

Housing for disabled children and their families

An information resource

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An overview of information about housing for disabled children and their families, and ideas for improving their circumstances.

The purpose of the resource is to raise awareness of this important aspect of community care and to help non-specialists find out more about promoting positive change in this complex field.

The information resource contains:

- a summary of research evidence about the housing circumstances of disabled children and their families;
- an indication of the role of front-line workers in relation to housing for disabled children and their families;
- potential ways of improving housing, including moving house and adapting a family's existing home;
- a summary of the relevant law in England;
- a series of case studies to help consolidate and expand knowledge of some of the issues involved; and
- guidance on running workshops to provide information to interested practitioners and families.

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Executive summary

Housing is a core component of community care. However, its significance for disabled children and their families is only now being fully recognised. This resource draws together information from multiple sources to aid access to relevant research, law and policy guidance. Its aim is to present key messages about housing for disabled children and their families to workers who are not specialists in housing, their managers and affected families. It is intended both as a resource to be read and as a guide about the provision of training. It comprises four main parts.

Messages from research

The first chapter draws on research evidence which analyses issues relevant to housing provision for disabled children and describes the views of families themselves. The following messages are highlighted:

- Families with a disabled child are a disadvantaged group in relation to housing.
- Families with a disabled child have varied and often multiple needs.
- Some families with a disabled child are especially disadvantaged.
- Unsuitable housing has a negative impact on disabled children and their families.
- Achieving improvement in housing is not straightforward.
- Information from professionals endorses families' reports.

Research provides evidence of the very positive impact that the provision of more suitable housing can have on the lives of disabled children and their families. However, studies also demonstrate that mistakes are possible and that these may be costly in terms of finance, effort and family stress. Families with a disabled child need input

which helps them navigate their way through a complex and fragmented service system so they make informed choices. Where they face multiple problems with housing, families may also need help to prioritise their housing needs so that they are as satisfied as possible with the outcome of any efforts at improvement.

Ways of achieving better housing

Chapter 2 provides information about how problematic housing issues can be addressed. In order to help families with disabled children most effectively, front-line workers need a full appreciation of the significance of satisfactory housing to families with disabled children so that this knowledge informs their performance of generic tasks. They also need a basic knowledge of how improvements can be achieved, either by the family moving to a more suitable property or by adapting the family's home.

Front-line workers can contribute to successful outcomes in housing for families with disabled children by:

- providing accessible information which begins by raising awareness and follows up with more specialised information which is appropriate to a family's particular situation;
- including a thorough consideration of families' housing circumstances in assessments and plans which must be holistic in nature;

- consulting fully with disabled children and their families about the needs of the whole family;
- working jointly with colleagues, especially occupational therapists and other housing specialists.
- the significance of housing in affecting the well-being of disabled children and their families;
- the need for specialist assessment of the suitability of the domestic environments of disabled children and their families;

Negotiating improvements in families' housing circumstances is a complex task since families may be faced with a variety of housing issues. These include:

- overcrowding and lack of space;
- lack of access and inadequacy of functional rooms;
- location;
- condition of their home;
- safety.

The ways available to deal with these deficits depend partly on the nature of families' tenure of their home. Chapter 2 includes:

- a table which indicates potential means of addressing different housing difficulties, according to tenure;
- questions about local housing services which workers can usefully consider;
- a summary of English laws relevant to overcoming housing issues.

Case studies

Chapter 3 aims to help consolidate the information in Chapters 1 and 2. It briefly describes the circumstances of some disabled children and their families in order to illustrate issues associated with achieving suitable housing. The families' stories highlight:

- the fact that children with very different types of impairment are affected by poor housing;
- the complexity of factors which affect the outcome of efforts to improve the suitability of a family's home, and the need for foresight, planning and review;
- the important role that front-line workers can play in promoting improvements in the housing circumstances of disabled children and their families.

Workshops about housing

Chapter 4 presents information about providing training to non-specialist workers, by drawing on experience of running workshops about housing for disabled children and their families. It suggests potential materials for use in workshops and highlights the essential information required. The underlying aim of such workshops and of the information resource itself is that efforts to improve the housing circumstances of disabled children and their families should be as effective as possible, thus ensuring a wise investment for the future.

Introduction

Housing is critical to the well-being of any individual yet it is treated as a 'poor relation' by the three agencies typically thought of as being responsible for children's health and welfare.

(Beresford and Oldman, 2000, p. 41)

Housing receives a great deal of media attention. Rising or falling house prices and mortgage rates are major news items, as are the aspirations people have for acquiring a home and the fears they may have about losing one. This focus on the cost of housing and the potential for associated monetary gains and losses in part reflects the major financial investment that housing represents.

Media attention also highlights other types of significance that housing has in people's lives. Several popular television programmes are concerned with property acquisition and improvement, demonstrating the way status and achievement, issues of self-identity and self-development, and questions of taste and aesthetics are important factors in housing choice.

Our homes have many functions, both practical and emotional. They offer shelter, a place to relax and rest, the promise of privacy, control and freedom. Home is the place where our most important relationships are fostered. For parents, homes offer a space to nurture their family. For children, homes should offer sufficient space to be able to play, develop and eventually gain sufficient autonomy and competence to move on to their own establishment. A family home is expected to help accommodate the multiple and changing needs of each of its residents. The complexity involved in meeting this requirement is compounded when one or more members of the household are disabled.

Despite the prominence homes and housing have in the national consciousness, the provision of suitable housing for disabled people and their families has received relatively scant attention.

This is particularly perplexing in the light of the now general acceptance of the social model of disability which pinpoints the central significance of an appropriate environment for people with impairments. More positively, however, the situation whereby housing is seen as the 'poor relation' has begun to change in the light of the recent recognition of the rights of disabled people to equal life chances (see, for example, Prime Minister's Strategy Unit, 2005) and the accumulating weight of research evidence about the significance of a suitable domestic environment for disabled people.

Emerging from the growing body of research is evidence that housing for disabled children and their families warrants particular attention. Although disabled children spend more time at home than non-disabled children, their homes can prove the most restrictive environment they experience (Beresford with Rhodes, 2008). The importance of housing is acknowledged in recent policy developments, including the National Core Offer, the Government's recent statement about the standards which families with a disabled child can expect from local services across the country (Department for Children, Schools and Families, 2008).

However, training for workers with disabled children and their families has generally placed little emphasis on housing as an important aspect of day-to-day life. Assessments of the needs of disabled children sometimes focus relatively little on issues related to the provision of an enabling home environment. This is despite the fact that the suitability of a disabled child's home may well have an impact on their need for other services and despite the emphasis families themselves place upon it.

This resource provides information about housing research, law and policy in order to address this imbalance. The module is designed

for front-line workers who have not previously received specialist education about housing. It has been developed with the needs of workers in health, education and social care in mind, but also contains information useful to housing professionals who are unfamiliar with the needs of disabled children and their families. In addition, it is hoped that some of the information the resource contains will be of value to families who are acting as their own care co-ordinators, either through choice or because of the non-availability of professional help. (A version of this resource designed specifically for key workers is available on the Care Co-ordination Network UK website.)

The resource comprises four chapters. The first draws on research evidence and summarises what is known about the housing needs of families with disabled children. The second chapter outlines how front-line workers can address housing issues affecting the families with whom they engage and includes information about the relevant legal framework and potential routes to housing improvement. The third chapter presents scenarios which serve to illustrate the information contained in Chapters 1 and 2 and to highlight the complexities, tensions and compromises which

may be part and parcel of working in this field. Chapter 4 describes how training workshops about housing for disabled children and their families can be developed.

For brevity the words 'child' and 'children' have been used to indicate children and young people up to the age of 18 years. Although the resource is based on English references in terms of its legislative background and some of its evidence base, it is hoped that some of its content will also be relevant for front-line workers in Wales, Northern Ireland and Scotland. 'Housing' is used here to focus attention both on the fabric of the building and any fixed alterations or 'adaptations'. Equipment which is movable is not the subject matter of this information resource although a domestic environment which is suitable for a disabled person may well contain both fixed adaptations and movable equipment. The aim here is to focus on housing for disabled children and their families as the importance of this aspect of service delivery has often been overlooked. Because housing is a technical field, at the end of this resource there is a glossary of the terms about housing which are used in the text.

1 Evidence about housing for disabled children and their families: key messages

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.

(Beresford with Rhodes, 2008, p. 11)

Evidence from research with families with disabled children highlights the high incidence of housing problems they experience and their varied nature. It underscores the need for attention to be paid to these issues by front-line practitioners.

The information presented below is chiefly derived from a recent review of research evidence about housing for families of disabled children, the sources for which were multiple studies (Beresford with Rhodes, 2008). The research reviewed utilised a variety of methodologies, including large-scale quantitative surveys and more qualitative approaches which allowed families to indicate their perception of their needs. (Further details about this review are available on the Joseph Rowntree Foundation website.) This information has been supplemented by reference to other research which focused specifically on the provision of housing adaptations. The implications for families of the findings summarised briefly here are explored more fully in the family scenarios described in Chapter 3 of this resource. Details of where to find related case studies are indicated in the text in brackets at the end of the relevant subsection. Key messages from research are set out below.

Families with disabled children are a disadvantaged group in relation to housing

The housing circumstances of disabled children and their families have been found to be worse

than those of the rest of the population of England in the following respects.

Housing conditions

Research found that the condition of the housing in which families with a disabled child lived were on average poorer than that of families with a non-disabled child on every criterion, except in respect of the presence of central heating. Families with a disabled child were more likely to report problems regarding heating their home adequately and its state of repair, and that they lived in overcrowded conditions. They were more dissatisfied with their housing than other families.

Suitability of housing for children requiring adapted accommodation

A large government survey of housing which asked about the suitability of the accommodation available to people who require specially adapted homes found that children (aged 0–15 years) were more likely to be living in unsuitable accommodation than any other age group. Older people who needed specially adapted accommodation were significantly more likely to be suitably accommodated than disabled children and young people.

Families with a disabled child have varied and often multiple housing needs

Housing need is multifaceted and liable to affect all families with a disabled child. Housing need is not purely about issues related to physical impairment and access. Problem areas include the following.

Space

Lack of sufficient family space was the most commonly reported issue in a survey of the housing needs of English and Welsh families with a disabled child. Families reported that insufficient

space was available for all family members to be able to undertake their own activities and for shared, communal activities. Other common problems were lack of space to store equipment or lack of space to use equipment and to carry out therapies. Families with a severely disabled child were much more likely to report lack of space was a problem than were families with a non-disabled child. (See case studies on pages 28–29 and 29–30.)

Lack of suitable kitchens, toilets and bathrooms

Deficits regarding the suitability of kitchens, toilets and bathrooms were the second most commonly reported problem area. These rooms were sometimes unsuitable for the disabled child themselves to use or for their parents to carry out tasks for their disabled son or daughter or there was only one toilet and/or bathroom. (See case studies on pages 27–28 and 32–33.)

Unsuitable location

Over a third of families reported that there was a problem with the location of their home. Sometimes the location was regarded as unsafe for the disabled child or it suffered from a lack of local services or there were difficulties with the neighbours. (See case studies on pages 29–30 and 31–32.)

Access issues

A third of families reported difficulties with access. These might relate to getting into and out of the house or to getting about inside the house or they might be because the lack of a downstairs toilet or bathroom caused problems. (See case studies on pages 27–28 and 28–29.)

Condition of the home and safety issues

More than a quarter of families reported that the condition of their house was a problem; a small number felt their house was unsafe for their child. (See case study on page 32–33.)

Some families with a disabled child are especially disadvantaged

Among this general picture of disadvantage, some families with a disabled child were in the greatest need. These included the following.

Families in certain types of tenure

Families with disabled children were less likely than families with non-disabled children to own their own homes. Those families with severely disabled children were even more likely to be renting property. Families who rented from the local authority or private landlords reported more housing needs than owner-occupiers or those renting from housing associations.

Where adaptations are concerned, Heywood *et al.* (2005) have also pointed out that there are inequalities between tenancies:

Private tenants are in a weak position; tenants of housing associations suffer from divided responsibility and fudging; council tenants cannot share in the DFG ring-fenced allocation.

(Heywood *et al.*, 2005, p. 6)

Families with the lowest incomes

Families with the lowest incomes were the worst housed in that they faced a greater number of problems in relation to their homes than higher-income families, although even these better-off families reported an average of three housing problems.

Families from black and minority ethnic groups

Families from black and minority ethnic groups with a disabled child reported a greater number of difficulties with their housing than white families. Families from Pakistani and Bangladeshi communities have been found to be particularly badly affected.

A review specifically of this area (Beresford, 2007) noted gaps in the research evidence available. However, there were three key issues which contributed to the especial disadvantage faced by black and minority ethnic families. One factor was housing condition. Unless there are improvements to the housing conditions affecting some minority ethnic families, especially those of Pakistani and Bangladeshi origin, they will continue to face housing difficulties, even if their homes are provided with equipment and adaptations. The second issue which particularly affected those of Pakistani and Bangladeshi origin was a lack of space and overcrowding. The third issue was

the problem of accessing both information about housing support and services to improve the home environment. (See case study on pages 32–33.)

Unsuitable housing has a negative impact on disabled children and their families

Impact of unsuitable housing on disabled children

Research suggests that disabled children spend longer in their homes than non-disabled children so it is especially important that their home environments are safe and conducive to their development. However, there is some evidence that disabled children are more restricted in their homes than elsewhere. Disabled children want to be able to get about their homes and gardens as autonomously as possible. Unsuitable housing may restrict opportunities to play and to learn new skills, so inhibiting development and the growth of self-esteem. There is a danger that for some disabled children a lack of control over their environment may lead to feelings of helplessness and dependency. Disabled children who were asked their views about their home environments tended to dislike clutter and wanted more space. Parents reported physical risks to their disabled child which resulted from unsuitable home environments – these included falls, accidents and pain from being lifted awkwardly. Parents also reported that lack of space limited their ability to carry out some therapies and thereby had a negative impact on their child's development and well-being. Unsuitable housing may also delay the discharge from hospital of disabled children.

Impact of unsuitable housing on parents

The physical consequences of unsuitable housing for parents of a disabled child have included back injuries, injuries from falls and interrupted sleep. There is evidence that a psychological cost has been increased stress in mothers. (See case studies on pages 28–29 and 29–30.)

Impact on siblings

Parents have reported a negative impact on siblings of unsuitable housing, especially where

they share a bedroom with their disabled brother or sister. One problem may be disturbed sleep; and, if the disabled sibling has behavioural problems, there may be a lack of a private space in which their brother or sister can relax. (See case studies on pages 29–30 and 32–33.)

Families' experiences demonstrate that achieving improvement in housing is not straightforward

Research evidence about families' experience of achieving improvements in the suitability of their housing by moving house or adapting their homes is limited. However, the following are key messages.

Gaining access to information and to services relevant to housing was difficult for parents

Difficulties in getting information about housing and access to services have been commonly reported. They were especially difficult for black and minority ethnic groups, low-income families and for families with a child with learning and/or behavioural difficulties. (See case study on pages 32–33.)

Only a minority of families with housing needs received expert advice about ways of meeting those needs

There is evidence that only families receiving funding or part funding for a Disabled Facilities Grant (DFG) received expert advice about housing need, but these were a minority of families reporting unsuitable housing. In one survey (Beresford and Oldman, 2002), only a quarter of families reporting housing difficulties indicated that an occupational therapist had assessed their housing need. (See case study on pages 32–33.)

Experiences of the Disabled Facilities Grant process indicated difficulties

In the same study the most common outcomes for families who received an assessment were alterations or an adaptation to their existing home, though a third of families reported nothing had changed following the assessment. Several studies have indicated difficulties and delays in the

overall adaptation delivery service. These problems occurred at a variety of points in the process and for several different reasons, which included:

- lack of co-ordination between services;
- delays in the adaptation and assessment process;
- problems over meeting the child's changing, developmental needs and those of family members (see case study on pages 28–29);
- disagreements between parents and professionals about the best solution (often complicated by funding constraints).

Housing improvements produce positive outcomes for families

Parents have reported positive outcomes for their children of improvements in their housing situation, such as greater confidence, independence and self-reliance. Children themselves have also reported increased independence and enhanced participation in self-care and play. (See case studies on pages 27–28 and 32–33.) Parents reported improvements for themselves as reductions in the physical and psychological stress associated with caring for their disabled child. (See case studies on pages 27–28 and 29–30.)

Some adaptations are unsuccessful

Heywood's research (2001), looking at the effectiveness of housing adaptations for both adults and children, found that, although adaptations generally produced high levels of satisfaction, there were also some expensive failures. Shortcomings resulted from failure to:

- implement the adaptation properly (e.g. inattention to detail);
- consult adequately;

- understand and assess psychological needs or cultural requirements;
- take into account the need for space and warmth.

Examples about unsatisfactory adaptations for disabled children are instructive:

Some extensions for children were so small there was no room for a parent to sleep when the child was seriously ill, and some were too cold to be usable. In other cases, through-floor lifts and hoists were barely, if ever, used.

(Heywood, 2001, p. 45)

Adaptations which were unsuccessful failed to take into account the meaning of 'home' (Heywood, 2005). They neglected families' need for privacy, plus a sense of security and control within their own home.

There was also evidence that disregard of home as a base for relationships and for childhood and a lack of understanding of the nodal nature of home and the importance of rootedness all had consequences in determining whether investment was efficient.

(Heywood, 2005, abstract)

Moving or adapting may not achieve a complete solution

While 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.

(Beresford with Rhodes, 2008, p. 10)

Some of the unresolved issues identified related to space, location, the changing needs of the child, inadequate assessments or workmanship and insufficient funding.

Information from professionals endorses families' reports

The key messages above emerge from large-scale surveys and research with families with disabled children. Data collected from professionals tend to corroborate and amplify this information. Research with professionals working in the field of housing highlights the following points.

Housing services are fragmented and complex to navigate

The fragmented nature of housing services, and how this impacts upon disabled children, has been noted for many years (e.g. see Oldman and Beresford, 1998; Beresford and Oldman, 2002). The way in which housing services are organised varies from one local authority to another, making them difficult to understand for those without inside knowledge. For those seeking socially rented housing, there may be multiple housing associations operating locally, each with their own policies for accessing tenancies. This complexity poses problems for families and professionals alike in terms of getting housing need recognised and acted on. It has been found that housing services do not systematically collect data to aid the evaluation of services already provided to families with disabled children or to inform future planning; and there was a lack of expertise and clarity about roles and responsibilities (Beresford and Oldman, 2002).

Professionals with housing expertise may be more critical of improvements than families themselves

Large-scale research about the effectiveness of housing adaptations for both adults and children provides ample evidence about their potential to improve disabled people's health, quality of life and opportunities. Successful adaptations were found to be an effective use of public funds as they '

Keep people out of hospital, reduce strain on carers, and promote social inclusion'

(Heywood, 2001, p. 1)

Recipients of adaptations rated them very highly. However, when professionals themselves scored the same adaptations they were often less satisfied. Moreover:

Adaptations for children received the lowest average scores from officers and families alike. Failure to allow for the child's growth was particularly noted.

(Heywood, 2001, p. 4)

(See case study on pages 28–29.)

Providing adaptations for children can be time-consuming and stressful

Occupational therapy managers, interviewed for research purposes, noted that delivering adaptations for children raises more issues than providing them for adults:

- *children grow and hence their physical, social and emotional needs change, often quite rapidly;*
- *the progress of their condition may not be known, some impairments will grow worse, some stay the same and some get better;*
- *adaptations need to be child-focused but they also have to accommodate the needs of parents and siblings;*
- *children have needs which are specific to childhood, such as play.*

(Oldman and Beresford, 1998, p. 64)

Time is needed in order to carry out careful assessments, but availability of housing specialists may be in short supply. Moreover, producing housing change is a slow process and may involve delays. Parents can feel frustrated by waiting a considerable time to achieve a much-needed adaptation. In addition, predicting future needs may be difficult for parents and professionals alike. However, early referral may be necessary to ensure that a suitable housing environment is ready when a family requires it. (See case study on pages 28–29.)

Conclusion

Chapter 1 has summarised research evidence demonstrating how extensive and complex is the unmet housing need experienced by families with disabled children. Families face multiple shortcomings with their home environments. Children with all types of impairment are affected. Families find it difficult to elicit useful information about housing issues and to gain access to services. Improvements to the housing situation of families with disabled children may involve moving to a more suitable property or adapting their existing home. When executed well, either option can produce very positive effects for disabled children and their families. However, costly failures can result when families are not fully informed of the options available or are not consulted properly about their needs and wishes. Even when improvements are made, some housing needs may remain unresolved. The implications of this research evidence are that families may need help both in prioritising their housing needs and in negotiating a complex service system.

2 Achieving a home environment suitable for disabled children and their families: underpinning knowledge

Getting an adaptation or move right is very difficult.

(Oldman and Beresford, 1998, p. 76)

Chapter 2 indicates the combination of specialised knowledge about housing and generic skills which can be utilised to bring about improvements in the housing situation of families with disabled children. The chapter begins by considering how dealing with housing issues should be regarded as part of the generic tasks workers regularly undertake. It then summarises how the different types of housing issues families face can be addressed, indicating what action can be taken in the light of families' different housing circumstances. The final section identifies key pieces of legislation which provide the framework for intervention.

The contribution front-line workers can make

Those working with disabled children and their families are faced with a situation of varied and ubiquitous housing need. Key questions for front-line workers who are not housing specialists relate to what is their role in facilitating improvement and what tasks they should be undertaking.

We know from research which features of housing services families with disabled children value. From this evidence we can identify key tasks for front-line workers, and examine these tasks in the light of government policy and research evidence.

Features of services which families appreciate

When families were asked to commend housing services they particularly liked (see Bevan, 2002) they highlighted those which:

- raised awareness of need;

- involved key workers, 'one-stop shops' or named individuals who were on hand to listen;
- promoted effective joint working;
- had an ethos of putting them at the centre of decision-making;
- recognised the specific needs of children.

Bevan (2002) reports that many families pointed to the value of advice and information sources, especially at the time when their child's impairment was first identified. Agencies which raised awareness of housing needs and services were appreciated, as were those which were committed to offering a full range of housing options to families.

Working from what we know families with disabled children want, it is possible to consider workers' tasks under four headings:

- provision of information about housing;
- thorough assessment which recognises the significance of housing;
- listening to what families want regarding their home;
- joint working with relevant housing professionals.

Providing information

The National Core Offer (Department for Children, Schools and Families, 2008) highlights information and transparency as an overarching theme in the Government's recent statement of standards which families with disabled children can expect. Housing is specified as one of the services about which disabled children and their families

can expect information and transparency. This information should be accessible, available, relevant, accurate, joined-up and user-focused (Department for Children, Schools and Families, 2008). Information about housing should not be so limited in its scope that it does not recognise both moving and adapting as possible options. Workers will need to make sure that any information they provide is current since this is a field where publications and websites rapidly become out of date. They may be misleading, therefore, and need to be treated with caution.

The initial identification of housing as an issue for a family may have been aided by information to which the family has had early access, through, for example, reading basic information about services already made available to them or as a result of personal or professional contacts or their own research. Workers for some families may have a role to play in the initial identification of housing as an issue through observation of its poor quality and state of repair, as well as regarding any lack of adaptation to the needs of the disabled child.

Once a difficulty or potential problem in the environment of a disabled child and their family has been identified, families are likely to require more than any basic information about housing that they have already acquired. Information produced locally by services related to housing is one important source of information of which families should be made aware:

Local authorities, health bodies and other relevant partner agencies ... should jointly produce a pack of literature and ensure it is suitably disseminated. Its purpose will be to inform the service users, their advocates, the wider public, other professions and agencies, of service availability and process.

(Department for Communities and Local Government, 2006, p. 18)

Good practice requires that this suite of literature is available for people with sensory impairments and in additional languages appropriate to the local community. It should not be exclusively in written format, but employ other media also (Department for Communities and Local Government, 2006).

Specialised information offering advice about adaptations relating specifically to the child's condition may sometimes be available from parents' groups which can be contacted via the Contact a Family organisation. In particular, the Campaign for Muscular Dystrophy has an extensive range of information and advice about housing which is available free on their website. A major part of this advice comprises a manual about adaptations (Harpin, 2003) which includes a chapter for families who decide to act as their own key worker. This includes advice of relevance to families with disabled children who do not have muscular dystrophy. For example, their 10-point plan for families who decide to take a DIY approach advises families who are applying for an improvement in their housing that they may need to compromise on less important items which may be added later, but that space should be a priority.

Workers will need to liaise closely with colleagues with specialist knowledge and expertise in housing in order to facilitate the process of achieving improvements in the suitability of a family's domestic environment. In relation to information, as the process of gaining improvement progresses or falters, it is important that the disabled person and their family are kept informed 'at all stages of the provision of service' (Department for Communities and Local Government, 2006, p. 26).

Knowledge about local services is an important factor in ensuring front-line workers are sufficiently prepared for their information-giving role. Relevant background knowledge relates to how adaptation services are organised locally.

In Metropolitan Boroughs, London Boroughs and Unitary Authorities, social services and housing authorities operate within the same tier of local government.

(Department for Communities and Local Government, 2006, p. 7)

However:

The situation in county authority areas is significantly different. Here the county council is usually the social services authority whilst

housing and environmental health are the province of district councils.

(Department for Communities and Local Government, 2006, p. 7)

Thorough assessment

The inclusion of a thorough consideration of housing issues in general assessments of need is an important means of facilitating better recognition of families' requirements and thereby helping them obtain access to appropriate services.

Housing needs assessment should not simply be tagged on to the end of assessment but be considered of fundamental importance to the health and well-being of children, siblings and parents.

(Beresford and Oldman, 2000, p. 66)

Assessments should be informed by an awareness of all impairments (sensory, physical, learning, behavioural) (Bevan, 2002) and include a discussion of the merits of moving and adapting (Beresford and Oldman, 2002).

Needs must be tackled holistically.

Often it is not recognised that a housing intervention can complement or even substitute for other services.

(Beresford and Oldman, 2000, p. 49)

The Common Assessment Framework for Children and Young People (CAF) does include a consideration of housing and of social and community elements and resources. Workers need to assess whether accommodation has appropriate amenities and facilities and to explore the wider context of a child's neighbourhood and its impact on them, including their social integration or isolation (Department for Education and Skills, 2006).

Beresford and Oldman point out:

It is not simply a question of recognising a housing need in the assessment process but having a sound and transparent system of referring that housing need and acting upon it.

(Beresford and Oldman, 2000, p. 49)

Thorough assessment is the second overarching theme in the National Core Offer. Assessments are to be 'holistic, multi-agency and co-ordinated' (see Department for Children, Schools and Families, 2008, p. 3) and:

Undertaken by staff with the right skills for onward referral or diagnosis, assessment, treatment and ongoing care and support.

(Department for Children, Schools and Families, 2008, p. 3)

Workers need to know how to facilitate a specialist assessment with reference to housing:

Assessment for adaptations will generally be carried out by a member of the Community Occupational Therapy Team.

(Department for Communities and Local Government, 2006, p. 31)

In addition, paediatric occupational therapists may be involved in the provision of adaptations, and information collected in assessments at school may also be relevant (Department for Communities and Local Government, 2006).

Research suggests that housing assessments and interventions should consider the needs of the whole family (disabled child, parents, siblings) and take into consideration developmental and long-term needs (e.g. Bevan, 2002). Policy documents make the same points.

Assessments should take into account:

the child's changing developmental need and his or her progress towards maximum independence.

(Department for Communities and Local Government, 2006, p. 33)

The use of some type of self-assessment is considered 'good practice' (Department for Communities and Local Government, 2006, p. 32) and, in the case of disabled children, this means involving the carers, as well as the child, where possible:

Any assessment or review of needs should include the views of the child or young person and his or her parents.

(Department for Communities and Local Government, 2006, p. 33)

As well as an exploration of the needs of carers and the disabled child, a consideration of the needs of siblings is an integral part of the assessment process (Department for Communities and Local Government, 2006).

Listening to families

Families need to be presented with a full range of housing options and to be able to choose without risk of losing specialist support (Bevan, 2002). Mechanisms need to be in place to ensure:

families are fully consulted and listened to throughout the process of addressing their housing needs.

(Bevan, 2002, p. 3)

Where families are not properly consulted about their housing needs, a variety of costly mistakes are possible. Where families cannot access expert advice, they may act alone and later find their action does not lead to a satisfactory resolution of their difficulties. In particular, in the relatively common situation where a family has multiple housing needs, they may need help to decide which issues to prioritise in order to maximise their satisfaction with any changes that are made to their housing situation.

Research shows that one reason for the fitting of unsuccessful and sometimes expensive adaptations has been found to be failure to consult fully and to appreciate the family's perspective (Heywood, 2001). It is imperative that the needs of all family members are understood.

The starting point and continuing focus of those seeking to provide an adaptation service should be the needs experienced and identified by the disabled person and his or her carers.

(Department for Communities and Local Government, 2006, p. 6)

Government guidance about housing adaptations is firm in its adherence to working in partnership with families:

The process that delivers an adaptation should be one of partnership in which the person and carers experiencing the disabling environment are key partners.

(Department for Communities and Local Government, 2006, p. 6)

All aspects of provision should recognise the needs of black and minority ethnic families (Bevan, 2002). Delivering a service which meets the needs of black and minority ethnic families should take into account not only the disadvantages they may face through disability and sometimes language but also those due to workers' lack of knowledge about cultural or religious issues. Government guidance points to the dangers of:

erroneous assumptions being made by those assessing or providing service as to their cultural or religious practice or needs.

(Department for Communities and Local Government, 2006, p. 21)

Joint working

Agencies working with disabled children and their families need to share a common understanding of the housing services available and to develop joint approaches to housing at a strategic level (Bevan, 2002).

Front-line workers are required to work in partnership not only with families, but also with workers from a variety of professional groups. Sometimes they have a role to play in representing the needs and views of a disabled child and/or members of their family in negotiations about housing issues with other professionals. These workers may be colleagues who are part of the same multi-agency team, or professionals who operate at a greater distance from the point of view of active collaboration.

A modern service for the provision of adaptations needs to embrace and utilise the skills and experience of a wide range of disciplines.

(Department for Communities and Local Government, 2006, p. 6)

As indicated above, workers for disabled children and their families need to know to whom they should refer families with housing issues who need specialist advice, information and assessment. They need to establish good working relationships with occupational therapists and other housing specialists, recognising their expertise and complementary skills.

There is often a lengthy and complex process to be gone through before an improvement in the suitability of a disabled child's home can be accomplished. Workers will need to be aware of the variety of stages which are necessary and liaise with the professional who is handling this process and with the family themselves.

Government guidance about adaptations notes the 'high levels of stress experienced by parents with a disabled child' (Department for Communities and Local Government, 2006, p. 33).

Families may be in need of emotional support throughout the process associated with achieving improvements in their housing circumstances, whether their means of gaining improvement involves moving house or adapting their existing property. Possible delays or obstacles may exacerbate their stress levels. Families may need support in terms of both obtaining an improved environment and then adjusting to their changed housing circumstances.

In some situations, practical support may be required which workers can facilitate. For example, the actual process of moving or adapting may make increased access to short breaks or domiciliary care essential at the time of greatest upheaval and disruption.

Families appreciate having a single point of contact or staff member who will take a family through the whole process (Bevan, 2002). Government guidance about housing indicates the value of key working in this area:

There is clear evidence that key workers can have a vital role in liaising with social workers, occupational and physiotherapists, educational and other staff to ensure that assessments and services meet the family's needs as far as possible.

(Department for Communities and Local Government, 2006, p. 33)

While specialist work in housing is not the province of non-specialist workers, front-line workers can play a part in:

- assisting in the identification of housing need (including such issues as disrepair);
- provision of information about making housing improvements;
- ensuring that meeting a family's housing need is considered as part of inter-agency assessment and planning;
- referral to the appropriate housing specialist;
- liaison and negotiation with the professionals involved;
- supporting the family through what may be a complex and lengthy process;
- monitoring a family's housing situation on a continuing basis.

Knowing routes to housing improvement

Negotiating improved housing

Families with a disabled child may be faced with a variety of housing issues. These include:

- overcrowding and a lack of space;
- lack of access and inadequacy of functional rooms;
- location;
- condition of their home;
- safety.

Some of these issues are most successfully resolved by moving, while others can be overcome by improving a family's existing home, sometimes by the installation of adaptations.

Where unsuitable housing is identified as an issue for a disabled child and their family, research suggests that slightly more parents would prefer to move than to adapt their present home. Where families faced a problem because of the location of their home or because of lack of space, they preferred to move. However, tenure also influenced families' preferences about how to overcome the housing issues they faced and owner-occupiers were more likely to prefer to adapt (Beresford and Oldman, 2002).

A key question for families and their workers is: What improvements are possible and how can they be negotiated? The answer to this question depends in part on whether the family is an owner-occupier or a tenant – and, if they are a tenant, on the legal status of the tenancy. Table 1 sets out which courses are available to families with a disabled child according to the type of housing issue faced and the type of tenure.

Further information about the legislation referred to in Table 1 can be found later in this chapter.

Housing law can be very complicated and if there are any questions regarding the type of tenancy or the housing status of the family, specialist advice should be sought. Specialist advice may also be necessary before taking enforcement action against private landlords as the family may not have secure tenure.

Getting to know local housing services

Those working with disabled children and their families who are not specialists in housing may well be unfamiliar with all or part of their local pattern of housing services. The box opposite sets out questions they can ask themselves about services in the area where they work so that they can establish what they know and what they may need to find out.

Good practice and housing for disabled children and their families

Bevan (2002) has produced a useful checklist about housing and disabled children which highlights characteristics of good practice. It poses questions about local authority services which can be used to identify areas of good practice and those where efforts are needed to bring about more progress (see Table 2 below).

Knowing housing signposts

Local structures

- Who is the local housing authority?
- What section/s within the housing authority deal with the following issues:
 - Statutory overcrowding?
 - Housing renewal?
 - Disabled Facilities Grants?
 - Homelessness?
 - Anti-social behaviour?

Social renting locally

- Does the housing authority have any stock itself (council housing)?
- Which housing associations have properties in the local area?

Advice

- Is there a Home Improvement Agency available locally?
- Is there an independent housing advice service available locally?
- What other local organisations might be able to offer advice (e.g. CAB)?
- Do you have information about national advice links (e.g. Shelter)?

Table 1: Negotiating housing improvements

Overcrowding/lack of rooms/inadequate space within rooms	
All tenures (owner-occupation; private renting; social renting)	Statutory overcrowding (as defined by the Housing Act 1985) may give some priority to somebody wanting to access social housing or, if they already live in social housing, priority to transfer to another property Enforcement of the Act is either via the local housing authority or by private action
	If the lack of space directly relates to the child's impairment, it may be possible to apply for a Disabled Facilities Grant (see below)
Lack of access and/or difficulty using functional rooms	
All tenures (owner-occupation; private renting; social renting)	If the family wants to stay in their current home, this sort of issue is classic territory for applying for a Disabled Facilities Grant (DFG) . DFGs fund adaptations and are funded through, and administered by, local housing authorities . An assessment of whether work is 'necessary and appropriate' is required and this duty falls to children's services authorities who also have the power to contribute towards the costs of work carried out
Private renting	Private tenants can use the Disability Discrimination Act 1995 (as amended by the Disability Discrimination Act 2005) to ask private landlords to approve any 'reasonable adjustments' proposed for their home
Social renting	Some council housing departments have their own process for adaptations and do not require their tenants to apply for a DFG. However, this does not mean their tenant does not have a legal right to do so, and the terms of the landlord's own scheme should not be less favourable than that of the DFG system
	Some housing associations contribute towards the costs of adaptations for their tenants but this should not be used by the landlord or the local housing authority as a reason for delaying the DFG process
Location (including problems with neighbours)	
All tenures (owner-occupation; private renting; social renting)	If a family intends to move and their child's needs mean they require specific features in their new home, they may want to seek the professional advice of an occupational therapist (OT) . Some local authority or health service OTs will offer this service
	For neighbour problems, the first point of call might be the local authority which must by law have an Anti-social Behaviour Strategy . This should outline what is available locally to tackle problems, including preventative measures such as local mediation services The Environmental Protection Act 1990 applies to noise nuisance and statutory nuisance that is prejudicial to health. Enforcement is via the local housing authority or by private action
Owner-occupation	If the family has the necessary resources, they can obviously buy elsewhere. If not, they can apply for social housing or seek a private let The Regulatory Reform Order 2002 gives local housing authorities the flexibility to assist with moving costs in some circumstances
Social renting	The moving options open to social tenants who are not able/do not want to buy include applying through the waiting list to other social (or private) landlords, applying to their own landlord for a transfer , or pursuing a ' mutual exchange ' (whereby tenants literally 'swap' properties with the prior approval of their landlord/s) Social landlords are required to have a policy in place relating to neighbour nuisance and anti-social behaviour which may be of use to families whose problems relate to these issues
Private renting	As for owner-occupation
House condition (e.g. problems with damp; disrepair)	
Owner-occupation	The local housing authority should have a Housing Renewal Assistance Scheme in place. This will outline which homeownership households may be eligible to apply for grants or other means of assistance to improve the condition of their homes (in some circumstances, this includes help with moving). Schemes must be flexible and consider individual needs
	In some areas, there may also be a local Home Improvement Agency (HIA) . HIAs sometimes administer financial help on behalf of the local authority and also provide practical assistance with things like specifying what work is needed and supervising building works
Privately rented property	Landlords have a legal duty to maintain property in good repair , encompassed in various pieces of legislation (Defective Premises Act 1972; Landlord and Tenant Act 1985; Environmental Protection Act 1990; Housing Act 2004 (Housing Health and Safety Rating System)) Enforcement of this legislation is either via the local housing authority or by private action

Socially rented property	<p>Most social landlords will have service-level agreements with their tenants for repairs, giving response times for works to be carried out. If they are not delivering on their obligations, they will have internal complaints procedures</p> <p>If there has been ‘maladministration’, tenants also have recourse to the Local Government Ombudsman (council tenants) or the Housing Ombudsman (housing association tenants)</p>
	The means of legal redress under the Landlord and Tenant Act 1985 is also open to social housing tenants. However, since local authorities do not prosecute themselves, enforcement for council tenants relies on private action
All tenures (owner-occupation; private renting; social renting)	In the worst situations it may not be reasonable to continue to occupy the accommodation and a homeless application may be appropriate. Local housing authorities deal with statutory homelessness (as defined by the Housing Act 1996). However, the property’s condition will be judged in relation to the prevailing conditions of properties in that area in deciding ‘reasonableness’
Safety within the home	
All tenures (owner-occupation; private renting; social renting)	If the safety issue is related to the child’s impairment, the householder can apply for a Disabled Facilities Grant (see above)
	If the safety issue is extreme , it may not be reasonable to continue to occupy the accommodation and a homeless application may be appropriate (see above)

Table 2: Housing and disabled children - checklist for change

<p>Is there an awareness and acceptance of all impairments (physical, sensory, learning, behavioural)?</p> <p>Is there an awareness and acceptance of the particular needs of black and minority ethnic families?</p>	ACCESS	• Is there a common understanding between agencies of what housing services are available to families with disabled children?
		• Is information about housing services widely promoted to families with disabled children themselves?
		• If families approach non-housing agencies for advice/ information (e.g. health services) are possible housing issues identified and referred/sign-posted on?
		• Do Children Act assessments of disabled children routinely investigate possible housing problems?
		• If so, is this interpreted more widely than ‘access’ (i.e. space, location, disrepair)?
		• Do families have access to an independent advocacy resource with an understanding of likely housing issues?
	DELIVERY	• Are families presented with a full range of housing options (moving, adapting, etc.)?
		• Can they choose between available options without risk of losing specialist support (e.g. OT input)?
		• Are mechanisms in place to ensure that families are fully consulted and listened to throughout the process of addressing their housing needs?
		• Is there a single point of contact/designated member of staff who will take a family through the whole process?
		• Do housing assessments/interventions consider the needs of the whole family (disabled child, parents and siblings)?
		• Do services take into consideration developmental and long-term needs (e.g. ‘incremental adaptations’)?
	STRATEGY	• Is there a common understanding between agencies of the extent/range of unmet housing need in this group?
		• Are there specific joint arrangements that are or could be utilised to meet housing needs (e.g. pooled budgets)?
		• Are the needs of disabled children made explicit in local housing strategies?
		• Are needs translated into planned actions (e.g. targets for new-build provision, adaptations to facilitate safe play)?
		• Is advantage taken of housing policy developments in other spheres (e.g. choice-based lettings, renewal grant targeting) to address issues faced by this group?
		• Are families with disabled children consulted as part of strategic developments or in-service reviews?
ALL	IF THE ANSWER IS ‘NO’, WHAT ACTION COULD BE TAKEN?	

Information from Bevan (2002).

The legislative framework

The legal framework which underpins this area of work is complex (Department for Communities and Local Government, 2006), but an awareness of key laws relevant to housing provision and improvement is a useful background for workers responsible for service co-ordination for families with a disabled child. However, workers need to be aware that laws and government guidance are liable to change, through case law decisions as well as through government action. They are also susceptible to differences of interpretation at local level.

The legislation included here is presented in chronological order.

Chronically Sick and Disabled Persons Act (CSDPA) 1970

Section 2 of this Act sets out a broad range of local authority services for which arrangements must be made if the local authority is satisfied that it is necessary to meet a person's needs.

The services include:

the provision of assistance for that person in arranging for the carrying out of any works of adaptation in his home or the provision of any additional facilities designed to secure his greater safety, comfort or convenience.

(Mandelstam, 2005, p. 19)

The CSDPA 1970 was passed at a time when the extent, severity and complexity of need affecting disabled people, and especially disabled children, were very different from those prevalent today. Despite this, it has been accepted for many years that the provision of substantial adaptations comes within the orbit of the CSDPA 1970. Mandelstam (2005) points out that:

Successive sets of guidance issued by central government have consistently assumed that if a person's needs are not met through a disabled facilities grant, then in some circumstances local social services authorities may have substantial responsibilities for arranging and, if necessary, funding adaptations under the 1970 Act.

(Mandelstam, 2005, p. 13)

The CSDPA 1970 continued to apply to children after the implementation of the Children Act 1989. This is significant because the 1970 Act creates 'a strong, enforceable duty' (Mandelstam, 2005, p. 19) which section 17 of the Children Act 1989 does not (for more details, see below and Mandelstam, 2005).

Defective Premises Act 1972

The Act makes landlords liable for compensation where damage or injury results from disrepair. No notice is required to be given to the landlord and the Act covers anyone who might reasonably be expected to be affected such as members of the family and visitors.

Housing Act 1985

Under Part X of the Act there are two standards taken into account when determining whether a property is overcrowded. A dwelling is overcrowded when the number of persons sleeping in it contravenes either the room standard or the space standard.

The room standard, set out in section 325 of the Act, is contravened when the number of people and the number of rooms in the property available as sleeping accommodation mean that two people of the opposite sex, who are not living together as a couple, must sleep in the same room. Children under the age of 10 are ignored and the rooms available as sleeping accommodation can include most rooms in the property.

The space standard, set out in section 326 of the Act, is contravened when the number of people sleeping in a property is in excess of the permitted number, having regard to the number of people and the floor area of the rooms available for sleeping accommodation. For this purpose children under the age of 1 will not be taken into account and children under the age of 10 will be counted as half a person.

Applying the figures set out in Tables 2 and 3, and disregarding rooms with a floor area of less than 50 square feet for both, the permitted number of persons is the lesser number.

Table 3: Permitted number of persons in relation to number of rooms (Housing Act 1985)

Number of rooms	Number of persons
1	2
2	3
3	5
4	7½
5 or more	2 for each room

(Adapted from Table I of section 326)

Table 4: Permitted number of persons in relation to floor area (Housing Act 1985)

Floor area of room	Number of persons
110+ sq. ft	2
90–110 sq. ft	1½
70–90 sq. ft	1
50–70 sq. ft	½

(Adapted from Table II of section 326)

Landlord and Tenant Act 1985

Section 11 states that the landlord must keep in repair the structure and exterior of the property and keep in repair and proper working order installations such as water or gas pipes, electrical wiring, water tanks, boilers, radiators and other space heating installations such as vents for underfloor heating. The obligation requires the landlord to put the property in repair if it was not so at the start of the tenancy.

The landlord must be informed of the problem and a reasonable time allowed for the repair. There is no definition of ‘reasonable’, but for local authorities or housing associations there may be some indication in their housing repairs policy.

If the landlord fails to carry out repairs required by section 11 the tenant may take action in the county court. However, they must follow a set protocol and timetable from the date of the first letter to the landlord before action can be taken in court.

Specialist advice should be sought as to whether the type of letting is covered, whether legal action might jeopardise the future tenancy, and what the necessary protocols are.

Children Act 1989

Section 17 introduces a duty to safeguard and promote the welfare of ‘children in need’, including

disabled children. Harpin (2003) noted that while some social services departments did help to fund adaptations for disabled children under section 17, many did not. She continues:

It is reasonable to say that the overwhelming priority to Social Services of child protection issues has led to a failure to implement adequately the provisions of the Children Act as they relate to disabled children and their siblings.

(Harpin, 2003, Chapter 12, p. 19)

Monies for improving the housing circumstances of disabled children may be made available under section 17 in certain circumstances and local authorities have sometimes taken this course. However, it seems reasonable to assume that children’s services agencies are unlikely to take this type of action under section 17 very often, in light of the continuing pressure from child protection cases. (For information about the position of disabled children who receive foster care, see the case study outlined on pages 30–31.)

Environmental Protection Act 1990

Under the Act the local authority is under a duty to take steps to investigate complaints of statutory nuisance. Statutory nuisance is defined as where any premises are ‘in such a state as to be prejudicial to health or a nuisance’ (section 79(1)(a)). The Court of Appeal has ruled that this is limited to disease and not to risk of accidental injury, so matters such as a dangerous staircase are not covered by this Act.

Where the local authority is satisfied that a statutory nuisance exists, it must serve an abatement notice, normally on the owner, requiring the abatement of the nuisance or the execution of necessary work. It is a criminal offence not to comply with an abatement notice. The local authority can also take action itself to abate the nuisance and then recover its costs.

As a local authority cannot take action against itself this procedure does not assist those in accommodation rented from the local authority. However, any person affected by a statutory nuisance can start proceedings in the Magistrates’ Court and may obtain redress whoever is the landlord.

Disability Discrimination Act 1995

The Act, as amended by the Disability Discrimination Act 2005, generally prohibits discrimination on the grounds of disability in the provision of housing. Some tenants, for example tenants of local authorities, already had rights concerning a landlord's consent to make improvements. Since December 2006 landlords cannot unreasonably refuse other tenants consent to make a disability-related improvement. Even in cases where the tenancy prohibits the tenant making any alteration or improvement, the tenant may be able to have this term changed. In all cases the landlord may give consent subject to reasonable conditions.

Housing Grants, Construction and Regeneration Act 1996

This Act is the legislative basis for Disabled Facilities Grants (DFGs), which is a system of mandatory grants operated by local housing authorities to fund the provision of adaptations to enable disabled people to live comfortably and as autonomously as possible:

The DFG has proved to be a highly successful programme providing adaptations to around 35,000 people each year, enabling them to continue to live independently in their own homes.

(Department for Communities and Local Government, 2008, p. 5)

For an indication of the breadth of the provisions regarding the DFG, see Appendix 1. From May 2008 access by a disabled person to their garden falls within the scope of the DFG. Also since May 2008, the maximum limit for the grant has been raised to £30,000. There is no means test for an application for a grant made on behalf of a disabled child.

The conditions for a Disabled Facilities Grant:

are basically that the person be disabled according to the relevant definition, that the adaptation be adjudged necessary and appropriate (by the local housing authority but on the basis of social services recommendation) – and that the adaptation be reasonable and practicable having regard to the age and condition of the dwelling.

(Mandelstam, 2005, p. 31)

Housing Act 1996

The Act requires a local authority to have a scheme for determining priorities and the procedure generally to be followed in allocating housing.

Specifically the Act, as amended, now provides that:

As regards priorities, the scheme shall be framed so as to secure that reasonable preference is given to ... people who need to move on medical or welfare grounds including grounds relating to a disability.

(Housing Act 1996, section 167(2)(d), as amended)

The words 'including grounds relating to a disability' were added in April 2005.

Carers and Disabled Children Act 2000

According to government guidance, this Act:

provides powers for the social services to provide any services which the local authority sees fit to provide and which will in the local authority's view help the carer care for the person cared for.

(Department for Communities and Local Government, 2006, p. 9)

Regulatory Reform (Housing Assistance) (England and Wales) Order 2002

This Order provides local authorities with discretionary powers to provide financial assistance for housing adaptations. There is no restriction on the amount that may be given, which may be provided in addition to or instead of a mandatory DFG. Importantly, the Order's provisions are flexible and can be used, for example, to assist with moving costs.

Housing Act 2004

Part 1 of the Act replaces the previous housing fitness standard with the Housing Health and Safety Rating System. It also adapts and extends the powers of enforcement available to local housing authorities to tackle poor housing conditions in residential premises generally. Residential premises include self-contained dwellings of all types and homes in multiple occupation (see sections 1(4) and (5) of the Act).

These powers help local housing authorities prioritise their intervention based on the severity of the health and safety hazards in the home. Local housing authorities have a general duty to take action to deal with the most serious hazards, as well as discretionary powers to take action to deal with less serious hazards. These provisions came into effect on 6 April 2006.

Conclusion

Dealing effectively with the housing issues which face disabled children and their families requires that front-line workers carry out generic tasks in a way which recognises the major significance of a suitable domestic environment. Families need adequate and timely information about housing which recognises the variety of potential issues and possible remedies. Assessments should be genuinely holistic, recognising the importance of housing circumstances to families' well-being. Full consultation with families is essential to ensure the best available outcome. Joint working by professionals is needed to facilitate a complex process. In addition to generic skills, knowledge specific to housing is necessary. This includes being aware of the national legislative framework and the means by which this can be utilised to bring about housing improvements. Workers also need a critical awareness of local housing services.

3 Housing issues and outcomes: the experiences of some disabled children and their families

Our life has been transformed.
(Beresford and Oldman, 2000, p. 28)

This quotation from a parent who had just moved into a specially designed home highlights the potential of appropriate housing to promote very positive changes in the lives of disabled children and their families.

This chapter provides descriptions of the housing circumstances of some disabled children and their families in order to illustrate the positive change possible and some of the complexities involved in achieving the best housing outcomes. The discussion which follows each family's scenario pinpoints some of the salient aspects of the particular circumstances described.

Each family's circumstances are inspired by real life experiences of disabled children. The first four scenarios are described prior to and following a referral for an occupational therapist's assessment. The fifth deals with a situation where the local authority's decision was contested in court. Information about the last two families' stories emerged from research studies.

The resolution of the problems the families faced tended to rely heavily on the award of a Disabled Facilities Grant. This is because a Disabled Facilities Grant has often proved in practice to be the principal route to housing improvement. However, the other potential routes to housing improvement indicated in the previous chapter are also relevant and should not be overlooked.

Addressing access issues

Jane, who was 9 at the time a housing assessment was requested, uses a wheelchair and has significant learning difficulties. Her parents are owner-occupiers. At the time of the referral to an occupational therapist Jane lived with her family in an unadapted dwelling, close to her maternal

grandparents. She was dependent on her mother for getting into the house, getting upstairs, going to the toilet and bathing. At the time of the occupational therapist's assessment Jane appeared to feel anxious when her mother's attention was engaged elsewhere, and her behaviour was described as 'clingy'. Her mother was keen to improve the house to suit Jane better, but was very unsure about how this might be accomplished.

The occupational therapist's assessment was that Jane's needs and her housing circumstances qualified for a Disabled Facilities Grant. During the decision-making process about how to improve Jane's domestic environment, the occupational therapist took Jane, her mother and grandmother on a visit to the local Centre for Independent Living where Jane and her family could see and try equipment which might be helpful to Jane. Subsequently Jane's home was provided with ramps, wider doorways, an electric shower, a self-cleaning toilet and a vertical lift. After the adaptations had been completed, Jane was able to get into and around the whole house independently, and could go up to her bedroom and the toilet unaided, as and when she chose. By the time of the occupational therapist's final visit Jane's behaviour had changed dramatically, and she was occupied independently carrying out activities in different parts of her home according to her preference. Now that Jane was no longer reliant on adult help to achieve basic tasks she had ceased to monitor her mother's availability, since she was busily engaged in enjoyable activities around her home. Her demeanour suggested a much happier, more confident child who could make autonomous decisions. Jane's mother endorsed this impression.

Discussion

- This scenario illustrates the *positive changes* that are made possible by the provision of

appropriate housing. It also highlights how an unsuitable environment may have a negative effect, not only on the workload of care-givers and the autonomy of the disabled child, but also on that child's development and emotional well-being. Jane's demeanour and behaviour had changed markedly by the time the family's occupational therapist carried out a follow-up visit, demonstrating how powerful an effect a domestic environment can have on a child's confidence levels, as well as a family's day-to-day experience.

- This scenario also demonstrates direct *positive outcomes for Jane's family* since the adaptations also markedly reduced the danger that Jane's mother might damage her back when lifting her.
- The outcomes for Jane and her family were enhanced by the care taken to *consult fully* with them about what was possible. Time was spent in negotiations with the family to ensure that they felt they had ownership of the solution to their housing constraints. Where a service user has a cognitive impairment, communicating about potential improvements may be difficult if the communication used is solely verbal. In this case, actually seeing and trying equipment helped Jane and her family to be better informed and more fully involved in making decisions about what adaptations would work for them. Where service users and their families want to see and/or try a particular type of facility they may be assisted by a visit to a Centre for Independent Living – this is particularly useful for those who need help to envisage an option by seeing a concrete example.
- The *whole family* were involved in the consultations. This family also found it helpful to involve members of the extended family in the process of deciding about the solution to a family's housing problems, as it offered an extra sounding board for parent and child.

Space as a barrier

Anna has a progressive condition which affects her mobility and is a wheelchair user. Anna's parents are owner-occupiers. Six years ago, when she was 9, her family home was assessed for its suitability to meet her needs. Space was at a premium in Anna's home where a vertical lift would have been unsuitable, as would a stair lift. A Disabled Facilities Grant was awarded and a downstairs bedroom was built with a small shower room in one corner.

Although this bedroom extension met Anna's needs for some years, her condition is now such that she cannot move in bed. Anna's situation has been reassessed and it is clear that it could be improved by the provision of a profiling bed. (Profiling beds are electrically adjustable in order to enable the user's position to be changed without strain for anyone else involved.) However, Anna's bedroom is not large enough to accommodate the new bed, while still allowing for the adequate circulation of her wheelchair and for the carrying out of prescribed therapies. The solution which has been agreed is that the en-suite shower room will be demolished in order to enlarge the bedroom. The original extension is to be further extended by the addition of a new bathroom for Anna. This work is to be supported by a Disabled Facilities Grant.

Discussion

- Research about the housing circumstances of families with a disabled child suggests that Anna's experience of *needing more than one improvement* to her home is *not an unusual one*. Some families may experience a series of changes in their housing situation in order to meet developments in their circumstances as appropriately as possible. This scenario highlights how improvements in housing may meet a child's needs in the short term, but that earlier solutions may eventually become unsuitable and need reassessment and revision.

- Anna's story also demonstrates the requirement for *likely longer-term needs to be taken into account* when devising solutions to housing problems, especially where a child's condition is expected to deteriorate in the future. Although the original extension provided a suitable environment for Anna and her family for some years, in the medium term it could not adequately accommodate a growing girl with increasingly poor health. However, these are difficult areas to manage, both in terms of foreseeing future developments and in discussing sensitive issues with a disabled child and her family. With the value of hindsight, to have built a larger original extension for Anna would have been the preferred option.
- Sometimes *funding constraints* prevent an ideal solution becoming a reality. However, when a major adaptation will cost more than the mandatory maximum for a Disabled Facilities Grant the local authority may have mechanisms for 'topping up' the grant.

Utility of specialist advice

Jack was 3 years old. Jack had learned to crawl and to walk, despite being affected by a cognitive impairment. However, he was very overweight; this is a common aspect of Prader-Willi syndrome by which Jack was affected. It was difficult for Jack's mother to get him up and down stairs. An occupational therapist's advice was therefore sought. On superficial analysis it appeared that a stair lift might be helpful to the family. It also seemed that a shower might be useful, so that Jack's mother did not have to lift him in and out of the bath and risk hurting her back.

The occupational therapist's assessment was that these adaptations were not 'appropriate and necessary' at this stage, as it was important that Jack took exercise and did not continue to gain weight at the rate that he had to date. She proposed that a banister be fitted to the stairs at a height which suited Jack so that he could be encouraged to begin to learn to negotiate the stairs and develop further skills. For the same reasons, it was suggested that a useful addition in the bathroom would be a step and rails to the

bath to encourage Jack to get in and out of the bath under his own steam. On the occupational therapist's follow-up visit, Jack enjoyed demonstrating the new skills he was acquiring.

As part of the effort to keep Jack's weight gain to a minimum, a lock for the family's fridge was also supplied. This was provided by Remap, an organisation of volunteers, who can develop 'one-off' pieces of equipment that are not commercially available.

Discussion

- Sometimes the provision of housing adaptations is not the best option. Jack and his family may benefit from major adaptations to their home as he grows older and bigger. However, the decision not to provide major adaptations for Jack after the initial assessment was because his health and development were best promoted by this decision at this stage.
- In the sense that a review may be necessary as he grows older, his situation is similar to that of Anna and her family when her needs were first assessed and the original extension was designed. The scenarios of Jack and Anna illustrate that *a family's housing circumstances need to be kept under review*. Some families with disabled children need further improvements in their housing situation as their child develops and circumstances change over the years.

Promoting the well-being of the whole family

Alfie and Eddie are twins who are autistic. Until the age of 10, they shared a bedroom. Although this room was large enough to accommodate the two boys, their parents reported that Alfie was edgy and irritable with Eddie and disliked sleeping with his brother. Alfie said that the noise of Eddie's breathing 'gets on his nerves' and kept him awake at night. He became aggressive towards Eddie who was getting fearful of him. The family did not have a spare bedroom which one of the twins could occupy.

The occupational therapist's assessment was that this family needed more space on safety

grounds, because of Alfie's tendency to bully Eddie. One solution to the space problem would have been to build on a downstairs bedroom. The parents, who were tenants of a housing association, did not think that providing a bedroom downstairs would be a suitable solution since they felt the boys needed them close at hand at night and in the early morning. The family were keen to move to a larger property. The occupational therapist negotiated on their behalf and the tenancy of a house with an additional bedroom was offered by their landlord. Although the accommodation in the house on offer was perfect for the family, the family declined the tenancy because they judged that the area where the new house was available was unsuitable for their sons. Eventually the family were offered a house in a more familiar location with fewer social problems and better community facilities, which they accepted. After the move the relationship between the boys was less fraught; both were less anxious and more relaxed because they had more space and privacy. As a consequence the stress on the family as a whole was reduced.

Discussion

This family's situation raises several issues.

- This is a family where the well-being of all members was improved by a change in housing circumstances. In particular a *sibling's welfare* was a major issue which needed addressing.
- Regarding the boys' *specific impairment*, government guidance in respect of autism is:

Housing arrangements for people with autism need to take account of the social isolation inherent in their condition. Additional quiet private space may be needed, particularly for someone with autism in a shared tenancy, when disputes about TV and music channels are frequent, sometimes with serious adverse consequences. Services should be sensitive to the difficulties of children who have an autistic sibling.

(Department for Communities and Local Government, 2006, p. 36)

- Even if only one of the boys were affected by autism, there would have been clear grounds for seeking more spacious accommodation.
- As tenants of a housing association property, the family would have been eligible for a Disabled Facilities Grant, had the option of a downstairs bedroom been suitable for one of the twins. However, the provision of downstairs facilities requires an *in-depth discussion with carers* as to whether they are ready for their child to sleep downstairs. Such a solution is not right for all families. Parents need to feel that their child will be safe and happy sleeping at a distance from the rest of the family. Some parents will judge that their child is not ready to sleep so far away and that they need to be close at hand. Where supervision of a child in a downstairs bedroom is a concern, sometimes the provision of CCTV is useful, since it allows parents to keep a watch from a distance, so that they feel reassured that they are aware of their child's well-being. However, this approach needs careful consideration since it might infringe the privacy of children, especially as they mature into young people.
- The family's decision to reject the first property which was offered to them resulted in a delay to the resolution of their housing problem. However, their decision was based on the judgement that the *location* of the first property would have resulted in more problems than it solved, because Alfie and Eddie would have been at risk of bullying in a neighbourhood with a history of social deprivation. In addition, their sons' anxiety levels would have been heightened by a move to a locality which was unfamiliar to them and where the family had no social bonds.

Living in two homes

(This scenario is modified and summarised from a case described by Mandelstam. See Mandelstam, 2005, pp. 17–18 for more details.)

Liz was a disabled girl, 15 years old, who lived for part of the week with her mother. In the past the local authority had spent a considerable sum on adapting the mother's house to improve its

suitability for Liz as regards bathing, showering and going to the lavatory.

Liz also spent a proportion of each week with a foster family. This was because Liz's mother was herself unwell. The arrangement with the foster family was long-standing and Liz had a close bond with the family. However, the physical environment provided by the foster family's home was becoming increasingly unsuitable as Liz grew and matured. The foster family's house was assessed as unsuitable for adaptations, and the family wanted the local authority to support their application to buy another property under a housing association scheme. Supporting the purchase would have cost the local authority nothing, but this solution might have incurred costs for adapting the new property. Instead, the local authority deregistered the foster parents and arranged for Liz to board at school for four nights a week. This was not what Liz herself wanted. A court found that the local authority's actions had breached four provisions of the Children Act 1989.

Discussion

While Liz's situation has some unusual characteristics, circumstances where disabled children spend significant periods of time in two different homes are relatively common – typically either because of regular breaks provided with foster families (as here) or because of the relationship breakdown of the child's parents. The possibility of the provision of major adaptations to a second house may then arise.

Government guidance about children in foster care notes the variety of placement which is possible, and the responsibility of the local authority to assess the child's needs and provide appropriate services. It notes:

Foster carers are eligible for DFGs on behalf of the foster child but provision may depend on the type and length of placement.

(Department for Communities and Local Government, 2006, p. 34)

Guidance goes on to advocate the development of local agreements and protocols involving:

Housing and health partners to ensure that the welfare of children and young people in foster

care is actively promoted and that adapted property is available to meet the needs of the disabled child.

(Department for Communities and Local Government, 2006, p. 34)

The provision of adaptations for two homes may have appeared to the local authority an expensive option. However, this was not a defence in law. In any case, expenditure on the provision of a suitable home environment may reduce costs which draw on other parts of the local authority's budget. For example, where parents do not live together adaptations to the home of both may obviate the need for short breaks commissioned by the local authority. For some disabled children, improvements to their housing circumstances may help to keep the children within their communities and in a family setting, thus maintaining relationship bonds and avoiding the need for the provision of care in residential settings.

In Liz's case, the local authority's failures under the Children Act 1989 related to:

- failure to *promote her welfare*;
- failure to *minimise the effects of her impairments*;
- failure to *give due consideration to her wishes*;
- failure to *secure accommodation that was suitable for her particular needs*.

(Mandelstam, 2005)

Location may be key

Jonathan, who was 10 and had a visual impairment, got about his home independently and generally experienced few problems accessing any of the rooms, so long as they were kept tidy, with the furniture in its usual place. From early childhood he developed a 'mental map' of his home and could negotiate its layout. He also acquired a good mental map of his locality which he had learnt through walking to school with one of his parents. He was relatively familiar with the layout of neighbouring homes because they were built with a similar layout to his own. However,

his mother reported that he could not proceed safely beyond the garden gate without an adult, because the environment outside the garden was dangerously unpredictable for him. The road was sometimes very busy, and while this barrier might have been overcome, there were other aspects of Jonathan's immediate environment which were hazardous and a potential threat. Discarded hypodermic needles were sometimes to be found locally and some children in the neighbourhood had been unpleasant to Jonathan so that he was isolated socially in his home and his opportunities for mixing with his peers were very restricted. Moreover, his opportunities for developing autonomy were reduced. Jonathan's family, who were tenants of a housing association, applied for a move to a more congenial location. This took a great deal of negotiation and persistence on their part. Part of the delay was induced by their landlord's lack of appreciation of Jonathan's strengths and needs.

Discussion

The history of Jonathan and his family highlights the following:

- The importance of the *location* of a home, rather than what it has to offer in terms of facilities, space or repair, may be highly significant to some disabled children and their families. The neighbourhood in which Jonathan was raised presented problems to many members of the local community. However, Jonathan was particularly adversely affected because of the nature of his impairment.
- The family faced delays in negotiating a move partly because the right housing in the right place was in *short supply*. This is a common phenomenon.
- The nature of Jonathan's *specific impairment* had consequences which were not appreciated because of the narrowness of the landlord's understanding of disabled people's needs.

Research (Allen *et al.*, 2002) with visually impaired children has demonstrated how they are active within their own homes and neighbourhood. The children in their study appeared to develop 'mental

maps' of the built environment so that they gained the capacity to negotiate the built environment well, so long as it was predictable. Where external circumstances were unpredictable, then the situation could become unpleasant, or even unsafe.

Where their parents tried to negotiate moves from inhospitable areas to a location which offered their child more opportunities to explore, socialise and use local facilities, they could find their landlords' comprehension of 'disabled housing' was limited to buildings suitable for physically impaired people (typically single adults or adults-only households). Allen *et al.* (2002) recommend that social needs should be taken into account when decisions are made about rehousing children with visual impairments.

Effects of multiple disadvantage

Rafiq and Joshua were two boys of about 12 years of age whose circumstances came to light in the course of a research study. The situations of the two boys are included here because it is informative to compare the difference in housing outcomes for the boys, who shared some common characteristics in terms of age, impairment, family income and housing issues.

The research explored the effects of a congenital condition which necessitated, for each boy, several operations and left them with marked degrees of incontinence of the bowel. The boys, who lived in different parts of England, attended mainstream schools and were assumed to be non-disabled by their peers, from whom they kept their condition secret. Each boy lived in owner-occupied accommodation. Their family homes each had one bathroom in which both boys needed to spend a good deal of time, which had negative repercussions for the rest of their families. The boys faced problems relating to cleanliness and privacy at home. Out of the house they had to cope with embarrassment and potential shame in social situations.

Rafiq's family originated on the Indian subcontinent and his parents' first language is Bengali. His parents had many anxieties about Rafiq and the effects of his incontinence as regards his acceptance by his peers and the family's broader community. They lived in an inner London

borough with many pressures on housing, so that the house they could afford was small and in poor repair. Rafiq had a brother with whom he shared a bedroom. The lack of a separate bedroom for Rafiq resulted in his incontinence impinging much more acutely on his emotional well-being and on that of his brother.

Joshua's family lived in a semi-detached house in a metropolitan area where housing cost less than in London, so that the family had a more modern property, which was in better repair and had a garden. Unlike Rafiq, Joshua did not have to share a bedroom with his brother. However, as in the case of Rafiq, the inadequacy of the family's bathroom facilities impinged on his physical and emotional well-being and that of his family. Joshua's social worker referred the family for an occupational therapist's assessment which eventually resulted in a shower and lavatory being installed for Joshua, which improved his hygiene and ensured his privacy, as well as maximising his opportunities to be as clean as possible.

Discussion

The impairment of these two boys resulted in a good deal of physical and emotional discomfort because incontinence is so socially unacceptable. Their families had many difficult practical issues to deal with. However, only one boy had been referred for an occupational therapist's assessment, although the other boy and his family faced more multifaceted housing problems. This disparity highlights both the randomness as to who is referred for assessment and the important role that can be played by front-line workers and other professionals, who are in a position to act as referring agents.

The most significant difference between the two boys, in terms of achieving improvement in housing, was that Joshua and his family were in contact with a worker who acted to ensure as positive an environment for him as possible. By comparison, Rafiq's family were much more isolated from services and were unfamiliar with the pattern of service delivery. This situation was exacerbated by the fact that English was not the first language of Rafiq's parents.

The situations of Joshua and Rafiq illustrates that:

- Children with impairments which are not readily apparent or even hidden may require an assessment of their housing circumstances.
- The isolation of Rafiq's family from local services meant he and his family were particularly disadvantaged in terms of accessing housing improvements.
- The availability of sufficient bathroom accommodation for disabled children and their families is important if the dignity and privacy of all family members are to be ensured. However, full discussion of a family's situation may sometimes be limited by social constraints.

If Rafiq and his family received specialist advice there are several factors which would have to be taken into account which did not apply to Joshua:

- Great care would have been necessary in negotiations with the family in order to ensure a solution which was culturally sensitive. These negotiations were likely to need the assistance of an interpreter.
- Rafiq's home was in a poor state of repair. Assuming similar adaptations to those for Joshua were assessed as being 'necessary and appropriate', it is possible the family would not have been awarded a Disabled Facilities Grant because of the poor state of repair of the house. (Adaptations must be judged 'reasonable and practicable' before a DFG is awarded.) Therefore the state of repair of Rafiq's family home would have needed especially urgent attention.
- Another area of need related to the family's lack of space and, in particular, the shared bedroom accommodation. Government guidance requires assessments and reviews to take account of the needs of any non-disabled children in the family.

The housing situation of Rafiq and his family could be held to typify the research evidence which points to a higher incidence of multiple housing problems in some minority ethnic groups. It also highlights the need for informed intervention.

Conclusion

The housing experiences outlined above highlight:

- the significance of housing in affecting the well-being of disabled children and their families;
- the need for specialist assessment of the suitability of disabled children's domestic environments;
- the need to consider the suitability of the domestic environment of children with all types of impairment, while also taking into account the needs of their families;
- the complexity of factors which affect the outcome of efforts to improve the suitability of a family's home, and the need for foresight, planning and review;
- the important role that front-line workers can play in promoting improvements in the housing circumstances of disabled children and their families;
- the need to consult fully with disabled children and their families about their housing circumstances.

4 Training about housing for disabled children and their families: designing and running a workshop

Tackling issues of discourse, to shift the thinking from 'welfare' to 'investment', is part of the strategic challenge.

(Heywood *et al.*, 2005, p. 7)

Heywood *et al.* (2005) have argued that the provision of an enabling home environment is a key part of community care and that housing suitable for disabled people should be regarded not as welfare, but as an investment for the future. In light of what is known about the significance of housing to disabled children and their families, disseminating information about the subject as widely as possible is an important way of bringing about change. Described below is experience gained in the course of providing relevant training for interested non-specialists.

Development of housing workshops

While this information resource was being developed, Care Co-ordination Network UK ran three half-day workshops about housing for disabled children and their families which drew on its contents. Some of the materials developed are reproduced here as an aid to others who may wish to make a similar effort. These materials may be copied and adapted. They are not intended as blueprints, and workshop leaders may well wish to improve on the materials or to design their own. However, the workshops were generally well received and it was obvious that there is a good deal of interest in the subject area.

The target audience was people with responsibility for co-ordinating services for disabled children and their families who were interested in training about housing. Many participants were key workers, but some managers and some parents also attended. Most had little or no prior training in housing, although the subject was relevant to their role. Many participants had acquired related experience as a consequence of their work and

often had a practice-based awareness of issues which families might face.

The aims of the workshops were:

- to expand and enhance participants' knowledge of housing issues faced by families with a disabled child, with special reference to recent research findings;
- to highlight the role of non-specialist workers in addressing housing need and explore their possible courses of action.

The programme for the workshops was as follows:

- An introductory exercise was used, which was intended to encourage an interactive approach and focus participants' attention on the central and multifaceted significance of housing in their own lives and, by implication, those of families with disabled children (see Appendix 2).
- A quiz was presented as a series of written questions on a sheet for completion by the participants individually. The sheet was titled 'Housing for families with a disabled child: how much do you know?' The questions concerned areas of housing issues about which recent research evidence is available (see Appendix 3). Answers were shared as a group, and subsequently quiz sheets complete with answers were available for participants to take away (see Appendix 4).
- Participants were invited to assess the housing services for the locality with which they were familiar against the checklist produced by Bevan (2002); see Chapter 2.
- Case studies (developed from some of the families' stories in Chapter 3) were considered in small groups, prior to a plenary session in which issues emerging from the case studies

were shared and discussed. Written details of each of the case studies were available for participants to take away.

- A DVD available from the Joseph Rowntree Foundation was used to reinforce learning. The DVD highlights the significance of housing for disabled children and their families. This information is presented from the perspective of young people themselves and that of their families, supplemented by the views of experienced professionals.

The workshops, which were each attended by about 20 participants, were evaluated by questionnaires completed by the participants. Overall the participants liked the variety of methods used to deliver the information. In terms of content they were interested in both the research evidence which was presented in the first half of the workshop and in the practice issues which emerged from the case studies. They were keen to learn about research, policy guidance and legislation which could help to improve the circumstances of service users. Subjects about which participants raised questions included research which demonstrates the cost-effectiveness of improved housing, policy guidance which recognises the needs of overlooked groups (e.g. autistic children) and legislation which facilitates access to better housing.

The workshops lasted about three hours including a short break. Where time is available for more extended coverage of the subject matter, more detailed training would be desirable, especially about the specific ways of negotiating housing improvements for families. There is scope for the development of exercises for a longer workshop to be designed utilising the materials within this resource, so that more thorough coverage of relevant information is possible. For example, Table 1 and the box 'Knowing housing signposts' in Chapter 2 offer potential training materials.

While the specific content of workshops will vary according to the resources available and the

sophistication of the participants, it is important that workshops should indicate sources of further learning and information so that participants can pursue the subject further.

Conclusion

Training about housing for disabled children and their families should include key messages from research evidence about the extent of housing need among families with disabled children, plus information about how improvements can be facilitated.

Training is useful when it presents information about:

- the extensive research evidence underlining the importance of suitable housing to families of disabled children;
- government policy which now recognises the significance of an appropriate domestic environment to disabled children and their families;
- the legal framework which, despite its complexity, provides opportunities for the improvement of disabled children's housing;
- the role that professionals, working with disabled children and their families, can play in the identification of housing needs and the co-ordination of an effective response.

The rationale for these efforts is what we know are the very positive outcomes of the provision of a more suitable domestic environment for disabled children and their families.

Disabled children and their siblings benefit in development, education and social contact. Carers suffer less stress and have reduced likelihood of back injury.

(Heywood *et al.*, 2005, p. 5)

Glossary

Adaptations

Housing adaptations are:

permanent or fixed alterations to make homes more suitable for disabled occupants and their families.

(Heywood, 2001, p. 1)

Disabled Facilities Grant

The Disabled Facilities Grant was introduced in 1990. Subject to a means test, it gives a mandatory right to any eligible disabled person to a grant to alter their dwelling so that they are able safely to gain access to and use all the normal facilities at home, and to take care of others where this is relevant.

(Heywood *et al.*, 2005, p. 4)

See Appendix 1 for more details.

Equipment

Equipment (formerly referred to as ‘aids’) is movable and generally free at the point of consumption, being provided either by the local authority or a health agency. Beresford *et al.* have presented an illustration of the distinction between an adaptation and a piece of equipment:

Thus, for example, a ceiling hoist to assist with lifting a child in and out of the bath is an adaptation. A portable hoist or bath (pillar) lift are the remit of Community Equipment Services.

(Beresford *et al.*, n.d., p. 2)

Home Improvement Agencies

Home Improvement Agencies (HIAs) are generally small non-profit-making bodies managed by housing associations, local authorities, independent management committees or charitable organisations. Their main functions are:

- to help older, disabled, and vulnerable people to remain independent in their chosen home by identifying necessary repairs and improvements, finding suitable contractors and ensuring the work is properly carried out;
- to help people to access public resources for housing renewal, including Disabled Facilities Grants, where available;
- to help make use of other sources of funding through information on loans, insurance, charitable finance and equity release.

Home improvement grants for private households

See Housing Renewal Assistance Scheme.

Homelessness

Under sections 175–7 of the Housing Act 1996, as amended, a person is statutorily homeless if they have no accommodation available to them either in the UK or anywhere else in the world which they are legally entitled to occupy and which is available for occupation by them together with their family members or any other person who might reasonably be expected to reside with them. A person is also statutorily homeless if they have accommodation but cannot secure entry to it, or in the case of a mobile home or boat have no place where they are entitled or permitted both to place it and to reside in it.

A person is treated as homeless where it would not be reasonable for them to continue to occupy accommodation generally and, by virtue of section 177, specifically if there is a probability of violence against them, their family members or any other person who might reasonably be expected to reside with them. Under the Homelessness (Suitability of Accommodation) Order 1996 (SI 3204) a housing authority, when determining the suitability of accommodation, must take into account the affordability of the current accommodation given the person’s financial resources.

Housing Renewal Assistance Scheme

In order to improve living conditions in its area, a local housing authority has powers to provide, directly or indirectly, assistance (usually in the form of a loan or grant) to any person. It is therefore possible for the local authority to provide assistance to homeowners, tenants and/or landlords to enable them to:

- acquire alternative living accommodation under certain circumstances;
- adapt or improve living accommodation;
- repair living accommodation;
- demolish a building in which accommodation is situated and construct a replacement.

Ombudsman

Where a council or housing association tenant is dissatisfied because their landlord has failed to carry out repair work or has taken an unreasonable length of time to deal with the complaint, the tenant may, after exhausting any internal complaints system, request the Ombudsman to investigate. Council tenants should make a complaint to the Local Government Ombudsman and housing association tenants to the Housing Ombudsman.

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Appendix 1: Mandatory Disabled Facilities Grant: purposes and how it is organised

The Housing Grants, Construction and Regeneration Act 1996

The Housing Grants, Construction and Regeneration Act 1996 (as amended by the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 (S.I. 2002/1860) provides in section 23(1) that:

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

- (a) facilitating access by the disabled occupant to and from
 - (i) the dwelling, qualifying houseboat or qualifying park home, or
 - (ii) the building in which the dwelling or, as the case may be, flat is situated;
- (b) making
 - (i) the dwelling, qualifying houseboat or qualifying park home, or
 - (ii) the building,

safe for the disabled occupant and other persons residing with him;
- (c) facilitating access by the disabled occupant to a room used or usable as the principal family room;
- (d) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room used or usable for sleeping;
- (e) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a lavatory, or facilitating the use by the disabled occupant of such a facility;
- (f) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a bath or shower (or both), or facilitating the use by the disabled occupant of such a facility;
- (g) facilitating access by the disabled occupant to, or providing for the disabled occupant, a room in which there is a washhand basin, or facilitating the use by the disabled occupant of such a facility;
- (h) facilitating the preparation and cooking of food by the disabled occupant;
- (i) improving any heating system in the dwelling, qualifying houseboat or qualifying park home to meet the needs of the disabled occupant or, if there is no existing heating system there or any such system is unsuitable for use by the disabled occupant, providing a heating system suitable to meet his needs;
- (j) facilitating the use by the disabled occupant of a source of power, light or heat by altering the position of one or more means of access to or control of that source or by providing additional means of control;
- (k) facilitating access and movement by the disabled occupant around the dwelling, qualifying houseboat or qualifying park home in order to enable him to care for a person who is normally resident there and is in need of such care;
- (l) such other purposes as may be specified by order of the Secretary of State.

Note

The Housing Grants, Construction and Regeneration Act 1996 only applies in England and Wales. Different legislation applies in Scotland and Northern Ireland.

The Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008/11

The Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008/1189 provides, in section 3, that:

- (1) Subject to the provisions of Chapter 1 of Part 1 of the Act, an application for a disabled facilities grant must be approved where the application is for the purpose specified in paragraph (2).
- (2) The purposes are:
 - (a) facilitating access to and from a garden by a disabled occupant; or
 - (b) making access to a garden safe for a disabled occupant.
- (3) For the purposes of paragraph (2) 'garden' means a garden belonging to, or usually enjoyed with, a dwelling, caravan or flat occupied by a disabled occupant and includes:
 - (i) a balcony adjoining the dwelling of a disabled occupant;
 - (ii) a yard, outhouse or other appurtenance within the boundaries of the land in which the dwelling or caravan of a disabled occupant is situated and belonging to it or usually enjoyed with it;
 - (iii) a yard, outhouse or other appurtenance within the boundaries of the land in which is situated the building in which the dwelling or, as the case may be, flat, of a disabled occupant is situated and belonging to it or usually enjoyed with it; and

- (iv) the land adjacent to the mooring of a disabled occupant's qualifying houseboat.

- (4) If in the opinion of the local housing authority the relevant works are more or less extensive than is necessary to achieve a purpose set out in paragraph (2), they may, with the consent of the applicant, treat the application as varied so that the relevant works are limited to or, as the case may be, include such works as seem to the authority to be necessary for that purpose.

Notes

- 1 The Act referred to in section 3(1) of the Order (see above) is the Housing Grants, Construction and Regeneration Act 1996.
- 2 The Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008/1189 came into force on 22 May 2008, but only applies in England. Different legislation applies in Scotland, Wales and Northern Ireland.

The DFG and how it is organised

The DFG is administered by housing authorities, usually in close co-operation with social services because community occupational therapists are usually needed to assess and recommend what adaptations are required. Each housing authority receives a ring-fenced allocation from Government which may be used to fund 60% of any DFG. This ring-fenced budget may be used for adaptations in all tenures except council housing. DFGs for council tenants are funded from the Housing Revenue Account, or capital.

The ring-fenced budget of the DFG is only part of the system for funding adaptations. During 2003–4, 19% of adaptations were funded from this source. Social services and social landlords between them fund most adaptations under £1000. Council housing departments fund all major adaptations to their stock from capital or the housing revenue

account. Many housing associations use their own resources (with occasional help from the Housing Corporation) to fund adaptations for their tenants, because the DFG system is too overloaded. Social services departments contribute to adaptations over the DFG grant limit and in some other ways.

(Heywood et al., 2005, p. 4)

Appendix 2:

Housing workshop: introductory exercise

Ask participants to turn to their neighbour (preferably someone they do not already know) and ask them each to identify what their home means to them and to assess its importance in their lives. After a short interval, the workshop leader should ask the participants for their conclusions and note these on a flipchart.

The aim of this exercise is to encourage some interaction between participants, while (more significantly) highlighting the central importance and key functions of people's homes in their lives.

Finally, workshop leaders should contrast the importance participants assign to their homes with the lack of emphasis often placed by agencies on housing for disabled children and their families. Workshop leaders should note that the significance of housing to disabled children and their families has often been overlooked, despite the fact that disabled children often spend longer in their family homes than do their non-disabled peers.

The quotation below highlights this point:

Housing is critical to the well-being of any individual yet it is treated as a 'poor relation' by the three agencies typically thought of as being responsible for children's health and welfare.

(Beresford and Oldman, 2000, p. 41)

Appendix 3:

Housing workshop:

‘Housing for families with a disabled child: how much do you know?’ – Quiz

	Question	Answer
1	Which is likely to be the most restrictive environment many disabled children experience?	
2	How do the housing conditions of families with a disabled child compare with those of families with non-disabled children?	
3	Looking at the suitability of the accommodation available to people who require specially adapted homes, which age group is most likely to be living in unsuitable accommodation?	
4	Which sort of impairment is likely to affect disabled children living in unsuitable housing?	
5	What is the housing problem most commonly reported by families with a disabled child?	
6	What are the next three most common housing problems reported by families with a disabled child?	
7	Which families with disabled children are in the greatest housing need?	
8	What is the impact of housing which is unsuited to the needs of families of disabled children? (i.e. Who does it affect and how?)	
9	How easy is it for families with a disabled child to achieve housing improvement? What are the likely problems?	
10	What do families with disabled children who are in housing need want from workers who are not housing specialists?	

Appendix 4:

Housing workshop: ‘Housing for families with a disabled child: how much do you know?’ – Answers

	Question	Answer
1	Which is likely to be the most restrictive environment many disabled children experience?	Family home (Beresford with Rhodes, 2008)
2	How do the housing conditions of families with a disabled child compare with those of families with non-disabled children?	Worse on all criteria, except the presence of central heating (families with a disabled child are more likely to report problems regarding adequate heating, state of repair and overcrowding)
3	Looking at the suitability of the accommodation available to people who require specially adapted homes, which age group is most likely to be living in unsuitable accommodation?	Children aged 0–15 years (older people who need specially adapted accommodation are significantly more likely to be suitably accommodated)
4	Which sort of impairment is likely to affect disabled children living in unsuitable housing?	All groups are affected (housing need is not purely about issues related to physical impairment and access)
5	What is the housing problem most commonly reported by families with a disabled child?	Lack of sufficient space (for family, for use and storage of equipment, and for carrying out therapies) (reported in a large-scale survey of housing in England and Wales)
6	What are the next three most common housing problems reported by families with a disabled child?	<ol style="list-style-type: none"> 1. Unsuitable kitchens, toilets and bathrooms 2. Unsuitable location 3. Access (getting into, out of and around the family home)

	Question	Answer
7	Which families with disabled children are in the greatest housing need?	<ul style="list-style-type: none"> • Families in some types of tenancies (families with disabled children are less likely than families with non-disabled children to own their own homes, especially families with severely disabled children). Families renting from local authorities and private landlords report more housing need than owner-occupiers or housing association tenants • Families with the lowest incomes (though even better-off families report an average of three housing problems) • Families from black and minority ethnic groups. Problem areas are housing conditions, space, overcrowding, plus access to information regarding housing support and services. Pakistani and Bangladeshi families are particularly badly affected
8	What is the impact of housing which is unsuited to the needs of families of disabled children? (i.e. Who does it affect and how?)	<ul style="list-style-type: none"> • Disabled children themselves – in terms of both their safety and their development (poor housing can restrict disabled children’s opportunities for autonomy, play and the growth of self-help skills and self-confidence) • Parents – in terms of risk of back injuries, falls and interrupted sleep. Also stress on mothers • Siblings – especially where there is a shared bedroom and lack of private space
9	How easy is it for families with a disabled child to achieve housing improvement? What are the likely problems?	<ul style="list-style-type: none"> • Getting information and access to services; • Getting expert advice. Only families applying for a Disabled Facilities Grant generally receive expert advice – i.e. from an occupational therapist. But only 25% of families reporting a housing need received an occupational therapist’s assessment (Beresford and Oldman, 2002) • Even where families are eligible for a DFG, problems are commonly reported (regarding delays, lack of service co-ordination, problems with changing family needs and disagreements over funding) • Improvements in housing circumstances do result in positive outcomes, but problems often remain
10	What do families with disabled children who are in housing need want from workers who are not housing specialists?	<ul style="list-style-type: none"> • Provision of information about housing • Thorough assessment which recognises the significance of housing • Listening to what families want regarding their home • Joint working with relevant professionals

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