

Housing and disabled children

The art of the possible

Mark Bevan



First published in Great Britain in November 2002 by

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

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E-mail tpp-info@bristol.ac.uk
www.policypress.org.uk

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Published for the Joseph Rowntree Foundation by The Policy Press

ISBN 1 86134 464 3

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

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

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Acknowledgements

I am very grateful to all the practitioners and families who gave their valuable time to talk to me about their experiences and views.

This project was funded by the Joseph Rowntree Foundation. I would like to thank the members of the advisory group for their advice on this project; in particular to Alison Jarvis for her help and support. Special thanks are due to Wendy Mitchell and Sue Clarke, Social Policy Research Unit, University of York, for their help throughout the project.

Introduction

Background

Previous research has drawn attention to the key role that good housing plays in the well being of disabled children and their families. On the other hand, unsuitable housing can be disabling and exacerbates the difficulties faced by children with an impairment or functional limitation, and their families.

The aim of this report is to highlight housing services that have been commended by families with disabled children. Specifically, it draws together examples of individuals and agencies that are currently addressing the housing needs of disabled children and their families in a positive and beneficial way. The services include those focused specifically on providing for disabled children, or generic services which disabled children or any other disabled people can use.

Context

Recent research has highlighted the range and type of difficulties that disabled children and their families can experience with their housing (Beresford and Oldman, 2002). This research emphasises that problems with housing can relate, not only to the internal and external home environment, including garden or backyard, but also the neighbourhood and the location of the home.

A fundamental weakness in trying to address the housing needs of disabled children is the lack of sufficient focus on this group within current legislation, with the result that such children may 'fall through the net' (Heywood and Smart, 1996).

Part of the problem identified by Beresford and Oldman (2002) is that there is no one single legislative framework for responding to the housing needs of families. This issue is further complicated by the fact that families living in different tenures will have their needs addressed in different ways. While a significant proportion of families with disabled children are reliant on rented housing, Oldman and Beresford (1998) note the impact of the Right to Buy on the public sector stock which has resulted in larger family-sized properties being sold.

On a more structural level, a significant constraint on what can be achieved to meet housing needs is the type of housing available to families. Families have to cope with the fact that a large proportion of the housing stock is disabling in some way.

One issue relates to the difficulty of adapting existing housing due to their design, which is often unsympathetic to the needs of disabled people. A positive development in this respect has been the extension of Part M of the building regulations in 1999. This means that all new homes in England and Wales must incorporate a downstairs toilet, doors wide enough to allow a wheelchair to pass through and level access thresholds.

However, it is not only the legacy of house-building that has failed to consider people with impairments, but also current space standards that have limited people's options. One of the most significant difficulties faced by disabled children and their families is the lack of adequate space in and around their homes (Beresford and Oldman, 2002). A particular factor is the amount of equipment often required by disabled children,

which can create difficulties in relation to space in which to use and store such equipment. Adaptations to a home can sometimes exacerbate this problem by cutting down the amount of space available, or failing to consider the specific needs of children, such as the need for play, or for bedrooms that may need beds for both the child and a parent or carer. Wider consideration must also be given of the needs of the family as a whole – both parents and siblings – which can include privacy for the disabled child and other members of the family, especially where a disabled child and siblings share a bedroom. Closely linked with this issue are difficulties with access both within and outside the home, perhaps because rooms are too small – particularly kitchens, bathrooms and toilets – or because access is constrained by steps or narrow doors.

Research has also highlighted that, while a home may meet all a family's housing needs, its location may make the house unsuitable. Limitations may be imposed on a child because of the nature of the surrounding area, for example, steep hills and busy roads. A home may also be unsuitable because of the occasionally hostile attitudes of neighbours towards disabled children and their families.

However, it is not just the type and size of stock available that can make housing unsuitable, but its condition. Beresford and Oldman (2002) also show that families with a disabled child are twice as likely to report problems with damp or cold than a similar population of families with non-disabled children.

In addition, changes may need to be made to the home to respond to different stages in a child's development. The changing needs of children exacerbate the fact that the housing needs of disabled children often require expensive and highly complex solutions. Indeed, service providers face a difficult task in responding to the housing needs of disabled children, working within severely constrained resources.

The difficulty of providing for the needs of disabled children is reflected in recent research highlighting satisfaction with adaptations. Heywood (2001) found that adaptations for children were rated the least satisfactory by both practitioners and by families themselves. Existing research (Beresford and Oldman, 2002) has identified a number of key reasons *why* the

housing needs of disabled children and their families are not being met: a lack of money, lack of awareness and service fragmentation. Heywood and Smart (1996) stress that legislation has not been drafted with the needs of children in mind.

There are a number of implications for policy that flow from these causes of dissatisfaction. Beresford and Oldman (2002) specify a number of directions that services for meeting the housing needs of disabled children could take – identified as an agenda for change. As part of this agenda, Shaw (2002) highlights that the social model of disability should underpin any framework for developing good practice and the way that housing need is defined. Further themes include:

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

A key consideration is the need to provide for the whole family: parents, carers and siblings. Allied to these themes are implications for local practice and national policy that derive from research on the specific subject of adaptations, but which have a bearing on the way that broader housing needs are addressed by service providers (Heywood, 2001). A number of these issues are picked up in the following chapters, which highlight the way that user-commended services approach these aspects of housing need.

Background to the research

Previous research has drawn attention to the difficulties that families face with unsuitable housing (Oldman and Beresford, 1998). This project provided an opportunity to focus on services that help to meet the housing needs of disabled children that have been nominated or commended by families themselves. The overall objective of the project was to provide accessible information about good practice and innovation related to meeting the housing needs of disabled children and their families.

Project aims

- To identify examples of good local policy and practice in meeting the housing needs of disabled children and/or overcoming the complexity and barriers that may inhibit addressing those needs.
- To collate clear information about selected ideas that could be included in a good practice website.
- To make recommendations about service development and implementation.

The project links to other research that has recently been completed by the Social Policy Research Unit (SPRU), University of York. In 1999, Barnardo's and the Family Fund Trust successfully applied to the National Lottery Charities Board for funding to develop a website and print directory of user-commended support services for disabled children and their families. Entitled 'Sharing value', the work by the SPRU highlights a range of user-commended support services, including advice and information, play activities, financial support, overnight/weekend short breaks (respite care), counselling, carers support and support groups (Mitchell et al, 2002), and www.sharingvalue.co.uk.

Methods

As part of research for the 'Sharing value' website, the SPRU conducted a survey of 16,000 families with disabled children, stratified by age-band, ethnicity and local authority. The sample was drawn primarily from the Family Fund database, but was supplemented by media advertising to reach families who do not meet Family Fund criteria. The survey targeted parents, disabled children and their siblings, and asked respondents to nominate examples of good service provision. By including questions that specifically related to housing, the survey was able to identify user/carer-commended services that could be used as part of the housing project.

A survey was also sent out to the occupational therapy service with responsibility for disabled children in each welfare authority in the UK. The survey invited each respondent to nominate a service in their area that they felt was promoting good or innovative practice in meeting the housing needs of disabled children. Contact was

also made with a range of national and local organisations and individuals.

Interviews were conducted with nominated service providers to obtain key information about how the service operated, and how people could get further information about or access to those services. In those cases in which the service was not directly nominated by families with disabled children, an interview was conducted with families who had used the service to maintain the focus on users.

The research for this report highlights some of the services nominated or commended for providing a good or innovative service by families with disabled children. The report also draws on the comments made by practitioners and families as part of the interviews, to highlight their views on some of the issues surrounding key aspects of service delivery. However, the limitations of the report must be noted. It does not offer an independent evaluation of the services. Further, it should be stressed that this is not a comprehensive list of *all* good practice and there will be services not listed that are routinely meeting the housing needs of families with disabled children in positive and innovative ways.

Structure of the report

Chapter 2 considers how families obtain the information and advice they need to access housing services. One of the key barriers facing families is lack of information and clarity about what may be on offer. The chapter goes on to describe advice and information services that help families to access housing through empowerment, advocacy, and finally how providers interact with families to make information and services readily accessible.

Chapter 3 describes a number of key features about the delivery of services that help to meet the housing needs of disabled children and their families. This chapter highlights the importance of presenting a range of housing options to families, describes issues about changes to people's homes to meet their needs and discusses the option of moving home. Finally, the chapter highlights the need for follow-up after services have been delivered, to keep track of the impact

of solutions to a disabled child's housing needs and to monitor children's changing needs.

Chapter 4 highlights a number of implications arising from Chapters 2 and 3 in relation to the way that services can be organised around the needs of disabled children (rather than families needing to accommodate the way services are organised). The chapter sets out the approach that a number of agencies have taken to address the way that services are organised to meet the needs of disabled children.

Examples of services are referred to throughout the report, highlighted in boxes. The services cited in this report catered for families with children in a number of ways. Some services were aimed at any disabled children, while others were targeted at children of a particular age or with a particular type of impairment. Further details of each service, highlighting the circumstances and eligibility for help, can also be found on the 'Sharing value' website (www.sharingvalue.co.uk).

Note

For the purpose of this report, children are defined as anyone aged between 0 and 18 years of age. Drawing on Shaw (2002, p 11), disability is defined as the loss or limitation of opportunities to take part in mainstream life of the community on an equal level with others due to physical and social barriers.

Accessing services

Why is this theme important?

A fundamental issue for families is how to get information and advice to help them gain access to the services they need to meet their housing needs. Oldman and Beresford (1998) have highlighted a range of difficulties faced by families including a lack of knowledge about how services work, and how to begin the process of asking for help. While referral mechanisms may help in terms of bringing families to the attention of different providers, research has indicated that families tend to have a low awareness of the services that are available to them, sometimes feel that they have to fight to get the services they need and suffer from an organisational 'lack of ownership' in following their problems through (Beresford and Oldman, 2002).

Research has also highlighted that parents worry that statutory services may be giving advice on the basis of cost rather than suggesting the best option for their child (Oldman and Beresford, 1998). Also, when adaptations are being pursued, there is the suspicion that information may be withheld to slow down or stall the process of application. These types of concern were reflected by a couple of parents in this study, who commented on the struggle they had faced in accessing key services. These parents talked about the benefit of having someone fight on behalf of the family, in the form of an advocate:

"Before, the council were saying, 'You don't need it'. They were like a brick wall. She [worker from the advocacy service] backed us up and argued our case. She pushed it, and we would never have got this far."

Finally, evidence suggests that minority ethnic households face particular difficulties, over and above those experienced by white families with a disabled child (Chamba et al, 1999). This research found that minority ethnic families find it difficult to access services and highlighted families' need for information and services for themselves and their children. In particular, poor interpreting support and limited availability of translated materials make access to information difficult. Other research has noted that minority ethnic disabled people frequently fall between services for minority ethnic households and services for disabled people (Evans and Banton, 2001).

This chapter highlights a number of services commended by families that assisted in facilitating access through the system to the housing services they needed. The examples fall within the following categories:

- information and advice;
- empowerment and advocacy;
- promoting services and maintaining contact.

Information and advice

Parents highlighted a range of organisations that provided advice and information. Often, these services were not primarily focused on housing issues, but had been able to help families as part of their overall service. For many, they represented a first point of contact in helping them address broader concerns about their child's welfare. Crucially, they provided a means of accessing services to address the concerns of families about housing circumstances arising out of their child's impairment or condition. Some of

the organisations put forward by families provided a general information and advice service across a range of conditions and impairments.

Leeds Keyworker Project

The Leeds Keyworker Project coordinates services for families who have a child or children (aged 0–5) with complex health needs and/or multiple impairments. They will become involved as early as possible, when a family has first had news of their child's health needs or impairments and when the family is trying to find out what help may be available to them. The type of help they provide depends on what a family wants – they can provide practical or emotional support. They can coordinate all professionals and services involved in helping the child and family. The project informs families of all existing provision in Leeds and the availability of these services, and will refer them to other agencies where appropriate. The project also helps families initiate the process of rehousing or obtaining adaptations if this is needed. The project has established links with the Housing and Environmental Services Department, Leeds City Council, who will take forward the family's housing needs.

Information Service, The Children's Centre, City Hospital Campus, Nottingham

This service arose out of a need identified by the hospital to provide information to families immediately after a prognosis of a child's condition. It became clear that there was a need to provide information on a much broader range of issues, including housing. The centre, which works in the Nottingham area, has general information on housing issues and adaptations as well as other issues. They will signpost families to other organisations if they do not have the information themselves. They can explain to families where they can go to get an adaptation done to their homes.

Families also nominated a number of voluntary organisations and charities that dealt with specific impairments or conditions. These services were primarily on hand to help families with information about their child's impairment or condition, but could also act as a resource for

families on housing issues, or as a signpost to other agencies providing help with housing.

Association for Spina Bifida and Hydrocephalus (ASBAH)

This service has branches around the country. The particular branch highlighted by a family was in Somerset, and provided information and support in Somerset to families of children or adults with Spina Bifida and/or Hydrocephalus. This covered a range of issues including medical, social, environmental and educational. As part of its service, it provides information and support to families on housing issues, including working with housing officers in the local authority.

A further issue for families is being able to access the most appropriate service. Families may be faced with a range of services and organisations, without necessarily knowing which ones they should approach. One advantage of a disabled persons housing service is that they can offer a one-stop shop for people and help to guide them through the process of meeting their housing needs.

Sheffield Disability Housing Service (SDHS)

SDHS provides a one-stop shop for people who require help or advice with moving to a new home, adapting an existing home or exploring the range of housing options available. They keep a register of people wanting to be rehoused and offer a service to match people with appropriate properties. They can also assist landlords in finding suitable tenants for their property.

Empowerment and advocacy

While having access to information means being able to find out about what services may be available and who to get in touch with, it is also about families being able to exercise genuine choice (rather than being steered towards certain options).

Families thus need to be able to both identify the range of options available to them and to be in a position to choose how to act on the information. This principle of families being empowered to make their own choice on the basis of information provided was highlighted by a number of agencies that were commended by families.

PAMIS, The Pentagon Centre, Glasgow

PAMIS provides a holistic service to people with profound learning disabilities. It holds events and workshops on topics that have been identified as important by families and that they would like to be addressed. They will respond to whatever a family may need, but aim to empower the family to make their own choices. This includes meeting the needs of the whole family, including siblings.

Disability North, The Dene Centre, Newcastle upon Tyne

One of the key principles of Disability North is that it works to empower disabled people by providing information and advice to maximise the choice and control they have over their lives and placing disabled people's needs at the centre of the service. One example of its work is the Young Disabled Person's Project. This project is user led and the development worker responds to issues raised by young people, including housing issues.

Muscular Dystrophy Campaign, London

The Muscular Dystrophy Campaign has developed an adaptation manual to provide families with the information they need to get the right adaptation for someone with a neuromuscular condition (but could be a helpful resource for anyone who needs an adaptation). The manual has a number of features: it offers a step-by-step guide to getting an adaptation; it aims to place the disabled person in control of the adaptation from start to finish; it provides a template and overlay sheets to help with the design and checking of architectural plans; and provides a list of contacts and equipment literature.

However, only part of accessing services is about choosing from the range of services on offer and deciding who to approach. The next step is interacting with housing services. Independent advocacy can reassure families that the information and advice they are receiving is impartial, can make sure that families are kept informed about what is being provided in their area, and ensure that they achieve the services to which they are entitled.

A number of agencies offered advocacy as part of their services. This activity could be part of a service delivered by people with expertise in the needs of families whose child had a particular impairment or condition, as indicated in the example below.

Society for Mucopolysaccharide Diseases, Amersham, Buckinghamshire

A multidisciplinary development team provides telephone support and face-to-face individual advocacy in a range of areas, including respite care, palliative care, welfare benefits and special educational needs. The service also helps professionals to understand the needs of families and to support professionals in providing needs-led services. The service provides an information and advocacy service to help families deal with their housing issues, and to access and obtain adaptations to their homes. This service includes representing families at multiagency meetings.

A number of commended advocacy services were specifically focused on ensuring that minority ethnic families' need for information and advice were met and their needs for services addressed.

Positive Action in Housing, Glasgow

Positive Action in Housing provides impartial and independent advice, information and representation to assist people from minority ethnic and refugee communities to overcome their housing problems. The Homelessness and Racial Harassment Crisis Support Service is the only dedicated multilingual housing advice and information service for ethnic minority communities in Scotland. One of the problems that the service deals with is unsuitable housing for disabled people.

Action for Black Children with Disabilities (ABCD), Cardiff

This service developed as a result of some local research that identified the need for support for black and minority ethnic families in the area. ABCD works with black and minority ethnic disabled children, or children with a chronic illness, and their families. ABCD focuses on the needs of the child and can work with a family to provide an advocacy service, or highlight other services that a family can use. ABCD works with families to help them meet their housing needs, especially to get equipment and adaptations.

Sandwell Asian Family Support Service, Health and Social Care Centre, Smethwick

This service provides a wide range of care and support services to South Asian families with a disabled child or young adult. As part of the focus on the individual needs of families, the collaborative care worker and the liaison officers provide an advocacy and networking service with local housing agencies to help families deal with any aspect of their housing. This help may include rehousing or adaptations, getting grants, filling in forms and attending meetings with families.

Promoting services and maintaining contact

Some organisations have taken a proactive stance to making families aware of their services by making sure that information is readily accessible. As highlighted in the two examples below, a number of agencies have promoted their services and outline what families can expect from them.

Habinteg Housing Association Ltd, Head Office, London

Habinteg have published a manual to describe their policy on aids and adaptations for their tenants. The manual sets out what tenants can expect from their service. Details are also available on the Habinteg website.

Kirklees Council

Kirklees have published information on their adaptations policy, which describes how disabled people can apply for an adaptation. The information is available in English and Urdu on the website of Kirklees Council (the website information in Urdu is also available as a sound file).

Finally, there is no doubt that trust, dignity and respect were seen as important features of a positive relationship between families and service providers. Parents commented on how individual members of staff worked hard for them on an ongoing basis. For example, a parent described how she felt about the help she had received from one practitioner:

“She deserves a medal the size of a bin lid.”

When these principles were absent, the contrast was stark. One parent commented that whenever a particular practitioner visited her:

“He always made me look stupid.”

Parents placed a great deal of value on having somewhere to go where they were confident that they would always be listened to, and where someone would always make themselves available to discuss the families' needs. One

parent commented on the help provided by her housing officer:

“He was always so helpful. Whatever time of day, whatever it was, he would always find the time to talk to everybody. You knew there was always someone at the end of the 'phone who would always be helpful.”

This principle was a key ethos for some agencies, as indicated in the following example.

Talbot House, Monsall Street, Harpurhey, Manchester

Talbot House supports parents and carers of children and adults with learning disabilities. There is a drop-in centre for parents and families, which also provides advice and information on a range of issues, including advice and information to parents and carers on housing issues. People can either drop in or telephone. No appointment is necessary – the service will always aim to offer time and availability and aims to 'never say no' to families who call for advice and information.

Conclusion

This chapter has highlighted a number of frontline organisations that provide information and advice, particularly when families first find out about their child's impairment or health needs. A key issue is the lack of awareness among families that specific help may be available to meet their housing needs. This has implications for the way that non-housing services can help to highlight housing issues or can signpost families to other agencies that will help to meet their housing needs.

A number of agencies emphasised that a key principle of their services was the empowerment of families, which can be defined in terms of families being able to make informed choices about how to deal with their needs. As indicated by others (Oldman and Beresford, 1998), this does not mean families having to do everything themselves. Rather, it means being able to choose the level of support that they need. The adaptations manual published by the Muscular

Dystrophy Campaign is one example of a resource through which parents can take on the role of their own keyworker. Other examples highlight the benefit to families of having a designated keyworker or point of contact, and of the important role that can be played by information, advice and advocacy agencies that are independent of statutory bodies.

The success of advice, advocacy and information services can be gauged, not only by the high proportion of commended services that fell into this category, but also by comments from a number of practitioners that their jobs were being made more demanding because families were increasingly more knowledgeable about their rights and the types of services they could reasonably expect. This trend is to be welcomed, but with the caveat that practitioners should themselves be able to access the resources and structures that would allow them to meet these rising expectations.

Finally, and importantly, there were examples relating to service providers themselves taking a proactive stance to families' needs for information. If disabled children and their families are to be able to access appropriate services – either through an independent agency or on their own behalf – this requires first and foremost that there is transparency and clarity about what services are available to them. This is a key question that could and should be considered in every local context.

Similarly, the importance that families attached to quality relationships, based on trust, honesty, openness and dignity, should not be overlooked.

Delivering services

Introduction

The previous chapter was concerned with how families gain access to services, in particular, obtaining the information and advice to make an informed decision to get what they need. This principle also applies to the way services respond to the individual needs of families and ensure that the views of families are central to the whole process of meeting their housing needs. Services can present the range of housing options available to families and allow families to make an informed decision on their own terms. These choices often revolve around carrying out an adaptation to the existing home, moving home, or moving and also adapting the new home. Heywood (2001) has drawn attention to the importance of the philosophy of a service, as well as a focus on specific mechanisms for delivery to meet the housing needs of disabled people – “a generous spirited whole approach” (p 45). Practitioners reflected on this point by describing that they wanted the emphasis of their service to be a ‘can do’ approach to meeting needs. In particular, a focus on what will work for the family over and above what may be the cheapest solution for the provider.

This chapter looks at the way in which housing services are delivered. The chapter first considers needs assessment, before moving on to changes that can be undertaken to people’s homes. In particular, this part of the chapter focuses on the way that adaptations are delivered, namely, the length of time it can take for adaptations to be completed and the amount of money that families have to find to pay for them. This section then addresses changes to the home that are of specific relevance to children, with a focus on the issue of space. The chapter discusses the option

of moving home, before discussing how families can have input into the way that services are delivered.

Needs assessments

A number of housing organisations have moved away from a medical model approach of service provision towards bringing the social model of disability into their practice. In particular, in giving families a greater input into how their housing needs are assessed. Some services have moved towards self-assessment of the need for minor adaptations by service users (such as grab-rails). An important contributory factor here has been a recognition that the small cost of providing minor adaptations does not justify the resources it takes to provide an occupational therapy assessment of a disabled person’s needs to ensure that it is necessary. Whatever the motivating factor, a number of organisations are recognising that disabled people are the experts on their own needs.

Habinteg Housing Association Ltd, Head Office, London

Tenants of Habinteg Housing Association can assess their own need for a minor adaptation without further assessment by Habinteg, although advice is available from community assistants to help tenants with this. Feedback on the adaptation is obtained from a feedback form.

Leeds City Council

Disabled people in Leeds assess their own requirement for a minor adaptation. The Council has set out a menu of adaptations that will be ordered for people if they request them. Recipients are also given an information pack advising them to get back in touch with the Council if the adaptation does not meet their needs.

However, it is important that when a family assesses their own need, the views of the child in this process are considered. Research has highlighted that a child's view of their needs may differ from a parent's view (Oldman and Beresford, 1998).

Another factor is that services can provide information to allow families a broader choice, because practitioners are more likely to be aware of the range of solutions available for a family's particular circumstances: they are more aware of what can be achieved. A key issue here is also providing for the long-term needs of children, as they grow up. One parent commented on the way her occupational therapist (OT) had helped her in this respect:

"We didn't know what we were entitled to. The occupational therapist was very important. We wouldn't have thought of the shower. She [the OT] was thinking of the future, about later on."

If possible, there should be the potential for incremental changes, with staged adaptations at different points in the child's development, reflecting their changing needs.

Changes to the home

Speed of delivery of adaptations

The length of time it can take for adaptations to be completed – from the initial assessment to final completion of the works – can result in lengthy delays for families. Practitioners noted the attempts they were making to streamline their adaptations service, identifying blockages and delays within the system. An important part of this process was to benchmark the service against

other authorities. Local authorities in Wales have recently completed the first stage of the process of benchmarking housing adaptations. Part of the next stage may consider the needs of disabled children.

Heywood (2001) has drawn attention to delays due to a shortage of OTs, and also highlighted a range of possible solutions. Some authorities had employed a housing OT to reduce the waiting time for assessments. Other authorities had dedicated OTs for children, again, reducing the length of time waiting for an assessment. One outcome of the recent review of the adaptations service in Northern Ireland was the recognition of the shortage of OTs, and extra funding has been put in place to try to remedy this situation (Northern Ireland Housing Executive, 2002).

Paying for an adaptation

One family commented that a significant delay was the length of time it took to get the means test for a Disabled Facilities Grant (DFG). This particular family noted that, when the result of the test was made known to them, their contribution was so large that they felt they could have saved a lot of time by just paying for the adaptation themselves. A number of authorities give a provisional means test as early as possible to give families an idea of what they are likely to get in terms of grant monies, which can help them to make a decision about how to proceed.

However, one authority noted that they always recommend that a family goes through the process of applying for a DFG, even if it is unlikely that they will get any grant. This is because the *successive applications* rule comes into play, which can apply for up to ten years. It is particularly significant for disabled children, because a family may need different adaptations as the child gets older and their needs may change.

Some large organisations deal with a variety of local authorities, each with their own ways of dealing with adaptations. Habinteg have a policy to ensure consistent treatment of its tenants, regardless of which authority may be dealing with the process of getting an adaptation.

Habinteg Housing Association Ltd, Head Office, London

Habinteg will support their tenants through the process of applying to local authorities for a DFG. Their aim is to provide a consistent and fair service for all their tenants, regardless of which local authority is assessing the tenant's claim. If there is a wait of longer than two months for an assessment by an OT, Habinteg will fund the assessment themselves, using a list of approved private OTs.

One of the principal sources of funding for an adaptation is the DFG, which is available as a mandatory grant. However, people applying for the grant are subject to a test of resources because the grant is means tested. A number of practitioners were critical of the way that the means test was applied in relation to disabled children. One of the criticisms levelled at this means test is that, although it is the disabled child who is in need, it is the income of the parents that is assessed.

A further criticism is that insufficient account is taken of the expenditure of households compared with income. In particular, McKeevor (2002) notes that the allowance for housing costs is inadequate compared to actual housing costs. Parents can be left with significant contributions to make towards the cost of adaptations. Heywood and Smart (1996) draw attention to the role that social services departments can take in alleviating the burden of the contribution that parents may have to find – either because the total cost of an adaptation is above the maximum grant available (£25,000 in England), or because parents cannot afford their assessed contribution. While there are a number of different sources of funding available, social services departments' responsibility to help is dictated by the 1970 Chronically Sick and Disabled Persons Act. However, Beresford and Oldman (2000) note that social services departments can sometimes be reluctant to take action. Nevertheless, as indicated in the two examples below, a number of local authorities are committed to helping parents with the amount of money that they may have to find to pay for an adaptation.

Adaptations Service, Birmingham City Council

The City Council provides financial support to households to help pay for an adaptation. Once a family has applied for a DFG, they may not be able to afford their assessed contribution for an adaptation, or the cost of the works may be above the maximum grant available. The Council will ask the family for their permission to have an independent financial assessment by 'HouseProud'. This assessment can have three outcomes: 1) it may find that the family can afford to pay for the adaptation; 2) it may find that a loan at a competitive rate of interest, or interest free, can be given to the family, set against the property; 3) the assessment may find that the family cannot afford such a loan, in which case the council may give a discretionary grant.

Community Services, City of York Council

City of York Council provides a financial safety net for people applying for DFG to pay for an adaptation. As noted above, when a family applies for a DFG, the means test only takes into account the income of a household and cannot take into account the family's outgoings, meaning that a family may be left with a large contribution to find. York's approach to helping families with their contribution is to use a Disability Support Budget. The Council will undertake a supplementary assessment of a family's financial means, taking into account outgoings, such as mortgage repayments, rent (if a private tenant), Council Tax, buildings insurance and water charges. By taking into account a household's outgoings as well as its income, the Council can calculate how much it feels a household is able to afford to pay for the adaptation. If, in the Council's view, the supplementary financial assessment shows that a family could not afford its contribution, the Disability Support Budget can be used to pay for the adaptation instead.

If a family has a small contribution left to find, the Disability Support Budget can sometimes be used to cover this amount as a loan to the family. The Disability Support Budget can also be used as a way of paying for urgent cases (such as to speed up a hospital discharge) and where the household has no contribution to make.

Play

Space for play is a crucial developmental need for children that should be reflected in the delivery of adaptations. However, Heywood (2001) has noted the failure of national policy to consider disabled children's need for play. Nevertheless, local policy offers the opportunity to make specific commitments to these needs of children. There are two ways in which this can be achieved.

The potential scope within the 1996 Housing Grants, Construction and Regeneration Act to meet children's housing needs for access and safety through a mandatory DFG can be made into an explicit recognition of the specific circumstances in which adaptations will be undertaken to help disabled children. The need for an environment that includes a safe space for play or providing access to play facilities are two examples.

Unfortunately, the provision of space for play by itself is only available through discretionary grants, which a local authority may or may not choose to pay. A number of local authorities have made a commitment to funding these kinds of adaptations to meet the needs of children, as indicated in the example below.

Caerphilly County Borough Council

The Council's criteria for works eligible as adaptations include the needs of disabled children, such as access to play facilities. Further, while the Council has outlined that adaptations may be required to meet exceptional circumstances, it takes the view that nothing is ruled out. For example, provision of toughened glass to prevent a disabled child from injury, security locks on windows and fencing for safety and privacy may all be eligible.

Sharing bedrooms

The way that a number of local authorities interpret adequate housing with regard to whether or not siblings should share bedrooms is one instance of the way that the specific needs of disabled children and their families are often not reflected in current housing practice. One local authority officer noted that there was often a debate within her office over the number of cases

involving disabled children that were about overcrowding. A rigid application of bedroom requirements fails to appreciate the need for the extra space that disabled children may need for equipment, the greater need for privacy – both for the disabled child and their siblings – or the disruption that a child with behavioural problems can cause to a brother or sister who shares a bedroom with them.

Extensions

One way of tackling lack of space is through the construction of an extension where practicable (one practitioner noted that parts of the housing stock in their area were so cramped that extensions were virtually impossible). One family felt that their extension had provided an ideal solution for them. However, for other families, it can cause difficulties in terms of the disabled child being isolated from the rest of the family. One authority had provided an extension with space for beds to accommodate the parents and the disabled child in the same room. This solution was particularly important to the family concerned because the parents had to be on hand to attend to their child's needs at a moment's notice.

Moving home

An alternative to adaptation is for a family to move home. There was some discussion by housing providers over rehousing, especially in the social rented sector. One comment was that rehousing a family was difficult to do well, and required considerable investment in time by practitioners to be effective. In addition, the difficulty of finding a home in a new area can be compounded by the attitudes of individuals, which can make some neighbourhoods unwelcoming. Oldman and Beresford (1998) have highlighted that families with disabled children can often be subject to harassment and abuse, for a variety of reasons.

Other issues can add to these difficulties. A voluntary agency described instances in which minority ethnic families with disabled children had become targets for racist abuse. One registered social landlord worked with a local community on an estate with a poor reputation to

develop a number of new dwellings including accommodation for disabled people. This work included a neighbourhood code of conduct, care plans between neighbours and awareness training (see Shaw, 1999).

Beresford and Oldman (2002) identify a number of key features about families that would like to move home. One finding is that families typically make the decision to move home in response to unsuitable housing, without any professional advice or support. Families living in social housing most frequently reported that the main problem for them was a lack of suitable housing for them to move to. One local authority had attempted to prevent further erosion of its housing stock that was suitable for disabled people by placing restrictions on sales of properties that have been adapted.

A number of agencies offered advice and information on moving home.

Housing Disability Team, Greenwich Council

There are two OTs working within the Housing Disability Team of Greenwich Council who focus on rehousing. The OTs help to assess the needs of people who want to move house, and try to match them with an appropriate property from a register of adapted or adaptable houses.

Shaw (1999) has highlighted the role that disability housing registers can play in helping to match disabled people with properties that can meet their housing needs.

Disabled Persons Accommodation Agency (DPAA), Rochester, Kent

This service aims to match disabled people with suitably adapted, adaptable or accessible housing in Kent. The matching service is for disabled people who want to move within Kent, or would like to move to Kent from elsewhere. DPAA keeps a register of people who want to move and works with local authorities, housing associations, estate agents and private landlords to provide information on properties to rent or buy.

An emerging policy development is the growth of choice-based lettings. This approach to the allocation of social housing offers great potential for disabled people (and other people wanting to live in social housing) to be able to choose where they want to live. However, as Shaw (2002) identifies, mechanisms must be built into the way that choice-based lettings work, in order to be effective for disabled people. A particular concern is that properties that would meet the needs of disabled people, because they have already been adapted, or are adaptable, are allocated in a sensitive manner to the people who need them, including families with disabled children. Disabled persons housing services offer an emerging approach to working with choice-based lettings, as indicated by the example of Bradford HomeHunter.

Bradford HomeHunter, Bradford Disabled Persons Housing Service

Bradford City Council uses a choice-based lettings service to let their properties. People can respond to advertisements to signal their interest in properties, as they become available. The Bradford Disabled Persons Housing Service operates a matching service as part of choice-based lettings. Properties that are suitable for disabled people are let separately to ensure that adapted properties are allocated to people who really need them. Disabled people register their interest in moving by completing a self-assessment form. Notably, this form distinguishes between health needs and impairments.

Occasionally authorities offered financial help to families to move home.

Kirklees Council

Kirklees Council offers a rehousing package up to £5,000 for disabled people wanting to either transfer, or move, to council housing.

Beresford and Oldman (2002) highlight that the dominant barrier for owner-occupiers is financial constraints. Some organisations promote and help to facilitate access to home ownership.

Housing Services, Leeds City Council

The Council is working jointly with estate agents in the city (Manning Stainton and Halifax) to flag up properties for sale, which have either been adapted or that are suitable for adaptation.

Support. The mortgages are interest-only, since the households are often unable to afford to pay off the capital repayment as well.

Growing up: making the transition into adulthood

Recent research has highlighted the extent to which transition plans fail to meet their potential to help support young people in their choices as they move towards adulthood (Heslop et al, 2001). Among other issues, young people stated that they would have found information about their future housing options helpful.

Ownership Options in Scotland, Edinburgh

Ownership Options aims to create equal access for disabled people to home ownership as a mainstream housing option. It pioneers models that demonstrate how some of the barriers to home ownership that currently exist can be overcome – be they financial, legal or technical. Ownership Options provides information and advice on home ownership. This includes access to independent financial advice, access to specialist technical advice and advice on benefits in owner-occupied property. Ownership Options also coordinates multiagency funded projects to help disabled people to buy their own homes.

Ability Housing Association, Staines, Middlesex

Ability has links with specialist schools, where they give presentations to young people who are leaving school about the opportunities and availability of accommodation, as well as residential care. Ability provides tenancies for young people leaving school (aged 16-18).

The housing project at Ealing Mencap makes use of the fact that Income Support can be used to pay the interest on mortgages up to £100,000 when it can be shown that the household must move to obtain housing more suited to the needs of a disabled person. This point was highlighted in previous research that focused on promoting housing options for disabled people (King, 1996).

Housing Project, Ealing Mencap, Greenford, Middlesex

Ealing Mencap provides an advice service for families to assess the housing options available to them and, specifically, to help facilitate housing solutions in the owner-occupied sector. It has worked with a local housing association to help families obtain homes on a shared ownership basis. The families are able to choose their own home on the open market, which is then bought by the housing association. The property can be adapted to suit the family's needs. Ealing Mencap has also negotiated with a number of building societies that are willing to lend to households on Income

Purpose-built housing

Ideally, a barrier-free environment would be available for disabled people, in which all parts of the home are accessible to the disabled person, as well as the environment external to the home. One family described how a move to a bungalow developed by a registered social landlord specialising in the provision of barrier-free accommodation had allowed their son the freedom to do things for himself, not just around their home, but also in the immediate neighbourhood.

Outcomes for families rather than outputs for services

In a recent study, Heywood (2001) has drawn attention to the effectiveness of housing adaptations and the extent to which their provision has matched what families may actually need. One provider ruefully remarked that they had visited families after adaptations had been

put into a home only to see the adaptations gathering dust. It was felt that perhaps more attention had been given to reducing backlogs than to ensuring that what was being provided was what the family really wanted, or could afford to use.

A number of providers were in the process developing ways of assessing the effectiveness of adaptations in terms of outcomes for families. The aim was to make sure that the services delivered really work for families. A number of organisations had put in place feedback mechanisms after an adaptation had been completed. These mechanisms usually involved a survey or questionnaire to give families an opportunity to comment on different aspects of the delivery of the adaptation (for example, what the family thought of the contractor, the architect, the OT and so on), as well as how far it matched their needs. Current research around adult services may lead to developments in this area, which could be applied to disabled children.

Caerphilly County Borough Council

After an adaptation has been completed, an OT from the Council visits the family to ensure that the adaptation meets the needs of the family.

Conclusion

Informed choice for families is a key principle and extends to the way that families are presented with a full range of options to meet their housing needs. This includes changes to the home, alongside advice to help families to move. This help could take the form of an assessment of potential properties, or financial help to move to social housing or to help facilitate access to home ownership.

This chapter has highlighted instances of services that have made an explicit recognition of the circumstances that children face, which require tailored solutions. One example of this approach includes designing or changing a domestic environment that accommodates the need for space and especially for play.

Strategic and organisational issues

Introduction

A central theme running through the report by Beresford and Oldman (2000) is the need for practitioners to work together to tackle the housing needs of disabled children. They stress that there is a severe fragmentation of service provision for families with a disabled child, as well as a low level of awareness on the part of different professionals of the importance of housing. Arblaster et al (1998) have put forward a number of recommendations for developing effective and successful collaboration between agencies, including:

- clarifying relationships;
- building trust;
- developing understanding;
- recognising mutual compatibility;
- developing resources.

Arriving at a shared understanding of what can be provided and who can be helped can be crucial, because the use of different criteria of need between various agencies can have an adverse impact on families. Heywood (2001) notes that some social services departments' use of the 1970 Chronically Sick and Disabled Persons Act occasionally precluded families from being referred to housing services that might otherwise provide them with adaptations to their home. A further issue is the level of priority that may be accorded to disabled children over and above other considerations by service providers, including looking at the circumstances of the parents or carers rather than the needs of the child. For example, the needs of a disabled child may be compromised because their parent or carer has rent arrears or an antisocial behaviour order against them.

This chapter focuses on strategic and organisational issues and, in particular, recommendations for the way that services are organised so that they can provide the best help for families to achieve satisfactory outcomes for their housing needs. As part of this focus, the chapter describes a number of approaches to multiagency working by a variety of agencies. Another key issue for service development is inclusive strategies that enable families of disabled children to be part of discussions and reviews. The chapter then describes the awareness raising required about the needs of disabled children and their families within services.

Multiagency working

One issue highlighted by Arblaster et al (1998) concerned collaboration in the use of budgets. One advantage to families of effective multiagency working is that flexible use of agencies' respective budgets can be utilised to achieve a joint solution to help meet the housing needs of disabled children, as highlighted in the example below.

Housing Project, Ealing Mencap, Greenford, Middlesex

Ealing Mencap chairs a Learning Disability Housing Panel, which is a partnership between the housing department, two registered social landlords, and the social services department in Ealing. This panel discusses how the agencies involved can work together to meet the housing needs of individual families. For example, in one case, the

social services department helped a family to pay the stamp duty and legal fees associated with a house move.

Good practice can sometimes result from exceptional working relationships developed between individuals either working in one organisation or department or across different service areas. However, when these individuals move on, this good practice and trust may be lost. One way of dealing with this issue is to formalise shared working as part of a local strategy, rather than relying on informal relationships. One example of joint working, highlighted below, is Caerphilly County Borough Council, which has set out agreed shared working procedures for adaptations.

Caerphilly County Borough Council

Caerphilly County Borough Council produces a manual that establishes agreed shared working between environmental services and the housing and social services departments on adaptations and daily living equipment. There are ongoing, joint training sessions each time the manual is revised.

A further benefit of joint working between agencies is a pooling of knowledge and expertise. In the context of housing, Shaw (2001) highlights the important role of OTs with appropriate expertise in the area of housing. An additional concern is that knowledge of housing issues can be combined with expertise in children to arrive at a housing solution that can be specifically tailored to meet the needs of children. A number of authorities provide assessments that combine this area of housing expertise with professionals specialising in the needs of children.

Community-based paediatric service, Foyle Trust Western Health and Social Services Board, Northern Ireland

This community-based paediatric service is a multidisciplinary centre. Each family has a named paediatric OT, and children's housing needs are initially identified by the OT. A joint visit is then carried out with the paediatric OT and a

community therapist who has expertise in housing. The joint process aims to tackle the current and future housing needs of children and families. There is no waiting time for community OT involvement.

Ceredigion Family Support Team

The Family Support Team exists to help children with a disability and their families. The team provides a one-stop shop, with a keyworker for each family. It is a specialist multiagency team consisting of a manager, a teacher, two health visitors, three social workers, a paediatric OT, a paediatric physiotherapist, two respite care workers, an early intervention worker, project worker, a secretary and a clerk typist. There is no waiting list for an assessment by an OT for a child with a housing need – there is a dedicated post for children, and housing is always given a priority. The one-stop shop approach means that the team can respond quickly to a family's needs. Equipment needs are identified in line with the completion of an adaptation to ensure that the provision of both corresponds.

The above examples illustrate how the housing needs of children can be met in a multiagency setting, while also providing a single point of contact for families to facilitate easier access to services. However, there is also an issue about how families can readily gain access to housing services in an area with a large number of different housing agencies. In particular, Beresford and Oldman (2002) highlight the impact of large-scale voluntary stock transfers (LSVT) on services for disabled people, especially in relation to the potential for greater confusion on the part of families about who they should contact for housing. The value of a one-stop shop in these circumstances can be seen in the services provided by Glasgow Disabled Persons Housing Service, in a city that has over 80 different social housing providers.

Glasgow Disabled Persons Housing Service, Centre for Independent Living in Glasgow

The Glasgow Disabled Persons Housing Service offers a one-stop shop for disabled people in housing need. There are over eighty housing associations and social housing providers within Glasgow. The Housing Service has a database of all the available and planned accessible and barrier-free housing in the city, and helps disabled people to apply to housing providers who have the type of property that they need. A matching service is available using the database of housing and a register of disabled people in housing need. This register can also help housing providers identify disabled people who really need their vacant properties. The service contacts everyone on the register each six months to one year, to find out if they have resolved their housing needs, or if their needs have changed.

families with disabled children and try and tackle these issues through joint working. The Council also has a disabled users reference group.

Other organisations take on a facilitating role to bring families and services together.

Disability North, The Dene Centre, Newcastle upon Tyne

Disability North hosts the Newcastle Special Needs Network. This support group for parents campaigns to bring service providers and parents closer together to ensure that the needs of children are being met. This network includes enhancing user involvement in housing services.

Involving families in how services are run

The previous chapter highlighted consultation with families with disabled children to consider their personal housing needs. However, it was also apparent that there were a number of mechanisms, in a variety of organisations and within different tiers of government, through which families with disabled children were able to have input into reviews and service development.

These involved services delivered by individual local government departments, and a number of families and local authorities highlighted consultation using regular meetings with groups of parents, or as part of a process of consultation around a Best Value review. Some of these organisations have regular user groups or panels including families with disabled children.

Leeds City Council

Representatives of housing, health and social services departments of Leeds City Council work with parents and carers who use the Council's services to identify issues that are important to

However, it was also noted that families could have an input into service development at the national or regional level, either as invited members of user groups, or as part of a campaigning group, lobbying for change. One instance when lobbying activity by parents with disabled children and others has had an impact on local government is in Northern Ireland. The Family Information Group and others have campaigned for an end to the means test for the DFG for children. The steering group of a joint review of the housing adaptations service in Northern Ireland (Northern Ireland Housing Executive, 2002) recently recommended a change in the legislation to exempt adaptations for children from the means test. However, while the minister concerned has rejected the abolition of the means test for children, it has been announced that there will be a review of the means test to see if it does fairly take into account the costs associated with caring for a disabled child. This is a positive development that would potentially put Northern Ireland ahead of the rest of the UK in this respect. As such, it demonstrates the effect that families, as part of a lobbying campaign, can have on the local policy process.

Recent research highlights the need to include minority ethnic households in reviews of service delivery (Evans and Banton, 2001). In particular, the authors highlight the stereotypical views of minority ethnic households held by providers and how these may affect the delivery of services. Two of the services discussed delivering services

to minority ethnic groups and how the service had been tailored with respect to consultation. One service had found that South Asian users stated that they were not concerned about the ethnic background of their advisors. In contrast, another project offering support to parents had developed separate support groups in response to users' needs to be able to freely discuss their needs in the context of their own cultural background. The examples show the potential danger of replicating a style of delivery across different groups of users. Instead, it affirms the necessity to consult and listen to the needs of specific users and ascertain what they want from a service and how that service can be delivered most appropriately. Similarly, Greenwich Borough Council found that South Asian families were not using their in-house agency service for adaptations, because these families were uncomfortable with the builders contracted for the works. Greenwich Council is currently trying to engage builders from different ethnic backgrounds to add to its list of approved contractors.

Raising awareness

One role for services is to help raise awareness of the housing needs of disabled children among other service providers, including other housing agencies. The need to raise awareness of disability within organisations is reflected in the view of one parent, who expressed frustration when she went to her local council for help:

“The council are not up with housing disabilities. They need to employ people with disabilities or somebody in their family.... They don't really know.”

One example of raising the profile of the needs of disabled children was a project conducted by Ability Housing Association in Middlesex. One aim of this project was to highlight the needs of disabled children living in households which a local authority considered to be adequately housed. One of the results of this project was an increased number of referrals of families with disabled children from the authority to Ability Housing Association.

Ability Housing Association, Staines, Middlesex

Ability Housing Association ran a pilot scheme to raise awareness within a local authority of the housing needs of disabled people, and in particular of disabled children, in cases in which a local authority may consider the family to be adequately housed. The aim was to obtain information about disabled people approaching the local authority with a housing need. This led to an increase in the number of referrals of families with disabled children from the local authority.

While there is a role for raising awareness of the housing needs of disabled children per se, an additional factor is that service providers tend to recognise and provide for certain types of impairment or condition, but not others. One OT noted that housing departments seemed able to meet the needs of children with difficulties in terms of mobility or access to parts of the home, requiring changes such as ramps, stair-lifts and level-access showers. However, they were far less attuned to the needs of children with behavioural problems or learning difficulties. However, Beresford and Oldman (2002) have highlighted the problems experienced by children with learning difficulties and/or behaviour problems with regard to their housing, and noted that the need to move home is often a particular issue for these families, for example, difficulties may arise in terms of a troublesome or unpleasant local environment. They also noted that, despite this, the housing needs of these children are largely ignored.

A parent who discussed the attitude of the local authority in her area also picked up on this point. She felt that the housing needs of children with learning difficulties were not recognised by the council. However, this was not the case with all authorities, as evidenced by practitioners who emphasised changes undertaken to homes to ensure the safety of children with learning difficulties and/or behaviour problems. In particular, a number of local authorities highlighted the provision of toughened safety glass, security locks, soft play areas and fencing. A number of these authorities had responded, not only to the need to provide a safe home environment, but also to developmental needs of

children, such as safe bathing facilities for children with autism.

One practitioner emphasised that an awareness of the specific issues about the needs of disabled children should be raised among staff within local authorities. A key issue here was felt to be that spending on exceptional items, or on items that were costly, for disabled children was possible within the existing system, as long as the cost could be justified. An important step, therefore, is to demonstrate why such spending is required, by heightening awareness among the individuals who are in a position to approve such expenditure. An example cited is the importance of expenditure to provide a safe environment for children with behavioural problems. Approving a least-cost option is problematic because devices such as unsuitable safety locks are unlikely to last. Spending more money at the outset would ensure that the needs were met effectively. Crucially, money would be saved in the long run, because it would minimise the risk of breakdown in care, but also save money in the short to medium term because the adaptations were more likely to last.

A key role for some agencies is also to raise awareness of the needs of minority ethnic households among housing providers.

Project Alafia, Reading Council for Racial Equality

Project Alafia has developed links with Ability Housing Association and works jointly with the Association to improve access to housing services. The Project also works with Ability to raise awareness within that organisation of the needs of minority ethnic families with a disabled child.

Other projects have sought to raise public awareness of the housing needs of disabled children. In one instance, this has involved raising awareness of disability issues among school children.

Disabled Persons Accommodation Agency (DPAA), Rochester, Kent

The DPAA has developed an interactive CD Rom to be used in schools to raise awareness of disability and housing issues among children. The CD Rom will also be used to raise awareness of the housing needs of disabled people among housing providers, including developers, estate agents and letting agents in the private sector. It also provides information on the future needs of young disabled people in Kent for local authorities, housing associations and other housing providers.

Conclusion

The extent to which families are consulted and listened to by services is a key issue. Consultation can take place on three distinct levels:

- at an individual level, throughout the process of meeting the specific housing needs of a family;
- at a service level, where families can be involved in reviews of the way a service is organised and delivered, or the way that multiagency working meets housing needs in a particular locality;
- families may also have an influence on policy developments at the national or regional level, through formal processes of consultation or lobbying.

An important theme to emerge is raising awareness among families of how services may be able to help to meet their housing needs. Just as significant is raising awareness within, and between, organisations of the specific needs of disabled children and the responses available to services, including an awareness of needs of minority ethnic families with a disabled child. A focus for attention could be ensuring that there is a common understanding between organisations who work together of the response to families' housing needs, and an agreed understanding of the eligibility of families to receive help. Furthermore, awareness needs to be raised in frontline staff and access teams about the housing issues facing families with disabled children.

Linked to the theme of awareness is the extent to which the needs of a disabled child may be overshadowed by the circumstances of their parents or carers. For example, an authority may consider that a disabled child may need no assistance with their housing because it considers the parents to be adequately housed. Another example is the test of resources for a DFG, which is made against the income of the parents rather than the resources available for the child. This highlights that the child is not always central to the process of meeting their housing needs, and may become sidelined by other priorities.

Conclusions

This report has highlighted examples of the way that individuals and agencies around the UK are currently addressing the housing needs of disabled children. A key aspect of the services reported here is that they have been nominated or commended as providing a good or innovative service by families with disabled children. However, it should be stressed that this is not a comprehensive list of all good practice, and there will be services not listed which are routinely meeting the housing needs of families with disabled children in positive and innovative ways. Nevertheless, the examples cited illustrate the approach that individuals and organisations are taking to meet housing needs within the current UK policy context and, as such, can be put forward as recommendations for policy and practice. It must be noted that the specific examples may not necessarily translate into all contexts, but it is the underlying principles that are important. With this in mind, the conclusions to this report are presented in two sections: the first part draws out key issues for service providers; the second section has been framed in terms of questions for service providers arising from these themes and good practice principles.

Key issues

Chapter 2 highlighted a number of frontline organisations that provide information and advice – particularly when families first find out about their child's impairment or health needs – and can signpost families to services that will help to meet their housing needs. A key issue is the lack of awareness among families that specific help may be available to meet their housing needs and non-housing services can help by providing information, referring to other housing services,

or including housing issues as part of assessments.

Chapter 2 also discussed the issue of empowerment of families and the importance of ensuring that families are at the centre of decision making about their housing circumstances. This principle has a number of implications for the way that services are delivered, which includes consulting and listening to the family throughout the process of meeting their housing needs.

One of the underlying themes, as noted in Chapter 3, has been the extent to which the specific needs of children are recognised by services, including, for instance, the need for space, especially for play. A further issue is the way that a number of services have attempted to meet the needs of the whole family.

Other research has highlighted the breadth of impairments, including children with learning difficulties, behavioural problems or ill health, and the failure of policy or many service providers to acknowledge these needs in a housing context (Beresford and Oldman, 2002). Raising awareness of disability, as well as awareness of the services available to address related housing issues, is a crucial concern. Chapter 4 highlighted the approaches of a number of services in this respect. The issue of raising awareness of disability and housing services aimed at meeting the needs of disabled people cuts across a range of groups, including families themselves, members of staff within organisations and service providers working in a multiagency context. Chapter 4 also highlighted the role of multiagency working to bring about more effective solutions to the needs of families, either through effective coordination of services or joint funding.

From the possible to the probable

Although the focus of this study has been to highlight what *can* be achieved, other evidence cited in the report suggests that the services put forward here are likely to be the exception than the rule for many families.

Practitioners are generally in a difficult position: having to balance providing for individual needs with providing an equitable service to all, often within a context of severely constrained resources. This report has therefore sought to consider some of the key themes and underlying features of those services that have been commended by families themselves, in order to identify key questions that could help *all* agencies working to improve the housing circumstances of disabled children and their families.

The following checklist outlines a number of fundamental issues that have been drawn from the evidence and analysis presented. It does not attempt to be fully comprehensive but provides a framework through which local agencies and strategists could consider whether the configuration of local services in their area matches up to elements of 'good practice' from the perspective of families themselves.

HOUSING AND DISABLED CHILDREN				
CHECKLIST FOR CHANGE				
Is there an awareness and acceptance of all impairments (physical, sensory, learning, behavioural)?	Do all aspects (access, delivery, strategy) recognise the needs of black and minority ethnic families?	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 (such as health services) for advice or information, are possible housing issues identified and referred/sign-posted on?	
			Do Children's Act assessments of disabled children routinely investigate possible housing problems?	
			If so, is this interpreted more widely than 'access' (that is, 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 (for example, moving, adapting)?	
			Can they choose between available options without risk of losing specialist support (such as 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 or a 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 (for example, 'incremental adaptations')?	
		STRATEGY	Is there a common understanding between agencies of the extent and range of unmet housing need in this group?	
			Are there specific joint arrangements that are or could be utilised to meet housing needs (such as pooled budgets)?	
			Are the needs of disabled children made explicit in local housing strategies?	
			Are needs translated into planned actions (for example, targets for new-build provision, adaptations to facilitate safe play)?	
			Is advantage taken of housing policy developments in other spheres (for example, 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?			

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