and, on occasion, space), cannot be addressed by adapting the current home. In addition, inadequate assessments, poorly designed or constructed adaptations, insufficient funding, and the changing needs of the child are all factors also thought to contribute to these less than ideal outcomes (Beresford and Oldman, 2000).

Conclusions

This report has presented evidence on the housing circumstances of families with a disabled child and has compared, where possible, their situations with families with non-disabled children.

Families with a disabled child have a different tenure profile to families with non-disabled children and, on all generic measures of house condition, emerge as more disadvantaged than families with non-disabled children. They are also much less likely to be satisfied with their housing.

Disabled children also appear to be disadvantaged compared to other groups of disabled people. Among those needing specially adapted housing, they are least likely to be living in suitable housing compared to all other age groups of disabled people.

Research which has looked specifically at the housing needs of disabled children and their families has shown that families can (and many do) experience a multiplicity of difficulties with their home. It has also shown that any disabled child (regardless of their impairment) is likely to be living in unsuitable housing. The key, and universal, difficulty reported by families is a lack of space.

Though limited, the research evidence on the impact of living in unsuitable housing reveals its impact on the physical and emotional well-being on all family members.

The number of families living in unsuitable housing is, in itself, an indicator that statutory services are not addressing or meeting the housing needs of these families. More detailed work on the experiences of families who have tried to resolve their housing problems reveals that difficulties accessing expert advice and/or information about services, inadequate assessment processes, a lack of a holistic, multi-agency approach, and funding restrictions can all impact on the adaptation delivery process. For families who want to move, it is highly unlikely that they will have access to expert advice to help them identify and choose the most appropriate property.

Finally, whether families adapt or move, the complexity of their housing needs can mean certain aspects of housing suitability may not be addressed. The experience of living in homes that do not meet their needs is perpetuated, and the well-being of family members continues to be under threat, as is the opportunity to have an ordinary childhood and family life.

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Notes

1 Parents reported: i) their child had a long-standing illness or disability that resulted in extra care from their primary care-giver or affected their school attendance, and/or ii) had a significant intellectual disability that had a significant impact on their schooling, care needs and/or employment prospects, and/or iii) had been identified as having special educational needs due to physical disabilities.

2 For a dwelling to pass the decent homes standard it should meet four criteria: be above the minimum fitness standard for housing, be in a reasonable state of repair, provide reasonably modern facilities and services, and provide a reasonable degree of thermal comfort.

3 The Census' indicator of overcrowding counts the number of rooms in the accommodation (excluding bathrooms, toilets, halls, landings and rooms that can only be used for storage) and the number, ages and sex of household members to estimate an 'occupancy rating'. A one person household is assumed to require three such rooms (two common rooms and one bedroom), and an additional room is assumed to be required for: each additional couple, lone parent, or other person aged 16 or over; each pair aged 10 to 15 of the same sex; each pair formed from a remaining person aged 10 to 15 with a child aged under 10 of the same sex; each pair of children aged under 10 remaining; and each remaining person.

4 This figure should be treated with caution. Many professionals and services are involved with families with a disabled child and this can make it hard for parents to distinguish roles of different professionals/services. In particular, there is the potential for confusion with assessments for community equipment, also carried out by occupational therapists.