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## **The Central Role of the Occupational therapist in Facilitating Housing Adaptations/Home Modifications for Disabled Children**

Key Messages: Families need someone to guide them through the adaptations process, occupational therapists often fulfil that role. Families sometimes add to delays.

What the Study has added: This study has considered the views of families with disabled children on adaptations processes separately from adults for the first time.

### **Abstract**

***Introduction:*** Six reviews/inquiries into housing adaptations/home modifications processes occurred in Wales between 2004 and 2015. One resulted in the removal of the means test for children's Disabled Facilities Grants. This research investigated families' and professionals' experiences of the adaptations/home modification process to gain an understanding of their views and experiences.

***Methods:*** Mixed methods of an online questionnaire for professionals, and semi-structured interviews or an online questionnaire for families (depending on their preference). Forty eight families participated and an additional sixteen families responded to an online questionnaire. Analysis of qualitative data identified emergent themes; discussed in this article.

***Findings:*** The themes were: poor information and communication mainly aimed at older adults; negative experience of the process and the positive impact of the completed adaptation. Additionally, whilst undergoing the process, families felt that they needed a contact to guide them through the process. This contact was often by default the Community Occupational Therapist.

***Conclusion and recommendations:*** A single contact person be made available for families; and occupational therapists should consider their part in that role; more specific information on needs of children should be provided; families need to recognize the part they can play in adding to delays in adaptations' delivery.

### **Introduction**

A home that is inappropriate to occupational needs can create problems for a disabled person in maintaining or developing independence. The housing adaptations/modifications process for assessing, advising on and funding adaptations/home modifications has developed over a number of years in the United Kingdom (U.K.). Devolution in Scotland, Wales and Northern Ireland and local authority interpretation has led to differences in these processes, although many similarities remain. The study discussed in this article was undertaken in one of those devolved countries: Wales. Nevertheless, it is posited here that the findings of the study are relevant across a wide range of disabled adaptations/home modifications, regardless of the country in which they occur. Indeed, these adaptations can be central to the role of the occupational therapist in social care (Boniface et al 2013) in whichever country that role is carried out.

In Wales, mandatory Disabled Facility Grants (DFG) are available to all; regardless of what form of housing they live in; but funding (as in many other countries) is usually based on who owns the property (housing tenure) to be adapted (see figure 1). The wider policy and legislative context of housing adaptations is outlined in figure 2.

## Background to the Study

### General Issues with disabled adaptations

Many U.K. wide and devolved Government reviews and inquiries into disabled adaptations/home modifications have been undertaken between 2003 and 2015 (NIHE 2006; OPDM 2005; Scottish Government 2012, Jones 2005, Bibbings et al 2015). Issues identified in these reviews include: The complexity of the system: Access to adaptations/home modifications determined by housing tenure: poor provision of information: Poor communication: Fragmented service delivery: Lengthy waits (see figure 3) and differences in measuring the time taken. Many of these have been noted in the literature, where it has been argued that having adequate information on options and choices available for home adaptations/modifications is vital (Heywood 2004). Poor communication between professionals and individuals undergoing an adaptation has also been identified as problematic (Nord et al 2009). Existing research has shown that service user satisfaction with an adaptation was substantially derived from its aesthetic components (Heywood 2001). Although high levels of satisfaction with housing adaptations were identified, failure to consider the meaning of home was identified as a cause of wasted expenditure (Heywood 2005). Prior to this research being carried out, the Welsh Government had begun collecting data on the differences in time taken in Wales to complete a DFG funded adaptation for a child from other adaptations. Despite clear guidance issued by the National Assembly for Wales (2012), this new data identified differences in the ways in which the time taken to complete an adaptation was being measured. This issue of time measurement was later highlighted in the National Assembly for Wales (2013):

“The number of calendar days taken to deliver a DFG should be counted from the date of the client’s first recorded contact with the local authority, relating specifically to an adaptation, for which a DFG is subsequently offered, to the certified date.” (National Assembly for Wales 2013 p41)

However, some local authorities were found to be interpreting this guidance differently:

“there are examples where councils will close cases while they wait for an applicant to agree to progress with the adaptation work, only to then start the whole process again when they decide to proceed.” (National Assembly for Wales 2013 p43)

Thus, the different approaches adopted by local authorities, had a significant impact on the time taken for the adaptation to be progressed (see figure 3).

Since these inquiries and reviews, all of the U.K governments have implemented new legislation or policies (Social Services and Well Being [Wales] Act 2014, Care Act 2014, Social Care Self-directed Support [Scotland] Act 2013, Health and Social Care NI 2011) appertaining to the way responsibilities of social services and the way they work with other agencies are carried out. The ethos of the new U.K. acts and policies clearly place emphasis on a partnership type relationship with service users, in which they take more responsibility for their services. They also put meeting people’s perceived outcomes at the centre of services: Paragraph 1.21 of the statutory guidance of the Care Act (2014) for example states:

“At the heart of the reformed system will be an assessment and planning process that is a genuine conversation about people’s needs for care and support and how meeting these can help them achieve the outcomes most important to them”

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None of these policies or laws supersede the Housing Grants Construction and Regeneration Act (1996 and amended 2011) and different methods of organising adaptations/home modifications still apply. Therefore, the argument that being given adequate information on the options and choices available is a core component of informed decision making remains valid (Heywood 2004).

### Issues related to disabled children's adaptations

There are two aspects to consider when undertaking a home modification/adaptation for a disabled child: The current needs of the child and their future needs as they grow and develop: The needs of other family members who are often also children. These two aspects can sometimes conflict; and adaptations can meet one to the detriment of the other with compromises being needed (Beresford and Oldman 2002). These compromises were identified in their work as: Creating a suitable bathroom space for the disabled child which did not suit other family members: Difficulties with access in and around the home: A lack of storage space for specialized equipment resulting in such equipment creeping into the rest of the home: A lack of space to use equipment or carry out required therapies (Beresford and Oldman 2002). They also highlighted a lack of awareness among families with a disabled child of the availability of disabled adaptation grants provision and ignorance of the purposes for which they could be used (Beresford and Oldman 2002). A review of service provision for disabled children and their families, carried out by the Audit Commission (2003) concurred with much of this.

The housing adaptation/home modification process is a complex one. Complex processes can be expected to take time. However Beresford and Oldman's (2002) study described delays to the initial application process not just the overall process. A sixth of the families in their study described waiting between three and six months for a decision as to whether their adaptation process could begin; one in ten families waiting more than a year and some longer than two years. Additionally, a number of families were identified who had decided not to progress due to the level of bureaucracy, the time taken to process applications and ineligibility on income grounds.

The discussion so far has identified some of the problems. However, existing research has also identified evidence of good practice. A study by Shelter/Contact a Family (2008) highlighted good practice around the provision of information. However, this was found to be inconsistently implemented across all Local Authorities or housing providers. Aspects of the application process parents felt were positive included being supported by staff administering the grant, the quality of the adaptation and the efficiency with which it was processed.

The housing needs of families with a disabled child are complex. Families require space to accommodate a growing child and their equipment and foster independence in their child. Yet, families need functional rooms that facilitate the ability of the carer to carry out their role, but rooms which also offer the family the opportunity to function as a family. Any adaptation, therefore, must consider the long-term needs of the child with the disability, recognize their current and future developmental needs and their fundamental need for play; but also their need to function within their family as a full family member.

Given the number of issues identified in the literature, this research was deemed necessary and its overall aims were to:

- a. Identify families' with a disabled child (in specific Welsh local authorities) experiences of the adaptations process and their reasons for engaging with it or not.
- b. Collect the views of relevant professionals involved in administering adaptations grants processes for children with disabilities in Welsh local authorities.
- c. Explore Welsh local authorities' publicly available procedures for administering adaptations grants for children with disabilities.

This article will report on the first of these aims to identify family's experiences of the adaptations process and will also refer to the results from the second and third aim where families identified this as an issue.

## **Methodology**

The large study utilized a mixed-method design, with the families' data collected via an interview schedule in face to face interviews or online via a confidential Bristol Online Survey; depending on the family preference. The rationale for offering families the choice of both types of interview was due to time constraints imposed by caring responsibilities which meant that it was not always possible for families to devote time to engaging with interviewers. An online questionnaire helped overcome this barrier, giving voice to families otherwise unable to participate in face-to-face interviews.

A mix of quantitative and qualitative information was collected from local authority employed staff using the confidential Bristol Online Survey and is reported elsewhere (Morgan et al 2016). Information on local authorities' adaptations grants processes was identified through examination of publicly available documentation from local authority websites and housing policies available during 2014 and is referred to where relevant in this article.

### Sampling and recruitment

Family participants were purposively drawn from a population of families of children with disabilities aged 0 to 19 in different local authorities (see below) and stratified by housing tenure. The rationale for stratifying the sample was to ensure the views of families living in all types of housing tenures and who had experienced all types of different grant processes were captured (Disabled Facilities Grants DFG and Physical Adaptations Grants PAGs – see figure 1). In order to address the specific research questions, the samples from both populations were purposive and derived from 11 (of the total of 22) Local Authorities. The local authority areas selected for the family interviews or online questionnaire were ones which:

1. Had retained all four types of housing tenure (many local authorities no longer had council owned and rented properties)
2. Were from a range of geographical locations: urban, rural and valley
3. Had different application to completion rates for adaptations grants
4. Had different levels of deprivation on the health and housing measure for the Wales Index of Multiple Deprivation Child Index in 2011 (National statistics for Wales 2011).
5. Had families which had either received an adaptations grant (DFG or PAG) for a child aged 0 - 19 since April 2010 (when the grants performance indicators for children were first separated from adults) *or* met the criteria for an adaptations grant, made an application, but did not proceed to completion.

### Data Collection

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Trained interviewers (from Shelter Cymru) carried out interviews with families who agreed to participate. The interviews were recorded, with permission, transcribed verbatim and then uploaded into QSR International's NVivo 10 (NVivo 2012) for coding and theme identification by two of the researchers (Braun and Clarke 2006). Online questionnaires were completed by families in their own time. These online questionnaires asked for free text qualitative information, which was dealt with in the same way as the family interview transcripts. Some family responses referred to information or communication issues and these were considered in the light of publicly available information on local authority websites or considered in the light of professionals' free text responses in their questionnaires.

### Data Analysis

Previous adaptations' reviews of the potential issues informed the questions in both the interviews and questionnaires. Data analysis was carried out from the bottom up not via a pre-conceived conceptual framework (Brooks et al 2015). Codes were allocated to the text content of both interviews and the online survey; grouped together into categories and then into sub themes. Researchers moved backward and forward between the coding and categorizing process until more general overarching themes were identified. These overarching themes were then reinvestigated by the two researchers and reconsidered alongside the original transcripts and the research questions to enhance the credibility of the data analysis. Finally the themes were related back to the literature.

This study acquired a large amount of data around the three research questions in an intertwined manner. This article concentrates on the data (and its analysis), which illuminated the experiences of families in relation to types of input commonly offered by occupational therapists in the adaptations/home modifications process.

### Ethical Considerations

The anonymity of all participants, including local authorities, was guaranteed, in order to encourage in depth responses. This was particularly important as the rarity of some of the specific genetic disorders of some children could have made them identifiable. Therefore the research described in this article deliberately does not identify family comments to the disability of the child. The research proposal was approved by the xxxxxx Research and Ethics Committee and by the Wales REC 4 committee prior to commencement of the study.

### **Findings and discussion**

48 Families were interviewed in their own home, while an additional 16 families responded to the online questionnaire. The age of the children in the families ranged from 3 to a 23 year old who had had the first adaptation aged 5 and a second aged 15. The rest of the families interviewed had experienced the adaptations process much more recently. At the time of the interview, the majority of families had been through the adaptation process within the preceding two years, with five ongoing at the time of the interview. Thirteen families had undergone the adaptation process between 3 and 8 years previously, with a small number having had more than one adaptation within that timeframe. The average length of time taken from first contact to the completion of the adaptation/home modification process was 15 months (see figure 3). Disabilities experienced by the children included global developmental delay, autistic spectrum disabilities, learning disabilities, genetic disabilities and cerebral palsy. 39 professionals returned questionnaires with free text questions.

Respondents were: Occupational therapists (n=21), grant officers or other professionals directly involved with grant applications (n=8), managers in social services, housing departments or housing associations (n=10). Thus the majority of questionnaire respondents were directly in contact with families. 30.8% of the 39 staff respondents worked exclusively with disabled children.

This section describes the themes which emerged from the qualitative data from both the interviews with families and the free text responses in the professionals' and families' questionnaires. These will be related to the publicly available information and literature where appropriate.

Three overarching themes (see figure 4) emerged from this data: Information and communication: The families' experience of adapting the home: The impact of adapting the home.

### Theme 1: Information and Communication

#### *Signposting to grants*

This study found limited access to appropriate child specific information and poor communication to be key factors which contributed to delays and a poor experience for families. This communication gap needs to be considered in the context of guidance issued for Welsh Local Authorities by the Syniad Benchmarking Group:

*"the complex nature of any Adaptations Service means that a good communications process is essential[...] Service users should be fully aware of the process and all Departments and external agencies have a common understanding of the roles and responsibilities of those involved."*(SBC 2001:1).

Most families reported having had difficulty accessing information about the availability of adaptation grants and the nature of the work covered by the grant:

"I had never been told there was anything, that we would be able to get help." (Parent-5yr old physical disability)

The lack of information on the availability of adaptations and the options available to families' was also supported by some housing professionals.

"There is a need for better published information. I believe verbal information to be excellent but written information presenting the process and any options to families would be helpful..." (Regeneration and Strategy Manager)

Often families drew on their own resources to access information on the availability of adaptation grants and processes:

"For us it was quite easy cos we're quite sort of clued up and we know how to find out how to do things and who to ask." (Parent 9 yr old physical disability).

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Others had experiential knowledge of the adaptation's process, having been recipients of a previous Disabled Facilities Grant (DFG). Whilst a small number of families were signposted to DFGs by health care professionals:

"I asked [child's] occupational therapist who deals with all [child's] equipment, his wheelchair and all his other, his shower chair and everything he needs and then she passed us on to the occupational therapist from social services who actually does fixed things like roof, baths showers that sort of thing". (Parent 7 yr old physical disability).

However the analysis revealed that the majority of families had been unaware of the existence of help to adapt their home until they were signposted to the grants by informal contacts, who had been through the adaptations process themselves.

"I met up with another lady who happened to be an OT but also had a child with cerebral palsy and she, they'd had I can't remember if it was a garage but anyway they'd had a disabled facilities grant for their little girl and she was much, much younger than [my child]." (Parent 11yr old physical disability)

These comments concur with Heywood's (2004) argument that being given adequate information on the options and choices available is a core component of informed decision-making (a crucial part of new legislation and policies). This is important given the complexity of home adaptations processes and the range of funding routes available (see figure 1).

### *Paucity of child specific information*

The paucity of information given to families meant they were frequently drawing on their own resources and on informal networks to access information. Useful though these were, this had implications for the families' ability to give informed consent for the adaptation to take place. This resulted in families not always fully understanding the process they were undergoing or their rights and responsibilities in respect of the adaptation. The interrogation of publicly available information on home adaptations further revealed a paucity of information available to families. Where available, information on adaptations was frequently generic and mainly referred to or depicted older adults. The lack of appropriate child specific information was also highlighted by some professionals:

"Literature produced by the grants department always refers to the needs of adults and older people and the grants officer always has to put lines through sections that don't apply to families and supplement with info e.g. that means test doesn't apply. It would be good to have literature specific to families with children" (Social Services OT).

While another noted that:

"We are better at talking to each other and to parents than we are at giving written information out." (Social Services OT).

The need for information specifically targeted at families with disabled children is clear and well-illustrated by one parent:

"I work for the local authority but I didn't know that I didn't have to contribute towards it. (*the DFG*)" (Parent 13yr old Autistic Spectrum).

### *Communication with families*

Good communication was seen as a vital component of a successful adaptation. In particular, families valued regular updates by phone or email; these were found to foster confidence in the adaptations process. However, while some families reported having positive experiences, for others, poor communication was an issue throughout. Families highlighted the following: Not being listened to with regards to their needs and the use of technical language in describing adaptations to the family.

Also highlighted as an issue for families was a poor response to calls and emails. This frequently meant that families were chasing up Grants Officers and Occupational Therapists in order to access information and obtain progress updates.

Many families felt that the adaptations process was not adequately explained to them prior to the work beginning:

“It’s like everything else, every person only tells you about their slice of the cake you know that’s all they deal with the whole process isn’t their problem, they only deal with their own slice. (Parent 10 yr old disability not specified)

Many of the families felt strongly that an identified person was needed to coordinate the process and act as a single point of contact, with families noting they would like one person to ‘own the process’.

This was echoed by some professionals:

“The process is confusing sometimes for we professionals! It is critical that families have a point of contact they can rely on.” (Occupational Therapist)

In Local Authority areas where this had been implemented it was highly valued by families negotiating the adaptations process:

“the man we dealt with from the council he was good very approachable. I had his telephone number to ring so having good contact links and communication and if you’re having a problem being able to discuss it and say um I mean it’s great now it works and it works really well.”(Foster Parent 11yr old physical disability).

Poor communication emerged as a possible cause of delays, resulted in uncertainty and increased parental stress. The paucity of information specifically targeting families was a key factor and is acknowledged by Bibbings et al (2015:23) who noted that that the “deficit of information aimed at children and families should be addressed”. This is crucial as Picking and Pain’s (2003) research showed that when service users receive adequate information on what to expect from the process and the timescales involved; they are better prepared for the process itself. In contrast, the less knowledge service users have, the greater the input required from the professionals involved in the adaptation (Pettersson et al 2012) and the more likely delays become: Thus good communication is a potential time and money saver.

This communication issue concurs with Nord et al’s findings (2009) that while communication between professionals working on an adaptation was effective; communication with the

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service user was less so. In particular it was noted that the use of plan drawings as a communication tool, made it difficult for the service users to visualise the end product (Nord et al 2009). Our study's finding on communication reinforces the need for an identified person to support families' and coordinate the process and clearly enable families to visualise what the completed adaptation/home modification would be like. In Nord's study, families' experiences were generally more positive where families had such an identified person to deal with.

### Theme two: Impact of the Adaptation

#### *Process as Stress*

Families negotiating the adaptations process invariably found the process stressful. Families frequently commented on the stress of raising a child with sometimes complex disabilities, and they felt that the adaptations process significantly added to that stress.

Key stress trigger points highlighted by families included delays to the process, uncertainty around the nature and funding of the proposed adaptation:

“we have no idea about how much an extension costs because it also depends on what they are going to do doesn't it . How they are going to extend so we are a bit, I am quite stressed about that because we have no spare money whatsoever.” (Parent 3yr old physical disability)

A further trigger point was a sense of having to fight for what a family felt was required:

“at the end of the day why you have to battle for what's right you know that's my thing like. You know my mother kept saying well if they came and lived with (child) for a day to see what you need. [...] I mean, they go home to their little house and whatever, they don't realise” (Parent-13yr old physical disability)

#### *Time to care and quality of life*

Another key subtheme to emerge from the families' narrative was that a well thought out adaptation gave families the time to care:

“It was just knowing how much easier life could be if you have the right facilities to care for your disabled child and there is absolutely no doubt that when you've got everything in place life becomes easier. The day to day routine becomes easier, it's safer you know it just works out so much better. (Parent 10yr old physical disability)

This in turn had a positive impact not only on the quality of life for the disabled child, but also for the whole family. Families commented that a good adaptation was life changing, enabling them to function and live as a family.

A well thought out adaptation also enabled the whole family to function as a family unit:

“My own belief is that the investment up front and the more that we do to incorporate [child] into family life and playing and it’s easier to supervise [child] while doing something else you can see [child] and what have you and development is achievable. So I can have [child] in the standing frame and [child’s] brother and having some sort of family normality I suppose.” (Parent 5yr old genetic disability)

### Theme Three: Experiencing the Process

#### *Timing and timeliness*

Timing generally referred to the appropriate timing of the adaptation: E.g. the child’s needs were being met at a time appropriate for the child and the family. Timeliness referred to delays within the adaptations process. There was general consensus among both families and professionals that delays were due to the complexity of the system as well as the complexity of adapting a home to meet the current and future needs of a disabled child. However family circumstances and the families themselves also contributed to delays. For example, two of the families interviewed had adopted children from outside their Local Authority area and this had created delays within the adaptations process while it was established which Local Authority was responsible for funding the adaptations. While a third family were long term foster parents of a disabled child and found this fact considerably delayed the adaptation process:

“So [child’s] here permanently with us and it’s one of those catch 22 situations you can’t apply for adaptation until the child is placed with you permanently but you have to go through a certain length of time before that child is actually placed with you permanently.”(Foster Parent- 11yr old physical disability)

In other instances, some families contributed to the delays by placing demands on the staff constructing the adaptation to only work at certain times:

“I said it’s the summer holidays in two weeks’ time you can’t be building this out there with [child] off for six weeks.” (Parent 10 yr old disability not specified).

Delays to the adaptations process had significant implications for both the child and their families. A number of families reported that the strain of caring for a disabled child in an unadapted home had implications for health:

“it affected me in that I shouldn’t have been doing the lifting, I am awaiting surgery at the moment because it’s been a huge problem lifting and I’ve been told not to lift but you know it was exacerbated by that really.”(Parent 10 yr old physical disability).

It was also felt that the child’s safety and dignity were compromised by delays.

These issues could be seen as relating in some part to the lack of information and poor communication with families’ with regards to their rights *and responsibilities* in terms of the timing and timeliness of the adaptation.

Regardless of the reasons for delays in the process, where they occurred, delays were shown to have a negative impact on family life; on the health and wellbeing of parents and also on the safety and dignity of the child. This concurs with Littlechild et al (2007) who cited an example of a family unable to shower their teenage son for two years, while they waited for

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a bathroom adaptation. Long waits for adaptations, highlighted by families in this study also echo those reported in the 2008 Shelter/Contact a Family report, with delays to the process being the most frequently cited complaint.

### **Conclusion**

This research has shown that the housing needs of families with a disabled child are complex. The complexity in the general adaptations system, poor communication, and the paucity of child specific information has highlighted the need for an identified person to guide families through the process. A single contact person needs to be made available for families and occupational therapists should consider their part in that role. More specific information related to the needs of children should be provided; and families need to be enabled to recognize the part they can play in adding to delays in adaptations' delivery. This conclusion is in line with Baxter and Glendinning's 2011 study suggestion that in order to realize the U.K. wide desire of policies and legislation to increase service user choice and control: Information on the options available to service users need to be readily available in order to facilitate individuals in making informed choices about services.

### **Transferability/Limitations of the study**

Family participants in this study were self-selecting and therefore were likely to have issues to air. The study was based in one country: Wales. Although broadly similar throughout Great Britain and Northern Ireland, since devolution of power from Westminster the processes and legislation related to the adaptation of properties/home modifications for disabled residents have differed. These differences justified the need to base this study in one country, but need to be taken into account when considering this study's results. Nevertheless, the adaptations' processes remaining similarities and the investigation of the perspectives of families and professionals offer a wider view of the process of facilitating adaptations/home modifications for disabled people in many different settings. The findings are, therefore, potentially transferable to more than just one country.

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