

Shelter

Cymru

contact a family
for families with disabled children
incorporating
The Lady Hoare Trust

Family experiences of accessing Disabled Facilities Grants

A collaborative research study
in Wales and Northern Ireland



Our Vision

Shelter Cymru's vision is that everyone in Wales should have a decent home.

We believe

- a home is a fundamental right and essential to the health and well-being of people and communities.
- there must be major changes to law, to the culture and delivery of services and the level of resources if homelessness and housing need are to be finally eradicated in Wales.

Our Values

Independence

We work for people in housing need without fear or favour.

We will constructively challenge to ensure people are properly assisted and to improve practice and learning.

Respect

We work as equals with the people who use our services.

We provide information, advice and support to help people identify the best options to find and keep a home and to help them take control of their own lives.

Family experiences of accessing Disabled Facilities Grants: A collaborative research study in Wales and Northern Ireland
Written by Peter Mackie, Keith Bowen and Brendan McKeever

All photographs courtesy of
Katie Barrett Photography

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It is equally important to thank the Joseph Rowntree Foundation for their financial contribution, which made it possible to commit the necessary time to the research. In particular, we wish to thank Alison Jarvis for her commitment to supporting research which addresses issues associated with disabled children's access to suitable adaptations.

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Introduction and context

According to Beresford (2008: 2); ‘the past decade has seen an increase in the evidence base on housing and disabled children... The issue has also moved up the policy agenda, with government reporting that more needs to be done to improve the housing situation of families with disabled children.’ By drawing on existing data in England (Department of Communities and Local Government, 2007), Beresford (2008) establishes that where specially adapted accommodation is required, children (aged 0-15 years) are the group least likely to be living in suitable accommodation. The statistics show that less than half of disabled children who require specially adapted homes are living in suitable accommodation. Although Beresford’s work predominantly applies to England, it is likely that the situation is similar in Northern Ireland and Wales.

Research demonstrates that living in unsuitable housing can have a range of negative impacts on families’ lives. For example, it can restrict access to play and leisure activities, or reduce spontaneity of the children (Oldman and Beresford, 1998). Equally, unsuitable housing can impact on the physical health of parents or carers, who sometimes sustain injuries when caring for their disabled children (Heywood, 2004).

It is clear that many disabled children are living in unsuitable accommodation, the consequences of which are well established. In order to meet the accommodation needs of disabled people, local authorities are able to adapt properties through mandatory Disabled Facilities Grants (DFGs). This is just one of the available mechanisms. Between 2003 and 2005, separate reviews of the DFG process were conducted in Northern Ireland (DFG Working Group, 2003), Wales (Jones, 2005) and England (Heywood et al, 2005). The reviews identified similar concerns about parents’ access to this grant, including:

- High and increasing demands for DFGs
- The means test is poorly targeted and perceived to treat groups harshly, particularly children
- The purposes for which the grant can be used and the maximum limits for adaptation result in limitations
- The complexity of making an application is compounded because the grant is often administered independently from other social care services
- People in all tenures are entitled to the grant but complexities in funding streams mean that in practice inequalities occur
- The DFG process is not normally widely publicised

An almost immediate response to these reviews was the abolition of the parental means test in Northern Ireland (February 2004), Wales (September 2005) and England (December 2005)¹. To date, no research has been conducted to explore the impact of abolishing the parental means test, despite recent calls for such action (Beresford, 2006). Furthermore, anecdotal evidence presented by Contact a Family Wales, indicates that despite the ending of the parental means test, some parents of disabled children are still facing difficulties in accessing the grant.

¹ See McKeever (2006) for a detailed account of the Homes Fit For Children campaign which led to the abolition of the parental means test

In a response to the clear need for evidence on the impact of abolishing the parental means test; Shelter Cymru, Contact a Family Wales, and Brendan McKeever (previously of the Family Information Group in Northern Ireland) developed a brief and targeted research study with the overall objective of quantifying changes in parents' access to DFGs over recent years and exploring parents' experiences of accessing the grant. More specifically, the research aims to:

- Collate information on the number of parents who have accessed the DFG process since 2004
- Explore the experiences of families who have accessed DFGs since 2004
- Identify current issues and enablers faced by families with disabled children, in accessing housing adaptations.

The scope of the research is limited, hence it will maintain a focus on exploring the impacts of the parental means test. However, the study will also provide further evidence to existing literature on parents' experiences of accessing the grant.



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Methodology

In order to address the research questions, two separate questionnaires were administered: a questionnaire survey of local authorities in Wales and the Northern Ireland Housing Executive, and a questionnaire survey of parents of disabled children. Details on these methods are given below.

Questionnaire survey of local authorities in Wales and the Northern Ireland Housing Executive

Questionnaire surveys were distributed to 22 local authorities in Wales, the Northern Ireland Housing Executive (NIHE) and a regional NIHE office. The questionnaires were essentially a request for data on access to disabled facilities grants for children, between 2004 and 2008. The data requested included:

- Total number of enquiries received
- Total number of applications received
- Total number of adaptations completed
- Average time from enquiry to completion
- Range and average cost

In total, data was returned by 11 Welsh local authorities, the NIHE, and one regional office of the NIHE. This is a sufficient return rate to make assumptions about changes in access to DFGs since the abolition of the parental means test. Despite the adequate return rate, the inability to obtain data from all local authorities in Wales raises two key issues. Firstly, not all local authorities record whether or not a DFG application was made on behalf of a child. Secondly, in Wales, more than one department often holds data on access to DFGs (Children's Services, Grants etc), which causes difficulties for collation and consistency of the data. These are concerns raised by the researchers and by some local authority staff.

It is important to note that whilst the secondary data presented in the report illustrates changes in access over time, some local authority staff raised concerns that data is not collected in a consistent manner across Wales, which will account for some of the variation between administrative areas.

Questionnaire survey of parents of disabled children

A semi-structured questionnaire was devised for parents of disabled children. The questionnaire and an accompanying explanatory leaflet were piloted with a group of parents who have disabled children, in order to agree an effective final format. The questionnaire explored the following themes:

- Awareness of the DFG and how to access it
- Experiences of applying for a DFG
- Possible reasons for not applying for a DFG

Questionnaires were distributed to parents of disabled children in Wales and Northern Ireland via three mechanisms. Firstly, through the newsletter of a Welsh voluntary sector organisation working with families who have a disabled child. Secondly, to families who have enquired about DFGs, through teams administering DFGs in 11 Welsh local authorities. Finally, questionnaires were distributed by one regional office of the Northern Ireland Housing Executive.

In total, 137 questionnaires were returned. Table 1 illustrates the method by which respondents received the questionnaire. It shows that approximately 90% of respondents are from Wales, most of whom received the questionnaire through the voluntary sector organisation. More specifically, nearly 65% of respondents from Wales, live in just 8 local authorities. Similarly, 60% of respondents from Northern Ireland, live in one county. It is important to note that the low response rate from Northern Ireland was expected due to the limited scale of the research. The low sample size means that only basic frequency data can be drawn out in order to compare the experiences of families in Northern Ireland and Wales. Whilst experiences appear to be similar in most respects, any divergences are highlighted in the report.

Table 1. Methods of receipt of household questionnaire

Country	Method of questionnaire receipt	No. of households	Percentage of all households
Wales	Voluntary sector	65	48%
	Local authority	58	42%
Northern Ireland	Housing Executive	14	10%
Total		137	100%

The aim of the household survey was to gather views of parents who have experienced applying for the grant but also to consider whether parents are fully aware of the grant and perhaps if there are issues that have deterred them from making an application. The sample population, enables these different issues to be explored because 71% had made an application and 29% had not (Table 2).

Table 2. DFG applications by households surveyed

Applications for a DFG	No. of households	Percentage of all households
Application made	98	71%
No application made	39	29%
Total	137	100%

Table 3 illustrates that respondents who had applied for a DFG had done so in all years up to 2008. The majority of respondents applied for a grant in 2006, 2007 or 2008, although a significant percentage applied before the parental means test was abolished.

Table 3. Year of DFG applications by households surveyed

Year of DFG application	No. of households	Percentage of households who made an application
2003 or earlier	19	20%
2004	5	5%
2005	9	9%
2006	23	24%
2007	18	18%
2008	16	16%
Unsure	8	8%
Total	98	100%

Table 4 shows that the vast majority of parents who responded to the questionnaire survey were owner occupiers (89%), which, according to statistics for all DFG recipients in Wales (Local Government Data Unit Wales, 2007), is nearly 20% greater than the proportion of DFG recipients who are homeowners².

Table 4. Housing tenures of households surveyed

Housing tenure	No. of households	Percentage of all households
Private rented sector	3	2%
Owner occupier	122	89%
Local authority	9	6%
Housing Association	2	2%
Leased property	1	1%
Total	98	100%

² This data applies to all DFGs awarded, not only DFGs awarded on behalf of children.

Parents' access to DFGs: 2003 - 2008

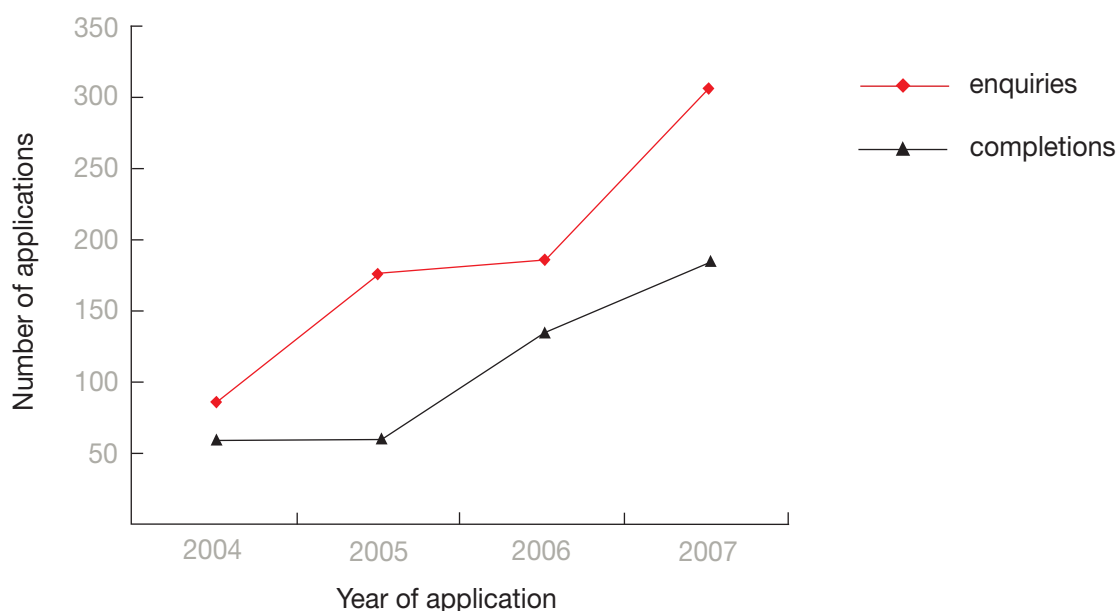
This chapter summarises recent changes in parents' access to DFGs, drawing on secondary data returned by local authorities in Wales, the NIHE, and one regional office of the NIHE. The chapter explores changes in three elements: the number of enquiries and completions, the average completion time, and the cost of the grants.

Enquiries and completions

Figure 1 demonstrates that in Wales the number of enquiries increased between 2004 and 2005 and again between 2006 and 2007. It is possible that the initial increase in enquiries relates to the volume of publicity about the grant prior to the abolition of the parental means test. The rise in enquiries between 2006 and 2007 probably reflects the fact that the parental means test had been abolished and parents had either delayed making an enquiry or they were aware that there had been a change to the DFG process. For example, some local authority staff reported that following the abolition, they contacted parents who had previously enquired about making an application, in order to encourage them to make an application.

Figure 1 also shows that the number of completions increased following the abolition of the parental means test in 2005. Between 2005 and 2007 the number of completions in Wales increased from approximately 50 to 180. There is a time lag between enquiries and completions, which implies that the number of completions is likely to continue to increase in the following years. Notably, the significant increase in enquiries and completions is different from the relatively constant number of adult DFG enquiries and completions (Local government Data Unit Wales, 2007). It appears that the abolition of the parental means test has had an impact on the number of DFG enquiries and completions in Wales.

Figure 1. Average number of DFG enquiries and completions in Wales 2004 - 2007

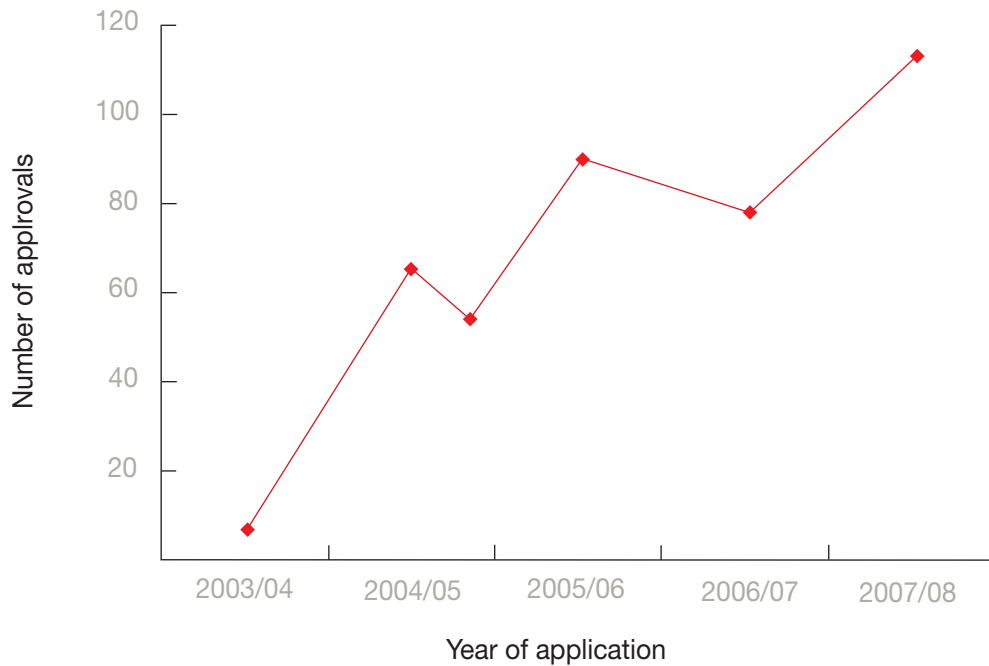


Source: Data returned by 11 local authorities in Wales³

³ Not all local authorities could provide data on enquiries and completions for all years. Data is extrapolated to provide a total for all of Wales. Enquiries: 2004 (n=7), 2005-2007 (n=8) Completions: 2004 (n=9), 2005-2006 (n=10), 2007 (n=11).

The NIHE provided data on the total number of DFG approvals in Northern Ireland (Figure 2). Figure 2 shows a similar pattern to the experience in Wales, although the increase in approvals begins at least a year earlier in Northern Ireland, which is likely to reflect the earlier abolition of the parental means test in 2004. The initial sharp rise in approvals is likely to be an immediate response to the abolition of the parental means test, with approvals increasing more gradually after 2005/06. Between 2003/04 and 2007/08 the number of approvals increased from less than 10 to approximately 110.

Figure 2. Average number of DFG approvals in NI 2003 – 2008

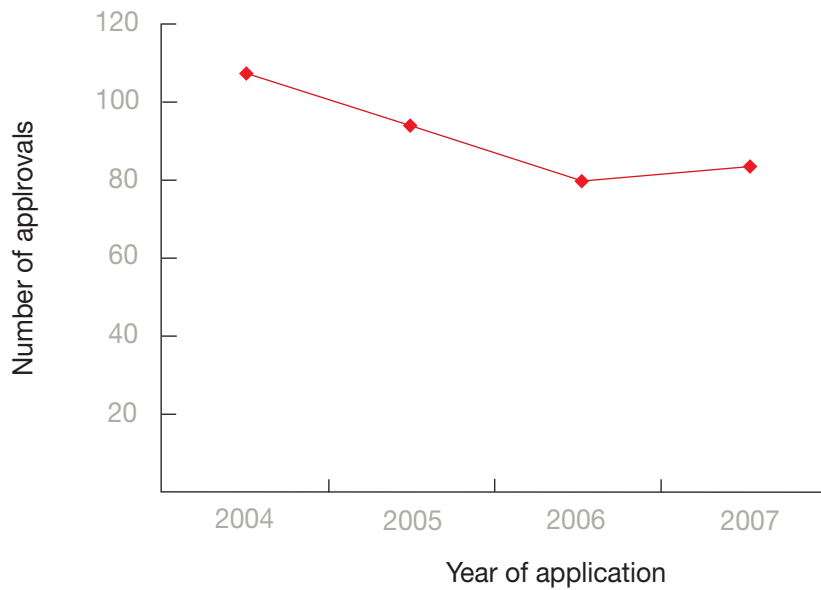


Source: Data returned by Northern Ireland Housing Executive

Completion time

Data on the time taken between initial enquiry and completion of adaptations was only available for Wales. Figure 3 shows that between 2004 and 2006 there was a gradual but significant decrease in the total number of weeks taken for adaptations to be completed. It is unlikely that this is a result of more straightforward processes (i.e. no means test) because the average completion time increases after 2006. Equally, it does not appear to be explained by changes in the cost of adaptations (Figure 4). It is more likely that improvements in completion time are a result of local authority efforts to improve completion times.

Figure 3. Average completion times for DFG adaptations in Wales 2004 - 2007



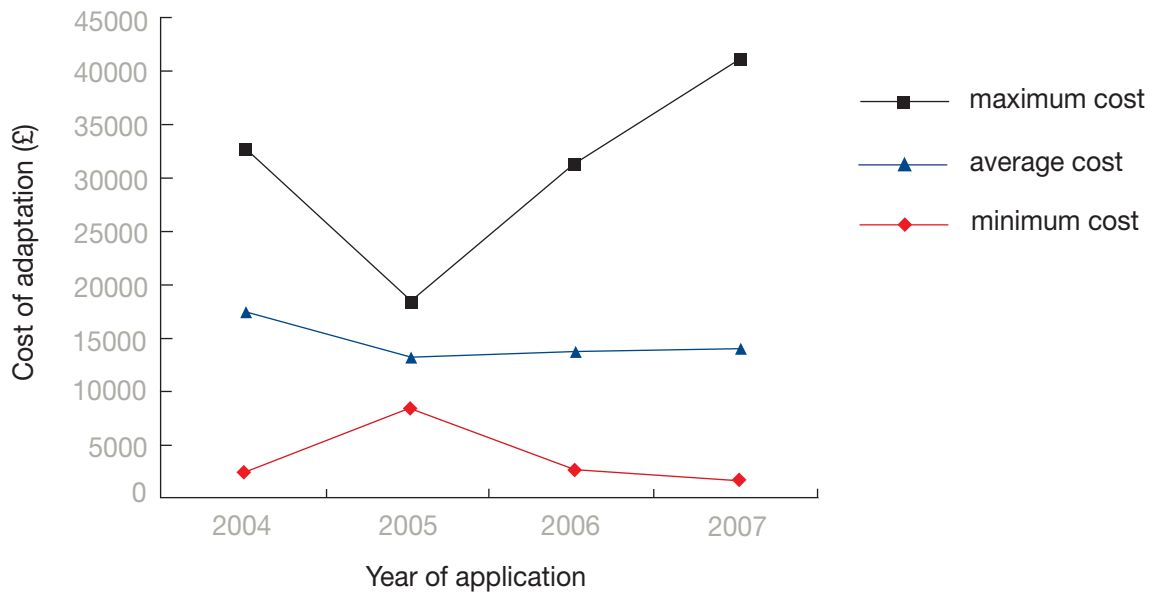
Source: Data returned by 11 local authorities in Wales ⁴

⁴ Not all local authorities could provide data on average completion time for all years. Average completion time: 2004 (n=4), 2005 (n=4), 2006 (n=7), 2007 (n=10)

Adaptation costs

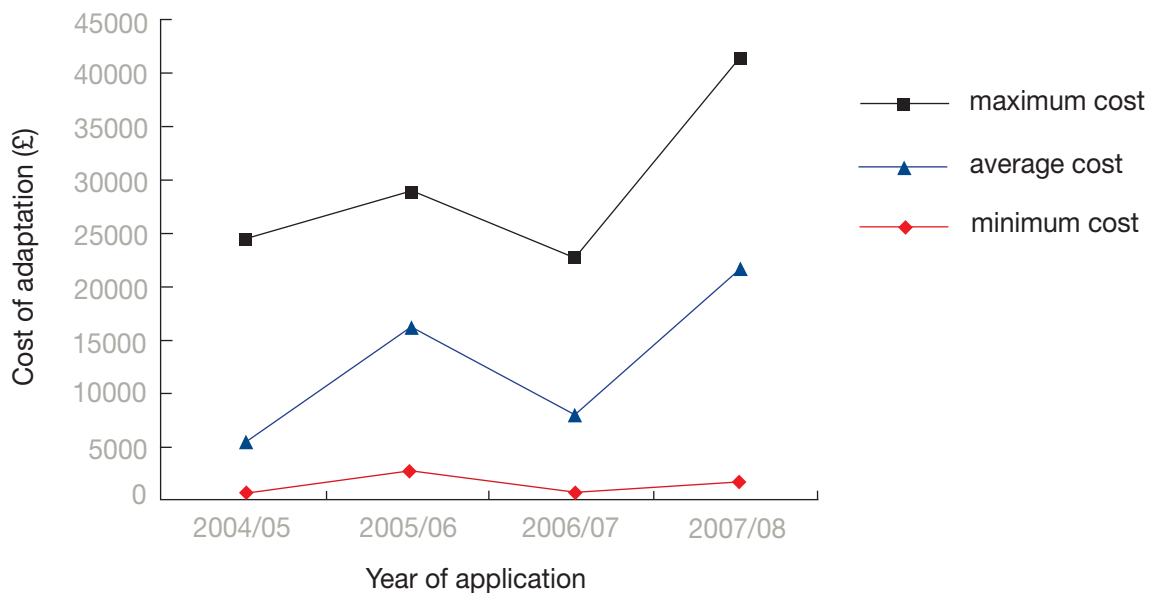
Figure 4 illustrates that the abolition of the parental means test has had no clear impact on the average cost of DFG adaptations in Wales, which has remained at approximately £15,000 per application. By contrast, since the abolition of the parental means test, there has been a general increase in the average cost of DFG adaptations in Northern Ireland (Figure 5).

Figure 4. Average DFG adaptation costs in Wales 2004 - 2007



Source: Data returned by 11 local authorities in Wales⁵

Figure 5. Average DFG adaptation costs in NI 2004 - 2008



Source: Data returned by Northern Ireland Housing Executive⁶

⁵ Not all local authorities could provide data on enquiries and completions for all years. Minimum and maximum cost: 2004 (n=2), 2005 (n=3), 2006 (n=6), 2007 (n=8) Average cost: 2004 (n=5), 2005 (n=6), 2006 (n=9), 2007 (n=11) ⁶ Data is from an area office of the NIHE, accounting for approximately 16% of all children's DFGs in Northern Ireland.

Accessing information and advice on DFGs

'I have never heard of this grant. How can we apply for it if it is not publicly advertised or information available to everyone receiving Disabled Living Allowance? How can this be improved and who are we supposed to approach to receive further information on this Disabled Facilities Grant?' (Parent)

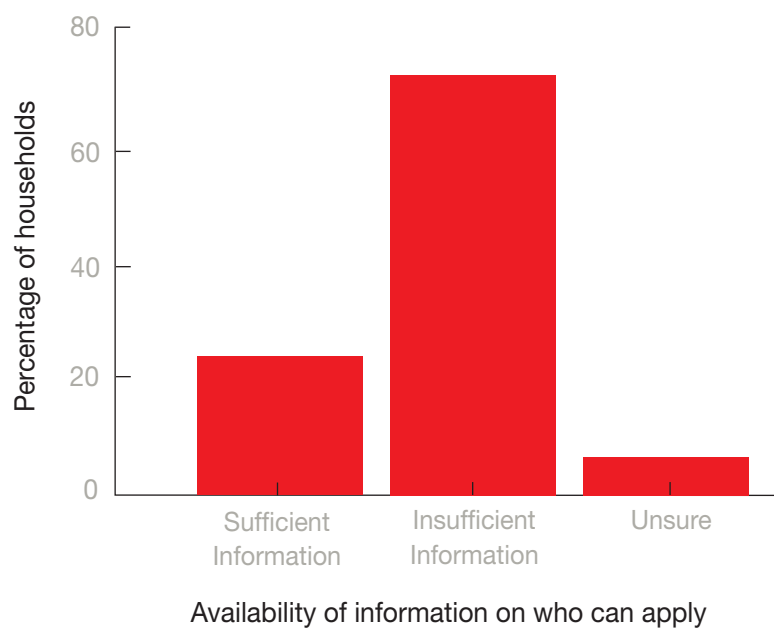
The quotation above is representative of the experiences of many parents who have disabled children. This chapter provides a summary of parents' perceptions about the availability of information on who can apply, where to apply, and what the grant can be used for.

Access to information on who can apply

The vast majority (75%) of parents who responded to the questionnaire survey stated that there is insufficient information on who is eligible to apply for a DFG (Figure 6). For example, one parent claimed:

'I was unaware of this grant because my husband and I are working I have been under the impression that we are unable to apply for any grants.' (Parent)

Figure 6. Perceptions on availability of information on who can apply for a DFG

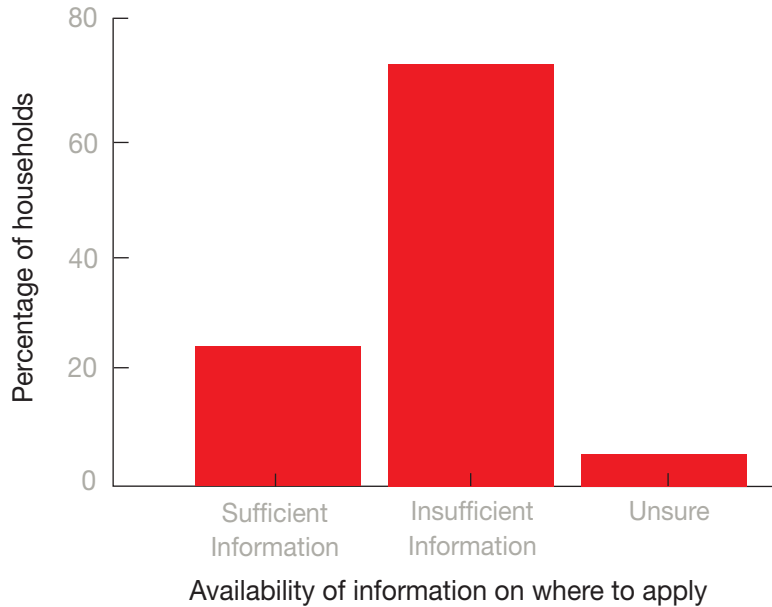


Access to information on where to apply

A high percentage (73%) of parents claimed that there is insufficient information on where to make an application for a DFG (Figure 7).

'There is no easily accessible information on which department within the council in which to get help, advice and apply.' (Parent)

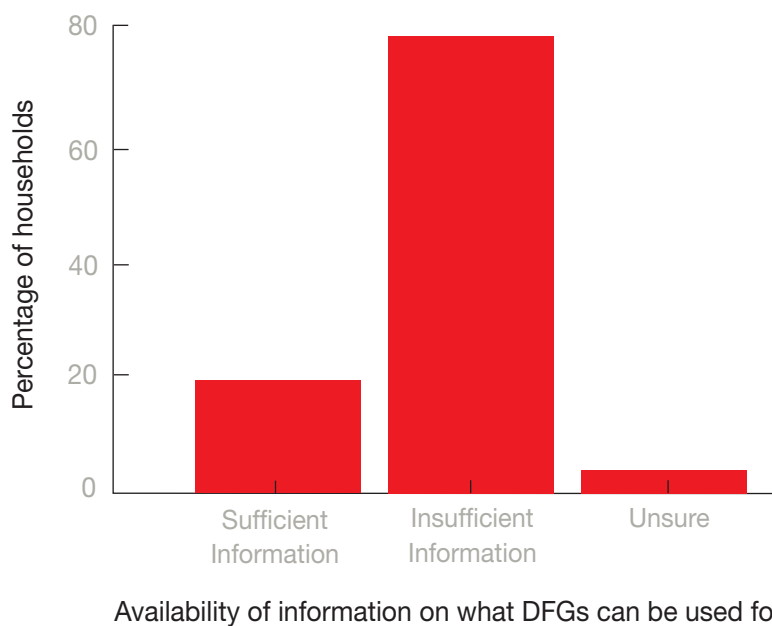
Figure 7. Perceptions on availability of information on where to apply for a DFG



Access to information on what DFGs can be used for

No fewer than 80% of parents questioned believe that there is insufficient information on what DFGs can be used for (Figure 8). Together with the data presented in Figures 6 and 7, it is clear that parents find it difficult to access information on DFGs.

Figure 8. Availability of information on what DFGs can be used for



Despite the clearly identifiable deficiencies in information provision, parents and local authority staff did identify a number of positive practices. This is supported in Figures 6, 7 and 8 which show approximately 20% of parents believe that there is sufficient information on DFGs. Two examples of positive practice were identified. The first is a local authority in Wales which proactively targets families of disabled children, through children’s charities and community groups, in order to raise awareness. The second example of good practice is that parents reported finding out about DFGs through a wide range of organisations and individuals, including; family/friends, social workers, Occupational Therapists, support workers, the internet, DLA office, health professionals, and charities/societies. Information is clearly being delivered using a broad range of mechanisms.

‘We found out about the grant through the MPS society, in their newsletter. If we hadn’t joined the society we would not have known.’ (Parent)

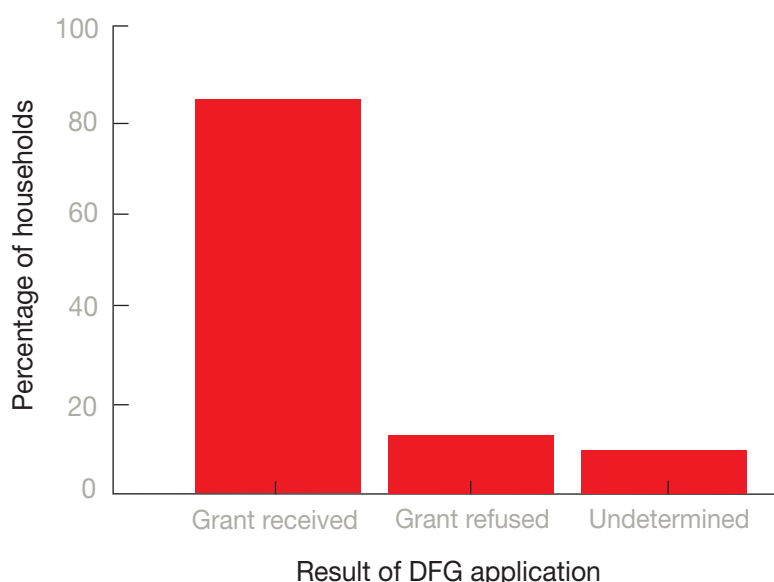
DFG application outcomes

The purpose of this chapter is to briefly describe the outcomes of parents’ applications for DFGs. Moreover, it describes what the grant was used for, and if the grant was refused it explores reasons for this. Finally, the chapter explores why some parents consider making applications but decide not to. The data is drawn from the questionnaire survey of parents in Wales and Northern Ireland.

DFG outcomes

Figure 9 illustrates that the majority of parents surveyed who had made a DFG application had received the grant (82%), 11% had been refused, and 7% of applications were undetermined. Outcomes for parents surveyed in Northern Ireland were slightly different from this general pattern, with fewer than 63% of parents receiving the grant. It is unclear whether these patterns reflect the general patterns of application outcomes across Wales and Northern Ireland but it does demonstrate that in both countries relatively few households were refused a grant.

Figure 9. Results of DFG applications for children



Adaptations funded by DFGs

Table 5 illustrates what adaptations were funded by the DFGs. Nearly half (46%) of all adaptations were for bathrooms, whilst a high percentage were for larger adaptations, such as an extension to the property (18%). The remaining 36% of adaptations were for smaller works, including garden adaptations and general disabled access improvements. There is some divergence from this general pattern in the surveys completed by parents in Northern Ireland. Approximately 50% of adaptations were for property extensions and 33% were for bedroom adaptations. This variation is unlikely to be representative of any variation in the types of grants funded in the two countries, it is more likely to reflect the small sample size for Northern Ireland.

Table 5. Types of adaptation funded by the DFG for households surveyed⁷

Purpose of adaptation	No. of households	Percentage of households who responded
Stairlift	3	4%
Extension of property	13	18%
Bathroom adaptation	34	46%
Bedroom adaptation	6	8%
Move home	1	1%
Central heating	5	7%
General disabled access	9	12%
Garden adaptation	3	4%
Total	74	100%

Reasons for being refused a DFG

A small proportion of households were refused DFGs and the research sought to explore why. Table 6 shows that for the majority of parents (67%) it was determined that no adaptation was required. Other reasons included, the need to make a financial contribution and difficulties accessing an Occupational Therapist.

'Plans were drawn up but there wasn't enough space to turn the wheelchair. Also, there was not enough money to pay for it.' (Parent)

'I was refused twice. The OT who made the referral thought adaptations would help but the powers that be thought differently – I give up.' (Parent)

Table 6. Reasons why households surveyed did not receive a grant

Reason for non-receipt of grant	No. of households	Percentage of households who responded
Required to make a financial contribution	2	22%
Difficulties getting initial OT assessment	1	11%
Determined no need for adaptation	6	67%
Total	9	100%

⁷ Not all parents stated what the adaptations were used for, hence the total does not equate to the total number of households who received a grant.

Reasons for deciding not to apply for a DFG

At least ten parents considered making a DFG application but decided not to proceed. Table 7 illustrates that the main reason for this is that some parents believe they are ineligible for assistance. Equally, some parents do not pursue an application because they believe the proposed adaptations are inappropriate.

'We decided that what was being offered was "too disabled." They insisted on providing full wheelchair access including a full adult turning circle. My daughter uses a wheelchair for distance only and this was too much. We live in a 3 storey house with steps inside – if she ever needed a wheelchair full-time we couldn't live here. We felt what was being offered was excessive.' (Parent)

Additional reasons for not making an application include; the perceived 'hassle' of applying, deciding to move house instead, and being informed that as a Registered Social Landlord (RSL) tenant or Local Authority (LA) tenant, they are ineligible. In fact, one local authority representative explained that parents are encouraged to take out a property appreciation loan.

'I have thought about applying but the hassle that comes with it puts me off. I imagine you have to get lots of letters and visits from the health profession and schools etc. My son is 11 now and we are finding it harder to bath him the older and bigger he gets. I know in the future we will need some adaptations made but as he can be lifted upstairs I think it might be too early to apply.' (Parent)

'I enquired in 2007 and was told that as a council tenant I'm not entitled. Housing could not identify a worker at all who gave advice on DFGs.' (Parent)

Table 7. Reasons why households surveyed decided not to apply for a DFG

Reason for not making a DFG application	No. of households	Percentage of households who responded
Thought they would not be eligible	4	37%
Informed that as an RSL or LA tenant they could not apply	1	9%
Proposed adaptations perceived to be inappropriate	3	27%
Decided to move house	1	9%
Hassle of making an application	2	18%
Total	11	100%

Experiences of the DFG process

This chapter draws on data from the questionnaire survey of parents and explores their experiences following a DFG application. The chapter begins with a summary of the general experiences of parents; identifying variations by local authority area, year of application, and type of adaptation. The chapter concludes with a discussion on parents' perceptions of the specific positive and negative aspects of applying for a DFG.

General perceptions

Parents' experiences of the DFG process were mixed (Figure 9). Whilst many (41%) parents had experiences classed as 'generally good', approximately 36% of parents had experiences classed as 'generally bad'. The experiences of parents in Northern Ireland appear to be worse than experiences in Wales: 63% of experiences were 'mixed' and 37% were 'generally bad'. Worse experiences in Northern Ireland are likely to reflect the fact that more parents in the Northern Ireland sample had been refused a grant and a higher percentage of successful applicants had applied for larger adaptations. Later in this chapter it is established that larger adaptations, such as an extension, are associated with worse experiences. Notably, this variation cannot be assumed to reflect the broad range of experiences in Northern Ireland due to the small sample size.

Figure 10. Parents' experiences of applying for a DFG

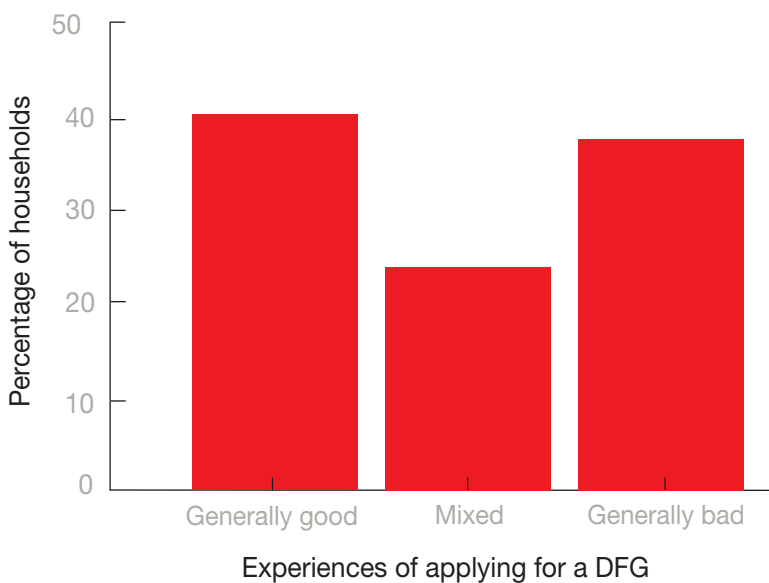


Table 8 demonstrates that parents' experiences of applying for DFGs vary according to where they live⁸. Five local authorities in Wales were selected for comparison, on the basis that no fewer than six parents indicated that they lived in each authority. Table 8 reveals that parents' experiences of applying for a grant in these local authority areas range from 83% 'generally good' to 43% 'generally good'. There is probably no single explanation for this variation, although it is likely that variations in systems for administering the grant will contribute.

⁸ The data gathered does not allow for this comparison to be made for Northern Ireland

Table 8. Experiences of households surveyed in applying for DFGs in a selection of local authorities in Wales

Local authority		Experiences of applying for a DFG			Total
		Generally good	Mixed	Generally bad	
Local Authority A	N	5	0	1	6
	%	83%	0%	17%	100%
Local Authority B	N	5	1	1	7
	%	72%	14%	14%	100%
Local Authority C	N	4	3	1	8
	%	50%	38%	12%	100%
Local Authority D	N	5	1	5	11
	%	46%	8%	46%	100%
Local Authority E	N	3	0	4	7
	%	43%	0%	57%	100%

Parents' experiences also appear to vary dependent upon the year in which they applied for the grant. Table 9 demonstrates that parents who applied after 2004 tended to report higher levels of satisfaction than parents who applied before. Although this variation is not statistically significant it does indicate possible improvements in the delivery of DFGs.

Table 9. Experiences of households surveyed in applying for DFGs according to the year of application

Year of application		Experiences of applying for a DFG			Total
		Generally good	Mixed	Generally bad	
2003 or earlier	N	1	7	11	19
	%	5%	37%	58%	100%
2004	N	2	0	3	5
	%	40%	0%	60%	100%
2005	N	5	3	1	9
	%	56%	33%	11%	100%
2006	N	10	6	7	23
	%	44%	26%	30%	100%
2007	N	11	1	6	18
	%	61%	6%	33%	100%
2008	N	8	4	3	15
	%	53%	27%	20%	100%
Unsure	N	2	2	4	8
	%	25%	25%	50%	100%

Table 10 provides a summary of variations in parents' experiences, according to the type of adaptation that was funded. It illustrates that experiences are particularly negative for large adaptations such as property extensions and bedroom adaptations. By contrast, smaller adaptations such as garden adaptations, or installation of central heating, result in more positive experiences.

Table 10. Experiences of households surveyed in applying for DFGs according to the type of adaptation funded

Type of adaptation		Experiences of applying for a DFG			Total
		Generally good	Mixed	Generally bad	
Stairlift	N	2	0	1	3
	%	67%	0%	33%	100%
Extension of property	N	3	5	5	13
	%	22%	39%	39%	100%
Bathroom adaptation	N	20	8	6	34
	%	59%	23%	18%	100%
Bedroom adaptation	N	2	2	2	6
	%	33%	33%	33%	100%
Move home	N	0	1	0	1
	%	0%	100%	0%	100%
Central heating	N	4	0	1	5
	%	80%	0%	20%	100%
General disabled access	N	4	1	4	9
	%	44%	12%	44%	100%
Garden adaptation	N	2	1	0	3
	%	67%	33%	0%	100%

Positive experiences

It is clear that many parents had ‘generally good’ experiences of applying for a DFG. Table 11 provides further detail on the specific aspects of making an application that made the experience positive. The majority (44%) of positive comments related to good service and support by staff administering the grant and by social services.

‘We found the social services occupational therapist who came so helpful and told us all we needed to know and had our daughter’s needs as paramount.’ (Parent)

‘Eventually we found the correct department and then things seemed to move very quickly and some changes we hadn’t even thought of were suggested to help. Everyone was very helpful and friendly at this point from advice to building contractors.’ (Parent)

The quality and volume of adaptations (27%) and an efficient process (29%) were also identified as positive experiences by parents. In fact, interviews with several local authority representatives revealed that a number of actions are being taken to reduce the delays in adaptation completions. For example, one local authority representative stated that they fast track children on the waiting list, while a second authority fast tracks any applications that are less than £5,000.

‘I was very grateful... excellent product installation to a high standard.’ (Parent)

‘The assessment was carried out within weeks and we had a decision straight away. We applied in February and work was completed by June because it was put as a priority. They were very considerate and helpful.’ (Parent)

Table 11. Positive aspects of DFG applications by households surveyed

Aspect of DFG application	No. of households	Percentage of households who responded
Quality and volume of adaptations	15	27%
Good service and support	24	44%
Efficiency of the process	16	29%
Total	55	100%

Negative experiences

Table 12 summarises parents' specific negative experiences of applying for a DFG. Notably, the total number of negative comments is much higher than the total number of positive comments (Table 11). Nearly half of all negative experiences mentioned by parents related to delays in the process, making it the most cited negative experience. In an earlier chapter it was established that completion times had reduced in recent years but this finding shows that improvements are still required.

'We are two years down the line with still no help. For some families one child could have died by now. It is the most exasperating experience I have ever had.' (Parent)

'When you need equipment you need it straight away not in months or years. It only causes more strain on carers/parents both mentally and physically which can cause injury to carers.' (Parent)

The second most cited negative experience was difficulties with support staff and builders. Whilst these are two discrete groups of people, the impact of poor support or a poor attitude from either, had a similar impact on the household. Problems with support staff included difficulties getting in contact and lack of support during the process. One of the main problems with contractors and builders was the lack of respect for the property and the family. Also, some parents had difficulties finding a builder who would undertake the adaptation.

'The worst part was being passed around from pillar to post all through the grant application. It could be a much less stressful experience if a 'key worker' or one person can see you through the whole process.' (Parent)

'The standard of the workmen and how they treat your property and the total lack of care and watch over by grants is shameful.' (Parent)

'Although the grant is available there are few builders prepared to do a job on a grant basis. I had to appeal on the local radio and had one response but the council want quotes from two. This could potentially make the grant inaccessible.' (Parent)

A third, and frequently cited, negative experience was a poor standard of adaptation, or adaptations that are perceived to be inappropriate. For instance, many parents explained that the local authority and the contractors were not willing to fix problems with adaptations. Also, some parents felt they were unable to influence what adaptations were installed. In a previous chapter it was established that this also deters some parents from pursuing an application.

'All control of the project seems to be lost once the grant is given. It's what the council wants, not what the disabled person needs.' (Parent)

Nearly 10% of all negative experiences cited related to difficulties with the assessment process and being deterred from making an application. A previous chapter established that some parents do not apply for this reason, and for those who do still make an application, it often makes the experience a bad one. One way in which parents are deterred is by highlighting that there is a long wait for assessment. Equally, some parents are told that they cannot apply due to their housing tenure.

'We were told that there is a very long waiting list to be assessed by the OT and that we would be placed on the list. In my opinion from the conversation with the council they tried to discourage me from applying because of the very long waiting list.' (Parent)

Table 12 shows that 8% of all negative experiences cited related to the need to make a financial contribution. Some parents commented that the amount provided by the DFG was insufficient and resulted in payments being made above the £30,000 limit. A previous chapter revealed that for some parents this is why they were unable to pursue the DFG application. Financial contributions are also sometimes made when the grant is less than £30,000. For example, a parent may be required to pay for redecorating after an adaptation has been installed.

'I have had to borrow money to top up the grant - £30,000 is not enough.' (Parent)

'The grant covered all the work that was needed to adapt my property but no money for decoration or flooring that was necessary. I do think money should be provided within the grant for re-decoration and flooring after the work has been carried out.' (Parent)

Table 12. Negative aspects of DFG applications by households surveyed

Aspect of DFG application	No. of households	Percentage of households who responded
Disappointment in not receiving a grant	9	10%
Delays in the process	45	49%
Difficulties with assessment/ deterred from making an application	8	9%
Difficulties with support staff and builders	13	14%
Requirement to make a financial contribution	7	8%
Poor standard or unsuitable adaptations	9	10%
Total	91	100%

The discussion above demonstrates that parents have a wide range of negative experiences when applying for a DFG. More detailed analysis of these experiences shows that particular types of adaptation are more likely to be associated with specific negative experiences (Table 13). Table 13 shows that parents who applied for larger adaptations, such as an extension to the property, had particular difficulties with delays in the process. Whilst delays in the process are also a key issue for parents applying for smaller adaptations, Table 13 demonstrates that difficulties with support staff are more prominent for small adaptations than they are when applying for larger adaptations. It should be noted that these findings are not statistically significant but they do offer a broad insight into variations in experience according to the type and scale of adaptation.

Table 13. Negative aspects of DFG applications according to the type of adaptation

Type of adaptation	Negative experiences					Total	
	Delays in process	Assessment difficulties	Support staff difficulties	Required to make financial contribution	Poor standard /unsuitable adaptations		
Stairlift	N	1	1	1	0	0	3
	%	33%	33%	33%	0%	0%	99%
Extension of property	N	10	1	1	2	3	17
	%	59%	6%	6%	12%	17%	100%
Bathroom adaptation	N	17	0	2	3	5	27
	%	63%	0%	7%	11%	19%	100%
Bedroom adaptation	N	2	0	3	0	2	7
	%	29%	0%	42%	0%	29%	100%
Move home	N	1	0	0	0	0	1
	%	100%	0%	0%	0%	0%	100%
Central heating	N	2	0	2	0	0	4
	%	50%	0%	50%	0%	0%	100%
General disabled access	N	4	0	2	1	1	8
	%	50%	0%	26%	12%	12%	100%
Garden adaptation	N	1	0	0	0	0	1
	%	100%	0%	0%	0%	0%	100%

Conclusions and Recommendations

Between February 2004 and December 2005, the parental means test for accessing Disabled Facilities Grants was abolished in Northern Ireland, Wales and England. This study is the first in the UK to begin to explore the impact of the abolition. The study does not claim to provide a comprehensive analysis, as it is limited in scale, it does however give an indication of how things have changed in Wales and Northern Ireland. The study also provides additional evidence to existing arguments on some of the wider issues associated with DFGs. Unlike many other studies, this additional evidence is based on family experiences. This final chapter draws together the main findings of the research and makes 10 recommendations for improvement under four broad themes: data collection, changes in access over time, access to information and advice, and experiences of the DFG process.

Data collection

- Not all local authorities in Wales collect separate data on DFG adaptations for children, hence local authorities and the Welsh Assembly Government have only limited awareness of access for children. Without this data it is difficult to guide service and policy interventions and to monitor the impact of changes to provision. By contrast, the Northern Ireland Housing Executive collates a range of data on access to DFGs for children.
- This study demonstrated that some of the data presented by local authorities in Wales is inaccurate and often incomparable with data from other local authorities. There is no clear audit process for monitoring the reliability of data on DFGs for children.

Recommendation 1

The Welsh Assembly Government should require all local authorities to return data on access to DFGs for children. This should mirror the data collected on all DFGs. This process will enable the Welsh Assembly Government to monitor poorly performing local authorities and improve consistency.

Recommendation 2

The Welsh Assembly Government must periodically audit the accuracy and comparability of any data that is returned on DFGs for children.

Changes in access over time

- Following the abolition of the parental means test in Northern Ireland (2004) and Wales (2005) there was a significant increase in the number of enquiries, approvals and completions for DFGs for children.
- Since 2004 there has been a steady decrease in the average completion times for DFGs for children in Wales. This improvement is likely to be attributable to improvements in local authority performance. However, between 2006 and 2007, improvements in average completion times stalled.

- The average cost of DFG adaptations per household in Wales has stayed relatively constant since 2004, whereas there has been a slight increase in Northern Ireland. It appears that the parental means test has had no significant impact on the average DFG cost.
- Parents' experiences of applying for a DFG appear to have improved slightly since the abolition of the parental means test, particularly between 2007 and 2008. Questionnaire surveys showed that 61% of parents who made an application in 2007, had a 'generally good' experience. By contrast, 40% of parents who made an application in 2004 felt their experience was 'generally good'.

Access to information and advice

- A large majority of parents (approximately 80%) believe that there is insufficient information on who can apply for a DFG, where to apply and what it can be used for. This demonstrates that in general, local authorities in Wales and the NIHE are not effectively promoting the availability of DFGs. This finding significantly contradicts point 5.21 of the 2007/08 National Service Framework self-assessment audit tool report produced by the Welsh Assembly Government. In the report, 20 of 22 local authorities in Wales stated that they had achieved the maximum rank (a score of 6) in making information available to families of disabled children regarding entitlement to Disabled Facilities Grants. This finding raises concerns over the effectiveness of the self-assessment tool currently used to monitor provision of information on DFGs to families and children.
- Despite clear deficiencies in the promotion of DFGs, nearly 20% of parents believe that there is sufficient information available. This is likely to be a result of some good practice by local authorities and area offices of the NIHE, who promote DFGs amongst agencies and individuals working with families of disabled children.

Recommendation 3

Local authorities in Wales and the NIHE should ensure that they are proactive in delivering information on DFGs. This will require greater communication with a wide range of agencies and individuals that support parents with disabled children.

Recommendation 4

Welsh Assembly Government should commission research to explore methods of improving information dissemination amongst families with disabled children. The research should also consider how information provision can be more effectively monitored

Experiences of the DFG process

- Approximately 60% of parents had experiences classed as ‘generally bad’ or ‘mixed’, which equates to a high rate of dissatisfaction. Many parents (40%) had ‘generally good’ experiences which highlights the inconsistencies in delivery of DFGs in Wales and Northern Ireland.
- General levels of satisfaction appear to vary according to where the children live and the scale of the adaptation. For example, 83% of parents in one Welsh local authority had ‘generally good’ experiences, whereas the figure is much lower (43%) in another area. Similarly, 80% of parents who had central heating installed through a DFG had ‘generally good’ experiences, whereas the figure is only 22% for parents who had a property extension.
- A high proportion (44%) of positive experiences of applying for the grant are due to good support by staff administering the grant and by social services. Other positive experiences include good quality and volume of adaptations and an efficient process. Inconsistencies in services are highlighted further by the fact that many of the negative experiences (below) also relate to staff support, quality of adaptations, and the efficiency of the process.
- Approximately half of all negative experiences of applying for a DFG relate to delays in the process. In particular, delays are common for larger adaptations, although they are also an issue for smaller adaptations. This clearly shows that despite recent improvements in completion times, further reductions are required.
- The poor standard and lack of suitability of some adaptations was often cited as a problem. It seems that families sometimes feel out of control of the process, with only limited capabilities of influencing the impact on their property. Inappropriate adaptations also sometimes deter parents from making an application.
- There is evidence that some parents are being deterred from making a DFG application. This seems to be deliberate, with parents perhaps informed that they cannot apply due to their tenure, or being told to take out a property appreciation loan. Alternatively, some parents feel they are deterred by waiting lists which are often very long.
- The parental means test is no longer an issue, however some parents are still having to find additional funding in order to complete an adaptation. This is a result of the previous £30,000 limit for which DFGs could be used. Whilst some local authorities and the NIHE are able to support parents through additional sources of funding, the threshold causes difficulties and in some instances results in parents being unable to pursue an adaptation. Equally, parents occasionally face financial concern when they are required to pay to redecorate after an adaptation has been completed.

Recommendation 5

Local authorities in Wales and the Northern Ireland Housing Executive must take action to reduce delays in the time from initial enquiry to completion. One possible mechanism might include automatic acceptance of Occupational Therapist referrals, reducing assessment times and time spent on disputes. A second mechanism might require local authorities to establish a service level agreement with contractors, therefore reducing the time spent searching for and commissioning contractors.

Recommendation 6

The Welsh Assembly Government and Northern Ireland Housing Executive should consider whether further funding is required for DFGs. This study does not provide adequate evidence to conclude that further funding is required but such action might reduce the occurrence of gatekeeping, where local authorities deter parents from making an application because of limited funds.

Recommendation 7

Although improvements are possible for all types of adaptation, local authorities in Wales and the NIHE should target improvements at larger scale adaptations because experiences appear to be particularly negative for these applications. Local authorities should consider allocating specific officers to deal with adaptations that exceed £15,000.

Recommendation 8

The Welsh Assembly Government and NIHE should introduce guidance on greater service user involvement for the authorities administering grants. The guidance should ensure that parents have the opportunity to comment on their requirements and these comments should be valued.

Recommendation 9

The Welsh Assembly Government should monitor approaches that local authorities take towards delivering housing adaptations, offering advice where approaches are perceived to be poor practice. In addition, the Welsh Assembly Government and the NIHE should promote and fund services that enable parents to challenge poor decisions.

Recommendation 10

The Welsh Assembly Government and NIHE should consider increasing the respective £36,000 and £25,000 limits for DFGs in order to ensure that all necessary adaptations can be completed.



Photo by Katie Barret Photography

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