

Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants: a Small Scale Pilot Study

**Our thanks go to the families who somehow found space
from their incredibly challenging caring roles to contribute to the research**

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Access Committee For Leeds

Information and support through the disabled communities of Leeds

As a parent of a disabled child it can be very challenging and stressful just getting through what is everybody else's day to day basic living. On top of this you are worrying and panicking that you may have to make the decision that you can no longer cope and safely meet your child's needs. The guilt of this though is overwhelming and never leaves you. You feel like you have let your child down, your family down and yourself down and it's on your mind from the minute you awake until the minute you go to sleep (if you manage to get any sleep).

In reality the adaptations do really change lives for the better. We were lucky due to the support and help we received from Access Committee for Leeds and one member of statutory services that we were able to have the strength and knowledge to fight for the Disabled Facilities Grant. These people have given us the opportunity to continue being a complete family with every member under the same roof. This has allowed our daughter to thrive and grow into a teenager in an environment that is safe and meets her needs, it has also made our job a little easier and a lot less stressful.

We are sure that if our daughter could speak she would agree that no price can be given for this gift and every disabled child or adult should be given this opportunity.

Legal Entitlements & Problem-Solving (LEaP) Project

LEaP is an innovative problem-solving project that helps families of children with brain conditions cope with the legal barriers they face.

We listen to families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent families getting access to services and we develop innovative ways of solving those problems. We aim to reach as many families as we can by sharing our solutions as widely as possible.

School of Law & community engagement

Community engagement is fundamental to the ethos of the School of Law at Leeds University. Students are given every encouragement and support to use their legal skills to benefit of the local community. In doing this students develop these skills and deepen their understanding of the role of the law in the real world: the central role of the law in fostering social justice. In furtherance of this aim the School supports (among other initiatives) a number of law clinics and the Cerebra LEaP project.

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Summary of Key Findings

A small scale pilot study of the economic and well-being impact of building adaptations to family homes to accommodate the needs of young people with Autistic Spectrum Disorders who have behaviours that challenge. The adaptations (which on average each amounted to £60,000) were primarily designed to provide additional 'safe space' (including safe garden space) for the young person.

- The principal cost impacts were that the adaptations had avoided the need for the young people to be 'accommodated' ie to become 'Looked After Children' (LAC) (para 5.11);
- The study suggested that possibly 14 years LAC funding had been avoided by the adaptations (para 5.15). The study considered the evidence as to the wide range of costs for accommodating LAC children from which it would appear that the economic cost benefits of adaptations (for the public purse) are considerable – even if the well-being impacts on the disabled young person and their families are ignored;
- The most commonly mentioned well-being benefit for the disabled young person was that she / he had space to relax and to be safe (para 5.18);
- The most commonly mentioned well-being benefits for the parents were that they felt under less pressure and healthier (5.19) – but generally they described their position as 'just coping' (para 5.27). A major concern in almost all cases was the need for suitable health and care services and in some cases, follow up adaptations to address the changing needs of the young person;
- The most compelling well-being findings concerned the disabled children's siblings who had been enabled to have safe space for themselves, privacy, independence, the ability to invite friends to the home and to study (para 5.21);
- Most families considered that the disabled young person's on-going care and support was inadequate and putting in jeopardy the benefits derived from the adaptations. This included the absence of suitably trained care assistants (or direct payment rates too low to enable suitably skilled people to be employed) as well as the failure of the local NHS to provide sensory therapy support services (para 5.26);
- In one case the adaptation building works had been mishandled and this had caused significant dangers for the young person and great hardship for the family members which they considered to have been a profoundly negative experience (para 5.30);
- All families stressed the importance of an independent advice and support agency to help them with the process of applying for home adaptation support funding and negotiating with the relevant public bodies (para 5.31);
- The pilot research indicates that significant problems exist for local authority staff trying to facilitate adaptations, as the work is generally funded from housing budgets with the consequent savings evident in social services and NHS budgets (para 5.35). The research also suggests that the potential benefit of changes made to the Better Care Fund may be limited, particular for young people with Autistic Spectrum Disorders (para 5.36).

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Cerebra Research Report

Introduction

- 1.01 In 2014 Cerebra, a unique charity set up to help improve the lives of children with neurological conditions, endowed a research Chair in Law to support disabled children and their families experiencing difficulties in accessing their statutory entitlements to care and support services. The project is now based at the School of Law, Leeds University¹ and the research programme titled the Legal Entitlements and Problem-Solving (LEaP) Project.
- 1.02 Requests for advice and support are received and assessed by Cerebra staff and those cases which meet our eligibility criteria are referred to the Project Team for consideration. We listen to families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent families getting access to services and we develop innovative ways of solving those problems. A key approach to tackling a commonly occurring problem is to commission a research project which benefits from the School of Law's excellent student '*pro bono*' researchers. We aim to reach as many families as we can by sharing our solutions as widely as possible.
- 1.03 As well as helping individual families, the Project generates vital information for the wider programme. The research is aimed at improving our understanding of the difficulties faced by families in accessing support services and learning how these problems can be resolved effectively. The team uses the research data (which is held securely and anonymised) to study practical problem-solving techniques and identify which approaches work best, with a view to refining the way we provide advice and disseminate good practice findings for the wider public benefit.
- 1.04 One commonly occurring problem families encounter concerns difficulties in obtaining support to adapt their homes to make them accessible for their disabled child and safe for the whole family. This is not a surprising finding as there is a wide range of evidenced based research highlighting difficulties in this field² including a specific 'focus report' in 2016 by the local government ombudsman.³ Nevertheless, so prevalent were the requests received by the Cerebra based LEaP team, that it was decided that this topic should be the subject of a specific 'problem solving' research.
- 1.05 Follow up casework by the LEaP Project has highlighted an apparent lack of understanding by housing and social services authorities in respect of three key aspects of their home adaptations and DFG roles for disabled children and their families. The three areas being: (1) the preventative nature of such support; (2) the cost effectiveness of such support; and (3) the nature of their legal duties to provide such support.

¹ Initially the research project was based at the Law School Cardiff under the direction of Cerebra Professor Luke Clements. The project moved, with Professor Clements to the School of Law Leeds University in 2016.

² See College of Occupational Therapists Specialist Section in Housing Written submission to the House of Commons Women and Equalities Committee Inquiry on Disability and the Built Environment 2016 para 1.2.

³ Local government ombudsman *Making a house a home: Local Authorities and disabled adaptations. Focus report: learning lessons from complaints* March 2016.

- 1.06 In 2016 discussions took place between the Access Committee for Leeds and the LEaP Project team to develop such a research programme. The Access Committee is an independent disabled people's led organisation that offers peer-support and empowerment to individuals and families who encounter barriers, exclusion and discrimination in all areas of public service and provision. The promotion of adaptations for disabled people with Autistic Spectrum Disorders has been pioneered by the Access Committee and the City Council has now made several awards for such works making it – in all probability – a leading authority in this respect in the UK.
- 1.07 17 *pro bono* students (both undergraduate and postgraduate) from the School of Law and 2 students from the School of Media and Communications volunteered to conduct the research concerning the cost benefits and associated impacts of home adaptations for children and young persons with Autistic Spectrum Disorders. The research programme was led by Professor Luke Clements and Sorcha Mc Cormack.
- 1.08 We are immensely grateful to the families who agreed to contribute to the research (including those who due to unforeseen health difficulties were not able to participate fully). The families were (as this report makes clear) under enormous strain from their caring responsibilities – and it is remarkable testimony to their sense of altruism that they found time to contribute to the project. For them there was no prospect of gain but they all made time to help – in the hope that their experiences (and this report) could assist others who may find themselves in a similar predicament and to influence future policy and practice.
- 1.09 We are also most grateful to the experts who agreed to be available to give guidance as the pilot project progressed. We must also record our thanks to the officers working for the public bodies whose decisions concerning adaptations and services form the back drop to the research – several of whom agreed to provide expert advice for the project.
- 1.10 This report includes analysis about the way local authorities make resource allocation decisions. We hope that this report contributes to a better understanding of the consequences of these decisions – and in no way is taken as a criticism of individual officers working in incredibly demanding and constrained environments.

For further information on the Cerebra LEaP research programme see <http://w3.cerebra.org.uk/help-and-information/legal-help/ask-for-legal-help/>

For further information on the School of Law pro bono programme see www.law.leeds.ac.uk/about/extra/cerebra-pro-bono-research-programme

Overview of research project and methodology

- 2.01 This report concerns the obligations of local authorities in England to assist disabled young people and their families with home adaptations.
- 2.02 English social services authorities are under a duty to facilitate adaptations to the homes of disabled young people⁴ where these are assessed as necessary. Similar obligations exist in relation to disabled adults.⁵ Separate obligations rest with housing authorities, who are under a duty to make payments to qualifying disabled people of any age to cover the cost of adaptations designed make their homes (including gardens) safer and more accessible. Such adaptations may be directed at: (1) improving the accessibility of the home by (for example) widening of doors, installing ramps and stair lifts, fitting disabled-friendly bathrooms or providing access to gardens;⁶ and/or (2) making the home safer for the disabled person and others living in the dwelling. It is in relation to this second category that the Access Committee for Leeds has developed expertise (particularly in relation to disabled young people) and on which this research project has focused.

Methodology

- 2.03 The research project was designed as an exploratory study to assess what the key practical barriers were to families obtaining necessary adaptations and what economic and well-being impacts resulted from the provision / non-provision of suitable adaptations. Given the scoping nature of the project, the uncertainty as to what would be revealed and the limitations on the availability of the student research team, the study only involved a small number of families.
- 2.04 The Access Committee for Leeds identified and facilitated contact with the participating families. The initial aim was to interview eight families, but due to illnesses and other unavoidable difficulties, the final sample consisted of only six families. A questionnaire was prepared to help structure and direct the interviews. It covered a wide range of topics and provided scope for the collection of quantitative data – as well as facilitating semi-structured interviews. It fulfilled the role of a topic guide to encourage responses from the families to enable us to gather more in-depth information on the various impacts they had experienced resulting from their request for home adaptations. A copy of the questionnaire is at Appendix 3. Families were provided with copies of the questionnaire at least 7 days prior to their interviews. Ethical approval from the Faculty Research Ethics Committee at the University was obtained for the project.
- 2.05 Given the highly conjectural nature of the pilot – ie asking (among other things) the question: “but for the adaptations what would have happened?” - a key premise of the research is that the principal carers are best placed to judge the likely impact of adaptations being (or not being) provided. This essentially adopts the well-being principle in the Care Act 2014, s1(3) that individuals are best placed to make a judgment on questions such as this. This assumption is one that can cut both ways: it has the potential to result in an over dramatisation of a family’s pre-adaptation predicament but it can also result in a family denying that a crisis would have occurred when the evidence strongly suggests otherwise. In this small study, it appears that the latter position (of denying the risk of a probable crisis) has predominated.

⁴ Chronically Sick and Disabled Persons Act 1970s2 and the Children Act 1989, s17.

⁵ Care Act 2014, s18.

⁶ The legal criteria are set out in the *Housing Grants, Construction and Regeneration Act (HGCR) 1996* and in the *Housing Renewal Grants Regulations*.

- 2.06 19 *pro bono* students (both undergraduate and postgraduate) from the School of Law and School of Media & Communications volunteered to assist with the research, including undertaking the family interviews and collating the responses. The *pro bono* research team worked in 6 teams comprising 3 or more students, one team was assigned a 'media role' and comprised of 4 students.
- 2.07 Training was provided for the students. This included an explanation of the relevant law (outlined at Appendix 1 below), the needs of young people with an Autistic Spectrum Disorders who also have behaviours that challenge, the needs of their families, the use of the research questionnaire and how to conduct an appropriate interview.
- 2.08 Visits to participating families comprised: one or more member of the student research team (who undertook the actual interview); Professor Luke Clements or Sorchá McCormack; a member of the Access Committee. All families had requested assistance with adaptations from the same local authority (a unitary authority). The research study contains no comparison group and this, together with its small sample size, means that statistical generalisations cannot be made and only limited conclusions can be drawn from the quantitative data.

Overview of the relevant statutory duties

- 3.01 There are various kinds of local authorities in England. Some authorities are responsible for the delivery of both housing and social services functions (eg unitary authorities and London Borough Councils) whereas others divide these functions under a two-tier system whereby the District Council provides housing services and the county council provides social services.
- 3.02 There are two distinct legal duties on local authorities to provide support for home adaptations for disabled people – one owed by social services authorities and the other owed by the housing authority. These duties are summarised below and the housing authority duty described in greater detail at Appendix 1 to this report.

Housing adaptations: the social services authority duty

- 3.03 Social services authorities have a duty to assist disabled young people ‘in arranging for the carrying out of any works of adaptation in [their home] or the provision of any additional facilities designed to secure [their] greater safety, comfort or convenience’.⁷ This duty arises where the authority has assessed the need for the specific adaptations.⁸ Almost invariably before the authority decides on whether it is necessary to assist with the adaptations it will expect the family to seek funding support from the housing authority by applying for a Disabled Facilities Grant (DFG). The maximum ‘mandatory’ amount of a DFG is currently £30,000. If the cost of the adaptations exceed this sum, a decision has to be taken as to whether it is necessary that the balance is funded by the public purse and if so, whether this should be done using a discretionary power in the housing legislation or the general duty that exists in the social services legislation. The local government ombudsman has held that it is maladministration for a council to fail to appreciate that it has a duty under the social services legislation to provide adaptations, separate to that under the DFG legislation.⁹
- 3.04 The duty on social services authorities to provide adaptations applies equally to disabled young people and adults alike – however these duties derive from separate statutes¹⁰ and adaptations for people over the age of 18 are subject to a means test.

Housing adaptations: the housing authority duty

- 3.05 Housing authorities are under a duty to receive and process applications for DFG’s (described in detail in Appendix 1 below). The application must establish that the adaptations are necessary and appropriate to meet the needs of the disabled person: this is normally dependent upon a social services occupational therapist assessing this to be the case. It must also be shown that the works are reasonable and practicable (which is determined by the housing authority).
- 3.06 The maximum mandatory grant is £30,000 in England,¹¹ although as noted above and in Appendix 1 below, authorities have power (and sometimes a duty) to award higher sums in appropriate cases.

⁷ Chronically Sick and Disabled Persons Act 1970 s2(6)(e).

⁸ For details of the assessment process and nature of this right see – Cerebra [Guide Social Care in England: A Guide for Parents](#).

⁹ Complaint no 05/C/13157 against Leeds City Council, 20 November 2007.

¹⁰ As noted above, the duty owed to disabled people under 18 years of age derives from the Chronically Sick and Disabled Persons Act 1970 s2(6)(e) whereas the duty owed to disabled adults is found in the Care Act 2014.

The importance of adaptations and their funding

- 4.01 Living in a home where a disabled person and/or their family are unsafe and/or where access to key living areas is restricted, may have a significant impact upon the well-being of everyone in the household. Substantial improvements to a home can be costly. Research shows that disabled children tend to spend more time in their homes than non-disabled children but ‘there is evidence to suggest that their homes are the most restrictive environments in which they spend their time’.¹²
- 4.02 Adaptations have the potential to build resilience in disabled people and their families. Successful provision can empower disabled people to live more independently, can significantly reduce family stress and improve their mental health and sense of well-being. Moreover, adaptations help deliver some key government health and social care policy objectives.¹³ Appropriate adaptations can prevent unnecessary hospital stays and promote the social inclusion and independence of people with long-term illnesses or disabilities.¹⁴

Prevalence of need

- 4.03 9% of households in England (about 1.9 million) have at least one disabled person that requires an adaptation to their home.¹⁵ On average however only about 43,000 DFGs are awarded each year¹⁶ and of these only 7% were for persons under the age of 21.¹⁷ While legal entitlement to support with adaptations is ‘impairment neutral’ the research evidence suggests that local authorities are reluctant to agree funding where there is no physical impairment, leaving people with learning disabilities, autism or other mental health problems unfairly disadvantaged.¹⁸
- 4.04 The focus of the pilot research considered in this report concerns adaptations for children and young people with Autistic Spectrum Disorders. For this group the adaptations needed are primarily concerned with making the dwelling ‘safe for the disabled occupant and other persons residing’ with them.¹⁹ These needs require a variety of responses, from the padding of walls and reinforcing of doors, to the construction of extensions to increase the disabled person’s personal space and to provide safe areas (including making secure and safe gardens). Central to much of the work is the need to cater for their physical and sensory needs. Young people with more severe forms of autism may have complex sensory processing disorders, particularly hypersensitivities. Such adaptations may also be critical to the safety and wellbeing of other family members: parents and siblings.²⁰

¹¹ The Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008 (SI 2008/1189).

¹² Bryony Beresford with David Rhodes (2008) *Housing and disabled children* (Joseph Rowntree Foundation).

¹³ Department of Communities and Local Government (2016) *English Housing Survey Adaptations and Accessibility Report, 2014-15*.

¹⁴ Ibid and see also S Nicol et al *The cost of poor housing to the NHS* (Building Research Establishment 2015). who estimate that poor housing costs the health service £1.4 billion pa.

¹⁵ Department of Communities and Local Government (2016) *English Housing Survey Adaptations and Accessibility Report, 2014-15*.

¹⁶ The average number of DFGs awarded each year between 2008-2015 amounted 43,095 – see S Mackintosh & P Leather (2016) *The Disabled Facilities Grant* (Foundations) para 5.2.

¹⁷ Ibid para 5.10: 71% were awarded to those aged 60 and over.

¹⁸ Carers Trust (2010) *Carers and Housing: Addressing their needs* (Carers Trust) p.7.

¹⁹ Housing Grants, Construction and Regeneration Act 1996 s23(1)(b).

²⁰ Carers Trust *Carers and Housing: Addressing their needs* (Carers Trust 2010) and see also Muscular Dystrophy UK (2015) *Breaking point The crisis in accessible housing and adaptations* (Muscular Dystrophy UK).

Previous research concerning the benefits of adaptations

- 4.05 Significant research exists concerning the cost benefits of adaptations for adults – particularly older people. A 2006 review by Heywood and Turner²¹ noted that where adaptations constituted ‘an alternative to residential care’ they had the potential to ‘save money, sometimes on a massive scale’. A 2015 Leonard Cheshire report referred to a survey of Occupational Therapists which found that 96% of considered that adaptations decreased individuals need for social care.²² A *Foundations* report of the same year found that older people were able to postpone the move to care and stay in their own homes for on average four years longer after adaptations – which a consequential major saving for local authorities.
- 4.06 A 2016 case study by the Isle of Wight Council²³ involving older people found that 67% of the adaptations had the effect of avoiding the need for a person to enter residential care and in 96% of the cases they reduced the risk of accident/incident and further hospital or social services intervention. In the same study the costs of care, social services and hospital intervention were compared to the average cost of a DFG. It was estimated that a potential one year savings for a DFG instead of home care was £13,883,407 (ie £69,417,035 savings over a 5 year period). As the forecast of the prevention savings is based on speculation, it was noted that even if merely 20% were realised this would still amount to significant savings for the authority of £2.78m in one year and £13.88m over a 5 year period.
- 4.07 The evidence of cost effectiveness of adaptations for adults is well established as the 2017 Better Care Fund policy guidance²⁴ notes:
- There is a growing evidence base on the contribution that housing can make to good health and wellbeing. At a system level, poor housing costs the NHS at least £1.4bn per annum. And there are also costs to local government and social care. On an individual level, suitable housing can help people remain healthier, happier and independent for longer, and support them to perform the activities of daily living that are important to them – washing and dressing, preparing meals, staying in contact with friends and family.
- The increase in funding for the Disabled Facilities Grant (DFG) – and the decision to move it into the BCF in 2015-16 – is recognised as an important step in the right direction. Further action to support people into more suitable accommodation

DFG funding streams

- 4.08 In 2012 a Department for Communities and Local Government (DCLG) commissioned report²⁵ estimated that 720,000 of households in England required some adaptations and that the amount needed to cover grants for all those who are theoretically eligible was (at 2005) £1.9bn: in comparison the central government contribution to the DFG budget at that time amounted to approximately £157m. In 2015 it was reported that the demand for

²¹ Heywood F & Turner L (2006) *Better Outcomes, lower costs: Implications for health and social care budgets of investment in housing adaptation, improvements and equipment: A review of evidence*, Office for Disability Issues (DWP) p.14.

²² Leonard Cheshire (2015) *The long wait for a home; Beware of the door*.

²³ A Barnes (2016) *Isle of Wight Council DFG cost savings research*.

²⁴ Department of Health & Department for Communities and Local Government (2017) *2017-19 Integration and Better Care Fund Policy Framework* p.12.

²⁵ Building Research Establishment (2012) *Modelling the current and potential accessibility of the housing stock*: (DCLG) and for critical analysis of the report's findings see S Mackintosh & P Leather (2016) *The Disabled Facilities Grant* (Foundations) para 5.53 et sq.

DFGs was rising at twice the rate that councils were able to meet that need²⁶ (even though legally council's must fund eligible applications regardless of their resource constraints – see Appendix 1 below).

- 4.09 Since their inception, core funding for DFGs has come from the central government although many housing authorities have made additional contributions. Despite research highlighting the increased demand and the cost effectiveness of the grants (discussed below) local authority contributions have reduced since 2010.²⁷ Central government funding now derives from the Better Care Fund²⁸ and allocations to this fund for DFGs increased by almost 80% in 2016/17 (to £394m) and the intention is that the funding will, by 2019/20, amount to £500m.²⁹
- 4.10 Although the funding is not ring-fenced the 2016-17 BCF Strategic Framework³⁰ stated that the government expected the DFG allocation to be used for this purpose.³¹ It is unclear if this happening, for example in 2015 one London Borough was reported as spending only 71% of its allocated funding despite having 900 people on their waiting list.³² In the context of the austerity economics experienced by local government this could be a rational decision: ie to use the allocation for more urgent priorities. Key factors in reaching such a decision would include an analysis of its 'disability impact' (which this report does not consider³³) and the cost benefits of such support – which is a central question addressed by the pilot study.

Funding delays

- 4.11 Delay is an inevitable knock-on effect of any funding shortage for adaptations. Delay can however result from other failures, as this pilot study demonstrates. This study also suggests that delay can have significant and negative economic impacts on councils – as well as creating hardship for disabled young people and their families. Delay can constitute maladministration and breach of statutory duty. The DFG legislation³⁴ imposes strict time limits for the processing and payment of grants and the distinct social services obligations³⁵ must be satisfied within a 'reasonable period of time'.³⁶ Delay is additionally problematical where the welfare of a child is engaged.³⁷ Young people's needs change and adaptations must not only be timely but they must anticipate – where possible - these future needs. In

²⁶ Leonard Cheshire (2015) *The long wait for a home* (Leonard Cheshire).

²⁷ Leonard Cheshire (2015) *The long wait for a home* (Leonard Cheshire) and see S Mackintosh & P Leather (2016) *The Disabled Facilities Grant* (Foundations) page 6.

²⁸ See Department of Health (2014) *Better Care Fund: how it will work in 2015 to 2016 Policy Framework*, para 3.5 and generally see Care & Repair (2015) *Disabled Facilities Grant Funding via Better Care Funds – An Opportunity to Improve Outcomes* (Care & Repair).

²⁹ S Mackintosh & P Leather (2016) *The Disabled Facilities Grant* (Foundations) para 3.14 and HM Treasury (2015) *Spending Review and Autumn Statement 2015* Cmd 9162 (HM Treasury) para 1.109.

³⁰ Department of Health (2016) *2016/17 Better Care Fund Policy Framework*.

³¹ Care & Repair England (2016) *Briefing Disabled Facilities Grant* (Care & Repair England).

³² A 2015 report (Leonard Cheshire (2015) *The long wait for a home* (Leonard Cheshire), p.7.) suggested that 37% of councils were not intending to spend any of their BCF allocation on housing related functions. Further research is required to ascertain whether this is indeed the position or if it is due to a misunderstanding relation to the Freedom of Information request which produced this data.

³³ Such a decision would have to be made with the benefit of an Equality Impact Assessment required by the Equality Act 2010, s149.

³⁴ Part 1 of the Housing Grants, Construction and Regeneration Act 1996 – see Appendix 2 below.

³⁵ For disabled children under the Chronically Sick and Disabled Persons Act 1970 s2 and for disabled adults under the Care Act 2014. As with their obligations to fund DFGs, councils must meet these duties when they arise, regardless of their resource constraints.

³⁶ A phrase that the courts and ombudsman have been prepared to interpret in meaningful terms where they consider the process has taken an 'unreasonable' time.

³⁷ See by analogy Children Act 1989 s1(2) the 'the general principle that any delay ... is likely to prejudice the welfare of the child'.

the pilot research to which this report refers, the evidence suggests that the failure to provide for predictable increased / changing needs has been problematical and would appear to have resulted in significant and negative economic impacts on councils – as well as creating hardship for the young people and their families.³⁸

- 4.12 2015 research found that: 62% of councils had failed to fund adaptations within the statutory (one year deadline); 44% of councils had examples of disabled people waiting two years for payment; 2,500 disabled people reported waiting over a year to get vital funding for adaptations; and that eight councils reported waits of over four years.³⁹

³⁸ 'Some families found that delays meant that the child's needs had changed by the time the adaptation was complete' Audit Commission (2001) *Services for Disabled Children: A review of services for disabled children and their families* (Audit Commission) para 80 and see also p.33.

³⁹ Leonard Cheshire (2015) *The long wait for a home* (Leonard Cheshire).

The pilot research project

- 5.01 The age of the disabled people for whom the adaptations were sought⁴⁰ ranged from 5 to 15 although at the time of the interviews they were of course older – including in more than one case, a young adult. All the disabled young people had behaviours that challenged and a diagnosis of an Autistic Spectrum Disorder. In every case the disabled person had been referred to a Child and Adolescent Mental Health Service (CAMHS). In every case the level of need of the disabled young person was considerable. All had behaviour that required constant supervision and with one exception all required 2:1 supervision in public settings and some required 2:1 supervision at all times. All had behaviour that carried a real and immediate risk of serious harm to themselves if unsupervised and all but one were considered likely (based on past actions) to cause serious damage to property and/or significant harm to other people, if unsupervised.
- 5.02 In each interview compelling evidence was provided of a dedicated, loving family facing caring challenges that were almost unimaginable for those without experience of such situations. In each case the ability of the family to continue their caring role could objectively be described as fragile – and in most cases this was the assessment of the families themselves. In five of the six cases convincing testimony was given by the family that absent a suitable adaptation there would be or would have been a crisis precipitating a breakdown preventing them from providing suitable care for their child (due to their inability to maintain the safety of the home environment) such that the young person would have had to become a Looked After Child (LAC).⁴¹
- 5.03 In three of the cases this crisis had been avoided (at the material time) by the adaptations being facilitated. The evidence of the families in these cases was that adaptations had avoided a total of 11 years Looked After Child funding. Looking to the future these three families estimated that they would, because of the adaptations, be able to sustain their caring role for a total of three further years (ie a total of 14 years LAC status being avoided as a result of their adaptations).
- 5.04 For the remaining three families, the factual position was different.
1. For one family, for whom adaptations had been carried out some time previously, there was not a willingness to consider that at any time could there have been a ‘crisis’ precipitating a breakdown leading to the disabled young person becoming a Looked After Child. As noted above, a key premise of the research is that the principal carers are best placed to judge the likely impact of adaptations being (or not being) provided. In this case the principal carer accepted that: (1) the disabled person’s behaviour could be characterised as particularly challenging; (2) that prior to the adaptations the accommodation was particularly cramped and inadequate for the family; (3) that these cramped conditions had led to not infrequent violent incidents; and (4) that the principal carer had serious health care needs. It was also accepted that as a result of the adaptations there had been a material change for the better in relation to all four of the above negative factors.
 2. For two of the families the adaptations had not yet been completed.
 - a) for one family the work had been delayed and had not yet commenced. The view of the principal carer in this case was (at the time of the interview) that if the works were not undertaken and completed within the next six months, the disabled person would become a Looked After Child;

⁴⁰ ie at the time family endeavoured to initiate the application for assistance.

⁴¹ Under Children Act 1989, s20.

- b) for the other family the works had been commenced but had been seriously delayed such that the family considered that the harm caused these protracted works (ie living in a building site for a prolonged period) outweighed any benefits that might result from their completion.

The nature and cost of the adaptations

- 5.05 Of the six families interviewed, four had had adaptations completed (or very nearly completed) and the cost of these appeared to range from about £20,000 to about £90,000 (the average being slightly under £60,000). In every case the work was funded by the council through the use of a DFG and/or other funding flexibilities.⁴² In no case had the council sought a 'top up' payment from the family in question.
- 5.06 The adaptations required, varied in every case, but all had as one of their central aims, to provide additional space for the disabled young person and their family. In every case the works required included the provision of extra space within the home (generally a bedroom and bathroom) and in all but one of the cases, the adaptations involved works to the garden to create a safe outdoors space to enable the disabled person to play / 'let off' steam outside safely. In addition the adaptations included such things as padding to walls, new doors, air-conditioning, secure shatter proof windows, as well as specialist equipment such as bedding and bathroom furniture.
- 5.07 As noted above, of these six families four had their home adaptations completed of which and three were very clear that without adaptations, the relevant disabled child/ young person would have become a LAC. Of the remaining two, one considered that absent the adaptations being completed within six months the disabled person would become a LAC and the other (for whom the building works had been the subject of serious delay) regretted having embarked on this process, believing that it had caused more harm to the disabled person and the family, than good.

Impact of doing the work

- 5.08 Where adaptations had been completed, the assessment of the family was that they had – most importantly – provided 'space': space for the disabled person to use their bathroom without having to wait; to have a room to spend time in, giving space for that person and the family; space for a play / therapy area inside and generally outside. This was viewed as essential – but in itself insufficient: as reducing the pressure to something tolerable (albeit in two cases for only a limited period). In addition to this, in every case the disabled person needed a personal care package – both when at home and when away – at college or in other community settings. In several cases the original adaptations were considered inadequate and further works were required. In similar fashion in several cases the disabled person's personal care package was considered inadequate. These concerns are considered below, but came to be a frequent theme of the interviews. Several of the families described the adaptations / care packages that had been provided as enabling them to 'barely cope' – to 'hold the fort' – to 'manage but no more' – to 'remain on a cliff edge'. What was being described by these families was a support arrangement that did the bare minimum. It enabled them to cope but for a limited period only.

⁴² eg those available under the CSDPA 1970 and/ or the Regulatory Reform Order (RRO) – see below.

Costing this impact

- 5.09 The above results are materially different to the responses we had expected to emerge from the pilot study. We had anticipated that as a result of a one-off adaptation, it would be possible to point to a quantifiable reduction in the local authority care package and the care demands made on the family.
- 5.10 The interview results tell a different story. They describe, in many cases, families who without the adaptation would have been unable to cope such that the disabled young person would have had to have been 'accommodated'. In those cases where adaptations had been completed, their impact was considered to have avoided such a breakdown. However this was generally seen as a limited duration impact. For reasons discussed below, none of the families considered that the provision of the adaptations had meant that the young person's care package could be reduced. In terms of 'the demands made on the family' their responses suggest that the adaptations have enabled them to cope with these demands for a longer period but not to reduce these demands to tolerable levels.
- 5.11 In terms of cost impacts, therefore, a relevant factor in the study concerns the costs that would be borne by the local authority or the NHS if the family was no longer able to provide care. The quantitative costs analysis in most cases is stark: the probability of the young person becoming a Looked After Child. As one family explained:
When we were granted the DFG, we were at crisis point - had we not received an adaptation [my child] unfortunately would have been put in care. My health would also have deteriorated by a significant amount.
- 5.12 The pilot research project does not enable us to assess precisely the financial cost to the local authority or NHS⁴³ of one of the young people in this study becoming a Looked After Child. All these young people (with one possible exception) had such forceful behaviours that their accommodation arrangements would have necessitated a highly adapted and specialised setting to address their care needs.
- 5.13 Although all the young people in the study have behaviours that challenge, these behaviours differ and would inevitably require distinct personalised packages of care. In more than one case it was probable that the care package would necessitate accommodation within a secure setting⁴⁴ and in one case at least (where the disabled person is now an adult) the placement would most probably necessitate authorisation under the Mental Capacity Act 2005, Deprivation of Liberty Safeguards.
- 5.14 It follows that it is not possible to calculate the 'avoided' LAC costs with precision. It is however clear that these would have been not inconsiderable. A review of recent reports concerning the cost of LAC placements (but not necessarily involving children with ASD whose behaviours pose significant challenges) reveals:
- In 2014 the Department of Health estimated that the average cost of children's home placements to be £2,900.00 per week, but the variation was considerable;⁴⁵
 - In the same period (ie 2014) the Audit Office⁴⁶ estimated that a council residential care placement was in the range of £129,000 to £215,000 compared with a range of £122,000 to £200,000 in a voluntary, private or independent home.

⁴³ The evidence suggests that many, if not all, of the young people in the study might be eligible for NHS Continuing Care funding (or at least jointly funded packages of care) – see National Framework for Children and Young People's Continuing Care (2016).

⁴⁴ ie a setting authorised for the purposes of section 25 Children Act 1989.

⁴⁵ Department for Education of Health (2014) *Children's homes data pack* see page 44-45. In 2012-13 English authorities spent £997.2m on residential care for children (p44).

- In 2014 a Freedom of Information request to Sheffield City Council concerning the cost of a 'welfare bed' for a LAC in secure accommodation revealed that this amounted to £690.00 per night (ie 250,000 pa);⁴⁷
- In 2015 the Department for Education estimated that the cost of a residential care placement for a LAC ranged from £1,750 to £6,400 per week;⁴⁸
- In 2015 the PSSRU estimated that the annual cost of a residential placement for children with disabilities, emotional or behavioural difficulties plus offending behaviour amounted to £513,252 with an additional cost to other agencies of £16,000;⁴⁹

- 5.15 The above evidence suggests that the adaptations had avoided the cost 14 years' Looked After Child funding. The young people in this study had challenging behaviour and in most cases, severely challenging behaviour. If one adopts a figure of £2,000 per week for the cost of accommodating such a child then the total cost (at today's prices) amounts to almost £1.5 million (and if the assumption is £3,000 the figure is almost £2.2 million). Such a computation is clearly lacking in methodological rigour and based on a small sample size. It nevertheless gives an indication of the potential cost impacts of adaptations.
- 5.16 These figures may be an under or an over-estimate but given that the total cost of the adaptations involved amounted to slightly under £300,000 the disparity is marked. The calculation does not take into account the on-going costs borne by the local authority – as in most cases it was also providing day support work for the young person (and in one case the young person was a weekly boarder at a residential college). The figure also fails to account any health and well-being impacts on the young person (eg of living with their family in a non-institutional setting) as well as the wider health and well-being impacts on the family: parents and siblings.

Well-being impacts

- 5.17 Families were asked about the impact of the adaptations in terms of the young person's 'well-being' (which the questioner did not define) as well as the 'well-being' impact on the parents and siblings.
- 5.18 In all but one case (the case of the delayed adaptations) the impacts were considered to be positive. Comments relating to the young person included:
has a place to relax and can play in the backyard; has a place to unwind; has much better relationship with me and his [sibling]; the most valuable thing for me about the adaptation is that it gives me a lot of satisfaction knowing that my son has a safe area and his own space; he has had less injuries and the extension has reduced damage made around and to the house; he is more resilient now that he is able to enjoy his own safe space.
- 5.19 Comments relating to the parents' sense of well-being included:
my health has greatly improved, because of the safe environment that has been created; I am under less pressure now, as I no longer have to constantly follow him around; the whole family is at ease and are a lot happier; had we not received the adaptation, our family would no longer be together. I personally do not know if I would have been able to survive the stress and strain;

⁴⁶ National Audit Office (2014) *Report by the Comptroller and Auditor General Department for Education Children in care HC 787 SESSION 2014-15 27* (National Audit Office) p.10.

⁴⁷ FoI request to Sheffield City Council 9th June 2014

⁴⁸ Department for Education (2015) *Financial stability, cost charge and value for money in the children's residential care market* p.38.

⁴⁹ Curtis, L and Burns, A. (2015) *Unit Costs of Health and Social Care 2015* (PSSRU) para 8.4.4.

my health has got much better; the most valuable thing for me about the adaptation is that, it has provided me with a safe space during [her] challenging behaviour.

- 5.20 In two cases it was considered that the adaptations had enabled a parent to remain in work. In no case, however had the adaptations enabled a parent to return to work. This was generally because in these cases the family considered that additional support was needed – ie that parents were having to be available full-time to fulfil the caring role – due to the inadequacy of the adaptation or the lack of suitably skilled carers or the lack of suitable healthcare therapies (discussed below). In these cases the parents expressed a strong desire to return to paid work or engage in voluntary roles. Comments concerning this possibility included:

I'd be able to go back to work which I used to really enjoy and look forward; I used to work long hours and on skilled work; I'd very much like to be involved in school transport work for children such as my son; I would go back to work – I have a [named] skill that I would very much like to resume;

- 5.21 One of the most compelling findings of the interviews concerned the parents' perception of the impact that the adaptations had had on their other children: describing how profound and negative impacts on siblings had been materially ameliorated by the adaptations:

My [other children] are able to enjoy their privacy and independence, as [my son] has no desire to go upstairs because he has his own space downstairs; he has his own room now – previously shared with his [sibling]; [siblings] were disturbed during night and they couldn't enjoy a good night's sleep; it affected [my other children's] education - they had to be pulled out of school due to negative effects his behaviour had on them; [they are now] studying for GSCs and they cope better at school now; [siblings] have personal space to study; he now has his own room – he spends more time by himself, quietly entertaining himself with iPads and is of less disturbance to [his siblings]; [his siblings] like him more now – improved relationships; his sister can study better – she wants to be a doctor and help people like her brother; our other child is also a lot happier; the adaptation made it possible for [our adult children] to remain at home ... [without the adaptation they would have been] forced out and resentment would have followed. The adaptation made it possible for them to continue living together.

Other impacts

- 5.22 Although a number of other post-adaptation consequences are capable of being partially quantified – this has not been attempted. Nevertheless they give an illustration of the range of positive impacts that may result from interventions of this nature. These include:

- the young person suffering fewer injuries: 'we used to be at the GP or A&E (alternating) once a month and now we are not visiting about his injuries – (although still having visits in relation to illnesses etc)': – a quantification exercise might attempt to calculate the cost savings of fewer emergency visits to GP and Accident and Emergency departments;
- the potential for an adaptation (which was not forthcoming) which could limit the ability of a young person to abscond: – a quantification exercise might attempt to calculate the resulting cost savings, for example on one occasion this had necessitated the use substantial police search resources including a force helicopter.

Unmet continuing needs

- 5.23 In all but one of the families interviewed, the failure to complete adaptations (including follow on work) and/or to provide adequate health and social care support was jeopardising the sustainability of the care arrangement.

Adaptations

- 5.24 In one case a long outstanding request for support with adaptations had been delayed. In interview the parent expressed the view that 'if something is not done in terms of the additional space / adaptations and the care package [the young person] will probably be in care in 6 months' adding 'we are on a cliff edge and begging for help' and elsewhere in the discussion 'we are hanging in the balance'. Three months after the interview the family notified the research team that the authority had provided a formal response but had failed to address the need for adaptations and as a result the young person was now a 'Looked After Child' accommodated by the local authority.
- 5.25 A serious problem expressed directly by four of the families concerned the limited nature of the support that was provided – in the sense it averted a crisis but its impact was short-term. In relation to this question comments included the fact that the adaptation 'has allowed us to hold the fort'; to 'manage'; to 'keep going'; that it has 'just kept us ticking over but none of this is simple, we are all just treading water'. Families were waiting for further adaptations and/ or suitable health and care support services. One family thought that the additional support would probably take 2 years to 'come through' – stating that 'if we don't have a suitably adapted home, we can only continue for a further 18 months'. Another family stated that:
- the most detrimental thing about the adaptation is that it has not looked into the future, the adaptations have just done enough for us to keep 'coping' but it has not considered any future needs: needs that are now becoming urgent. Getting the adaptation was also very difficult.

Suitable health and social care support

- 5.26 An associated and significant problem concerned the inadequacy of the health and social care supports available to enable the family to continue to cope with their caring role. The view was that for young people with Autistic Spectrum Disorders and associated behaviours that result in significant challenges, adaptations were seldom if ever going to be sufficient on their own. Work of this nature had to be integrated with suitably skilled social care support arrangements and appropriate health interventions (particularly in the form of sensory therapies).
- 5.27 As with almost all the health, housing and social care support discussed in this report, there is clearly an economic case for 'non-provision' or the offer of inadequate provision. In two cases the families referred to the failure of the social services authority to provide suitably skilled care assistants to support the disabled young person while the parents looked after needs of their other children. The result in both cases was that this support was rejected as the use of unskilled workers had exacerbated the young person's challenging behaviour. Family comments on this issue included:
- Because of the failure to provide us with the care package he requires – ie trained / specialist care assistants who can manage his care needs – we have had no support. He needs 2:1 care and we do this 24 x 7. In this respect the local authority has actually saved money by not providing the suitable assistance
- At the moment he has a care package of [number] hours as a direct payment (ie 2 people [number] hours a week as he needs 2:1 care) but for most of the time I am unable to find anyone suitable and/or able to help. The hourly rate of the direct payment is £7.50
- We just 'cope'. We have other children and it has clearly restricted the time we can devote to them and their opportunities. We had to stop working and even a small activity, like our youngest going to the theatre requires military planning as it would mean there would only be one of us left with our son.

- 5.28 Economically the local authority gains from this approach (eg by avoiding having to pay for the care assistants) – at least in the short term. In similar vein, by delaying an adaption a local authority will gain a cash flow benefit. The same holds true where a local health body refuses to provide a necessary sensory therapy – and in this case the long term cost consequence⁵⁰ may well be borne by the local authority and not the NHS (the issue of ‘budget silo’s is considered further below).

Sensory therapy

- 5.29 Three of the families interviewed raised concerns about the absence of sensory therapy support services in their area. The families had researched the nature and challenges posed Autistic Spectrum Disorders and the difficulties many young people with this condition experience in processing sensory information – sometimes resulting in over-responsive actions (for example to visual information) and sometimes to inconsistent responses– for example to tactile information. Not unusually young people with this condition also have a poor perception of their body position in space resulting in (for example) the excessive use of force in many tasks – slamming doors, repeatedly striking hard objects (such as walls), throwing objects (including very heavy objects) etc. Although therapeutic interventions exist to help young people adjust their responses and to enable carers to better understand and address these behaviours none of the families had been able to access support of this kind. Two of the families reported that they had been told that such support was simply ‘unavailable’. Legally this failure appears troubling, given the statutory duty to promote a comprehensive health services,⁵¹ the specific health obligations to young people with Education Health and Care Plans⁵² and the likelihood that some, if not most, of the young people would be eligible for NHS Continuing Care funding.⁵³

Negative impact of adaptations

- 5.30 Problems with the quality and timeliness of building work are not uncommon⁵⁴ and can have a particularly detrimental impact on some people with Autistic Spectrum Disorders where changes in routine or environment can create distress (which may be an inevitable consequence of adaptations). Work of this kind can also create building site health and safety risks for young people with little understanding of danger. For one of the families these problems meant that the process had been a profoundly negative experience: so severe was the disruption that the parents described it as the most stressful 12 months of their lives. In their opinion the only reason they survived as a family unit was because of the length of their marriage – noting that ‘most new couples would have separated when under strain’. Although all adaptations need careful management the lesson would appear to be that for young people with Autistic Spectrum Disorders this need is acute: that if mishandled the adaptation may have the opposite economic impact – of increasing the young person’s risk of becoming a Looked After Child’.

⁵⁰ eg if the child becomes a Looked After Child.

⁵¹ National Health Services Act 2006, s1.

⁵² Children and Families Act 2014 s42.

⁵³ The National Framework for Children and Young People’s Continuing Care (2016).

⁵⁴ See for example ‘Jeff and Joan’s story’; described in the Local Government Ombudsman *Making a house a home: Local Authorities and disabled adaptations: Focus report: learning lessons from complaints* (2016) page 8.

Information

- 5.31 Boniface and Morgan have highlighted the lack of information given to families in need of adaptations. In their opinion the ‘complexity in the general adaptations system, poor communication and the paucity of child-specific information’ points to the need for an identified person to guide families through the process.’⁵⁵ Although all participants to the research identified with this view they stressed that a key element was the need for an independent advice and support agency and all considered that the Access Committee for Leeds had been outstanding in this role.

Integration and budget silos

- 5.32 The pilot research project indicates that the quantifiable cost impact of providing / not providing adaptations for some young people Autistic Spectrum Disorders can be significant. The research additionally provides overwhelming evidence that other less easily quantifiable impacts on the well-being of the household members – collectively and individually – are no less significant.
- 5.33 The evidence from this small scale study is that relatively small scale ‘savings’ are being made by the statutory sector which have a disproportionate impact on the families. In this context we would include care assistant direct payment rates insufficient to attract suitably trained staff; the failure of the NHS to provide sensory therapy services; and the delay in the payment of funding for an adaptation. These savings are being made at the expense of families that feel themselves to be on a ‘cliff edge’ and the pilot research suggests that the macro economic consequences of a family not coping are potentially very substantial. Put simply, the short-term protection of budgets appears to be a very expensive policy.
- 5.34 Some of the student researchers considered it extraordinary that a grant of £60,000 might be refused even though the consequence was a five-fold (or more) cost impact to the public purse – but this in organisational terms is not extraordinary at all. In a time when local authority and health care finances are experiencing an unprecedented squeeze, managers are under enormous pressure to ‘stay within budget’. Where a payment from one budget makes a saving in another budget then, in the absence of integrated decision making, the manager has little or no power to act outside her or his mandate: namely to ‘stay within budget’. This study has considered a series of requests to a housing department to fund adaptations – at not insignificant expense – where the cost benefits of such expenditure appear on another department’s balance sheet – namely children’s services. This organisational challenge can be addressed by the local authority having a strategic overview and there appeared good evidence that the authority at the centre of this study has sought to implement such a ‘macro analysis’.
- 5.35 The problem of integrated decision making becomes considerably more challenging when the cost impacts and cost benefits rest with different public bodies. For example, in the context of this research, where a substantial DFG award is made by a district council but the cost benefits are experienced by a social services authority – or where the NHS invests in the provision of sensory therapy support but the bottom line saving appears on the social services balance sheet.
- 5.36 To a limited extent, central government policies can address this problem – as for example the development of the Better Care Fund (discussed above). The evidence suggests that

⁵⁵ Gail Boniface and Deborah Morgan ‘The central role of the occupational therapist in facilitating housing adaptations/home modifications for disabled children’ in the *British Journal of Occupational Therapy* (2017) 1–9.

this mechanism has not succeeded in tackling the problem – for at least two reasons. Firstly it appears that the full DFG allocation in the Fund may not be reaching the local authority DFG budgets (and even where it does, it may not be being spent on DFGs); secondly, adaptations for disabled young people are not central to the Fund’s aims - which largely focuses on integrated care arrangements for older people and freeing up pressure on NHS facilities.

The law relating to adaptations / DFGs

The following section has been taken from Chapter 6 of Broach, S. Clements, L and Read, J *Disabled Children: A legal Handbook* (Legal Action 2016)⁵⁶. A special thanks to the authors and to Legal Action publishers for their permission and to reproduce the text.

DFGs are made under Part 1 of the Housing Grants, Construction and Regeneration Act (HGCRA) 1996. The duties and powers under the 1996 Act are expanded upon by regulations, principally the Housing Renewal Grants Regulations 1996, which are updated regularly.⁵⁷ Separate regulations are made to deal with the maximum amount of the grant⁵⁸ (currently set at £30,000 in England⁵⁹) and for other related matters. Detailed non-statutory practice guidance on the DFG scheme was issued in England in 2006⁶⁰ and is referred to in the remainder of this chapter as ‘the 2006 guidance’. 2013 guidance concerning best practice in relation to the award of DFGs has been published by the Home Adaptations Consortium whose membership comprises a broad spectrum of national non-governmental organisations – albeit that the guidance states that it is ‘supported by’ the Department of Health and the Department for Communities and Local Government.⁶¹ Guidance concerning the process by which local authorities must formulate and consult on their DFG policies is provided in a 2003 circular issued by the (then) Office of the Deputy Prime Minister.⁶² Definition of ‘disabled’. For the purposes of the 1996 Act (s100), a person is disabled if he or she: (a) has sight, hearing or speech which is substantially impaired; (b) has a mental disorder or impairment of any kind; or (c) is physically substantially disabled by illness, injury, impairment present since birth, or otherwise. Section 100(3) explains that a person under the age of eighteen is to be considered to be disabled if, either they are in the authority’s register of disabled children,⁶³ or if not, the authority is of the opinion that they are a disabled child for the purposes of CA 1989 Part III.

Grant Eligible Works

Section 23 of the HGCRA 1996 sets out the purposes for which a grant must be approved, which can be summarised as follows: facilitating access to the home; making the home safe; facilitating access to a room used or usable as the principal family room; facilitating access to, or providing for, a room used or usable for sleeping; facilitating access to, or providing for, a lavatory, or facilitating the use of a lavatory; facilitating access to, or providing for, a bath or shower (or both), or facilitating the use of such; facilitating access to, or providing for, a room in which there is a washbasin, or

⁵⁶ Accessible at <https://councilfordisabledchildren.org.uk/help-resources/resources/disabled-children-legal-handbook-2nd-edition>

⁵⁷ The most recent updating regulations being the Housing Renewal Grants (Amendment) (England) Regulations 2014 SI No 1829.

⁵⁸ Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008 SI No 1189.

⁵⁹ Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008 SI No 1189 art 2.

⁶⁰ Department of Communities and Local Government/Department for Education/Department of Health, Delivering housing adaptations for disabled people: a good practice guide, 2006.

⁶¹ Home Adaptations Consortium, Home Adaptations for Disabled People: a detailed guide to related legislation, guidance and good practice (‘2013 Homes Adaptations Consortium Guidance’), Care & Repair, 2013, para 1.15

⁶² ODPM circular 05/2003, Housing Renewal, 2003, chapter 4 ‘Preparing A Policy’.

⁶³ In other words, the register maintained under CA 1989 Sch 2 para 2

facilitating the use of such; facilitating the preparation and cooking of food by the disabled occupant; improving any heating system in the home to meet the needs of the disabled occupant or, if there is no existing heating system there or any such system is unsuitable for use by the disabled occupant, providing a heating system suitable to meet his or her needs; facilitating the use of a source of power, light or heat by altering the position of one or more means of access to or control of that source or by providing additional means of control; facilitating access and movement by the disabled occupant around the home in order to enable him or her to care for a person who is normally resident there and is in need of such care; and such other purposes as may be specified by order of the secretary of state. Since May 2008, local authorities are also required to fund works which facilitate a disabled occupant's access to and from a garden or works which make access to a garden safe for a disabled occupant.⁶⁴ Entitlement to a DFG arises following an assessment which identifies the need for one or more adaptations to be made (see below)⁶⁵ and the duty to make a DFG cannot be avoided by reason of a shortage of resources.⁶⁶ The main purposes for which grants must be made to families with disabled children are discussed further below.

Facilitating access

This heading includes works which are intended to remove or help overcome obstacles to the disabled child moving freely into or around the home and accessing the facilities and amenities within it.⁶⁷ These include family rooms, bedrooms and bathrooms.

Making the home safe

Works under this heading may include adaptations to minimise the risk of danger posed by a disabled child's behavioural problems⁶⁸ as well as (for example) the installation of enhanced alarm systems for persons with hearing difficulties.⁶⁹ Any grant made under this heading must reduce any identified risk as far as is reasonably practicable, if it is not possible to entirely eliminate the risk.⁷⁰

Room usable for sleeping

The building of a new room 'usable for sleeping' should only be grant-funded if the adaptation of an existing room is not a suitable option.⁷¹ Grants can be made to expand the size of a shared bedroom used by a disabled child and (for example) a brother or sister.

Bathroom

The HGCR 1996 separates out the provision of a lavatory and washing, bathing and showering facilities in order to emphasise that a grant must be available to ensure that a disabled child has access to each of these facilities and is able to use them.⁷² Any failure to ensure that a disabled child can access each of these facilities with dignity may be unlawful and/or constitute maladministration.⁷³ On some occasions, an existing room may be capable of adaptation to provide

⁶⁴ Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008 SI No 1189 art 3.

⁶⁵ *R (Fay) v Essex CC* [2004] EWHC 879 (Admin) at [28]. The 2013 Homes Adaptations Consortium Guidance notes, however, that the 1996 Act 'makes no reference to assessment of need for an adaptation'.

⁶⁶ *R v Birmingham CC ex p Taj Mohammed* (1998) 1 CCLR 441.

⁶⁷ 2006 guidance, Annex B, para 16.

⁶⁸ 2006 guidance, Annex B, para 18.

⁶⁹ 2006 guidance, Annex B, para 19.

⁷⁰ *R (B) v Calderdale MBC* [2004] EWCA Civ 134; [2004] 1 WLR 2017 at [24]

⁷¹ 2006 guidance, Annex B, para 21.

⁷² 2006 guidance, Annex B, para 22.

⁷³ See, for example, Complaint nos 02/C/8679, 02/C/8681 and 02/C/10389 against Bolsover DC, 30 September 2003

such facilities – but the ombudsman considers it unreasonable for DFG grants officers to expect disabled persons and their families to give up a family room in order to make way for a ground floor shower/toilet.⁷⁴

Fixtures and fittings

One potential problem with the DFG scheme is the lack of clarity as to whether fixtures and fittings, including items such as specialist equipment, come within its terms. The 2006 guidance is silent on this point. However, the previous practice guidance suggested that equipment which requires structural modifications to a building should come within the DFG scheme, with smaller items (for example grab rails, lever taps, small scale ramps etc) remaining the responsibility of children's services departments under the CSDPA 1970 (...). The 2006 guidance does, however, stress that where major items of equipment have been installed, arrangements for servicing and repairs should be made at the time of installation and the costs factored into the grant payable.⁷⁵

In this context, the 2013 Home Adaptations Consortium Guidance advises that in deciding if specialist equipment comes within the terms of the legislation, regard should be had to its primary purpose – ie facilitating access; making the dwelling/building safe; providing or improving heating systems and facilitating the preparation and cooking etc. Accordingly, the provision of some equipment will clearly contribute to these purposes, commonly the use of stair lifts. Other equipment, particularly in the context of assistive technology and monitoring equipment may form part of a wider package of care contributed to by health and social care services.⁷⁶

The 2013 guidance further advises on the potential cost savings to local authorities of bulk buying/recycling the most frequent kinds of equipment such as stair lifts and level access showers.⁷⁷ Individual eligibility for DFGs.

Main residence

DFGs will be available to make adaptations to the disabled person's only or main residence.⁷⁸ If the child's parents are separated, this may cause difficulties since the mandatory DFG remains only available for the 'main' residence.⁷⁹ Adaptations to the home of the other parent may need to be carried out under CSDPA 1970 s2 if they are assessed as necessary.⁸⁰ The 2013 Homes Adaptations Guidance notes that, in addition, authorities 'can use their discretionary powers in considering multiple applications to adapt the homes of disabled children in these situations'. The discretionary powers available to local authorities are considered below.

Tenure

⁷⁴ Local Government Ombudsman Complaint no 05/C/13157 (Leeds City Council), 20 November 2007.

⁷⁵ 2006 guidance, para 8.1.

⁷⁶ 2013 Homes Adaptations Consortium Guidance, paras 2.13–2.14.

⁷⁷ 2013 Homes Adaptations Consortium Guidance, para 9.23.

⁷⁸ HGCRA 1996 ss21(2)(b) and 22(2)(b).

⁷⁹ Confirmed by the 2006 guidance, Annex B, para 50.

⁸⁰ For a detailed analysis of this question, see Cardiff Law School, Cerebra Legal Entitlements Research Project Opinion 'Rosi's Story', 2014.

A DFG is available for the disabled child's main residence regardless of tenure⁸¹ (ie for owner-occupiers, tenants and licensees⁸²) and regardless of whether the child is living with his or her parents, foster-carers⁸³ or others. Where the applicant is a tenant, the consent of the landlord will be required. Authorities should seek to obtain this consent from private landlords and should offer to 'make good' the adaptations once the family leave the home in appropriate circumstances.⁸⁴ The 2006 guidance is clear that the nature of a person's housing tenure is irrelevant in relation to access to a DFG.⁸⁵ Any material difference in treatment of applicants who have different tenure (for instance, council tenants and private tenants) would constitute maladministration.⁸⁶

A problem with the DFG scheme which has been identified by the local government ombudsman is that it only applies to existing tenancies.⁸⁷ However, if a family with a disabled child propose to move house and, therefore, acquire a new tenancy, it would be unreasonable and maladministration for an authority not to expedite the works once the family have taken on the new tenancy.⁸⁸

Occupancy requirements

DFGs are made subject to a requirement that the disabled person lives or intends to live in the accommodation as his or her only or main residence for the grant condition period.⁸⁹ This period is currently five years from the date certified by the housing authority as the date on which the works are completed to its satisfaction.⁹⁰ The 2006 guidance states that any belief by the assessor that the applicant may not be able to live in the property for five years as a result of their deteriorating condition should not be a reason for withholding or delaying grant approval.⁹¹ However, the guidance somewhat qualifies this otherwise clear statement in a later paragraph which suggests that if the disabled person's 'degeneration' may be 'short-term', this 'should be taken into account when considering the eligible works'.⁹² This may be read as little more than a reminder that each applicant's individual circumstances need to be taken into account.

Decisions on individual eligibility

The administration of the DFG scheme is the responsibility of the housing authority in whose area the relevant property is located. The housing authority is required to consult the relevant children's services authority (if it is not itself a children's services authority, as it will be in a unitary authority such as a London borough).⁹³ A housing authority may not approve a DFG application unless it is satisfied that: the relevant works are necessary and appropriate to meet the needs of a disabled

⁸¹ In the government's opinion DFGs are 'tenure neutral' see Wendy Wilson Disabled Facilities Grants (England) SN/SP/3011, House of Commons Library, 2013, p3.

⁸² See HGCRA 1996 s19(5) re licensees.

⁸³ The 2013 Homes Adaptations Guidance notes (para 7.32) that in such a case provision may depend upon the type and length of placement.

⁸⁴ 2006 guidance, para 6.3.

⁸⁵ 2006 guidance, para 3.21.

⁸⁶ See, for example, the ombudsman reports on complaint 99/B/00012 against North Warwickshire DC, 15 May 2000 and 30 November 2000.

⁸⁷ HGCRA 1996 s24(2).

⁸⁸ See, for example, Complaint no 00/C/19154 against Birmingham CC, 19 March 2002.

⁸⁹ Or for such shorter period as his health and other relevant circumstances permit: HGCRA 1996 ss21(2)(b) and 22(2)(b).

⁹⁰ HGCRA 1996 s44(3)(a) and (b).

⁹¹ 2006 guidance, para 6.7; see also para 5.22.

⁹² 2006 guidance, Annex B, para 29.

⁹³ HGCRA 1996 s24(3). It is, however, a matter for the housing authority whether it accepts the children's services authority's advice following consultation: 2006 guidance, Annex B, para 34.

child; and it is reasonable and practicable to carry out the relevant works, having regard to the age and condition of the home.⁹⁴

The decision as to whether requested works are 'necessary and appropriate' must be taken with reference to the views of the relevant children's services authority on the adaptation needs of disabled people.⁹⁵ Although under the CSDPA 1970 all assessed needs must be met once a child is deemed eligible, an authority is entitled to consider a range of ways of meeting the need.⁹⁶ The Court of Appeal has stressed that the question of whether the works are of a type which come within the provisions of the scheme must be answered separately and prior to the question of whether the specific works requested are 'necessary and appropriate'.⁹⁷

A situation may arise where the housing authority would consider it to be more cost-effective to relocate a family with a disabled child, but accepts that, otherwise, the proposed adaptations were 'necessary and appropriate' and 'reasonable and practicable'. It is doubtful whether a refusal to award a DFG to fund adaptations for this reason alone would be lawful although much will depend upon the individual circumstances of the case – especially the practical reality of an alternative property being available. The 2006 guidance⁹⁸ suggests that this option should be considered where major adaptations are required and it is difficult to provide a cost-effective solution in the existing home – but the 2013 Homes Consortium Guidance notes:

"Experience in recent years has shown that some housing associations and local authority landlords are withholding their approval on the basis that the dwelling is "inappropriate" for adaptation, even when there is no physical reason why the property cannot be adapted. Tenants have been asked to move to alternative property where the DFG applicant is judged by the landlord to be under-occupying the dwelling or where the landlord has decided they do not allow adaptations in certain types of property, i.e. level access showers in accommodation above ground floor level. In such circumstances landlords should be reminded that they 'may not unreasonably withhold their consent' to the adaptation being undertaken."⁹⁹

Maximum grant

The maximum mandatory grant awarded as a DFG is £30,000 in England.¹⁰⁰ Local authorities are empowered to make higher awards as discretionary grants: see below.

If an adaptation is required to meet an assessed need and the cost of the works will exceed the maximum cap for a DFG, the remainder should be met either by the housing authority exercising its discretionary powers, the children's services authority meeting the additional costs (under CSDPA 1970 s2) or by a combination of the two. It will not be lawful for an authority to refuse to make adaptations which have been assessed as necessary solely by reason of cost.

Difficulties can arise in relation to the provision of advice and assistance with the design, layout and implementation of an adaptation. These costs do of course fall within the meaning of s2(6)(e) of the 1970 Act and it should be noted that section 2(3)(b) of the 1996 Act (and the associated regulations¹⁰¹) makes clear that all ancillary costs ought be included in the grant. Additionally, local

⁹⁴ HGCRA 1996 s24(3). Guidance is given on the meaning of 'reasonable and practicable' in the 2006 guidance, Annex B, para 37.

⁹⁵ HGCRA 1996 s24.

⁹⁶ *R v Kirklees MBC ex p Daykin* (1997–98) 1 CCLR 512.

⁹⁷ *R (B) v Calderdale MBC* [2004] EWCA Civ 134; [2004] 1 WLR 2017

⁹⁸ 2006 guidance, para 6.15.

⁹⁹ 2013 Homes Consortium Guidance, para 7.67.

¹⁰⁰ Disabled Facilities Grants (Maximum Amounts and Additional Purposes) (England) Order 2008 SI No 1189 art 2.

¹⁰¹ See also Housing Renewal Grants (Services and Charges) Order 1996 SI No 2889 art 2.

authorities have power to provide the technical assistance under Local Government and Housing Act 1989 s169.

Means testing

Applications for a DFG for a disabled person under the age of 19 are not subject to a means test.¹⁰² Timescales and grant deferment 6.68 Housing authorities must approve or refuse a DFG application as soon as reasonably practicable and no later than six months after the date of application.¹⁰³ The actual payment of the DFG, if approved, may be delayed until a date not more than 12 months following the date of the application.¹⁰⁴ If any hardship is caused by delay even within these timescales, the children's services authority should be pressed to carry out the works under their parallel duties under the CSDPA 1970.

Despite these clear statutory provisions, housing authorities routinely adopt a range of extra-statutory procedures to delay the processing of DFG applications. For instance, authorities have been criticised for creating inappropriate administrative hurdles prior to applications being received¹⁰⁵ and for delaying preliminary assessments, citing a shortage of assessors.¹⁰⁶ The 2006 guidance is unhelpfully not as strong in calling for authorities to expedite grant applications as its predecessors.¹⁰⁷

The 2006 guidance accepts that some DFG applications will be prioritised ahead of others by housing authorities. Although particular priority should be given to those with deteriorating conditions,¹⁰⁸ authorities are also reminded to take a broader approach reflecting the social model of disability, which would consider wider risks to independence.¹⁰⁹ It would of course be unlawful for an authority to operate a blanket policy which discriminated against applications made by families with disabled children in comparison to those made by disabled adults, or to adopt any similar policy which penalised one group of disabled people in relation to any other as a matter of course. The Local Government Ombudsman has found maladministration where a local authority failed to provide clear information to applicants concerning the way its priority system for the processing of DFG applications operated.¹¹⁰

The 2006 guidance provides a table which illustrates a 'possible approach' to target times for each stage of a DFG.¹¹¹ The indicative targets for the total process amount to 83 working days for high priority applications, 151 working days for medium priority applications and 259 working days for low priority applications.

¹⁰² For details of the means test that applies to people over 19 see L Clements, *Community Care and the Law*, 6th edn, LAG, 2017.

¹⁰³ HGCRA 1996 s34. Any delay beyond six months from the referral by children's services to the execution of the works will generally be considered unjustified and will constitute maladministration: Complaint no 02/C/08679 against Bolsover DC, 30 September 2003.

¹⁰⁴ HGCRA 1996 s36.

¹⁰⁵ Complaint no 02/C/04897 against Morpeth BC and Northumberland CC, 27 November 2003.

¹⁰⁶ Complaint no 90/C/0336, 9 October 1991: delay of nine months for an occupational therapist assessment constituted maladministration. As noted above, the 2013 Homes Adaptations Consortium Guidance notes, at para 7.14, that the 1996 Act 'makes no reference to assessment of need for an adaptation' and it refers to advice from the Department for Communities and Local Government 'that an occupational therapy [(OT)] assessment is not a legislative requirement' and that OT assessments should 'not be used in every case'. See also R (Fay) v Essex CC [2004] EWHC 879 (Admin) at [28].

¹⁰⁷ See L Clements and P Thompson, *Community Care and the Law*, 5th edn, LAG, 2011, for references to the predecessor guidance documents.

¹⁰⁸ 2006 guidance, para 4.8.

¹⁰⁹ 2006 guidance, para 5.21. See L Clements and P Thompson, *Community Care and the Law*, 5th edn, LAG, 2011, paras 15.88–15.93 for further discussion of DFG prioritisation processes.

¹¹⁰ Complaints no 97/B/0524, 0827–8, 1146 and 1760 against Bristol CC 1998.

¹¹¹ 2006 guidance, para 9.3. The table is reproduced in L Clements, *Community Care and the Law*, 6th edn, LAG, 2017.

Authorities also have a duty to make interim arrangements to ameliorate any hardship experienced by a disabled child between the assessment of the need for adaptations to their home and the completion of the works. The 2006 guidance states forcefully that it is ‘not acceptable’ for disabled people to be left for weeks or months without interim help.¹¹² Furthermore, children’s services and housing authorities should consider meeting some or all of the costs occasioned if a family needs to make other arrangements while work is being carried out, and should consider moving the family to temporary accommodation when major works are required.¹¹³

The 2013 Home Adaptations Consortium guidance advises that ‘response should be as fast as possible and consideration given to expedited procedures and interim solutions where some measure of delay is inevitable’.¹¹⁴

Discretionary grants

Housing authorities in both England have a wide discretionary power to give assistance in any form for adaptations and other housing purposes (under what is commonly known as the Regulatory Reform Order – ‘RRO’).¹¹⁵ There is no financial limit on the amount of assistance that can be given. Specific guidance on the exercise of this discretion was given by the government in England in 2003.¹¹⁶ The 2006 guidance suggests that the types of assistance that can be provided under this power will include: funding for small-scale adaptations not covered by mandatory DFGs, or to bypass the lengthy DFG timescales for minor works; top-up funding to supplement a mandatory DFG where the necessary works will cost more than the maximum DFG cap; and help to buy a new property where the authority considers that this will benefit the disabled child at least as much as improving or adapting the existing accommodation.¹¹⁷

Discretionary support offered by an authority can be in any form, for instance as a loan or an outright grant. Any discretionary loan made to an individual family will not affect their entitlement to a mandatory DFG.¹¹⁸

As with all discretionary powers, housing authorities must exercise their power to fund additional adaptations rationally and reasonably and must ensure like cases are treated alike. It would be unlawful for an authority to operate a blanket policy of refusing to make any discretionary payments to fund adaptations; each individual case must be considered on its merits.

NHS-funded adaptations

The NHS has power to fund adaptations and brief guidance concerning the use of this power is provided in the 2012 National Framework for NHS Continuing Healthcare.¹¹⁹ This includes encouragement that partner bodies ‘work together locally on integrated adaptations services’ and that ‘CCGs should consider having clear arrangements with partners setting out how the adaptation needs of those entitled to NHS continuing healthcare should be met, including referral processes and funding responsibilities’.¹²⁰ The framework draws attention to the possibility of such adaptations

¹¹² 2006 guidance, para 5.40.

¹¹³ 2006 guidance, paras 5.43–5.44.

¹¹⁴ 2013 Homes Consortium Guidance, para 7.33.

¹¹⁵ Article 3 of the Regulatory Reform (Housing Assistance) (England and Wales) Order 2002 SI No 1860.

¹¹⁶ Office of the Deputy Prime Minister, Housing renewal, Circular 05/2003, 2003.

¹¹⁷ 2006 guidance, para 2.24.

¹¹⁸ 2006 guidance, para 6.22.

¹¹⁹ Department of Health, National Framework for NHS Continuing Healthcare and NHS funded Nursing Care November 2012 (Revised), DH 2012, – see PG Guidance (Part 2) and in particular PG 79 and 85–89. Although this framework applies to adults, the guidance on the principles is relevant to children.

¹²⁰ 2012 National Framework for NHS Continuing Healthcare, para PG 79.3. This guidance was cited with approval in *R (Whapples) v Birmingham Cross-city Clinical Commissioning Group* [2015] EWCA Civ 435 para 32.

being provided through the use of a DFG although if this is not possible, then the NHS will be responsible for the necessary support. As it notes, where individuals: require bespoke equipment (and/or specialist or other non-bespoke equipment that is not available through joint equipment services) to meet specific assessed needs identified in their NHS continuing healthcare care plan. CCGs should make appropriate arrangements to meet these needs.¹²¹

Similarly, the National Framework for Children and Young People's Continuing Care requires consideration of whether any adaptations to the child's home are required as part of the completion of the Decision Support Tool to assist with determining eligibility for NHS continuing care.¹²²

¹²¹ 2012 National Framework for NHS Continuing Healthcare, para PG 79.2.

¹²² Department of Health, National Framework for Children and Young People's Continuing Care, 2010, p41. At the time of writing (November 2015), the Department of Health is consulting on a revised National Framework.

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We are indebted to Sheila Mackintosh, University of the West of England for providing the core material in the selection that follows.

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DFG Questionnaire

Reference No.

Part 1 – basic information

Child's age today

Child's age when first DFG finished

Child's age when further DFG work done (if applicable)

Brief overview of child's behavioural and other characteristics

1. How much was the DFG you received?

Grant details

	£
--	---

2. What was the full cost of the works for the adaptations (including professional advice consultants etc)?

and

3. If applicable, how was any shortfall made up?

4. Did you have any help from a third party organisation with the grant application?

Yes / No

5. Was this an independent or public body?

Independent / public body / prefer not to say

6. If so, was this valuable? **Yes / No / Hard to say**

7. How do you feel about the way the grant was (or is being) processed by the local authority? In terms of speed, information sharing and 'person friendliness' how would you rate it from 0 (very bad) to 10 (very good)?

Speed	1 2 3 4 5 6 7 8 9 10
Information sharing	1 2 3 4 5 6 7 8 9 10
'Person friendliness'	1 2 3 4 5 6 7 8 9 10

Comments – note here any significant comments made

8. If any, what would you say is the most valuable thing for you about the adaption?

9. If any, what would you say is the most valuable thing for the Disabled Person about the adaption?

10. If any, what would you say is the most detrimental thing for you about the adaption?

11. If any, what would you say is the most detrimental thing for the Disabled Person about the adaption?

Part 2 – cost benefits relating to the child

12. What do you estimate, if any, are the quantifiable cost benefits in relation to your child from the adaptations?

13. Can you put a financial figure on these benefits [*prompt – ie is in terms of hours per day / days per year; the likely charge of the person per hour*]?

Yes / No / Hard to say / not applicable

If Yes

£

Comments – note here how this figure / estimate has been calculated:

14. Has your child faced and additional costs as a result of the adaptation, and if so what do you estimate these to be?

Yes / No / Hard to say / not applicable

If Yes

£

Comments – note here how this figure / estimate has been calculated:

15. Have there been any less tangible benefits for your child – things that are harder to quantify in terms of money but are important?

Yes / No / Hard to say / not applicable

Comments:

16. Have there been any less tangible problems / harms to your child as a result of the adaptations – things that are harder to quantify in terms of money but are of concern?

Yes / No / Hard to say / not applicable

Comments:

17. Do you feel that your child is more or less resilient having had a DFG?

More resilient / Less resilient / Hard to say / not applicable

Comments:

18. If you had had the adaptation earlier on (ie when the need first arose) do you think it would have made a difference for your child?

Comments

Part 3 – cost benefits for wider family

19. What do you estimate, if any, are the quantifiable cost benefits are in relation to you and your wider family from the adaptations?

20. Can you put a financial figure on these benefits?

Yes / No / Hard to say / not applicable

- | | | |
|---------------|---|--|
| If Yes | <div style="background-color: #e0ffe0; display: inline-block; width: 100px; height: 15px; vertical-align: middle;"></div> | cost benefits for me |
| If Yes | <div style="background-color: #e0ffe0; display: inline-block; width: 100px; height: 15px; vertical-align: middle;"></div> | cost benefits for other family members |
| If Yes | <div style="background-color: #e0ffe0; display: inline-block; width: 100px; height: 15px; vertical-align: middle;"></div> | cost benefits for the government |

[ie no longer have to pay me social security benefits for

Comments – note here how these figures / estimates calculated:

21. If any, can you estimate the what less tangible benefits have been for you and your family?

Yes / No / Hard to say / not applicable

Comments:

22. Are you able to put a financial figure on these 'less tangible' benefits?

Yes / No / Hard to say / not applicable

If Yes	<input style="width: 100px; height: 20px;" type="text" value="£"/>	cost benefits for me
If Yes	<input style="width: 100px; height: 20px;" type="text" value="£"/>	cost benefits for other family members
If Yes	<input style="width: 100px; height: 20px;" type="text" value="£"/>	cost benefits for the government

[ie no longer have to pay me social security benefits for ...]

Comments:

23. What do you estimate, if any, are the additional costs that you and/or your family / local or central government have faced as a result of the adaptations?

Yes / No / Hard to say / not applicable

If Yes	<input style="width: 100px; height: 20px;" type="text" value="£"/>	costs I have incurred
If Yes	<input style="width: 100px; height: 20px;" type="text" value="£"/>	cost incurred by other family members
If Yes	<input style="width: 100px; height: 20px;" type="text" value="£"/>	cost incurred by central / local government

[ie maintenance costs of adaptations/ extra therapy costs / increased social security benefits]

Comments – note here how this figure / estimate has been calculated:

24. Have you and/or your family experienced any less tangible problems / harms as a result of the adaptations – things that are harder to quantify in terms of money but are of concern – and if so what are these?

Yes / No / Hard to say / not applicable

Comments:

25. Do you feel that you and your family are more or less resilient having had a DFG?

Me - more resilient / Less resilient / Hard to say / not applicable

Family - more resilient / Less resilient / Hard to say / not applicable

Comments :

26. If you had received an early intervention adaptation what difference would it have made to you and/or your family?

Comments

Part 4 Post adaptation impact

27. What, if any, important benefits / problems were caused by the adaptation?

Benefits

Problems

28. Can you *briefly* describe how you would imagine your life would have been had you not have received an adaptation?

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29. How long, do you imagine, would you have been able to continue to care for your child at home if the adaptation had not been completed?

Do not know / not applicable / not applicable

Months	Years	Comment

30. How long do you consider you can continue to care for your child at home now the adaptation has been completed?

Do not know / not applicable / not applicable

Months	Years	Comment

31. If your child is now in living away – ie in residential care or supported housing or shared lives (ie adult fostering) – do you think that having the adaptation has made it easier for them to visit you and stay overnight (eg for family events/holidays).

Yes / no / not relevant / not applicable

Comments

--

32. If your child is still living with you, what do you think would happen to your child if this ceased to be possible (ie becomes unable to remain living with you)?

Comments

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33. If you and your child were to have all the necessary adaptations completed and a proper care and support package in place – so you could enjoy an 'ordinary life' like other people (who do not have such intense caring responsibilities) what do you think you would do / want to do?

Comments

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34. Are there any other things you wish to say / comments you wish to make about this survey?

Comments

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