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Housing, disabled children and their families

The majority of disabled children live at home on a permanent basis with their families. They have been identified as a group which 'slips through the net' in terms of meeting their housing needs. Researchers at the University of York have carried out the first in-depth study of the impact of housing on the lives of disabled children and their families. They found:

f Three out of four families reported one or more ways in which their housing was unsuitable and four out of ten reported that their housing was poor overall. Unsuitable housing affected families with children with a wide range of impairments, not just physical disabilities.

f Families felt that unsuitable housing made the task of caring harder and that it contributed to their high stress levels. Parents believed that they would have needed fewer care and support services if their homes had been more suitable. They were also concerned that, because their children were unable to get around their homes, the children's lives were characterised by a lack of spontaneity and by feelings of frustration.

f For the severely disabled children interviewed, unsuitable housing is a significant barrier to enjoying what are generally regarded as normal, even essential, childhood experiences. Their housing made moving around the house, playing, contributing to family life and learning to look after oneself much harder.

f Lack of resources and shortage of good information and advice constrained those families who wanted to adapt their homes. Referral, assessment, and funding systems and processes were fragmented, piecemeal and difficult to understand. The families in the study employed considerable resources of their own in attempts to address their housing difficulties.

f Where adaptations were perceived as being successful, the task of caring had become very much easier and the child gained greater independence.

f Housing and social services professionals had very little awareness of the impact of unsuitable housing on families with disabled children. Child-specific policies and procedures were rare.

The impact of unsuitable housing on families

Disabled children's housing needs are much broader than traditional issues of access associated with disability in adulthood; for instance, interviews with parents highlighted the following, in addition to access: quality of housing, amount of space, safety, and location. The interviews also showed that unsuitable housing affects the whole family: disabled child, parents and siblings.

Families with disabled children are more likely to live in rented housing on low incomes than families with non-disabled children. A significant minority of families in the study lived in housing which was overcrowded, cold, in poor repair or situated on unfriendly estates.

The amount of space in the home was a key issue for children with a wide range of impairments. Parents were worried that their children were not getting the exercise or therapy they believed were needed because wheelchairs, walking and standing frames could not be used in their house. A further worry was that their children did not have enough play space. Siblings, too, needed their own personal space. Sharing a bedroom, for example, with a child who may wake frequently during the night or destroy cherished belongings can be problematic. Lack of physical space highlighted issues concerning personal space, particularly in families with a child with learning or behavioural difficulties:

"We need two houses, one for him and one for us."

Problems of access were very common: stairs were difficult and houses often lacked a downstairs toilet. Bathrooms were often reported to be the most difficult room in the house. Lifting and handling a child up and down stairs several times every day took a particular toll. Parents believed that unsuitable housing directly caused some of their own physical illnesses, such as serious back problems, and was indirectly implicated in their other problems including, in some cases, relationship problems. They also felt that some services, such as care assistance to help with self-care activities and some respite services, would not have been so necessary if houses had been more appropriate to the child's needs. In a few cases housing affected parents' employment decisions. Partly because coping with the child around the house was so difficult, some fathers tried to take jobs that allowed them the flexibility to help out at home.

Homes were also considered inappropriate because they lacked suitable gardens, were located on

steep hills or were too far away from support and services. Safety was a major concern for families, especially so for these respondents. Kitchens, stairs, bathrooms and outside areas all posed safety problems, particularly for families that included children with learning difficulties and for those whose children were visually or hearing impaired. The study found that:

just under a fifth of all respondent families lived in cold, damp housing in poor repair
limited play space affected a third of families
a quarter of families reported difficulties with stairs
a quarter of families reported a lack of room for storing equipment.

Children's experience of their homes

In interviews with seven severely physically disabled children showed that the business of living involves a great deal more effort for disabled children compared with non-disabled children, and that unsuitable housing compounds these difficulties. A word often used by the children to describe their houses was 'hard'.

Like the parents, children talked about the problems created by lack of space. They described rooms they did not like because they were cluttered or cramped. As well as experiencing lack of space, the children's ability to move about their homes was restricted. Getting up and down stairs took considerable time and effort. It was difficult for the children to join in with other children's play as they were often stranded in one area of the house, having to rely on a strong adult to move them around. For most children gardens and outdoors are a favourite place to play, but for disabled children gardens can be inaccessible or unsafe. Life at home could be very frustrating and boring:

"When I'm at school I go round in ma [sic] wheelchair, and when I'm at home I just sit in my chair."

There were differences between parents' and children's perspectives on housing. Parents were more concerned about the risk that some of the areas of a home presented and they rarely talked about the problems their children may have had trying to use, for instance, the kitchen. Most of the children experienced difficulties using or even being in a kitchen. It was a room that some rarely ventured into, which meant they were unable to help out with family chores and could not learn to prepare drinks and snacks.

The children in this study also wanted to be independent in terms of their self-care, and particularly wanted more privacy. Where self-care aids had been installed they seemed to be used more as a 'care aid' for parents, as opposed to an 'independence aid' for the child.

"My mum doesn't use that (electric toilet) very often because she thinks, 'Oh, let's get you off'."

Responding to unsuitable housing

Just over a third of the families had made changes to their homes. In addition, there was a high incidence of moving house: 60 per cent of the families had moved since their disabled child had been born, usually for reasons associated with the disability. Self-financing of adaptations, particularly amongst owner-occupiers, was far more prevalent than publicly funded work. As well as bearing the additional everyday costs of disabilities, families had high housing-related costs arising from making adaptations, or moving house.

For those families living in unsuitable housing which had not been modified, the main constraints to getting things done were lack of resources and not knowing how to get a housing need recognised and acted upon by appropriate agencies. Families would have benefited considerably from good information and advice. Over half of all the families in the survey did not know that financial help for adaptations might be available from local authorities. However, where families did seek public funding they were often not successful. In some cases their need was not acknowledged:

"Because he is not in a wheelchair we are expected to get on with things ourselves."

In other cases, families were expected to contribute financially to the adaptation work.

Changes have been called for in the Disabled Facilities Grant (DFG) system, and in particular in the means test. The 1996 changes to the DFG benefited adults with disabilities but did not embrace children.

The means test for the DFG ignores the fact that owner-occupier families with children will almost always have mortgages, and will have much higher everyday costs than families with non-disabled children. Consequently families on modest incomes are obliged to make substantial contributions to the cost of adaptation work. Families have to face difficult options - financial hardship, doing without the adaptation or getting a much less satisfactory job done than the one they wanted.

Those families who had carried out adaptations often found the process problematic. Many of the families who had received public sector funding for adaptations had experienced difficulties because professionals did not understand their needs. Some families felt they had reluctantly had to agree to adaptations which gave their homes a medical or hospital-like feel. The subsequent adaptation sometimes exacerbated space problems. Overall assessment of needs was rare. A referral, for example, for a stair lift would be looked at in isolation from a family's other needs. Long delays at various points in the adaptation process were very common.

Table 1 shows that 19 per cent of those who had completed some adaptations said that their housing had no unsuitable factors and that 21 per cent were still reporting high levels of housing unsuitability - in effect, what had been done did not meet adequately either the child's or other family members' needs.

For those who had achieved a good adaptation their child's life was transformed:

"If you can get your home right you can cope. This house is like a cocoon. It doesn't matter what's coming to us now. How can you make a tough decision in a house that's not a home? Within 24 hours of being in this house it was like WOW. She was a different child. Her confidence increased overnight. I can't describe to you the difference in Debbie."

Some families wanted to move house. Moving to a more appropriate house can be more cost-effective than staying put. But statutory funding, such as the

Table 1: The relationship between adaptation and housing unsuitability

Have adapted	Number of reported factors making home unsuitable			
	None	1-3 factors	4-6 factors	7 or more factors
Yes %	19	46	14	21
In process %	11	33	44	11
No %	27	36	20	17

Disabled Facilities Grant, is currently not available for house moves.

Some families did not want to move. Adapting an existing property was perceived as a better option than moving home. However, those families who were council tenants often said that their authorities obliged them to move rather than adapting their present property. These moves were sometimes to inadequately adapted homes in unattractive locations.

The professionals' perspective

There was a general lack of awareness, particularly amongst housing grant officers, of the impact of unsuitable housing on parents, disabled children and siblings. Occupational therapists (OTs) were the most sensitive to the particular skills and expertise required when delivering adaptations to families. They observed that parents and children are not necessarily going to have the same perspective on the disability, and hence parents may respond to housing unsuitability in a way that does not meet children's needs. Nevertheless, OTs felt they were under pressure to contain budgets rather than be genuinely responsive to parents and children.

All the professionals interviewed saw the need for good collaborative working in order to get an adaptation successfully completed. However, in practice perspectives differed. OTs, generally, were concerned with the needs of individuals, whilst housing officers were motivated by the imperative to allocate scarce resources in an equitable and cost-effective manner. In a fundamental sense professionals did not work well together - the links between caring, independence and housing were not thought through in terms of operational policies and procedures which are child- and family-specific.

About the study

The study comprised four components: a postal survey of over 200 families, 40 in-depth interviews with parents, interviews with physically disabled children from these families and, finally, interviews with housing and social services professionals in four local areas. A wide range of impairment, age of child and housing circumstances were represented. All the fieldwork, which was conducted in 1997, was carried

out in the Yorkshire and Northern regions. The main sample of families was taken from the Family Fund Trust's case load. A further sample was drawn of families who had applied to the Trust for help but had been rejected on the grounds that their incomes were above £18,000.

How to get further information

A full report, **Homes unfit for children: Housing, disabled children and their families** by Christine Oldman and Bryony Beresford, is published by The Policy Press in association with the Joseph Rowntree Foundation and *Community Care* magazine (ISBN 1 86134 116 4, price £13.95)