Firefly
Illuminating Research

A Securer Future - Evaluation of the Health Grant to Thalidomide-Impaired People

Year 3 Final Report – July 2013

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Acknowledgements

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Executive Summary

1. Introduction

Background

Around 520 Thalidomide-impaired people were born in the UK between 1959 and 1962; 466 are alive today. They were affected by the drug in a variety of ways; most commonly they have missing, short and/or deformed limbs. Some people have damage to their eyes and ears or facial disfigurement; some have damaged or missing internal organs; and a few have brain damage.

The Health Grant

In March 2010 the English Department of Health (DH) confirmed it was to make a grant of £20 million to Thalidomide-impaired people in England. The English grant was matched proportionately by the Scottish, Welsh and Northern Ireland administrations, creating a UK wide grant of £26.4 million over three years. The grant was intended to help Thalidomide-impaired people to address the exceptional health and health related needs they are experiencing as they grow older. It has been distributed by the Thalidomide Trust in three annual payments to individual Thalidomiders starting in April 2010. It was agreed that individual Thalidomiders would not be expected to account to the Departments of Health for their expenditure. However, the Thalidomide Trust agreed with the DHs a set of health related needs categories which were intended to guide Thalidomiders in their expenditure. These are: Independent Mobility; Home Adaptations; Communications Technology; Medical Treatment Costs; Respite; Personal Assistance; and Social Activities.

The Evaluation

The evaluation began in May 2010 and ran for three years until summer 2013. Its main aims were to:

1) Provide evidence of the impact of the grant on the health and well-being of individual Thalidomiders
2) Assess how the provision of the Health Grant has (or may have) enabled individual Thalidomiders to reduce or avoid predicted future health needs
3) Bring together the learning from the evaluation to support a decision on whether and how to create a permanent scheme after the current three-year pilot has ended
4) Examine the effectiveness of working through a national organisation to meet the needs of other geographically dispersed groups with highly specialised needs

There are two main parts to the evaluation – a review of the operation of the Health Grant scheme which took place in the first and last years of the evaluation and an in-depth study of the experiences of 60 Thalidomide-impaired people (the ‘study group') of using their Health Grants, which ran across all three years. The study group represents just over 10% of the total population of beneficiaries in the UK; its composition is roughly in proportion to the total number living in each of the four UK nations; and is broadly reflective of the number of Thalidomide-impaired people in each of the five impairment severity bands used by the Thalidomide Trust.

The third year of the evaluation has focused on aims 1, 2 and 4 described above and has involved a further round of work with the study group, as well as interviews with Trust staff and other organisations supporting people with rare conditions or very specialist needs. There have been three main strands:

- An expenditure survey
- In-depth interviews with the study group
- Interviews with Trust Staff, NAC Representative and Other Organisations

2. Use of the Health Grant

As was reported in previous years, in the third year of the Health Grant, study group members used the money for a wide range of things, including:

- Directly addressing health problems, by paying for health treatments (e.g. physiotherapy) or investigations (e.g. tests, MRI scans)
- Self-management and reducing future health problems (e.g. through paying privately for complementary therapies or exercise regimes, or being able to reduce hours of work)
- Improving well-being and overall quality of life (e.g. by funding social activities or bespoke clothing
- Maintaining or enhancing independence (e.g. through funding adaptations and equipment)
- Maintaining mobility (e.g. funding wheelchairs and paying for adapted vehicles or trains/taxis)
- Reducing the impact of caring on family and maintaining positive relationships.

A few people were very cautious about their spending during this third year because they feared that the health grant might not be continued. Others explained that it had taken them some time to get used to having the Health Grant and/or to come to terms with the level of deterioration they were experiencing, and this had affected their spending patterns over the years. The issue of the adequacy of the grant was raised by a few people, who said that they were still having to prioritise spending, and the health grant was not covering all their health related needs.

Most people had no problem obtaining the products and services that they required. Some people said how much they appreciated the help of Healthlink (the Trusts health support and advice service), and a large number said they really valued the information that was shared within the Thalidomide community (e.g. via Facebook, networking events and personal contacts).

3. Changing Health Needs and the Impact of the ‘Pilot’ Grant

More than two thirds of study group members reported further deterioration in their health in the past year. The vast majority of people were experiencing either deteriorating and painful joints, and/or muscle weakness and strain. Several had numbness and/or partial paralysis. Weight management was a concern for many study group members. There were on-going difficulties associated with being able to exercise effectively and worries about the additional strain on joints, and implications for long term health conditions from being overweight. However, many people reported that without the measures they could put in place through the Health Grant, their decline might have been much worse, and some people said their health was the same or generally better.

There were mixed views about the difference the Health Grant had made to peoples' use of NHS and local authority social care services over the last three years. A few were clear that it had reduced their use of the NHS; other explained that they had avoided using NHS services for a long time because of their previous negative experiences of NHS care. It was hard for people to quantify what impact the health grant had made on their use of social care services but many felt that the adaptations and equipment the Health Grant had enabled them to purchase had reduced their need for care services. Those in receipt of direct payments also appreciated being able to use their grants to top these up and so have more flexibility.

The great majority of study group members said that over the 3 years the Health Grant had made a very significant difference to them; in some cases it was described as *"life changing"*. The Key benefits of the health grant included direct health benefits (e.g. through funding treatments); practical measures to aid mobility or improve daily life (e.g. adapted vehicles/ home adaptation and equipment); and lifestyle changes (e.g. reducing working hours or giving up work or improving fitness) to prevent further deterioration. Other benefits rated as equally important by many study group members were less tangible, but included improved emotional well-being, greater self-esteem and feeling more equal to their non-disabled peers within society

4. Plans for the Future – the Next Ten Years

Beneficiaries were generally very pleased and relieved that the Health Grant was to be extended for ten years but some were concerned about it being time-limited and not permanent.

Many people expressed uncertainty about their future health needs, although most of them expected some sort of deterioration and decline. The most common future health and support concerns were: reduced mobility/flexibility, linked to wear and tear on joints and limbs; increased pain (and the need for medication or treatments to deal with this); increased need for personal assistance; and loss of independence resulting from all these changes.

Nearly half of the interviewees said they would need to use some of their Health Grant for home adaptations/maintenance over the next ten years. Other projected uses included mobility, living aids/equipment, medical care, communications technology, holidays and personal assistance. Some said they would use the money to enable them to give up work or cut down their working hours. More than half of those interviewed did not think they would need formal advice in the future about their use of the Health Grant but about one third thought that they probably would seek advice over the coming years. It was thought that this advice would mostly be sought from the Trust or from other Thalidomiders.

The main benefits of having the Health Grant confirmed for ten years were a greater sense of financial security and the ability to plan for the future, as well as peace of mind. It also had a wider impact on peoples' partners/spouses and their families because they felt they would be less reliant on them for care and support.

5. Health Grant 'Model' - Administration and Wider Application

The majority of study group members saw the Health Grant as separate to their Annual Grant and for most the expectation that it should be used for health related purposes did influence and inform how they spent the money. Overall the study group thought that the spending guidance agreed with the Departments of Health and issued by the Trust was sufficiently broad to cover their health related needs. A few actively welcomed the spending guidance because they felt it gave them 'permission' to spend money on their health needs whilst others said it had helped them to think more generally about how best to address their health needs. The fact that it was 'high level' guidance and allowed a level of discretion was also appreciated; people felt it demonstrated trust and treated Thalidomide-impaired people *"like grown-ups".*

Administration and Distribution of the Grant

The overwhelming majority of study group members were very happy with the way in which the Trust has administered the grant. They particularly liked the flexible ways in which the Grant could be paid (i.e. a lump sum or staged payments). Going forward, the majority of study group members wanted the Health Grant and the Annual Grant to be kept separate. From the Trust's perspective, although the system for administering the Health Grant is based on that used for the Annual Grant, they have had to set up some new systems and incurred some additional costs. The main areas of direct costs were – accounting arrangements; changes to the Trust's website; and additional actuarial and auditing costs. In total these amounted to £387,228. Indirect costs are hard to quantify but the Trust estimates that these amounted to £412,772, and included – the time required to calculate and distribute grants; extra work in contacting beneficiaries about their grants; and the time needed to support beneficiaries (including those who lack capacity) in using their grants. Together, direct and indirect costs represent around 3% of the total grant of £26.4m.

The Health Grant is distributed in the same way as the Trust's Annual Grants (i.e. based on the impairment band the beneficiary falls into). The majority of study group members felt this was fairest and most transparent way to do it but a minority said that in some way the distribution needed to take account of problems that weren't evident when people were originally assessed and deterioration or loss of function due to the wear and tear on peoples bodies. However, several study group members and the NAC noted that the Individual Beneficiary Review (IBR) system is there to address issues such as significant deterioration. There was a suggestion that the IBR system may need up-dating.

Relevance of the Health Grant 'Model' to Other Groups

In many respects the Health Grant is highly unusual and so it might be assumed that the 'model' would be hard to use with other groups of people with rare conditions or specialist needs. However, there are features of the Health Grant model or underlying principles which are of relevance to other groups. Following the discussions with Trust staff, the NAC Chair and the chief executives of three national organisations with different origins, aims and resources – the MacFarlane Trust; the Motor Neurone Disease Association; and the CJD Support Network – the evaluation team identified six key issues which would need to be considered if the Health Grant model was to be used to meet the health needs of other groups of people with specialist needs:

- Systems for Allocating and Distributing Funds
- Additional Administrative Costs
- Wider Beneficiary Involvement
- Specialist Advice and Support Systems
- Freedom in the Use of Funds
- Selectively Replacing Some NHS and Social Care Services

6. Conclusions

Over the three years of the Health Grant evaluation a number of clear themes have emerged. The final year of the evaluation has confirmed and developed them, as well as highlighting wider issues about the potential of the Health Grant 'model' for addressing the health needs of other groups of people with rare conditions or specialist needs.

Thalidomide-impaired people are experiencing deterioration in their health. In the final year of the evaluation, concerns about further deterioration and new or additional health problems were again evident.

For many people the things they had been able to do, or the lifestyle changes they had been able to make, as a result of the Health Grant, were helping to either slow down this deterioration or at least enable people to manage it. People felt the impact of the Health Grant had been overwhelmingly positive, even *"life changing"*

At an early stage it was apparent that in using their Health Grants people were interpreting 'health' and 'health needs' very broadly. However, at the end of the three year pilot people continued to take note of the core purpose of the grant and the health-related needs categories agreed with the DHs

The announcement of the new ten year grant was universally welcomed, but many people were uncertain about their future health and support needs. However, there was a strong sense of people wanting to *"future proof"* themselves or find strategies for maintaining independence if their circumstances changed.

The 'review' of the administration of the Health Grant showed that the Thalidomide Trust was able to build on existing systems and processes to administer and distribute the grant, but nevertheless did incur both direct and indirect costs

The evaluation suggests that the Health Grant 'model', or at least the principles which have underpinned it, could be used be used to help meet the health needs of other groups of people with specialist needs, although further research would be valuable

Lastly, in making the Health Grant to Thalidomide-impaired people, the Departments of Health took the brave decision to give beneficiaries the freedom to use the grant in the ways that they felt would best address their health-related needs. This has been crucial to the success of the Health Grant. Whilst the spending guidance or criteria for use may be different if a similar approach were to be used with other groups, the principle of flexible use within clear guidelines should be retained.

Chapter 1
Introduction

The three year 'pilot' Health Grant, which was given to Thalidomide-impaired people across the UK in spring 2010 has now ended. A new ten year Health Grant was announced in December 2012 and commenced in April 2013. This is the last of three reports from the evaluation of the three year grant (the reports from the first two years are available on the Thalidomide Trust website[1]). It draws together the findings from the final year of the evaluation, in particular how people used their grants to address their health and support needs, and the overall impact of the 'pilot' grant on their health and well-being. It also looks ahead, and explores how people feel their needs may change over the coming years, and their attitudes to and plans for the ten year grant. In addition, it considers whether the Health Grant 'model' could be used to meet the needs of other groups of people with very specialist needs.

1.1 Background

Between 1958 and 1962 the drug Thalidomide was given to thousands of pregnant women in the UK to relieve morning sickness[2]. Many babies born to these women were still born or died soon after birth, and many others died in early childhood. However, around 520 Thalidomide-impaired people survived to adulthood and 466 are alive today. They were affected by the drug in a variety of ways, most commonly they have missing, short and/or deformed limbs. The most severely affected Thalidomide-impaired people have damage to all four limbs, others to arms or legs. Some people have damage to their eyes and ears or facial disfigurement and a few have brain damage. However, Thalidomide damage can also be unseen and includes damaged or missing internal organs (e.g. heart defects or only having one kidney). There is also clear and growing evidence that Thalidomide-impaired people are experiencing new, previously undiagnosed symptoms, almost certainly caused by the drug. These include numbness, tingling, and partial paralysis in different areas of the body due to nerve damage and extreme fatigue. Many more are also developing health problems caused by the way they have had to use their bodies to compensate for missing or damaged limbs.

The agreement to make a 'Health Grant' to Thalidomide-impaired people in the UK was the culmination of a number of years campaigning by a small group of Thalidomiders, supported by the Thalidomide Trust. They see the grant very clearly as compensation or reparation for the UK government licensing Thalidomide back in the late 1950s and early 1960s without adequate checks and controls. There is also a strong sense within the Thalidomide community that the Health Grant goes some way to achieving both social justice for the damage Thalidomide-impaired people suffered, and recognising the exceptional health problems Thalidomide-impaired people are experiencing as they age.

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[1] http://www.thalidomidetrust.org/govhealth

[2] Taken from an unpublished paper by Dr Martin Johnson, Director of the Thalidomide Trust

1.2 The Health Grant

In March 2010 the Departments of Health (DHs) for England, Scotland, Wales and Northern Ireland agreed to make a UK wide grant of £26.4 million to Thalidomide-impaired people, to help to address the exceptional health and health-related needs they are experiencing as they grow older. The grant was distributed by the Thalidomide Trust over three years from April 2010, usually in the form of an annual lump sum to individual Thalidomiders (although some beneficiaries choose staged payments). When they confirmed the grant, the DHs set down a number of conditions:

- The Health Grant must only be used to meet health-related needs
- It must not be used to meet needs that are already being met through NHS funding
- The Thalidomide Trust must account to the DHs for how the money is used
- The impact of the pilot scheme must be evaluated.

They agreed that individual Thalidomiders would not be expected to account to the DHs for their expenditure and would be free to spend it as they wished in order to meet their health and health-related needs. However, the Thalidomide Trust and the DHs did develop a set of 'health-related needs' which are intended to guide Thalidomiders in their expenditure. Seven categories of 'health-related needs' were set out in a guidance note:

- **Independent mobility** - (vehicles, vehicle adaptations, wheelchairs etc.) ensuring that you can lead an independent life without subjecting yourself to unnecessary stress and strain, and reducing your vulnerability to harm.
- **Home adaptations** - to ensure you can lead a safe and independent life in your own home as far as possible, also without subjecting yourself to unnecessary stress and strain or doing things that could be harmful.
- **Communications technology** - systems relevant to your disability, again aimed at protecting your body (including sensory organs) from harm, and also reducing your vulnerability in general terms - or providing information to enable the Trust and others to support your health needs effectively.
- **Medical treatment costs** - other than those already covered by the NHS. This could include various therapies found to be helpful of types not funded for you by the NHS.
- **Respite** - therapeutic 'breaks' for either yourself or your carer(s), intended to relieve such things as musculoskeletal pain, or the general stress experienced by people in unremitting care situations.
- **Personal assistance** - including care in the general sense, but also the range of tasks needed at home or work that would otherwise involve putting your body at risk of further damage. Many of you will already receive personal assistance funded by your local authority or the Independent Living Fund; the Health Grant can be used to purchase additional personal assistance with activities not covered by existing funding.
- **Social activities** - activities that help you get out, reduce isolation and improve your mental and physical well-being.

The Thalidomide Trust has a well-established and well-accepted system for distributing its Annual Grants[3] to beneficiaries, which is based on each person's level of impairment. Beneficiaries fall into one of five impairment severity bands, although people can move between bands if there is a significant loss of their functional ability. At an early stage it was agreed that the Health Grant should be distributed on the same basis. For reasons of good governance and financial security, each year beneficiaries have to confirm that they wish to receive their Health Grant (and their Annual Grant). However, this system also enables the Trust to re-confirm the purpose of the Health Grant.

In 2010 the Health Grant was set at 75% of beneficiaries' Annual Grants as in the first year there were a number of issues influencing the distribution of the Health Grant. In years 2 and 3 the Health Grants were adjusted and were approximately 90% of the Annual Grant.

In Year 3 the Health Grants for the evaluation study group members' (see 1.3 below) ranged from £9,653 (for the lowest in Band 1) to £45,046 (for the highest in Band 5). Table 1 below provides a more detailed picture. The final payment from the three year 'pilot' Health Grant was made in April 2012. However, as the pilot period came to an end and the new ten year grant was confirmed, the Trust decided to distribute to beneficiaries the money which had been held back for contingencies. This took the form of a small 'balancing' payment which was made in January 2013.

TABLE 1 HEALTH GRANT BY BAND FOR THE STUDY GROUP

Grant Year	For Band:	Band 1	Band 2	Band 3	Band 4	Band 5	Year Total
Year 1	Max	£9,798	£14,439	£20,112	£24,454	£36,098	
	Min	£7,735	£10,829	£15,470	£20,627	£18,049	
	Average	£8,767	£12,093	£17,469	£22,217	£28,534	
	Total	£35,066	£120,927	£349,373	£244,391	£428,014	£1,177,772
Year 2	Max	£11,213	£16,524	£23,606	£27,985	£41,311	
	Min	£8,852	£12,393	£17,705	£23,606	£20,656	
	Average	£10,033	£13,839	£20,485	£25,426	£32,774	
	Total	£40,131	£138,393	£389,211	£279,689	£491,603	£1,339,026
Year 3	Max	£12,227	£18,018	£25,097	£30,515	£45,046	
	Min	£9,653	£13,514	£19,305	£25,740	£22,523	
	Average	£10,940	£15,090	£21,799	£27,725	£35,608	
	Total	£43,759	£150,903	£435,978	£304,972	£534,113	£1,469,725

1.3 The Evaluation

The evaluation began in May 2010 and ran for three years until summer 2013. Its main aims were to:

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[3] Following the legal settlement in the 1970s, Distillers (now Diageo) set up a trust fund which is administered by the Thalidomide Trust and pays the Annual Grants to UK Thalidomiders, based on their level of impairment.

1) Provide evidence of the impact of the grant on the health and well-being of individual Thalidomiders, in particular how they have used their Health Grant to address their health and support needs, and what this has added to the Annual Grant received from the Trust
2) Assess how the provision of the Health Grant has (or may have) enabled individual Thalidomiders to reduce or avoid predicted future health needs
3) Bring together the learning from the evaluation to support a decision on whether and how to create a permanent scheme after the current three-year pilot has ended, including evidence on the likely future health-related needs of Thalidomiders, and any anticipated shortfalls in existing statutory services and/or the Annual Grant in meeting these needs
4) Examine the effectiveness of working through a national organisation to meet the needs of other geographically dispersed groups with highly specialised needs (including providing evidence of the transferability of this model and describing the necessary conditions for wider implementation).

There were two main parts to the evaluation – a review of the operation of the Health Grant scheme, taking place in the first and last years of the evaluation, and an in-depth study of the experiences of 60 Thalidomide-impaired people (the 'study group') of using their Health Grants, running across all three years. The study group represents just over 10% of the total population of beneficiaries in the UK, and its composition is roughly in proportion to the total number living in each of the four UK nations. The group is also broadly reflective of the number of Thalidomide-impaired people in each of the five impairment bands used by the Thalidomide Trust; for a more detailed profile of the study group see the report from the first year of the evaluation[4].

1.3.1 Approach to the Evaluation in Year 3

The third year of the evaluation has focused on aims 1, 2 and 4 described above and has involved a further round of work with the study group, as well as interviews with Trust staff and other organisations supporting people with rare conditions or very specialist needs. There have been three main strands:

- **Expenditure Survey** - in autumn 2012 we asked all study group members to complete a simple expenditure survey, designed to gather broad information about how people have used their second Health Grant. As in Years 1 & 2, the survey asked people to allocate their Health Grant expenditure to the 'health related needs' categories agreed with the Departments of Health and/or three additional categories added by the evaluation team– 'General Living Expenses', 'Other' and (on the basis of the first year's expenditure) 'Deferred Expenditure/Debt Servicing'.
- **In-depth Interviews** – In March/April 2013[5], all members of the study group were asked to take part in a telephone or face-to-face interview, in which their experience of using their Health Grant, the impact it was having on their health and well-being,

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[4] Newbronner et al (2011) Taking the Pressure off: *Evaluation of the Health Grant to Thalidomide-impaired People, Interim Report from Year 1*. See www.thalidomidetrust.org/govhealth

[5] In this final year, the interviews were delayed by a month to allow time for people to 'take stock' following the announcement of the ten year grant.

and their plans for the new ten year grant were explored in more depth. All the interviews were recorded and transcribed as detailed notes and quotes.

- **Interviews with Trust Staff, NAC Representative and Other Organisations –** to understand in more depth the organisational implications and costs of administering the Health Grant the evaluation team interviewed the Trust's Finance Director, the Welfare Manager and the HealthLink[6] Coordinator, and the Chair of the Trust's National Advisory Council (NAC). In addition, three national organisations which support people with specialist needs were selected and telephone interview were carried out with their Chief Executives/Coordinators. The organisations included a compensation and support fund (the MacFarlane Trust), a national rare disease charity (the Motor Neurone Disease Association) and a rare disease support network (the CJD Support Network). A brief profile of each organisation is given in 5.5. The interviews were used to gather more information about the organisation and to explore informally how the Health Grant 'model' or aspects of it might be relevant to their beneficiaries/members.

1.3.2 Study Group Participation in Year 3

Table 2 shows the response rates to the expenditure survey and the interviews for each year of the evaluation. Seven of those who originally volunteered to be members of the study group have never participated. In years 2 and 3 a small number of study group members have either withdrawn from the group (usually for personal/health reasons) or have not responded when contacted by the evaluation team. Between years 1 and 3 the drop-out rate has been 21%, which is similar to that which would be expected in a clinical trial.

TABLE 2 STUDY GROUP RESPONSE RATES BY YEAR

	Band 1	Band 2	Band 3	Band 4	Band 5	Total
Original Study Group	4	10	19	12	15	60
Year 1 Spend data	3	7	16	9	14	49
Year 1 interviews	4	8	16	10	15	53
Year 2 Spend data	4	9	14	9	13	49
Year 2 interviews	4	9	14	9	13	49
Year 3 Spend data	3	7	12	8	9	39
Year 3 interviews	3	6	12	8	12	41

1.4 Structure of the Report

Chapter 2 begins with an overview of Health Grant spending over the three years of the pilot grant and then goes on to look in more depth at how people used their grants in the final year. In Chapter 3 we briefly describe the changing health needs of the study group

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[6] In 2007 the Trust set up HealthLink, a health support service which aims to: empower and enable beneficiaries to access appropriate health care services; promote and support independent living for beneficiaries; provide advocacy support for beneficiaries when appropriate; gather relevant information about the health needs of beneficiaries.

and consider the overall impact of the first grant. Chapter 5 looks at the administration of the grant from both the beneficiaries and the Trusts perspectives, and then goes on to consider the relevance of the Health Grant 'model' to other organisations supporting people with very specialist needs. Finally, Chapter 6 draws together brief conclusions from the final year of the evaluation.

Chapter 2

Use of the Health Grant

In this chapter we present an overview of how people spent their Health Grants over the three year pilot period and briefly describe the main changes in expenditure. We also describe in more detail how people used their grants in the final year and consider the information and advice they needed to make best use of them. However, to bring to life the ways in which beneficiaries spent their grants we begin by setting out five ‘spending examples’, (one for each of the impairment bands used to determine the level of grant people received), showing individual spending patterns over the three years of the first grant. They are not intended to be ‘representative’ as perhaps one of the key points to emerge from the Health Grant evaluation has been that spending patterns were very individual. Peoples’ decisions about how they used their grants were not only based on the nature of their impairments and how they had affected them but also on their circumstances and the outcomes they wanted to achieve for themselves and their families.

Spending Examples

Band 1 Beneficiary with a total grant of £30k - This beneficiary was keen to remain in full time work although ill health (partially related to Thalidomide damage) had an impact on their ability to work over the period of the Health Grant pilot. As a consequence, 60% of the Health Grant across all three years was spent on general living expenses, to make-up for loss of income. Running a vehicle and regular chiropractic treatment for problems associated with her Thalidomide damage consumed a further 22%. At the end of the three year grant this beneficiary had returned to full time employment.

Band 2 Beneficiary with a total grant of £39k - This beneficiary worked full time prior to the introduction of the Health Grant pilot but was finding work hard. They reduced their working hours and each year used over 60% of their Health Grant to subsidise this loss of income; it was their view that this would have the most beneficial impact on their health. A further 15% went on health club/gym membership, again across all three years. Following the announcement of the 10 year grant this beneficiary decided to leave paid employment completely.

Band 3 Beneficiary with a total grant of £60k - This beneficiary’s main priority was accessibility in relation to both their home and garden and so 65% of their grant was spent on adaptations to their home. This was consistent over the three years.   This beneficiary was also keen to remain as mobile/flexible as possible and so a further 11% was spent on therapies and medical treatments to maintain mobility (though this was higher in years 1 and 2 than in year 3). Adapted clothing was also a priority in all three years, although it only took a small portion of the grant.

Band 4 Beneficiary with a total grant of £83k - This beneficiary was experiencing increased pain and reduced mobility; weight gain and growing reliance on their partner and teenage child were also concerns. They spent their grant across several of the grant categories in all three years. The greatest portion went on adapting/improving their home and this used close to 40%, with independent mobility and respite/holidays taking up around 20% each; in year 3, spending also included access to exercise programmes and purchasing gym equipment.

Band 5 Beneficiary with a total grant of over £94k - This beneficiary's priority was their independent mobility, partly because they lived in a rural area and partly because of the needs of their teenage children. Nearly 75% of their grant (33% in year 1 and nearly 90% in years 2 and 3) was spent on a specially adapted vehicle. A further £8k was spent in both years 1 and 2 on adaptations to their home but further major changes are needed.

2.1 Overview of Health Grant Spending

This section summarises the patterns of expenditure within the study group, across all three years of the pilot Health Grant. The analysis looks at the seven 'health related needs' categories agreed with the Departments of Health (see section 1.2), plus the three additional categories added for the evaluation (see section 1.3.1). The first pie chart (Figure 1) shows the amount actually spent in each category over the whole three years of the 'pilot' grant (it excludes the category 'deferred expenditure/debt servicing'). Figure 2 shows the expenditure in each category as a proportion of total amount spent in each year, and Figure 3 shows the proportion of all those contributing in each year, who spent their Health Grants in each category.

A higher level of caution is also required regarding the accuracy of the year 3 expenditure. Firstly, the overall number responding to the expenditure survey was around 20% lower than in the first two years. Secondly, by the third year of the grant, unless they had kept written records most people were finding it difficult to recall the exact level of expenditure in the different categories, and/or for large projects, exactly how much expenditure had fallen in each year. For some study group members their Health Grant and their other sources of income had become more intertwined and they found it harder to identify the expenditure which related to the Health Grant.

Figure 1 Amount spent in each category for all three years of the Health Grant

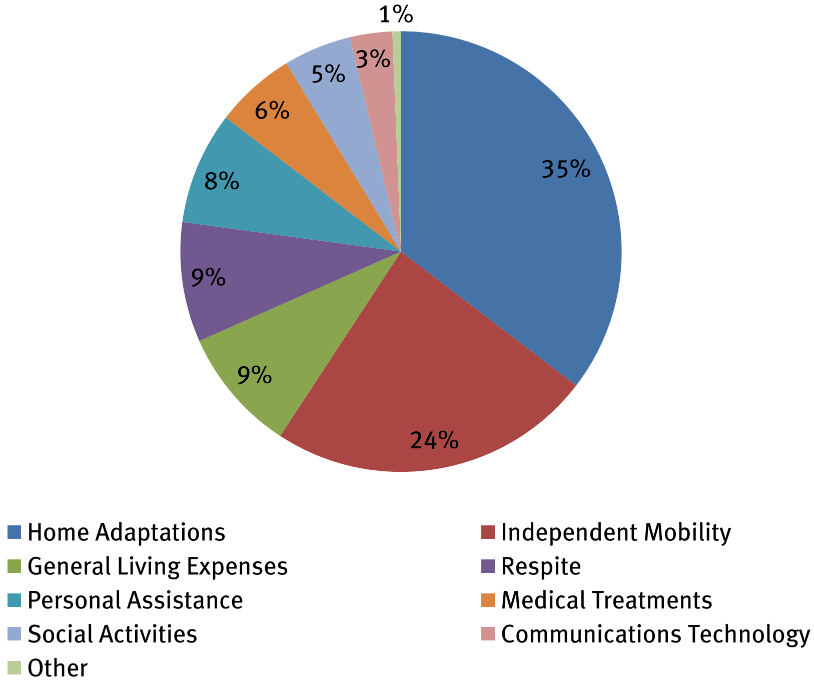

Figure 2 Each category as a proportion of total amount spent in each year

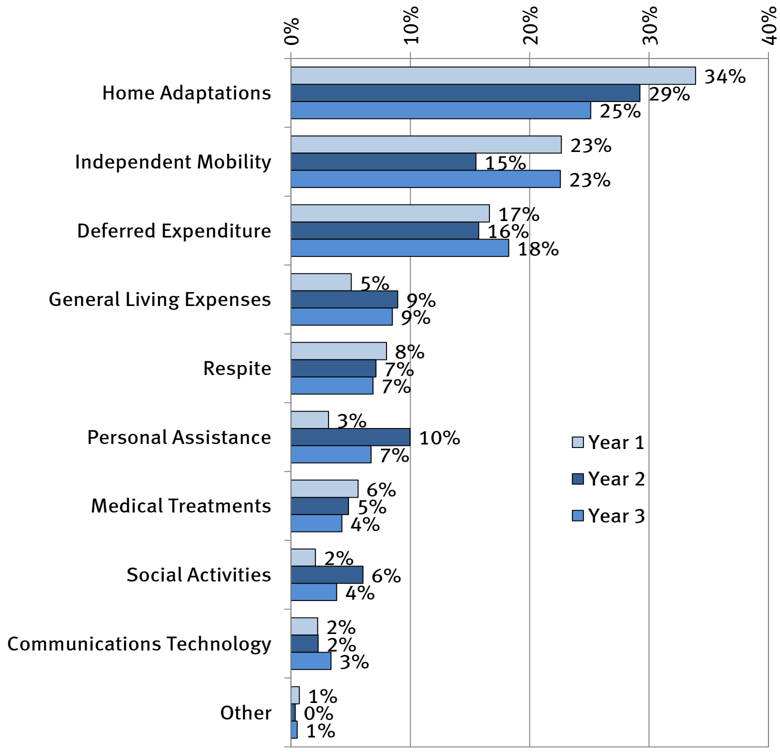

Figure 3 Proportion of Study Group Members in Each Year who Spent their Grants in Each Category

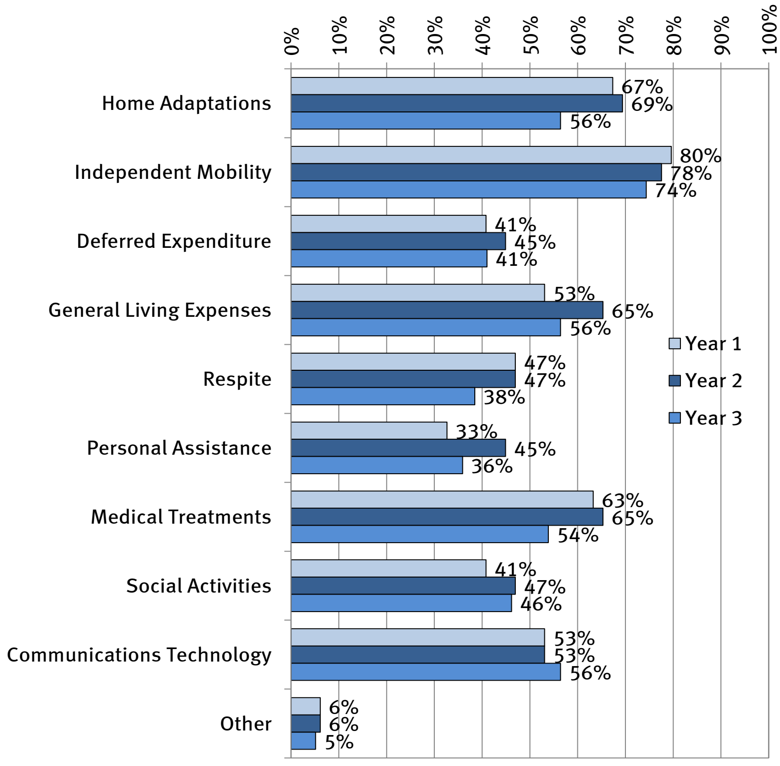

Figure 1 confirms that across the three years of the pilot almost 60% of the Health Grant was spent on Home Adaptation and Independent Mobility. Give the high cost of these things for many beneficiaries, this is not surprising. However, over the three years, home adaptation accounted for a falling proportion of the amount spent each year, as shown in Figure 2. Spending on independent mobility accounted for a high proportion of the amount spent in all three years and, as Figure 3 shows, the highest proportion of the study group members spent their grants in this category in each year.

The 'Deferred Expenditure/Debt Servicing' category continued to account for a significant proportion of the expenditure. The interviews suggest that this reflects the fact that the expenditure survey took place prior to the announcement of the new grant. At that time some beneficiaries felt uncertainty about their long term financial security and so saved some of their year 3 Health Grant in case it did not continue. Others were continuing to save for specific high cost items e.g. adapted vehicles or home adaptations.

2.2 How People Used their Health Grants in the Third Year

As reported in previous years, in the third year of the Health Grant study group members used the money for a wide range of things, including:

- Directly addressing health problems, for example paying for health treatments (e.g. physiotherapy) or investigations (e.g. tests, MRI scans)
- Self-management and reducing future health problems, for example, through paying privately for complementary therapies or exercise regimes, or being able to reduce hours of work.
- Improving well-being and overall quality of life, for example funding social activities or bespoke clothing.
- Maintaining or enhancing independence, for example through funding adaptations.
- Maintaining mobility, for example, funding wheelchairs and paying for adapted vehicles or trains/taxis.
- Reducing the impact of caring on family and maintaining positive relationships, for example, paying for help in the home and personal assistants or funding holidays together. As more people are taking on responsibilities in a caring role for aging parents, the grant was enabling some to travel to them or reduce hours of work.

Personal story

E has a fused spine which affects his movement and ability to sit/sleep in a comfortable position. It affects his ability to travel long distances because if he sits too long the pain can be considerable, especially in a confined space. He said that he primarily spent his Health Grant in order to promote his independence and keep as mobile as possible. He said how stressful travelling could be before the Health Grant, and he used to *"dose myself up with painkillers"*. Now he is able to afford to 'upgrade' to first class, in order to have more room, and to have access to a bigger toilet:

"It's taken a lot of stress out of things. Beforehand on long journeys I couldn't have a drink because of going to the toilet. And I have heard that is really not good for you in terms of what it does to you. I'm now stress free of that, so I haven't got to suffer in the same way."

E also appreciates being able to travel together with the whole family – before they often had to travel separately because of the cost: *"Now we go out as a family, it doesn't split the family."*

A number of people explained that because of their disabilities, cold weather was a particular problem for them. For some it caused increased pain and stiffness, whilst for others it created practical problems. For example, for people with short arms the difficulty of wearing extra layers of clothes and/or clothes with sleeves or the need for bare feet for people who use their feet for tasks around the home. As a result many people had their heating on for longer or at a higher level than a typical household. Two people specifically commented on the increase in utility bills and noted that having the Health Grant had stopped them worrying too much about these increases. One person said he did not know how he would have managed without it because his annual grant and benefits combined did not cover the increased expense, and keeping warm is essential for him to maintain dexterity and reduce pain.

A number of people described how they prioritised their spending on preparing themselves for the future, in anticipation of further deterioration and with a strong desire to remain as independent as possible. Receiving their Health Grant as a lump sum had been invaluable in helping them do this as they could use if for major items of expenditure such as household adaptations, vehicles, large pieces of equipment, and costly treatments.

Personal story

J has always had difficulties using her hands, and this is getting worse because of arthritis. She described how she had used her Health Grant to adapt her kitchen. She described how this was expensive, because Building Control required her to put ramps and railing on the outside of the extension and this incurred some extra costs, but it has made a huge difference:

"The kitchen was completely adapted for my use, so everything is at my height – it's absolutely fantastic....It took about 6 months in the planning but it was so well worth it - I'm actually cooking and baking myself for the first time in years. It's unbelievable!"

Further to this, J felt that these changes had helped set her up more securely for the future:

"I don't know if it's an age thing but since I turned fifty I've kind of been thinking well, what if something dreadful happened to my husband and I was on my own I'd have to cope some way. So I'm basically trying to set up my home and my surroundings so that should that awful thing happen I would be able to manage up to a point on my own. I've really had to be practical about it – you've got to think about these things."

A few people were very cautious about their spending during this third year, because initially they feared that the Health Grant might not be continued; either they kept some in reserve for the future or they resisted committing themselves to costly items/treatments. One person described how they stopped their physiotherapy sessions until they knew about whether it was continuing, and for some this was a cause of anxiety:

> *"At one point we thought it wasn't going to go through and it was a big worry. But in December when it went through I sorted myself out a car".*

As was noted in the Year 2 report, a number of people explained that it had taken them some time to get used to having the Health Grant and/or to come to terms the level of deterioration they were experiencing. This had affected their spending patterns over the years. For example, one person described how other Thalidomiders had taken out loans or extended their mortgages in order to get things done more quickly but she didn't want to get into debt – as a result, she had been much slower to address her problems/needs. However, she has now recognised that with the 'step changes' in her functioning she really needs to speed up the process of getting all the major things she needs in place or her independence is going to be severely curtailed. Another described the process she went through in deciding to pay for a toilet which included a washer/drier and remote control:

> *"It's just amazing – you wonder how you ever managed without it. I was struggling, so it's been a major thing for me….you fight against it all your life and then you think 'do you know what, I've got have these things' because I've got to have some help".*

She went on to say that at 50 she had found it quite hard to acknowledge that she couldn't do things or might need more help, but she has had to accept this. Having the Health Grant helped this process of acceptance, partly because the money was there to actually address her needs.

The issue of the adequacy of the grant was raised by a few people, who said they were still having to prioritise spending, and the Health Grant was not covering all their health related needs. Where major items were required, such as adaptations to housing and vehicles, this was sometimes at the expense of paying for other needs, such as complementary health treatments or signing interpreters. One person said they had had to arrange a significant loan from the Trust, because they required housing adaptations that were so expensive, and some of the examples provided in the 'personal stories' give an indication of the high costs that can be incurred.

2.2.1 Obtaining Products and Services and Access to Advice

Most people had no problem obtaining the products and services that they required, but a small number said they had to go to some lengths to shop around, and try out different therapists/products etc. For one person the lack of availability of suitable equipment was going to incur considerable extra expense:

> *"I can't find one* [a wheelchair] *small enough and light enough for my husband to be able to lift it into the car, so down the line I'm going to have to look at a transit van type thing which I really don't want to."*

Only one person said they had sought independent advice from a financial advisor and solicitor, and this was for the purpose of putting her Health Grant into a Disabled Persons Trust*.* A few people had paid for specialist advice/design, which came at some cost, but it enabled them to get the result they needed:

Personal story

L has difficulties using her arms and hands, plus she also has problems with her back and lower limbs. Her functioning is deteriorating due to neurological damage, which affects her day to day ability to do things for herself, so she needed to adapt her kitchen to make it more accessible. However, when she approached the OTs from the local authority she felt that they couldn't really understand the implications of having short arms and they came up with a design that was based on what a wheelchair user would need. She twice rejected designs that they produced, which was difficult because it caused delays. They were lower cost, but L felt that if she accepted them she would have ended up having to change them, and incur more expense and disruption. Instead, she went to a specialist kitchen design company (based some distance from where she lives) who spent a day with her watching how she used her body and what she could do. She said that it's often a question of finding a designer who will *"go the extra mile and use their brains with you and find creative appropriate solutions".*

However, most people said they did not need or want specialist advice. Some people said how much they appreciated the help of HealthLink (the Trust's health support and advice service), and a large number said they really valued the information that was shared within the Thalidomide community; this was obtained through a wide range of media (e.g. using online forums, Facebook, networking events) or using friends and personal contacts. One person emphasised how being able to communicate so easily now with other people in a similar situation makes a huge difference: *"Tried and tested by people with similar impairments – they know better than any professional."* Another person explained that because the Health Grant meant people actually had money to spend on their health related needs they were motivated to research and share information. She also highlighted the personal benefits to Thalidomide-impaired people in becoming their own experts:

> *"My expertise and clarity in being able to define what I need and why it is a million miles from where it was two or three years ago [before the Health Grant]. I used to just think 'Aah where do I start'. I've 'skilled-up' and I think that's reflected in the whole Thalidomide community. There is a lot of information sharing on Facebook, or people just asking questions…. We are really building up our combined knowledge, especially those of us with upper arm problems, because that it such a rare thing in the wider world and the whole system, like occupational therapy, often don't know what the issues and solutions are for those problems".*

However, there were individuals interviewed who might have valued this input but seemed unaware of the opportunities to communicate with other Thalidomiders.

Chapter 3
Changing Health Needs and the Impact of the 'Pilot' Grant

Key findings

- The majority of study group members reported further deterioration in their health in the past year. The vast majority of people are experiencing either deteriorating and painful joints, and/or muscle weakness and strain. Several have numbness and/or partial paralysis.
- Weight management was once again a focus of concern for many study group members. There were on-going difficulties associated with being able to exercise effectively and worries about the additional strain on joints, and implications for long term health conditions.
- However, many people reported that without the measures they could put in place through the Health Grant, their decline might have been much worse, and some people said their health was the same or generally better.
- The great majority of study group members said that over the 3 years the Health Grant had made a very significant difference to them; in some cases it was described as *"life changing"*
- Key benefits of the Health Grant included direct health benefits (e.g. through funding treatments); practical measures to aid mobility or improve daily life (e.g. adapted vehicles/ home adaptation and equipment); lifestyle changes (e.g. reducing working hours or giving up work) to prevent further deterioration
- Other benefits rated as equally important by many study group members were less tangible, but included improved emotional well-being, greater self-esteem and feeling more equal to their non-disabled peers within society.

The reports from the first two years of the evaluation[7] [8] set out in some detail the health problems the Thalidomide-impaired people in the evaluation study group were experiencing. In this chapter we briefly outline the health needs and problems people described in year three of the evaluation, and the difference the Health Grant has made to their ability to address these needs.

3.1 Health Needs and Health Problems

In the first two years of the Health Grant evaluation study group members described the health problems they were experiencing. These included:

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[7] Newbronner et al (2011) Taking the Pressure off: *Evaluation of the Health Grant to Thalidomide-impaired People*, Interim Report from Year 1. See www.thalidomidetrust.org/govhealth

[8] Newbronner et al (2012*) Looking to the Future: Evaluation of the Health Grant to Thalidomide-impaired People*, Year 2 Final Report. See www.thalidomidetrust.org/govhealth

- *Deteriorating and painful joints; muscle weakness.* This was often linked to wear and tear due to overuse. Many study group members reported these types of problems but the specific problems varied with the nature of their impairment, how they had had to use their bodies and sometimes the type of employment they had had
- *Numbness and partial paralysis.* In some cases this was associated with neuropathy (the incidence of peripheral neuropathy is evidenced through a study supported by the Thalidomide Trust and conducted by medical researchers from Imperial College Healthcare NHS Trust[9])
- *Dental problems.* In particular where people have difficulty cleaning their teeth properly, or where they rely on their teeth to do everyday tasks such as opening bottles, getting dressed or using a computer keyboard (with typing sticks)
- *Sensory impairment.* For some people affected by Thalidomide this caused hearing and sight impairment or loss, and in most cases this was deteriorating; a few other people reported finding it increasingly difficult to manipulate spectacles or contact lenses
- *Weight problems.* These were reported by a significant number of people, often associated with difficulties exercising where they had foreshortened limbs and/or used a wheelchair. Being overweight not only increases the risk of developing other health conditions such as diabetes and heart disease; for Thalidomide-impaired people it can also significantly reduce their ability to do everyday tasks
- *Other health conditions.* Some people had health conditions which were a direct result of, or are exacerbated by, Thalidomide damage, in particular where internal organs may have been affected (e.g. increased risk of chest infections due to underdeveloped lungs or the implications of reduced kidney function). Others highlighted the added difficulties managing health conditions unrelated to Thalidomide (e.g. administering insulin or coping with conditions like Meniere’s Disease and migraine which affects peoples balance and vision)
- *Mental health issues.* For some this was a generalised feeling of depression associated with living with constant pain. Others described on-going problems linked to coming to terms with disability, or dealing with the everyday barriers that disabled people face. One person reported on-going severe mental health problems.

Importantly in year three, more than two thirds of those interviewed reported a further deterioration in the problem(s) they had reported in previous years. People described how they were doing a number of things with their Health Grant (outlined below) to try and reduce the deterioration as much as possible but many felt that they would not be able to halt it completely. One person with neuropathy described how this appeared to be accelerating:

> *“It’s all sort of building up with bits of the body struggling and going down. It’s an incremental process and it seems to be happening fast. Over the last ten years I’ve found I’ve been losing a bit of function, getting more pain but now it seems to be really speeding up, which is a bit scary.”*

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[9] Malik O, Nicholas R, and Nicotra A (2011) *Evaluation of the peripheral nervous system in patients with thalidomide-induced limb malformations.* Unpublished report for the Thalidomide Trust

However, many people reported that without the measures they could put in place through the Health Grant, their decline might have been much worse, and some people described their health as the same or generally better. Where there was a reported improvement, for a small number of people this was associated with being able to reduce their hours of work or had given up work completely (and so putting less strain on their bodies); for a few the health improvement was linked to weight loss. As in previous years, weight loss was a focus of concern for many people. There were on-going difficulties associated with being able to exercise effectively and worries about the implications for long term health conditions, but a few people said they had lost a considerable amount of weight, e.g. through using the Health Grant for a personal trainer, gym sessions, etc. One person described how this had had a transformational impact:

Personal Story

S's original Thalidomide damage was exacerbated by an accident several years ago. Linked to this, she had been seeing a physiotherapist for some years (in part funded by the Health Grant). As a wheelchair user she found it difficult to exercise and was increasingly concerned about weight gain and the impact this was having on her. During the third year of the Health Grant, as well as continuing with physiotherapy, S used the grant to pay for swimming sessions and buying healthier food (which she felt tends to be more expensive). She also took advantage of two free personal health trainer sessions offered locally. The personal trainer helped her to work-out how she could use exercise equipment safely, and as a result she set up a 'mini gym' in the garage. She said she is now much more mobile as a result of the weight loss, is sleeping better, and has a much better sense of overall well-being.

One person reported a significant improvement in her health as a result of having a hip replacement.

> *"It's fantastic, I'm like a new woman….I don't think I realised how much I was affected* [by the hip problem] *until I looked at myself this year. I feel about 10 years younger than I did last year. I think it was the constant pain, the not sleeping. Yes, it's been really, really good".*

However, important as surgical procedures and health treatments can be in improving peoples' health, the benefits were sometimes reduced because of the original Thalidomide damage. For example, the beneficiary who had had a hip replacement explained that although the surgeon found the best prosthetic for her needs, there are now certain things that she cannot do with her foot (e.g. brushing her hair) as this involves extended movement of the hip and could risk dislocating it. She said she feels fitter and more able to do things than this time last year, but she hasn't gone back to doing all the things she could do before and is having to accept more help: *"I'm better than I was a year ago but not as good as I was five years ago".*

3.2 Use of NHS and Local Authority Social Care Services

There were mixed views amongst those interviewed about the difference the Health Grant had made to their use of services over the last three years. A few were emphatic that it definitely had reduced their service use, particularly in terms of fewer visits to the GP, reduced medication/interventions for pain and/or the fact that they were using privately funded treatments (such as physiotherapy) instead of using the NHS. One person described how they had been contemplating orthopaedic surgery to deal with painful joints but by giving up work, having time to rest and going to the gym she had been able to manage her pain levels; she felt that without the Health Grant she would not have been able to do these things she would have ended up having to have joint surgery to relieve the pain. However, a number of people said it was very hard to say how much their service use had been affected, and some explained that they had avoided using NHS services for a long time, because of their previous negative experiences of NHS care (which were outlined in previous evaluation reports):

> *"The NHS do not cater for us, they haven't got a clue."*
>
> *"She used this massage machine thing on my shoulder and made a total f***-up of it....another one of these people who don't know what they are doing....didn't even bother to look at my bone structure or check anything, just lie down and dive in so I said I ain't going back there and I ain't."*

Two people reported that they had been resistant to using complementary and private health treatments because of the high cost, but that now they know that the grant is being continued for another 10 years, it is something that they will actively consider.

Similarly, it was hard for people to quantify what impact the Health Grant has made on their use of social care services, and only a minority of those involved in the evaluation had had any social care input - but many people reported that the grant had helped to maintain or enhance their levels of independence. In particular, people felt that the money spent on adaptations and specialist equipment/vehicles, to enable them to do things for themselves and keep mobile, reduced the need for care input both now and in the future. Those in receipt of direct payments also appreciated being able to use their Health Grants to top these up and so have more flexibility.

In this final year of the evaluation, people continued to report somewhat varied experiences of the NHS services. As in previous years, many people were very frustrated that the damaged caused by Thalidomide was not properly understood or taken into account by clinicians. However, there were also positive experiences. For example, one person reported that after joint replacement surgery the physiotherapist and OT took extra time to understand their needs and ensure they could manage at home. Another person reported that whilst the GP could not help with new treatments for his foot problem the visit resulted in him accessing mobility Disability Living Allowance (DLA). Whilst these experiences are not directly related to the Health Grant, peoples' previous experiences of NHS services did sometimes influence their decisions about how to use their grant. They also have wider implications in terms of the relevance of the Health Grant 'model' for other groups of people with specialist needs.

3.3 Overall Impact of the Health Grant

The on-going impact of the grant has been outlined in detail in each of the two previous evaluation reports. In this final year, whilst there were issues of adequacy reported, everyone stressed the positive – and in many cases life changing - impact of the grant, not only in relation to themselves but to their wider family.

> *"Everything was focused around Thalidomide and disability. The people you live with have pressures connected to this as well – if the family is happy then you feel happy."*

In the final round of interviews, the study group were asked to assess, on a scale of 1- 10 (where 1= low impact and 10= high impact), the impact that the Health Grant had had on their ability to manage their health or health related needs over the last three years. The vast majority rated it very highly (8-10) with most of these being 10 – and some said even a 10 could not capture the difference it had made:

> *"Higher than 10! ... It's changed my life dramatically for the better."*
>
> *"To be honest, 10 is not high enough - my life's so much easier – physically, mentally, emotionally - it's altered everything."*

Where people rated it below this (a very small number were between 4 and 7) this was generally linked to a view that the level of the grant was not adequate to meet their needs.

One person was able to make an interesting comparison which threw some light on the difference the grant had made:

Personal story

H has fused spinal joints which cause pain and restriction in her neck, back, and upper limbs, plus she is experiencing further deterioration due to arthritis. For some time, H has been regularly travelling some distance to see her parents, who have both been unwell. Whilst her father was in hospital, she went to live with them for 4 months. As she could not drive all the way there she bought another car to keep at their household, and this was useful for taking her mother back and forth to hospital; this temporary move also meant she had to purchase some duplicates of essential equipment. She said it was really useful to have a lump sum to pay for these additional items and psychologically it has really helped to know she can deal with things when she needs to, and respond to emergencies. Through this experience H has a comparison of the difference the things she has bought have made – because when she is at her parents she does not have some of the equipment that makes her life more comfortable. For example, she said at home her recliner chair helps her to relax and she is ready for the next day – whereas when she is staying at her parents' house *"... I would be lying down by the evening because of sitting in chairs not designed for me... It's frightening when you are outside your comfort zone."*

As well as the practical steps people were able to take, (e.g. to improve their accommodation or fund treatments), a large number of people talked about the emotional benefits linked to the Health Grant. The quotes below illustrate how people described this:

> *“The emotional freedom I’ve gained is worth more than anything to me because I feel just normal, you know.”*
>
> *“You can sleep at night because rather than letting things mount up and worrying about them you can pay someone to do it for you”.*
>
> *“At the moment I feel relatively well, which is the first time in a long time. It’s not just because of the migraines, but also other things and family issues….and when you put them all together it’s a lot and so it’s nice to be able to think ‘at least the one thing I don’t have to worry about is money”.*
>
> *“The beauty of the Health Grant from my point of view is that it’s bought me the freedom that everybody else could have.”*

A small number of people who reported experiencing more severe mental health problems over the years (including suicide attempts) said they were buoyed by the Health Grant, and one described how it had made a huge difference to them on a preventive basis:

> *“If I’d stayed in, I’d have been more down, moping around. Honestly, without it I think I’d be in my grave.”*

The knock-on benefits for peoples’ emotional well-being and mental health of them having funds which they can control have been highlighted in other studies, including the evaluation of the national Personal Health Budgets pilots[10].

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[10] Davidson, J., Baxter, K., Glendinning, C., Jones, K., Forder, J., Caiels, J., Welch, E., Windle, K., Dolan, P. and King, D. (2012) Personal Health Budgets: Experiences and outcomes for budget holders at nine months: Fifth interim report, Department of Health, London.

Chapter 4

Plans for the Future – the Next Ten Years

Key Findings:

- Study group members were generally very pleased and relieved that the Health Grant was to be extended for ten years but some were concerned about it being time-limited
- Many people expressed uncertainty about their future health needs, although most of them expected some level of deterioration and decline.
- The most common future health and support concerns were reduced mobility and flexibility, increased pain (particularly in relation to joints), greater need for personal assistance and loss of independence.
- Nearly half of the interviewees said they would need to use some of their Health Grant for home adaptations/maintenance or to help them move house over the next ten years. Other anticipated uses included mobility, living aids/equipment, medical care, communications technology, and personal assistance. Some hoped to give up work or cut down their working hours.
- The benefits of having the Health Grant confirmed for ten years included financial security and the ability to plan for the future but it also gave people peace of mind, greater financial security and reduced reliance on family members for support and care.

The main focus of the Health Grant evaluation has been on the impact of the three year 'pilot' grant. However, the announcement of the new ten year grant was made during the final year of the evaluation and the Health Grant Advisory Group felt that it was important and valuable to capture peoples' thoughts about how their future health and support needs and how the new grant might help them address theses.

4.1 Reactions to the New Ten Year Health Grant

There was general relief all round amongst the study group members when they found out that the Health Grant was to be extended for ten years. *"Delighted"*, *"ecstatic"* and *"amazed"* were amongst the responses when asked how they felt about it. One person, who was with a group of other Thalidomiders when they heard the news, said:

> *"It's probably a bit dramatic to say, but it was probably a bit like VE day in the war. It was amazing. There was a huge sense of relief – a huge sigh – because everyone knew there would be no worries for 10 years."*

Many of them had been anxious that the grant might not be extended and were worried that they would not be able to cope without it.

> *"I just felt relieved because, had it gone away, quite frankly I don't know what I would have done because things have improved, you know, to such an extent,*

> *having been able to use the Health Grant for my needs that I just don't know what I would have done, I really don't."*

There were mixed feelings about the grant still being time-limited (albeit for ten years). Some people were sanguine about it:

> *"We all hoped it would be for life but it's maybe understandable that they couldn't perhaps go that far. God willing they'll look at us again but it's like a great big weight has been lifted."*

> *"I didn't think 'oh, why is it just ten years, why didn't they make it forever' because I work in the NHS and nothing is forever. I just think 10 years takes us nearly to retirement… It's quite a big burden lifted off us really and especially with it continuing at a really good level."*

Others, however, expressed concern about what would happen in ten years' time:

> *"I felt delighted but at the same time I also questioned it because if they really understood our real situation, why only extend it ten years. Naturally everyone's bodies are going to deteriorate so our needs are only going to increase."*

> *"I suppose there has to be a time limit on it really but I suppose in another way it would have been nice to have said indefinitely with reviews…. I suppose if we take the ten years as a review date as to whether the sum is enough to meet our needs, well, in ten years it probably won't be. But I just hope we're not having to face another major battle in ten years' time. That would be awful."*

In fact the stated purpose of the ten year review (for details see the report in Hansard[11]) is to assess whether the level of the Health Grant is still sufficient to meet Thalidomide-impaired peoples' health needs as they reach their 60's.

4.2 Future Health and Support Needs

Many people expressed uncertainty about their future health needs. Most of them expected some sort of deterioration and decline but did not know at what rate this would happen and to what extent over the next ten years.

> *"It's very difficult to tell what I'll be like in ten years' time."*

> *"It's a ticking time bomb at the moment and I don't know when that tick, tick, tick is going to go into a bang."*

Only two people did not anticipate any great decline over the next ten years but felt it would just be *"more of the same"* in terms of their health needs.

Almost half of those interviewed were concerned about reduced mobility in the future; they put it *"high on the list"* in terms of priorities for future health needs. For many, this was related to expectations that joint and limb problems would get worse due to increasing wear and tear. Some were also expecting their current experiences of numbness in limbs/extremities to increase. A number said that they already felt that their flexibility was reducing which made everyday tasks such as transferring, moving around, washing and getting dressed more difficult. People were keen to keep their

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[11] http://www.thalidomidetrust.org/SecureDocs/HansardDec2012.pdf

mobility for as long as they could – one person described his potential reduced mobility as a *"major game changer"*. Problems in the joints such as arthritis were thought to create a vicious circle whereby joint stiffness led to increasing inactivity which in turn led to joints stiffening up even more. A few people said that they were using the Health Grant to mitigate the effects of joint and muscle deterioration by paying for gym membership to keep active or by having physiotherapy and these would continue to be needed into the future.

Several interviewees anticipated worsening pain, mainly in relation to deteriorating joints, and therefore, correspondingly, an increased need for treatments to deal with pain.

About a third of interviewees indicated that they would probably need more assistance with personal care and domestic tasks over the next ten years, mainly in response to anticipated reduced mobility:

> *"My husband is fantastic and he's great at helping around the house but he finds the personal care more difficult so I may need to buy in some help with personal care."*
>
> *"I can see that I'm going to be buying in more help but nobody wants to look that far ahead… I worry about us getting old together and me needing more help."*

In conjunction with this, some feared the loss of independence that this would herald. A few people, who did not have family members to help them, were worried about how they would cope if they became less able to look after themselves, so the knowledge that the Health Grant had been extended was instrumental in helping to allay those fears. Some people were putting a portion of their Health Grant on one side in order to make sure that they had enough money in the future to pay for personal assistance.

Other health concerns that were mentioned included diabetes and an increasing need for dental care (particularly for those that use mouth sticks or find it difficult to clean their teeth properly).

One beneficiary (who lived with his parents) thought that he would probably have to move into a "*home"* at some point when they were no longer able to provide care for him.

4.3 Plans for the Use of the Ten Year Grant

It was clear from the interviews with the study group that at this stage the areas of expenditure are likely to be similar to those for the three year grant. However, there was greater emphasis on planning ahead for possible further deterioration in health, mobility and flexibility, and a strong desire to *"future proof"*, or find strategies for maintaining independence if circumstances changed.

4.3.1 Initial plans for the use of the new Health Grant

Nearly half of the study group said they would need to use some of their Health Grant for home adaptations/maintenance. For some this was finishing work that had already been started but, with the Health Grant being extended for ten years, others now felt able to go ahead and start larger capital projects. As with the three year grant the adaptations and maintenance mentioned included fitting accessible kitchens and bathrooms, building extensions, making gardens accessible and fitting an electronic (key pad) door system.

Some people also felt that there might be a need in the future for them to fit stair lifts as their mobility decreased.

A few people said they were considering moving house to be nearer relatives or in order to live somewhere more accessible or in a more accessible property. For example, one beneficiary was considering moving to a bungalow because stairs were becoming a problem for him, although he was not sure that the Health Grant would cover the expense that this would entail. Another person who lives in a very remote place thought that they needed to consider moving somewhere with supported accommodation as they felt they were likely to need care much earlier than their peers in the general population.

About a quarter of those interviewed said that they would be using their grant to buy equipment such as wheelchairs and living aids and a few people said that part of their grant would go towards mobility requirements such as vehicles and transport. Some beneficiaries said that they would need to buy new vehicles in the future or have vehicles adapted as their mobility reduced.

> *"It just snowballs, because you think you can manage this and that but when you are completely honest with yourself you realise 'no, I can't manage that anymore'."*

About a quarter of those interviewed said that a portion of their Health Grant in the future would go on health care (such as physiotherapy and private health care). For some people, this would be a continuation of the treatments they were already receiving but for others they thought there may be a need to access treatments as they got older.

A number of study group members said that they planned to use some of their grant for personal assistance and help around the home. As mentioned in section 4.1 above, quite a few people anticipated requiring more help with their personal care and day to day tasks in the coming ten years and so the Health Grant was considered a vital source of funding to pay for this assistance. One beneficiary said that having the Health Grant reassured her that if she needed high level care in the future, she would have more choice and control about how and where that care was provided. Another person felt that it was necessary to plan ahead for increased personal care needs as her husband became less able to do things for her or in case he became unwell. She felt there was a need for Thalidomide-impaired people to think about these things earlier in life than those in the general population.

A small number of people talked about using their Health Grant to help fund a reduction in working hours or giving up work. One person felt that his job was becoming too demanding for him as his health was deteriorating and he was considering either changing his job or maybe stopping work altogether. He had recently had an employment assessment to see what his prospects would be in the local job market but there were few options open to him (because of his age and disabilities) and felt that employers would be reluctant to take him on. He thought that combining his Health Grant and his Annual Grant may be enough to give him a basic income but he was concerned about all the uncertainties around benefit changes etc.

> *"It runs through my head, about giving the business up and just trying to manage on what I get but I'm scared because of the way the government is changing benefits, DLA and such and I want to work for what I get, I don't want to take off the state."*

Another beneficiary had been considering reducing her working hours and the confirmation of the ten year Health Grant enabled her to make the decision to go to down to part-time work from full-time work.

> *"I get very tired in winter. It's the fact that it takes longer to get dressed because you have to put more clothes on, you know getting in and out of the car, worrying about weather – just more pressure. In summer, it's just much easier. You don't have to worry about winter coats, defrosting cars – I just get much less tired. So I think having one less day commuting into town is going to make a big difference."*

Other planned uses for the extended Health Grant included holidays and communications technology. For some Thalidomiders, the communications technology that they require is extremely expensive because of their disabilities so the Health Grant is a very useful source of funding for keeping up to date with this. One person said that communications technology was *"vital"* for her and she was using it more and more for things such as online shopping because carrying shopping was very painful.

Two people specifically said that they planned to save their Health Grant until they needed it, e.g. to fund alterations on property or retirement, but others explained that they did not have any plans as yet for how they would use their grant; they were waiting to see what they would need in the future or else they had not really thought about it yet.

A small number felt that the grant was not adequate for their projected needs over the next ten years. There was a concern that many Thalidomiders would deteriorate rapidly and so their associated health needs would increase. It was felt that it was essential for the Health Grant to increase year on year and keep up with inflation. One beneficiary was worried because he felt that there was gap between what they need and what they get.

> *"Realistically, things are going to get worse, not better."*

4.3.2 Need for future advice about use of the Health Grant

More than half of those interviewed did not think they would need formal advice in the future about their use of the Health Grant. Some of these people said that they were capable of accessing the information they needed themselves. A small number were not sure whether they would need any advice in the future but about a third of those interviewed said that they would probably seek advice in the coming years. Mostly, people suggested that this would be from the Trust (e.g. HealthLink) or from other Thalidomiders via social networking (as many of them already had done over the preceding years – see section 2.2.1).

> *"They* [the Trust] *don't promote things like this, but always provide good advice and do a great job... They're not in your face but if you need them then they're there and that's reassuring."*

It was suggested that it is not so much about knowing what to do with the money, but rather about finding out how to get what you want, i.e. accessing services and equipment. One beneficiary felt that it was important that all Thalidomiders were able to take advantage of the opportunities provided by social networking:

> *"We need to strengthen the support network in the Thalidomide community. At the moment is quite a casual sharing of experience and I also feel that we are not reaching the ones who don't go online and use Facebook - it's a relatively small*

> *group of us who are doing this sharing of experience and knowledge. I feel that the Trust should take this on board and make knowledge about adaptations, accommodation issues, more open to the full community."*

Some said they would seek advice about investing their money. One interviewee was concerned that many beneficiaries did not really know what they were entitled to and felt it was important to keep *"up to speed"* on all the legislation around benefits etc. He felt that they were going to need more and more advice in the future. Another person said they would need to seek specialist medical advice because most doctors did not know about Thalidomide damage.

4.4 Benefits of a Longer Term Grant

4.4.1 Impact on how the grant is used

More than a third of the beneficiaries who were interviewed said that knowing the grant was for ten years enabled them to plan for the future – for example, they could undertake big projects or plan to buy new equipment such as wheelchairs. One beneficiary said that without the extended Health Grant he would have been unable to plan to get a wheelchair-accessible van. For him, the Annual Grant does not always cover even just day to day living costs, let alone large capital expenditure.

A quarter of those interviewed said that the extended Health Grant gave them security – a *"financial cushion"* – and gave them more confidence about the future.

> *"It makes a big difference because for the next ten years I know it's guaranteed. It comes back to relieving the pressure – you're not as worried because you know if things do go wrong you've got money in the bank."*

Feeling financially secure meant that some people were now able to consider early retirement or think about cutting down their working hours.

> *"It just means there's no pressure, that over the next ten years I can plan and I can do things such as giving up work early which I wouldn't, which before the Health Grant I wouldn't have thought of so seriously… That's probably something I wouldn't have been able to do and that will make a huge difference to the way I feel."*

One person had been thinking about reducing her working hours for about two years but did not feel like she could finally make the decision until she knew whether the Health Grant would continue or not. Once the ten year grant was confirmed she made the decision very quickly.

> *"Up to now it's enabled me to carry on working and now it's helping me reduce working."*

Another person said that having the grant extended helped him make the decision not to work anymore. He had been made redundant and had been looking for work but the ten year Health Grant has meant he no longer has to do that. A few beneficiaries said that they were not ready to give up work yet because they enjoyed their jobs, but having the extended grant would allow them to reduce their hours gradually if they wanted or think about retiring early at some point in the future. It would also provide a 'nest egg' for when they eventually did retire early. Not everyone, however, felt that the grant being extended for ten years was sufficient for them to think about giving up work:

> *"It would take a significant financial input before I could do this – I don't see the light at the end of the tunnel."*

A few people said that the grant being extended for ten years meant that the way they spent their money had altered. They were now able to get what they needed straight away without having to worry if they had enough money to pay for it – it was about being able to do *"what you want, when you want"* and not just having to go with your *"top priorities"*.

> *"I'm relying less on government help in the fact that just before Christmas my old wheelchair collapsed on me and I would have had very little money in my account to go out and buy one, and then I heard the Health Grant was going to be continued and that allowed me to go out and get one."*

For one person, having the extended grant meant that she could do things like have the heating on all day if it is cold without having to worry about the bill:

> *"I can't keep warm like everyone else and I can't put layers of clothes on, so I have to put the heating on."*

Another beneficiary said that carrying on with treatments such as massage was extremely important to him, so having the grant extended meant that that was possible.

A few people said that the grant being extended had not really altered their plans. For some, this was because they did not feel the grant was sufficient for their needs, which would always be above what the Health Grant provides for. One beneficiary worried that the grant would not be enough if there was a *"catastrophic"* change in her health:

> *"My big concern is that if we are going to keep getting these step changes – unexpected changes*

4.4.2 Impact on wellbeing and outlook

A number of interviewees said having the Health Grant confirmed for ten years had given them peace of mind – the pressure had been taken off and their financial worries had been removed. One person described it as a *"comfort blanket"*, another said that it had given him *"breathing space"*. People felt that it had given greater stability and security to their lives:

> "[The Health Grant] *gives me major, fantastic freedom and peace of mind."*

> *"It's made me feel a lot more secure, knowing that money is there, because I really took a chance when I retired. At that point it was only the pilot scheme but I thought 'I'm taking a chance', but then you can't take a chance with your health, you're only here once."*

Some beneficiaries felt that they had become happier, less anxious people since getting the Health Grant and knowing it has been extended for ten years meant that these psychological benefits were likely to continue. Knowing that they would be more able to cope financially had given some people more confidence in themselves and in the future. They felt they would be able to maintain their independence and stay healthy for longer.

One person said that mentally she has become a stronger person since she has had the Health Grant.

About a quarter of the interviewees said that the grant continuing had a wider impact on their partners/spouses and on their families. One person said that he and his wife were now *"more like a normal couple"* because he did not have to rely on her so much and another was pleased that her partner *"can stay as my partner and not my carer"*. People felt that their partners/spouses worried about them less because they had the security of the Health Grant and they also did not need to worry so much about becoming ill or unable to care.

Because many Thalidomiders' children are becoming adults and starting to leave home, the extension of the Health Grant is timely as it means that they will not be reliant on their children for increasing care needs. Some beneficiaries felt that having the grant had allowed them to think about ways of reducing the pressure on other family members. One person said that using some of her Health Grant on things like domestic help had made a big difference because she did not constantly have to ask family members to do things for her.

Some people said having the grant had had a positive effect on the whole family, not only because the financial pressures were lessened for everybody but also because the beneficiaries themselves were happier and less stressed which had a knock-on effect. There were also more opportunities to do things as a family, such as go on holiday, have days out and go out for meals. One beneficiary, who had paid for the whole family to have gym membership so that they could go together, said that this had been of real benefit to all of them.

One beneficiary felt that the grant continuing would relieve the financial pressure of putting her children through university as it would free up general household income to pay for things like this. She said that this was particularly important for her as she had been *"written off"* as a child due to her disability – she wanted her children to get the opportunities that she did not get herself. Another person, whose children have health problems themselves, felt that the Health Grant would enable her to continue to be there for them:

> *"My aim is to keep myself as healthy as possible for as long as possible."*

Just one person felt that there was a negative side to the grant being only for the beneficiary and not for their whole family as it left their family with no security of their own:

> *"If I die, my wife will say 'I spent 30 years looking after you' – neglecting herself – and yet there's no security for a partner or for a spouse. That's the one downside of it that possibly been overlooked. Because if you think, a lot of us have been looked after by people – the cost to them, but [they] have nothing left or maybe nothing to show for it. If I wanted to flag something up to the Trustees...that would be an issue."*

Chapter 5

Health Grant ‘Model’ - Administration and Wider Application

The letter (dated March 2010) from the Department of Health confirming the first Health Grant, stipulated that the evaluation should provide evidence about *“the effectiveness of working through a national organisation to meet the health needs of other groups whose members have specialised needs and are geographically dispersed”*. It agreed that this would be achieved through *“a general review of the scheme as a whole and its administration, examining the costs and benefits of this approach, and the possible lessons for other patient groups”*. This chapter focuses on this aspect of the evaluation.

5.1 Attitudes to the Health Grant and the Spending ‘Guidance’

The majority of study group members saw the Health Grant as separate to their Annual Grant; only two people regarded it as part of their general income (including their Annual Grant). Some kept the grant in a separate account to acknowledge and reinforce this separation, and for accounting purposes: *“I used it for what it was for. I opened up an account for it and it is my ‘well-being account’ basically”*. Even where it had merged with other household income, several people said that they tried to maintain in their heads some sense of how it would be used for slightly different ‘health related’ purposes. *“I’m always aware of the need to justify spending on things for me, I’ve always been in that way of thinking.”* Most people said that they would continue to regard the Health Grant as separate from their Annual Grant.

For most people the expectation that it would be used for health related purposes did influence and inform how they spent the money, but many people stressed that they did interpret ‘health’ quite broadly. As one person put it:

> *“I see it as being about health in a very broad sense, as something there to help me feel better. I get very anxious and frustrated when I can’t do something physically, so in terms of my mental health it is very useful, but also it means we can manage”.*

Others described how they used the grant for ‘general well-being’ and for preventive purposes, rather than for narrow, ‘medical’ needs. They emphasised how important this was. As was noted in Chapter 3, several people also emphasised the value of being able to use it to support emotional well-being and to reduce stress and some people also included the impact on their family/carers in their interpretation of ‘health needs’: *“It’s about what helps me or my family.”*

A few people evidently needed some reassurance that the definition of ‘health’ was broad enough to encompass their needs. A small number said that they had checked things out with the Trust or compared with other Thalidomide-impaired people, and one person with a history of more severe mental health problems said their mental health practitioner had advised him that it would benefit him to get out and socialise more, and this enabled him to feel it was legitimate to spend the money in this way.

Most of the study group thought that the spending guidance agreed with the Departments of Health and issued by the Trust was sufficiently broad to cover their health related needs, and a couple of people commented that it possibly helped them to think more generally about how best to address their health needs:

> *"I felt they were very generous and I didn't feel restricted by them at all. I think they were well thought out and contributed to all aspects of health and well-being. For me they were good".*

Some also commented that they liked the fact that it was 'high level ' guidance and allowed a level of discretion because this demonstrated trust and treated Thalidomide-impaired people *"like grown-ups"*. However, this meant that there were some differences in interpretation of the guidance, for example, a number of people said they had used the grant on utility expenses to help keep warm, whereas one person believed that the guidance did not cover everyday bill such as gas bills, which she said she would have valued. Just two people said they would have spent it how they thought best regardless of any guidance, because they believed it should be a personal decision, and not dictated by the Trust or the government:

> *"Each individual looks at what direction they need to direct their finance at. That rests best with the individual."*

Some felt that guidance was necessary and important to ensure a measure of accountability and enable monitoring for the purpose of evaluation, and a few believed it could continue to be of value in making the case for the grant, beyond the agreed ten years. However, one person said he felt it was a *"PR exercise"* on the part of the government; he said the government had to put a *"label"* on it to signal to Thalidomide-impaired people and to other disability groups that the grant was on a health basis rather than linked to any other reason:

> *"I think that was a PR exercise from their* [the government's] *point of view - I don't really think they gave a monkeys about how it was spent... It's rhetoric, it's just language that's used to justify the payment.... Having said that I think most of the payment goes on that* [health related needs] *- about 95% probably - and they know that."*

By contrast, as was noted in the report from the first year of the evaluation, a number of people actively welcomed the spending guidance, with some saying that they felt it gave them 'permission' to spend money on their health needs.

In terms of how people regard the Health Grant, the responses were nuanced and thoughtful. Very few study group members said they regard the Health Grant as compensation; most see it as acknowledgement of their health related needs:

> *"I don't see it as compensation at all. I see it is as paying for the things I can't get from the health services more quickly or in a timely fashion or in the right way."*

There was also a suggestion that some people did not want to see it as compensation because this had implications for how they coped emotionally with what had happened – they did not want to live their lives full of bitterness:

> *"The government admitted that they did cock up in terms of their control of it [the drug]. I don't really see it as compensation but on one level I do. I don't really think about it - I use it to the best of my ability. There's not a pot of bitterness there with me thinking they should have done it a million years ago, though if I wanted to I could."*

However, several people felt it was in part 'reparation' or recognition that past governments were culpable in making the drug available and this was important to them:

> *"Bitter is not the word. The people in power now are not the people who made that situation in the 1950s...What happened to us has been covered up on a high scale. This has gone some way to redressing the balance, perhaps a quarter of the way. It's some recognition that we have been wronged...It's been acknowledged."*

5.2 Administration of the Health Grant – Views of Beneficiaries

As was noted in Chapter 1, for reasons of good governance and financial security, each year beneficiaries have to confirm that they wish to receive their Health Grant (and their Annual Grant). The grant is then paid directly in to the beneficiary's bank account. The majority receive their grants in the form of an annual lump sum but staged payments can also be arranged.

The overwhelming majority of study group members were very happy with the way in which the Trust has administered the grant, describing it as *"brilliant"* or *"spot on"* and in the very few cases where minor glitches had occurred these were quickly resolved. Two people felt that the correspondence related to the grant could be in plainer English and just one person wanted the Health Grant payments to be made automatically, without having to request them.

People particularly liked the flexible ways in which the Grant could be paid. For some having a lump sum in April was ideal, either because they liked to plan their expenditure ahead or because it enabled them to purchase higher cost items/adaptations. Others preferred smaller, staged payments because they were worried that they would be tempted to spend it too quickly or inappropriately if they had it all at once. One person explained that - *"It would be too easy to fritter it away"* and so he thinks about a specific need before he approaches the Trust to draw down the money. Linked to this, people welcomed being able to look at their Health Grant and Annual Grant 'accounts' on line. They also liked the fact that once a payment was requested the money came through to them very quickly. Only one person criticised the system saying it was *"parental control being exercised"* by the Trust.

Going forward, the majority of study group members wanted the Health Grant and the Annual Grant to be kept separate. Many highlighted the fact that the Health Grant is time limited and the overall fund is largely fixed (at least for the next ten years), whereas the Annual Grant is there in perpetuity and the overall level of payments is linked to the performance of the financial markets. Others said that combining the grants would be *"sending the wrong signal"* in terms of what the Health Grant is for. A few said that for them the Health Grant was a *"bonus"* or an extra help and they didn't want to rely on it as they did on their Annual Grant.

5.3 Implications of Administering the Health Grant for the Thalidomide Trust

In the first report from the evaluation it was noted that, although the system for administering the Health Grant is based on that used for the Annual Grant, the Trust has had to set up some new systems and incurred some additional costs.

5.3.1 Direct Costs

There were three main areas of direct cost:

Accounting arrangements – for the three year Health Grant, the Trust had, in effect, to build a parallel accounting system within their management information system and this had quite a significant direct cost. Going forward, the new ten year grant has also required the Trust to create a separate ledger and set up a new bank account which has also had a direct cost but this was necessary in order to keep the financial recording of the initial grant and the new grant distinct. More generally the changes to accounting arrangements have also created additional work for Trust staff.

Implications for the Trust's website – Because beneficiaries of the Trust are able to look at their own Health Grant and Annual Grant 'accounts' on-line via the Trust's website, having a separate accounting system for the Health Grant had knock-on consequences for that part of the website. There was therefore a cost associated with making the necessary changes.

Additional auditing and actuarial costs – As was noted in Chapter 1, the Health Grant was only made to Thalidomide-impaired people currently living in the UK. However, the beneficiaries of the Trust felt very strongly that all UK Thalidomide-impaired people (i.e. those whose mothers were prescribed Thalidomide in the UK) should benefit from the additional fund. It was therefore decided that overseas beneficiaries should have their Annual Grants adjusted to ensure that the money they received was equivalent to their Annual Grant plus what their Health Grant would have been. This created some additional direct costs for the Trust in terms of additional time needed from the Trust's auditors to ensure that the adjustments and offsets have been done correctly, and a slight additional complication to the Trust's regular three year actuarial review.

5.3.2 Indirect Costs

Perhaps the biggest costs to the Trust have been indirect, in particular the staff time needed to administer the grant and the time lost to other activities. Three main areas of indirect cost were highlighted:

- The time required by the Finance Director and his assistant to calculate the grants and then distribute them. This includes the work to plan for contingencies (e.g. increases in the number of beneficiaries or beneficiaries moving to a higher impairment band) and to move money between the main fund and the Health Grant because of the different ways each of the devolved administration paid the Health Grant money to the Trust (see below). The Trust already had governance and security systems in place for doing this but it nevertheless proved to be quite onerous
- The extra work involved in contacting beneficiaries about their Health Grants. The Trust does not have an automated system for payment. To protect individuals and prevent fraud, they always require a request from each beneficiary for payment. Going forward this is one of the areas which the Trust feels it may need to strengthen.

- Time needed by Trust staff, including the HealthLink team to respond to individual beneficiaries questions about the use of their Health Grants, and support beneficiaries who lack capacity. In addition, because the Director and Finance Director have had to commit time to Health Grant related work, some of their work with individual beneficiaries on welfare issues has had to be picked up by other staff.

One of the main challenges for the Trust (in terms of staff time and resources) has been dealing with the four different Departments of Health (in England and the three devolved administrations). The contractual arrangements and paperwork for each of the DHs has differed, as has the payment arrangements. For example the English DH gave the Trust all the Health Grant money up-front, NI made three annual payments, the Scottish DH made two payments, whilst the Welsh DH made four staged payments. The fact that the Trust has a substantial main fund, which they could use to smooth out any temporary issues related to the Health Grant fund coming in, was a major advantage which most organisations would not have. The four governments also had different reporting and monitoring requirements which created additional work.

At the outset the Trust set aside funds to meet the costs for the setting up and on-going administration of the first Health Grant. Over the three years of the first grant the direct costs totalled £387,228. It is difficult to quantify indirect costs but the Trust estimates that these amounted to £412,772, with the highest indirect costs being incurred in the first year when the grant was being set-up. Together the direct and indirect costs represent around 3% of the total grant of £26.4m. The importance of ‘Full Cost Recovery’ (i.e. securing funding for all the costs involved in running a ‘project’ including direct project costs and for a proportionate share of the organisation’s overheads[12]) is increasingly being recognised in the charitable and grant giving sectors. However, there is no ‘accepted percentage’ (as cost must be calculated for each organisation/project), and so whilst the cost of administering the Health Grant seems modest, it is difficult to make direct comparisons with other organisations.

5.4 Distribution of the Health Grant

The NAC, which is made up entirely of elected beneficiaries, have, from the outset, felt strongly that the Health Grant should be distributed according to impairment band. This is partly because of the long held view that funds should be allocated to beneficiaries on the basis of the damage that Thalidomide caused to them, not on their financial or personal circumstances. They were also concerned that any distribution system that was linked to needs or financial means would be bureaucratic, costly and intrusive. This view was echoed by a number of study group members and by the Trust itself. Trust officers explained that when the first Health Grant was agreed they felt there was never any question of distributing it in a different way to the Annual Grant. They listened to beneficiaries views, via the NAC, and decisions about the distribution arrangements reflected this. The new ten year grant is being distributed in the same way and on the same basis as the three year pilot grant.

Nevertheless, in this final year of the evaluation study group members were asked whether, in the light of the Health Grant being confirmed for ten years, there should be

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[12] http://www.biglotteryfund.org.uk/funding/funding-guidance/applying-for-funding/full-cost-recovery

any change on the way the grant is distributed. The majority of people felt distributing the grant on the basis of impairment bands was fairest and most transparent way but they acknowledge that it wasn't a perfect approach. In particular some people suggested that the bandings may not fully take into account the emotional damage caused by Thalidomide (e.g. not being able to have children) or 'hidden' damage which has been identified since people were placed in a band. It was also clear from the interviews that not everyone understands the banding system or even what band they are in.

However, a minority of study group members suggested that the distribution of the grant should not be completely based on impairment bands. They felt that in some way the distribution needed to take account of deterioration and/or problems that weren't evident when people were originally assessed. In particular, they raised two concerns. Firstly, in their view, when Thalidomide-impaired people were originally allocated to impairment bands, relatively little account was taken of internal damage (e.g. underdeveloped or missing organs or nerve damage), partly because the problems associated with this have often only come to light later in peoples' lives. The second concern related to deterioration or loss of function due to the wear and tear on peoples bodies. This was a particular concern for those in the lower bands who had worked, sometimes in physical jobs, for most of their lives:

> *"When I left school I worked in agriculture for many years because that's where I could get jobs and I put the deterioration I'm getting now down to that. I might be deteriorating quicker than someone who has never been able to work because my body has taken more of battering than most people."*

One person felt these issues were particularly significant for people with upper limb damage:

> *"I think they [the Trust] have got to address this in the next few years, especially for those of us with upper limb disability who tend to range from Bands 1 to 3. We are getting equalising effects through of loss of function in our arms, regardless of the legs. The distinction between Bands 1, 2 and 3 is largely based on the length of your arms, but if you lose the function of your arms it has a big effect on your life"*

Several study group members and the NAC noted that the Individual Beneficiary Review (IBR) system[13] is there to address issues such as significant deterioration. However, there was a suggestion that the IBR system might need up-dating or adjusting in order to deal with these issues effectively.

There was also recognition that if a significant number of people were to move up the bandings, then others would see their Health Grants (and Annual Grants) decrease but almost all accepted this. As one person put it:

> *"We all know the pie has to be cut so many ways. We have a strong conviction if someone is worse off than yourself then they need the money. People understand it's all for one and one for all."*

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[13] Beneficiaries are free to request an IBR at any time but their request has to be supported by a letter from their GP indicating that they have deteriorated or have additional problems. IBRs are conducted by a member of staff from the Trust with a Volunteer Visitor (a beneficiary trained to support other beneficiaries).

5.5 Relevance of the Health Grant 'Model' to Other Groups

In many respects the Health Grant is highly unusual. Its primary purpose is to help address the health related needs of Thalidomide-impaired people and yet many beneficiaries do, in part, see the Health Grant as a form of 'reparation', or at least a recognition of the part past governments played in them being damaged. So, given the nature of the Health Grant and the way in which it has been delivered through the Thalidomide Trust (which is also a unusual organisation), it might be assumed that the 'model' would be hard to use with other groups of people with rare conditions or specialist needs. However, there are features of the Health Grant model or underlying principles which are of relevance to other groups.

5.5.1 Discussions with Selected National Organisations

To examine this issue further the evaluation team held exploratory discussions with three national organisations with different origins, aims and resources – the MacFarlane Trust; the Motor Neurone Disease Association; and the CJD Support Network. As is noted in section 1.3.1, the purpose of the discussions was to explore informally how the Health Grant 'model' or aspects of it might be relevant to three very different organisation and their beneficiaries/members, rather than provide direct comparisons. The discussions were supported by additional web based information searches. Brief information about these organisations, the key issues faced by their beneficiaries or members, and how they approach the distribution of funds is provided below:

The MacFarlane Trust

During the late 1970s and early 1980s more than 1,200 people with haemophilia were infected with HIV through their clotting factor treatment - 800 of them have since died. People with haemophilia and HIV have significant health problems: HIV treatment affects bone density so that broken bones may not repair properly, which can cause osteoarthritis; this, coupled with bleeds into joints leads to joint problems and a loss of mobility; and 'ordinary' health problems are complicated or made worse by haemophilia and HIV treatment. The MacFarlane Trust exists to give help to people with haemophilia who have to cope with the effects of living with HIV infection, and to their families and dependents. Currently the Trust supports about 360 primary beneficiaries plus widows and dependents across the UK.

The Trust is entirely funded by the Department of Health. It distributes most of its funds through discretionary, means-tested regular payments to primary beneficiaries and non-infected widows, and through a small grants programme. Beneficiaries complete an annual 'census' through which their household income is reassessed, although payments can be changed in year if a beneficiary's circumstances change.

Motor Neurone Disease Association

Motor Neurone Disease affects around 4000 people in the UK at any one time. People with MND usually deteriorate very rapidly, often dying within two years of diagnosis. The MND Association covers England, Wales and NI (there is a Scottish Association with which they work closely) and has three main strands to its work:

- Funding research
- Campaigning and awareness raising

- Providing support to people with MND and their families

Most of their funding comes from charitable donations but they do currently have a three year grant from the English Department of Health which enables them to provide specialist wheelchairs where local wheelchair services are unable to respond appropriately or quickly enough. They have an equipment loan service (e.g. for things like Clos-o-Mat toilets, special recliner chairs) and provide grants for home adaptations where a local authority is unable to meet a person's needs quickly enough or where the funding provided is insufficient. Over the last three years the Association has spent £3.7m on these two areas of support. They also have 92 local branches/groups and they provide smaller amounts of financial support to people locally (e.g. help towards the costs of things like physiotherapy treatment, complementary therapies, and respite care). Requests for help usually come from people with MND or their families but health and social care professionals also approach the Association. They normally apply through a local group or one of the Association's regional workers, who often know individual/families and their circumstances, but for specialist equipment, a letter of support from an appropriate professional is required (e.g. from a Speech Therapist for communication equipment).

CJD Support Network

The CJD Support Network is a UK wide patient support group providing help and support for people with all strains of Creutzfeldt-Jakob disease, their family carers and professionals. Established in 1994 by relatives of people with CJD, it is now recognised as the leading charity for all forms of CJD. It provides information about CJD and promotes good quality care for people with the disease, by providing training, conferences, and good practice guidelines. It is also a campaigning body. The Network directly provides practical and emotional support to individuals affected by CJD and their families by linking families for mutual support, running a national helpline and giving small grants. CJD only affects around one in a million people but there is little 'lead in' to the disease and once diagnosed people decline very quickly.

The Network's grants, which are funded entirely by charitable donations, are small (under £200) and are intended to help with practical needs such as heating bills and funeral costs, rather than direct care. However, the Network does direct families to the CJD National Research and Surveillance Unit, which has a National Care Team and can provide access to a CJD Care Package. The package has to be applied for by a health or social care professional and is a sum of money to pay for additional local health and social care services. Compensation payments for people with New Variant CJD and their families, are dealt with by the NVCJD Trust which is managed by a firm of solicitors.

5.5.2 Lessons for Other Groups

The discussions with these national organisations, together with the interviews with Trust staff and the NAC representative, suggest that there are lessons to be learnt from the Health Grant for the distribution of funds to other groups. In particular the evaluation highlighted the following six key issues:

Systems for Allocating and Distributing Funds

It is clear that there is no 'ideal' or preferred system for allocating funds to beneficiaries or members. Organisations have different purposes and histories, and groups of people with rare conditions or specialist needs vary in terms of their priorities and cohesiveness.

However, there were a number of things in place in Thalidomide Trust and within the Thalidomide community which made the allocation and distribution of the Health Grant easier. The Trust was established to *"provide relief and assistance for those people born, in the United Kingdom, damaged as a result of their mothers having taken the drug Thalidomide (as manufactured by Distillers Biochemicals Limited) during their pregnancy"*[14]. So from the outset, one of its key roles is to oversee the management of the Trust Fund established as part of the legal settlement, and distribute Annual Grants to beneficiaries which are generated from this fund. As such, prior to the Health Grant it already had an established system of distributing regular payments to a relatively large group of people. This included flexible payment arrangement and on-line 'accounts'. For example, Thalidomide-impaired people have the option to receive their Health Grant in one lump sum at the beginning of the tax year or take in a series of smaller regular payments or request payments as and when they need them. Around a quarter of beneficiaries opt for staged payments and those that do can look at the Health Grant (and Annual Grant) 'account' on line.

Furthermore, in terms of the allocation of funds there is general acceptance within the Thalidomide community that the financial support people receive should be directly linked to damage which the drug caused. So the impairment bands (which were established as part of the legal settlement) in effect provided a ready-made basis for the allocation of the Health Grant to individuals.

With the exception of the MacFarlane Trust few, if any, national charities supporting people with rare conditions/specialist needs have anything similar but many do already have systems for assessing needs and/or means before giving a grant, which could be strengthened and/or adapted. In doing so, however, the Health Grant evaluation suggests three things need to be considered:

- The costs to the organisation of operating the allocation and distribution systems
- The level (and frequency) of information beneficiaries are expected to provide and how intrusive or onerous they find this
- The extent to which the allocation systems is understood and accepted by the majority of beneficiaries or potential beneficiaries
- The importance of an equitable and transparent system for distributing funds

Additional Administrative Costs

It is inevitable that any national organisation distributing a Health Grant type fund will incur some additional cost. As was noted in 5.3 there are likely to be additional direct costs associated with the distribution of the funds, accounting and monitoring systems, as well as indirect costs such as increased liaison with beneficiaries/members, staff time in overseeing new systems and increased reporting. However the Thalidomide Trust's experience suggests that an organisation's existing infrastructure, and the way in which the grant is given, can substantially affect the level and nature of these costs. For example, if an organisation is having to deal with more than one of the UK Departments of Health, the administrative burden can be reduced if contractual agreements, the

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[14] http://www.thalidomidetrust.org/

arrangements for the transfer for funds and monitoring requirements, are the same or at least largely consistent. The extent to which the organisation is expected to account for and report on the use of the funds can also influence administrative costs.

Wider Beneficiary Involvement

The Thalidomide Trust is slightly unusual in that it has been supporting a fairly static group of people for many years, and the arrangements for beneficiary involvement are well established. In particular the National Advisory Council, which is made up entirely of elected beneficiaries, meets twice a year; they have observers at the main Trustees meetings and representative on the Trusts Health and Welfare Committee. The NAC as a group is consulted on 'policy' issues and was certainly influential in some of the wider decisions related to the Health Grant (e.g. ensuring that UK beneficiaries living overseas received an Annual Grant 'up-lifted' to reflect what their Health Grant would have been if they were living in the UK and the percentage of the Health Grant held back each year for contingencies).

However, the active involvement of people with rare conditions/specialist needs (and/or their families) in the governance of the national charities which support them is common and now generally expected. The CJD Support Network is by its nature a user/family led organisation and the MacFarlane Trust has three Beneficiary Trustees Meetings and a Partnership Group open to all beneficiaries. The Health Grant evaluation suggests that this level of active involvement by beneficiaries is key to ensuring that the way funds are used and managed is responsive to the needs and wishes of the beneficiary community.

Specialist Advice and Support Systems

Although most beneficiaries involved in the Health Grant evaluation felt able to manage and use their grants without assistance, a number highlighted ways in which formal and informal advice had helped them make decisions or find the right equipment, adaptation or treatment. The Thalidomide Trust provides support and advice to beneficiaries in many ways but the two that were particularly relevant to the Health Grant were: *HealthLink,* which offers beneficiaries information and advice on a range of health and related matters, including health problems/health care, home adaptations/independent living; and the Trust's Independent Mobility Adviser. Many charities supporting people with rare conditions/specialist needs provide similar types of support and advice. For example the MND Association has *MND Connect*, an advice, information and support service for people living with MND, people affected by MND, carers and health and social care professionals. If a Health Grant type models were to be used for other groups, access to this specialist advice and support would be important in enabling people to use their grants to best effect.

However, one of the things which emerged from the Health Grant evaluation was the importance of informal advice and the exchange of information within the Thalidomide community. Some beneficiaries used social media to seek advice or information from other Thalidomide-impaired people. The Trust does not have an on-line forum (which many charities do, including the MND Association) but there is a well-used Facebook page. Others exchanged information at meetings or through personal contacts. Interestingly, these sources, coupled with the fact that beneficiaries had the freedom to use their Health Grants in the way that they felt best met their needs, had the effect of empowering people to seek out information and a number of them said that at the end of the pilot grant both they and the Thalidomide community generally were more knowledgeable.

Freedom in the Use of Funds

Until 2004, when the Annual Grant to Thalidomide-impaired people in the UK became tax exempt, beneficiaries had to demonstrate that they had used their grants for things related to their disability. This was a source of great resentment and as a result the beneficiaries who campaigned for the Health Grant were adamant that individual beneficiaries should not have to account for how they spent their grants. The Departments of Health took the brave decision to give beneficiaries the freedom to use the grant in the ways that they felt would best address their health related needs. However, as is explained in section 1.2, the Thalidomide Trust and the DHs did agree a set of 'health-related needs' which were intended to guide beneficiaries in their expenditure. This arrangement of freedom of use within guidelines is hugely important and brought many benefits, and there is no reason to assume these would not apply to other groups. In particular it:

- Empowered people to focus on their health related needs and think through what would make the most difference to them in terms of improving or maintaining their health
- Gave people choice and control over how the money was used which often had a positive knock on effect on their well-being and even their mental health
- Encouraged people to find information and become more knowledgeable about how to 'self-manage' their health
- Highlighted the fact that people with apparently similar impairments and related health needs will often address them very differently given the freedom to do so, and it is difficult for professionals or organisations to second guess this. As the Chair of NAC put it:

  > *"I think it is really important that, having recognised that everybody is different, they have got to be able to choose how they meet their needs. Some people will go down the PA* (Personal Assistant) *route, other people see that as giving up independence and go down the gadget route...Some have really got into IT but others don't feel confident about that and you can't say that one is wrong or right."*

- Kept bureaucracy to a minimum for both beneficiaries and the Trust, which in turn reduced the cost of administering the grant

Interestingly, the un-bureaucratic interface which the Health Grant model created between the beneficiaries and the Thalidomide Trust was in contrast to beneficiaries' experiences of Personal Budgets/Direct Payments which were often quite negative.

Selectively Replacing Some NHS and Social Care Services

Lastly, whilst it was intended that the Health Grant should not be used to meet needs that are or should be being met by the NHS, the inability of some services (e.g. the wheelchair service) to meet people's needs in an effective and timely way, coupled with local variations in provision, has meant that some beneficiaries did use their grant to pay for alternative provision. Similarly, other beneficiaries (particularly those with upper limb disabilities) found that some local authority social care services (e.g. adaptations and equipment) did not meet their needs effectively and so used their Health Grants to purchase alternatives or top up what was offered.

From a Government perspective this could be seen as a bad thing and something to be discouraged should a Health Grant type model be used with other groups. However, the evaluation would suggest opposite – similar grants could be given to other charities precisely to enable them to selectively replace services, particularly things related to independent living, mobility and communications, which often the NHS and Local Authorities do not deliver effectively to people with rare conditions/specialist needs. Given the small number of people in rare conditions groups and the infrequency with which many health and social care professionals will work with then, it is not surprising that they find it difficult to understand and respond to their needs appropriately. A grant targeted on particular needs and distributed through a national organisation with specialist knowledge (and a nuanced and informed understanding of their beneficiaries/members' needs), has the potential to deliver better quality care, more effective service delivery and possibly better use of resources. As the Chief Executive of the MND Association explained:

> *"They* [people with MND] *hardly have any life left and want to get on and live it but they spend such a lot of their time fighting bureaucracy and trying to get some of the basic things they are entitled to, but the systems isn't sufficiently responsive, and part of that is that there is such a lack of understanding of the disease and the disease progression, and the sorts of needs that people with MND have".*

Chapter 6
Conclusions

Over the three years of the Health Grant evaluation a number of clear themes have emerged. The final year of the evaluation has confirmed and developed them, as well as highlighting wider issues about the potential of the Health Grant 'model' for addressing the health needs of other groups of people with rare conditions or specialist needs.

The findings from the first two years of the evaluation clearly showed that Thalidomide-impaired people are experiencing deterioration in their health as a result of their original Thalidomide damage or because of the abnormal way they have had to use their bodies in order to compensate for missing or short limbs. They also highlighted the fact that people are experiencing new, previously undiagnosed problems, in particular numbness and partial paralysis. In the final year of the evaluation, concerns about further deterioration and new or additional health problems were again evident.

However, for many people the things they had been able to do or the lifestyle changes they had been able to make as a result of the Health Grant, were helping to either slow down this deterioration or at least enable people to manage it. Again, people had used their grants flexibly to purchase or put in place the things that they felt would make the most difference to their health and well-being, and the choices they made in spending the grants also helped to enhance their independence and reduced reliance on family members. Specifically, in the last round of interviews, the study group were asked to reflect on the impact that the Health Grant had had on their ability to manage their health or health related needs over the last three years. The response was overwhelmingly positive, with many people describing it as *"life changing"*, not only in relation to themselves but to their wider family.

At an early stage it was apparent that in using their Health Grants people were interpreting 'health' and 'health needs' very broadly, and were using their grants for both treatment and prevention, and to address wider well-being issues. However, at the end of the three year pilot people still saw their Health Grant as distinct from their Annual Grant, and continued to take note of the core purpose of the grant and the health-related needs categories agreed with the Departments of Health.

The announcement of the new ten year grant was universally welcomed, although there were mixed feelings about the grant being time limited. Many people were uncertain about their future health and support needs or were finding it difficult to come to terms with the prospect of needing additional support. Most only described their immediate plans for the use of their health grant. However, there was a strong sense of people wanting to *"future proof"* themselves or find strategies for maintaining independence if their circumstances changed. Here again, the importance of the flexibility of the Health Grant was highlighted, as people saw different ways to achieve this. More generally, the continuation of the Health Grant for ten years gave people a sense of financial security and the ability to plan ahead.

The 'review' of the administration of the Health Grant showed that because of the history and purpose of the Thalidomide Trust it was able to build on existing systems and processes to administer and distribute the grant. In particular, the ability to distribute the Health Grant in the same way and on the same basis as the Annual Grant (i.e. based on the impairment band the beneficiary falls into) was a huge advantage. The Trust was also experienced in handling large sums of money and these resources also enabled it to cope with the different payment arrangements adopted by the four Departments of Health. Nevertheless, the Trust did incur both direct and indirect costs.

The evaluation does suggest that the Health Grant ‘model’, or at least the principles which have underpinned it, could be used be used to help meet the health needs of other groups of people with specialist needs, although further research would be valuable. In particular, there may be scope to replace selectively some NHS and social care services, and so deliver better quality care and make better use of resources for people with very rare conditions. In doing so, attention would need to be paid to the acceptability and transparency of any distribution arrangements, the advice and support systems needed to back them up, and the additional administrative costs associated with both. There also needs to be recognition of the importance of wider beneficiary involvement in ensuring that the way funds are used and managed is responsive to the needs and wishes of the beneficiary community.

Lastly, in making the Health Grant to Thalidomide-impaired people, the Departments of Health took the brave decision to give beneficiaries the freedom to use the grant in the ways that they felt would best address their health-related needs. This has been crucial to the success of the Health Grant. Whilst the spending guidance or criteria for use may be different if a similar approach were to be used with other groups, the principle of flexible use within clear guidelines should be retained.

Abbreviation List

CJD	Creutzfeldt–Jakob disease
DH	Department of Heath
DLA	Disability Living Allowance
IBR	Individual Beneficiary Review
NAC	National Advisory Council
PA	Personal Assistant

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