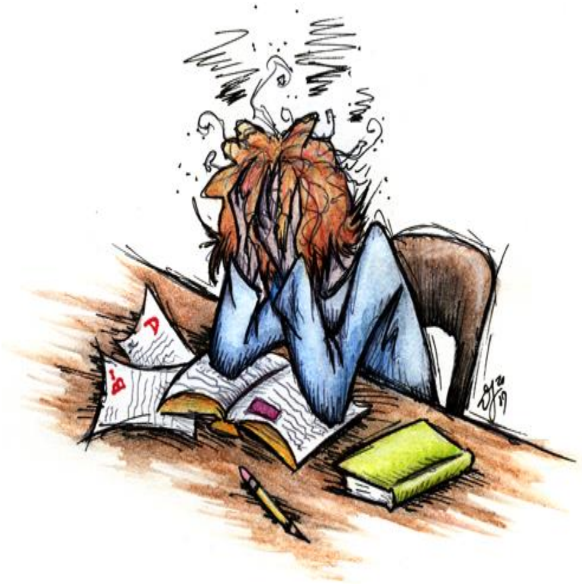
"The most soul-destroying thing…"



Supporting parent carers to claim disability benefits for their children and young people

The Amaze DLA PIP Project

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Contents

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Special thanks to all those parent carers who responded to the online survey or took part in the interviews and focus group. With thanks also to Amaze staff and volunteers who provided their views and feedback about the project, and to the young people who took part in the Amaze focus group.

Throughout the report we use the word ‘disabled children’ to include children and young people aged 0-25 years with a range of additional needs; and the words ‘parent’ or ‘parent carer’ as a generic term to include anyone in a ‘parenting’ role with a child or young person. The quotes included in the text are all from participants who took part in the research or Amaze evaluations, with the following colour coding to delineate their voices: parents blue, young people red, staff and volunteers purple.

Executive Summary

Introduction

This report presents findings from an independent study commissioned by AmazeSussex in November 2019, about the way in which its DLA PIP Project supports parent carers to make successful claims for disability benefits.

Amaze has been offering parents in Brighton and Hove (B&H) help to complete Disability Living Allowance (DLA) applications for the past 20 years. It does so, because the additional money makes a difference to how they can better support their disabled children and their families. In 2012, an independent evaluation of the Project highlighted why parent carers need help to complete applications, reporting on the significant strain and negative impact families caring for disabled children were managing. It shed light on the complexity of the application process and the skill involved in making successful claims. Then in 2016, the Project responded to the controversial and radically changing benefits landscape by expanding its service to assist parents to both complete applications for the newly introduced Personal Independent Payment (PIP) and help their young people prepare for the face to face assessment interview. The Project generates approximately £3 million additional income per annum for the families it helps.

This study was designed to assist Amaze to plan and develop their DLA PIP Project further and to better understand if and how the expansion of the Project was meeting the range of parent carer need. It provides insight into significant aspects of the DLA PIP Project including the experience of and barriers to applying for disability benefits, the complex nature and issues arising from the way the project is delivered, and the difference successful claims make to family life.

Methods

The research used a mixed methods approach and included parent carers, staff and volunteer's perspectives on their experience of the DLA PIP Project. In total, 131 parent carers responded to the online survey, 6 parents were individually interviewed, 7 parents attended a focus group, and 2 Project volunteers and the Project Co-ordinator were interviewed as well. All parent carers involved had children aged between 0-25 years with varying specials needs and disabilities. Desk research was completed, and a secondary analysis of existing survey materials routinely gathered by Amaze for the year 2018-19, were also reviewed.

Key Findings

There is good reason for Amaze to be proud of its DLA PIP Project. Our findings conclude that the Project is successfully supporting parent carers applying for disability benefits for their children and offering a differentiated service that meets their very diverse needs. The consensus among those taking part was that the Project had a major positive impact on family's lives. The complexity of the application process means that many parent carers do not attempt to navigate the system alone and instead rely on and need the expertise and help of the Project.

Conclusions

The DLA PIP Project sets out to raise and protect family income to sustain family life. Providing practical and emotional support helps parent carers to better meet their disabled children's and family needs. The way the Project assists parents and young disabled people to take up and complete successful benefit entitlements, is a convincing example of how this can be done holistically for the benefit of the whole family.

1. Parents highly rate the service.
2. Claims are successful and family income is increased.
3. Positioning the Project locally and in a voluntary organisation maximises the chances of increased take up, successful claims and effectively links parents to other types of support. Some parents would have given up without assistance from the Project, most were unsure about who other than Amaze could help, and none suggested approaching an alternative local organisation.
4. The Project workshops are well received and enabled some but not all to complete applications themselves.
5. Help to complete DLA and PIP applications ought to be available to parent carers wherever they live. The Project is well placed but not yet resourced to offer help more widely to areas outside B&H, either directly or as second tier specialist advice to others.
6. Parent carers in East Sussex were delighted to have access to help, but funding for this service ceases in December 2020.
7. Help to navigate the new PIP system and eligibility criteria and assist young people with assessment interviews is exemplary.
8. Young disabled people could not have managed the PIP assessment interviews well without help from parents and the Project Co-ordinator, which involves considerable extra project time.
9. It is difficult to decide who gets what service when all parent carers face disadvantage and warrant support.
10. The Project is effective and treasured by parent carers but is incredibly overstretched.

Recommendations

The DLA PIP Project is an excellent, highly regarded service that should *continue to offer its valued services to parent carers*. Deciding future developments may wish to consider these actions:

1. Promote the impact of increased income generated for ES and B&H families.
2. Secure new funds to sustain, grow and extend the Project locally and to other areas, including providing second tier expert advice to others, to generate more family income.
3. Encourage the local economy in ES and B&H to increase investment in benefits advice, to tackle family poverty.
4. Document the Project's exemplary approach to helping parents to support young people with PIP assessment interviews.
5. Recruit and prepare more staff and volunteers to share case work across the delivery team.
6. Identify, monitor and compare the inputs and outputs of the different types of services offered, to decide how best to allocate resources to some or all.
7. Make the baseline criteria for who is offered which level of support transparent.
8. Prioritise expanding Project staffing or cap the service in line with available resources.

1 Introduction

1.1 Background and Context

Around 8% of the child population under the age of 17 years in the UK (approximately 1,100,000), are living with a disability or a limiting longstanding illness (DWP Family Resources Survey 2019). Between 85% - 99% of these children live at home, supported by their families (Buckner and Yeandle 2006, Kagan et al 1998), who nearly always provide the love, emotional support and stability that maximises their children's potential and chances of happiness. But just a few facts and figures about the cost and strain of the experience of families detailed in the box below, paint a disturbing picture.

Family Costs and Strain

- The link between disability and poverty is well established. Families have lower incomes than average and are disproportionately likely to live below the poverty threshold, dependent on benefits for part of their income (Papworth Trust 2018, Baldwin 2015, DWP 2013, Royston and Hounsell 2011).
- Families are particularly vulnerable to poverty because low income is compounded by high costs. Estimates for the additional expenditure when caring for a disabled child are between £56 and £79 per week (Melnychuk et al 2018), or an average of £581 per month (Scope 2019).
- The groups with disabled children and the lowest incomes are lone parents, black and minority ethnic families and those with disabled parents and disabled children in the same household (Joseph Rowntree Foundation 2016, Blackburn et al 2010).
- The idea that work is the best route out of poverty is hard to apply to families, when many have to give up work in order to care for their disabled children. It is extremely difficult to combine caring for disabled children with full time employment (Bennett 2009, Beresford and Rhodes 2008). Mothers are less likely to be working, and if they are, it will be part-time. Mothers and fathers are less likely to be in high income jobs (Buckner and Yeandle 2017).
- Families report that having extra income relieves financial pressures as they use the benefits to make daily living easier and less stressful.

Disability benefits were first introduced in the 1970's and then deliberately expanded in the 1990s as part of the 'welfare safety net' to both acknowledge and help meet some of the additional costs of living with a disability. A key objective of this reform was to better target funds to disabled claimants in most need (Daly & Noble, 1996). In contrast, Personal Independent Payment (PIP) was introduced in 2013 to replace DLA for people between the age of 16 years and state pension age and was part of a 2010 government plan to begin the process of reassessing and reducing DLA costs by 20%, and save the government over £1 billion by 2014/15 (Office of Budget Responsibility 2019).

We know that far too many families fail to claim the benefits for their children to which they have an entitlement. Or, they are awarded lower rates of DLA and PIP than get agreed at appeal, and which, if received, could improve living standards or lift many out of poverty (Butler 2018, Machin 2017). Successful claims also passport parents to additional benefits and schemes like carers allowance, tax credits, blue badges and more. Even the government's own estimates suggest that billions of pounds worth of benefits go unclaimed each year (Resolution Foundation 2018).

There are no current data sources or government statistics that reliably show the number of children and young people eligible for DLA or PIP. Nor are there government indicators or set targets for take-up levels, which could help to drive improvements at a local level. In 2018, Turn2us unofficially estimated that £1.3 billion of Carers Allowance (a passported benefit if your child receives DLA or PIP), goes unclaimed (Evans 2018). Our own analysis of the available data indicates that in B&H, in August 2019, there were 1,917 children and young people receiving DLA (DWP 2020 Stat-Xplore), while in January of the same year, the Government's School Data Service reveals 6,100 pupils with an identified need (1,213 with a Statement or Education Health Care Plan, plus 4,887 receiving Special Educational Needs Support (SEN)). Although it is not possible to know how many of these 6,100 pupils with disabilities and SEN would be eligible for DLA, the stark difference in the figures supports other data and research (Office of National Statistics 2017, Banks and Lawrence 2005), that reveal under-claiming and a high rate of applications that are initially turned down for eligible children.

1.2 The Amaze DLA PIP Project

Amaze has been offering parent carers in Brighton and Hove (B&H) help to complete successful DLA applications for the past 20 years. In 2018, this generated approximately £3 million additional income per annum for the 302 families it helped that year (Amaze Impact Report 2018). Given the snapshot of adversity and the level of underclaiming outlined above, it is not surprising that one of the earliest services the organisation initiated was the DLA Project.

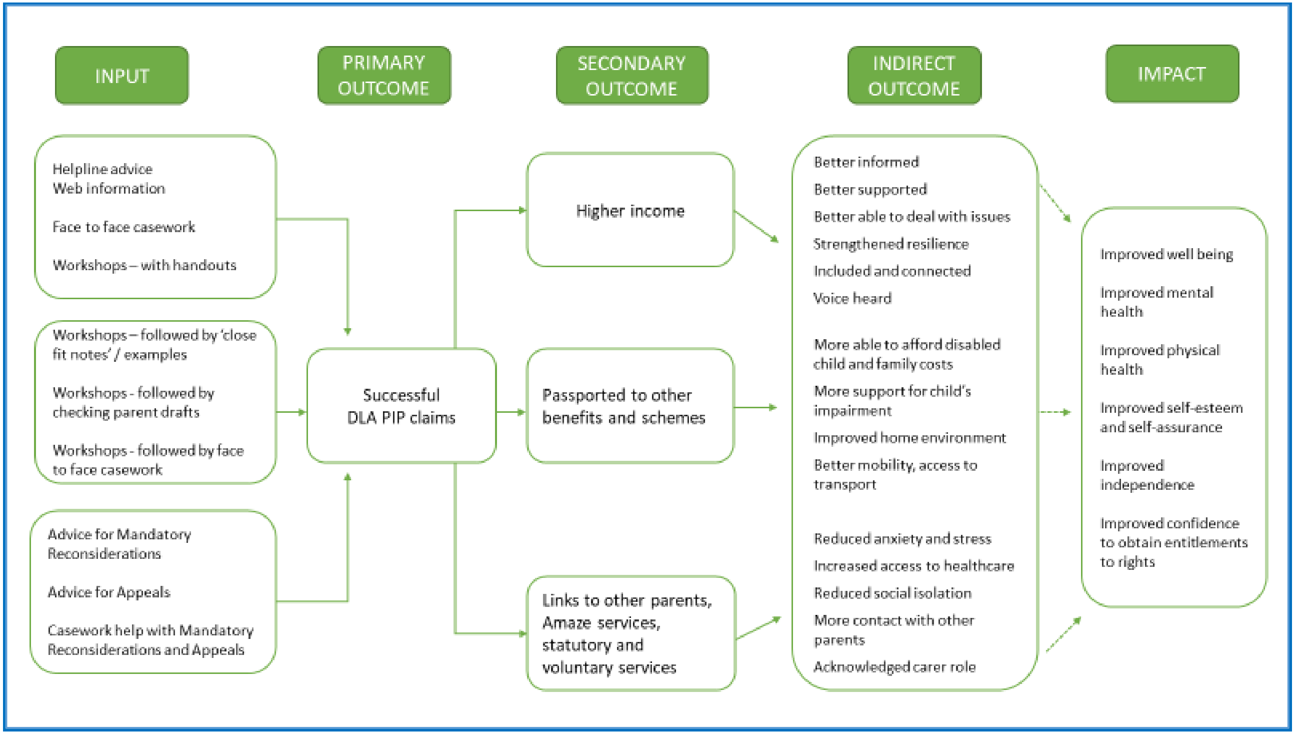
In 2012, an independent evaluation of the Project (Walker and Streatfield) clearly highlighted why parent carers need help to claim their entitlement to disability benefits. It demonstrated the significant strain and negative health, financial, social and psychological impact on families, shed light on the complexity of the application process, explained the skill involved in making successful claims, and reported on the essential and practical role the project plays in family's lives.

Since then, the Project expanded the way it offered the service in three ways. Firstly, in 2016 it responded to the radically changing benefit landscape by helping parent carers with children aged 16+, to complete applications for the government's newly introduced Personal Independent Payment (PIP), including assisting parents with their young person's assessment interview, a new aspect of the PIP application process. Secondly, following the information, advice and support work Amaze had started offering in East Sussex (ES) from 2017, the Project began supporting a small number of ES parent carers with DLA and PIP applications. And thirdly, over time, as demand consistently outstrips capacity, the Project has sought to reach more parents more fairly and effectively, by adding a newly designed and less intensive (arms-length) approach to its usual face to face casework and providing DLA and PIP parent workshops.

Key to understanding the Project, is that while its expertise lies in supporting parents to make successful DLA and PIP claims and increase family income, its broader intent is to contribute to improvements in health, social inclusion and family well-being. We know that families with disabled children face increased risk of relationship breakdown, physical and mental health problems, unsuitable housing and challenges with employment (Broach and Clements 2020, Contact 2012). And parent carers tell us that navigating their way through the maze of services is a frustrating, time-consuming, repetitive and distressing process (Prime Ministers Strategy Unit 2005). So, from its beginnings in 1998 , Amaze set out to establish a 'one stop shop' approach, so that parents avoided being passed from pillar to post and instead accessed more integrated information and help from one point of access that matched the reality of their needs and complex family lives.

For the DLA PIP Project, this meant that offering parents practical help to complete benefit applications, also aimed to provide a bridge for parents to other services and types of support that would improve better overall outcomes for families. The project rationale or 'theory of change' is summarised below.

DLA PIP Project Theory of Change



An ongoing challenge for the DLA PIP Project is to secure and decide how best to allocate its resources in a way that maximises support for a very diverse group of parents. Parent carers are not one tidy homogenous group but cut across socio economic, geographical, gender and ethnic divides, with varied individual backgrounds, resources, problem solving preferences, and challenges. While they share in common a distinct set of experiences as parents of disabled children (Contact 2012) and a high proportion live in the poorest neighbourhoods, there will always be some who need services more, some who face major access barriers, and some who need different types of help at different times. In this study, participants included parents with different and combinations of challenging life circumstances such as living solely on benefits, managing their own disabilities, mental and physical health illnesses, domestic violence and caring for more than one disabled child.

The task for the Project which is person-centred in approach and works alongside parents as partners in the application process, is to anticipate and adapt the service so that it can meet the changing and differing needs of the parents it supports.

1.3 Aims and purpose of this study

The study seeks to explore the effectiveness of the Project now that it has expanded to include a broader range of service provision. Amaze were keen to deepen its insight into the nuances of the DLA PIP Project and the study was designed to assist the organisation to develop the Project further. It combines desk research, secondary analysis of Amaze data, and an evaluation and consultation with parent carers, young disabled people, project staff and volunteers, about their experience of the DLA PIP Project. The researchers set out to find out if and how the Project was managing to meet the diverse needs of parents, by exploring parent carer experience of:

1. Potential barriers to applying for DLA and PIP
2. Receiving different types of help from the Amaze DLA PIP Project
3. The difference a successful DLA or PIP claim might make.

1.4 Methods Used

The research employed a mixed methods approach. The quantitative data was analysed using Qualtrics Data Collection and Statistical Package for the Social Sciences software, while the qualitative data was thematically analysed (Braun & Clarke 2006) to answer the research question and offer an indicative overview of service experience and impact. All desk research and data collection took place between December 2019 and February 2020 including:

- An online survey (with separate questions for those receiving help with DLA or PIP) sent to the 345 parent carers (308 Brighton and Hove, and 37 East Sussex) who had received a service in the year April 2018 - March 2019. In total, 131 (96 DLA, 35 PIP) parent carers completed the survey.
- A focus group advertised to the 71 parent carers who had received a PIP service were eligible to attend. Invitations were sent via email to parents on the Project's mailing list. The focus group was semi-structured, recorded and later transcribed. Small thankyou tokens and travel costs were reimbursed. In total, 7 B&H parent carers attended the focus group.
- A sample of 7 parent carers selected by Amaze for telephone interviews. Interviewees were emailed a Participant Information Sheet, Consent Form and an outline of the type of questions to be asked in advance. Individual interviews were semi-structured, recorded and later transcribed, small thankyou tokens were provided. In total, 6 parent carers (2 B&H, 4 ES) were interviewed individually by telephone.
- The Project Co-ordinator and 2 Project volunteers were interviewed face to face or by telephone.
- All participants agreed to the possibility of having their comments used in the final report.
- Both the focus group and interviews followed the same topic guide, which included questions about the experience of making an application, feedback about the service received, and views of the difference successful claims make, all of which are discussed in this report.

Parent carers responding to the online survey had children aged between 0-25 years, with different disabilities and SEN. Nearly all parents were aged between 35-59 years, most were women (92%), with 5% from black and minority ethnic communities, and 4% speaking a non-English language at home. A significant proportion of parents were living solely on benefits and this increased as children got older (18% DLA, 32% PIP). Only 60% of parents were in paid work outside of the home, and over half said this work had been negatively affected by their caring role (59% DLA, 52% PIP). One third of parents (27% DLA, 32% PIP) said they had experienced domestic abuse from a partner or family member and high numbers (40% DLA, 32% PIP) were managing their own disability, learning difficulty or long-term health problem. Parent carers taking part in the interviews and the focus group were mothers or grandmothers providing kinship care, and had children aged between 8 - 22 years, with different disabilities and SEN. A secondary analysis of existing survey materials routinely gathered by Amaze in the year March 2018 – April 2019, included:

1. Feedback forms completed by 105 (72 B&H, 33 ES) of the 127 (92 B&H, 35 ES) parent carers who attended 15 (11 B&H, 4 ES) DLA and PIP workshops.
2. Short postcard feedback forms about the service, completed by 76 parent carers.
3. Pre and post service ‘ladder outcomes’ forms completed by 85 parent carers.
4. Summary of feedback received from 7 young disabled people, aged 16-27 years, attending the Amaze young people’s PIP Focus Group.

2 Findings

This section explores the key themes that have emerged from the desk research, data collections, and secondary analysis of survey materials gathered by Amaze. The 38% response rate to the online survey from those who had received a service from the Project, compares very well to other psychological research and is sufficiently large to have confidence in the findings.

2.1 Barriers to applying for DLA and PIP

Parent carers, staff and volunteers reported the same obstacles to claiming disability benefits for children as documented in both the research literature (DWP 2018, Berthoud 2010) and the previous evaluation (Walker and Streatfield 2012). For example, parents mentioned uncertainty about eligibility, forms that are complex and long, difficulty deciding and getting supporting evidence, previous bad experiences of claiming, reluctance to ask for help, negative cultural attitudes to claiming or being labelled ‘disabled’, feeling embarrassed about mental health difficulties, poor language, literacy or form filming skills, and being too stressed to seek reviews or to appeal decisions. And it appeared to get more complicated for parents when young disabled people moved to PIP and were involved in the application process too.

> *“My son says there is nothing wrong with him and he doesn’t want the money, so the process is really hard.”*

Additionally, our findings point to barriers about knowing where and how to access help. When parents attending the interviews and focus group were asked where else they might get support with applications, most hesitated and were unsure about who to approach. Some parents said they would be reluctant to ask friends or family because they wouldn’t understand the detail, and others said they would not ask fellow parent carers because they were aware of the difficulties they would be going through, and so would try to complete the application themselves. A further suggestion was the Citizen Advice Bureau although parents commented that their advice was too general, while 2 parents thought they would approach national organisations such as the Downs Syndrome Association or the Autistic Society. The same question was asked of survey respondents and 60% said they would have to try to complete the applications themselves. About 20% (19% DLA, 23% PIP) said they would not have completed the forms alone or would have given up without assistance from the Project. There were only 4 suggestions for other places to seek help all of which were national disability organisations or Great Ormond Street Hospital. None of the parents in this study suggested an alternative local organisation and most of the young disabled people attending the Amaze focus group said they wouldn’t know who to ask either, although one said they would look online and another would ask Speak Out, a local advocacy group.

Studies about where people can go for benefits help, indicate that initiatives taken at a local level by voluntary sector organisations (or local authorities), rather than at a national level, are very effective ways of increasing benefits take up and successful claims, because the organisations are more accessible, known and trusted (Finn and Goodship 2014). Amaze is uniquely and well positioned to offer disability benefits support, as it works very closely with parent carers, holds a detailed knowledge of the experience of caring and an impressive understanding of the benefits system. With funding, it could extend this expertise to other areas and provide second tier expert advice to help other professionals to work with and refer parent carers for the Project's specialist support. For example, a small proportion of ES parents received help from the Project because Amaze was able to draw on funding from Henry Smith's (a chartable grant giving trust) to test the ES market, but this funding ceases in December 2020.

Helping to improve general misperceptions about eligibility would also improve the chances of parent carers making good claims and appealing poor award decisions. When parents completing the survey were asked how they found out about the Project, approximately 30% said from health, social care or education professionals. A larger number said via Amaze (40% DLA, 68% PIP). Hardly any parents were directed to the Project by family or friends, other community groups or the internet (between 2-6%).

Some parents mentioned how they had been discouraged from applying for DLA on the advice of professionals, teachers and friends, while others said they were put off or delayed making a PIP claim because of the negative accounts they had heard 'on the grapevine', about the system and the assessment interviews. We know from previous surveys that parents avoid claiming because they are misinformed, or think their children are not eligible, the task is too onerous, or the amount likely to be awarded is too small to bother (Contact 2016). This comment from the Project Co-ordinator suggests that some have a false perception that DLA and PIP are only for the most severely or physically disabled children:

> *"I think there is still a lot of misunderstanding about which children are entitled to DLA, and professionals make judgements about who they think ought to be claiming. It's still very much the traditional 'oh it's for those children who use wheelchairs or those in special schools', but about a quarter of the claims we do are for children with attachment and trauma issues, and nearly all of those children are in mainstream school often without a diagnosis."*

To illustrate the barriers further, we have summarised the difficulties parents mentioned into 3 broad and overlapping categories:

(i) The pressure to get it right
(ii) Forms with a terrible focus on the negative
(iii) An overall daunting and exhausting task.

(i) The pressure to get it right

Parent carers all talked about the anxiety and stress they felt about getting the application process right. They reported feeling a weight of responsibility about making a successful claim and were worried about using the correct language or unsure about what was important to include.

> *"I am their voice…it's such a massive amount of pressure on your shoulders."*
>
> *"There's something really scary about it, it's about their future as an adult and the importance and pressure of getting it right. If it's not right they won't get the support and will be with you forever and won't have any chance of independence."*

One of the volunteers added:

> *"Many young people haven't really got the degree of literacy to explain what's going on and they also get so used to it…a visitor can ask questions and find out more about it, you can try to draw out what they really have to cope and deal with."*

And some parents, as well as young disabled people, shared their view that the process seemed designed to deter or make it difficult:

> *"It felt like they were trying to trip me up."*
>
> *"I am gobsmacked that there is such a workshop to complete a form, why do you need a workshop to complete a form? The form is ridiculously inadequate. You don't have a workshop to fill out other forms, do you?"*
>
> *"It did feel like it was a constant trying to catch you out and it was confirmed in the assessment report, where it says, 'shook hand, had good grip so had no problem cooking'."*
>
> *"There was little understanding of mental health stuff, very limited understanding how badly it can affect all these activities and I felt like I had to prove all these things, which in a half an hour assessment is impossible."*

Parents seemed to feel culpable or carry the burden of unsuccessful claims. They did not refer to the possibility of assessors making poor decisions or the frequency with which initial assessments were incorrect and overturned via the appeal process. To demonstrate, for DLA applications in the quarter from January to March 2017, 61% of initial decisions were overturned at appeal (Office of National Statistics 2017), and not surprisingly, the 20% of parents in this study who had received help with DLA appeals, had found the support extremely helpful. For PIP applications, government statistics indicate that up until January 2018, while 84% of Mandatory Reconsiderations (MR) for new claims had resulted in no change to the award, 71% of appeals (which can only be heard after a MR) were found in favour of the claimant (Butler 2018). Consequently, helping parents to challenge poor assessment decisions is a necessary but very time-consuming part of the Project's service. In this study, one third of the PIP survey respondents had received information and support on MR and Appeals and all said they found the support extremely or very helpful. A total of 70% of these parents had face to face support with the remainder accessing a mix of workshop, telephone and email help.

(ii) The problem with forms that focus on the negative

The DLA PIP system is widely criticised for being based on a ‘deficit’ model, focusing on what children and young people cannot rather than can do (Davies et al 2017, Rooney 2009). While the application form obviously seeks to ascertain the personal, social and practical issues a disabled child or young person has, it is extremely difficult for a parent to dwell on the negative about their children. For example, parent carers have to comment on their children’s need for frequent or constant supervision, the risk and danger daily life presents to them, the level of care to help with everyday routines like washing, toileting, dressing, eating, personal hygiene, walking and being out and about.

> *“It’s just horrendous…it took me about 2 months to write up, it’s the most soul-destroying thing...to have to write. It’s all about the things your child can’t do…I was totally overwhelmed filling it in and it was so lonely and massive.”*

> *“If I did it on my own, I probably wouldn't document it as fully as I should. I wouldn’t put the appropriate weight to things as not wanting to dwell on it…it wasn’t nice saying all negative things about my child.”*

> *“It’s detrimental to my relationship with my son as I have to point out all the negative things in this face to face PIP interview in front of him.”*

Young disabled people also noticed the focus on the negative.

> *“I found it quite a struggle thinking of things I’m bad at, it got me down a bit, thinking about it*.”

Project staff and volunteers try to mitigate this overarching negativity by talking with parents about the things their children do well, taking time to ask them to share their children’s qualities and strengths, and help to normalise their reactions by pointing out that all parents find the forms unpleasant to complete. Young disabled people appreciated the way the Project Co-ordinator helped with the negative too.

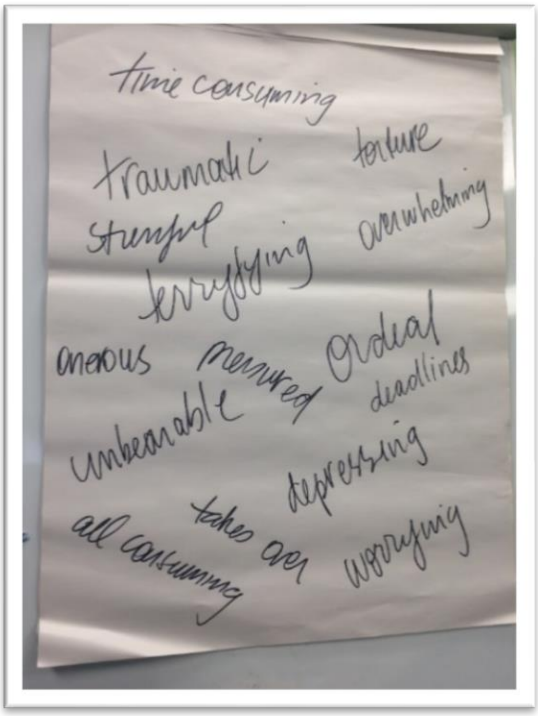
> *“…it is always a really difficult thing to go through all the things you find difficult. And Lizzie said you can have a little breather that’s ok, as sometimes it can get a little ughh a bit you know...”*

> *“Toilet needs are always awkward questions and a hard bit to go through and to sit through with someone who is not immediate family, Lizzie handles it brilliantly.”*

Despite the forms being 44 pages long, parents are not asked in the application process to comment on the social, environmental barriers their children might face. The DLA assessment process has long been criticised (Noble et al 1997) for aligning with the medical model, and researchers in the disability studies field agree that the introduction of PIP has done little to reverse this association (Roulestone 2015). The current process fails to take account of social barriers or emphasise the rights of disabled people. (The medical model views the disability as the defining characteristic, whereas the social model (Oliver 1983) widely accepted by the disabled community, focuses on the support that people with disabilities need and the disabling obstacles that they encounter).

(iii) A daunting and exhausting task

When the House of Commons called for written evidence for various inquiries into disability benefits, decision making and appeals, or valuing and supporting carers, critics concurred that the benefits assessment process is complex and unwieldy and that completing application forms is gruelling, confusing, time consuming and even traumatic for some (DWP 2018, 2010, 2008). The following flipchart was generated by parents attending the focus group, in response to being asked what it felt like to apply for DLA or PIP.



"I work full time and with the care I need to give at home, being overwhelmed and tired and with a new task of filling something in like this, I automatically start feeling depressed and shutting down."

There are other pressures that can make claiming difficult. For example, we know that many parents have their own disabilities or long term physical and mental health difficulties, a higher proportion are single parents, those from black and minority ethnic communities face the additional dimension of racism, a high percentage experience domestic abuse, some are caring for more than one disabled child, most are simply worn down and too many are managing combinations of challenging life circumstances. In this study, approximately 25% of parents were living solely on benefits, only 60% were in paid work with over 50% of these parents reporting that their work had been negatively affected by their caring role, almost 30% had experienced domestic abuse and approximately 35% were managing their own disability or long-term health problem. The following comment from one of the Project volunteers provides a further insight into the pressures involved in completing the forms:

> *"I went to see a parent earlier this week and although she is quite literate and has filled in the forms before, she has 5 children with additional needs and has her hands full. One of her children is only at school for 30 minutes a day, so where can she find the time to fill the form in?"*

Young disabled people also shared that they would not attempt the PIP assessment interviews or filling in forms without help from their parents and the Project.

> *"Very rushed and when you are talking about really intense and very personal things it felt like really like belittling when they say we aren't on that question any more, move on…I got so frustrated and the angrier you get the more you forget to say."*

> *"It feels like they rely on you giving up and testing you as much as possible to make you give up. If I hadn't had the support, I wouldn't have persevered at all."*

2.2 The experience of receiving different types of help from the DLA PIP Project

Parents were asked in the online survey to identify which of the 5 types of service they had received. (Parents were able to tick all that applied, and so the numbers do not tally with the total survey respondent numbers – 96 DLA and 35 PIP). Without exception, and irrespective of the type of service received, parent carers have indicated very clearly that the service is highly regarded by them. For example, parents who were interviewed or attended the focus group referred to the service using words such as excellent, professional, expert and thorough, and nearly all survey respondents said they would recommend the service to others (100% DLA and 96% PIP). Plus when Amaze sent out brief feedback postcards, using a Likert type scale of 0-5 (with 0 being very unsatisfied and 5 being very satisfied), it received 76 returns of which 96% reported feeling very satisfied with the service, and 100% very likely to recommend the service to others. For the 33 survey respondents who had help with MR or Appeals (20 DLA and 13 PIP), 29 said the information and support was extremely useful, and 4 said it was very useful. Notably, when parents completing the survey were asked if there was anything the Project could have done better, their overwhelming response was 'no', with this parent comment echoed by others:

Type of help received	**DLA**	**PIP**
Face to face casework >2 hrs	25	10
Face to face casework <2 hrs	19	7
'Arms-length' workshops	16	12
'Arms-length' telephone	41	12
'Arms-length' email	33	11

> *"Amaze is a lifeline, gives confidence, guidance, I can't think of a single thing that would make it better."*

Only 1 parent applying for PIP suggested the service would be better if it had brief information sheets with a simple overview, and 6 parents applying for DLA wanted more, suggesting improvements such as a drop in, staff to answer calls full time to avoid leaving messages, more timely follow up after initial calls, more access to face to face support, more written information about how to prepare for making an application and wider marketing about the availability of the service.

Amaze asked a sample of 85 parents to complete a pre and post service 'Ladder Outcomes' questionnaire, which is a Likert-type scale evaluation used to assess the indirect outcomes (summarised earlier in the Theory of Change box in Point 1.2). The results charted in the following diagram, indicate a positive mean improvement in all overall outcome measures. The strongest of these was parents feeling better informed, better supported and more able to deal with issues or problems. Parents also reported feeling better listened to and connected to others and emotionally stronger or more resilient, which is clear in the parent case study in Appendix 1.

Data Source: Amaze evaluation materials

For us, there were 3 dominant features arising from the qualitative data which we discuss here:

(i) The importance of the style, approach and way help was offered
(ii) The reason the arms-length workshops are enough for some and not all
(iii) The significance of including young people in part of the PIP application process.

(i) The way help is offered

The literature indicates that parent carers value the significance of the *way* in which practitioners relate to them, explaining that often it's not what they do, but how they do it (Mukherjee et al 2006). This was made obvious in the feedback from parents about the DLA PIP Project, with typical comments about how sharing the problem made the application process easier to deal with.

> *"It's exceptional, so useful. It came to crunch time and I was behind and she turns up at my door and there are psychological reasons also why I can't do it on time, she just said come on we are going to do it."*

> *"It stops me going into crisis…thankfully I live in a city where we have a service like this."*

Some parents specifically commented on how much they valued the Project Co-ordinator being a parent herself, as it positively role modelled that they too would be able to get the task done. Others noted the practical tips and welcomed working in partnership together.

> *"They don't come in as the expert but more we will get this done together."*

> *"I was told to keep a diary so we can identity what is normal to do for a 16-year-old…"*

> *"She has a record of when the forms are due and keeps giving us a reminder."*

Perhaps this comment from one of the volunteers illustrates the careful way the service is offered:

> *"I don't tend to fill in the form while I am with them, I concentrate on listening and make notes and then I take it home and write it up. They feel it's a weight off their shoulders…actually it takes a couple of days work."*

We located many publications that identified evidence on good practice ways to provide benefits advice and support, promote take-up and reach less resourced parents (Joseph Rowntree Foundation 2019, Care Act 2014, Finn and Goodship 2014, Kasparova 2007). The DLA PIP Project appears to have much of this in place. For example, whilst many people now have access to mobile phones and the internet, national guidance warns against advice initiatives being reliant on these communication means alone, hence the Project offers digital and face to face contact support and frequently sends information by post too. Evidence also points to improved accessibility when advice and information is provided in the manner preferred by those requesting it. In this study, while face to face contact seems to be the preferred option for many, it remains important to the Project to offer information and advice in a range of ways and formats especially given parent carers are a very diverse group. And taking information into communities through outreach activities or partnering with other organisations to provide community-based advice sessions has been shown to work well, hence the workshops happen in different localities and in partnership with host organisations such as schools. For example, the project has taken the service out to Traveller sites, but such work is time intensive and needs resourcing. More funding would enable more direct work and provide the Project Co-ordinator with time to develop further resources and test new ways to reach those parents who phone the Amaze helpline but then don't seek further benefits help, or those parents who the Project never hears from.

(ii) The reason the arms-length workshops are enough for some but not all

In 2016, the Project introduced DLA and PIP workshops as an additional way of helping and reaching more parents. Distinctly different to face to face casework and referred to as 'arms-length' support, the hope was that workshops might effectively reach and offer more resourced parents enough information to get started and complete applications themselves. This would then free up time for the Project Co-ordinator and volunteers to prioritise face to face casework hours for less resourced parents and helping with time-consuming MRs and appeals.

The workshops provide information and handouts, relevant examples via 'close-fit' notes, practice activities, the chance to meet fellow parents, links into other Amaze services and the offer of ongoing support if needed. Parents evaluated the workshops very highly and used and appreciated the offer to have their drafts checked afterwards. They found the information about different PIP eligibility criteria and the PIP assessment interviews very helpful, valued both the link to other Amaze services and the chance to meet other parents especially in small rather than large groups.

> *"I saw the [DLA] workshop advertised … so I thought I would go to get help to complete it. I put in an application as a result of going. I took loads of notes and we got lots of really helpful hand-outs. Absolutely the workshop helped me make a thorough claim…there was something in the workshop that shows what the assessor needs to know."*

Amaze's routine evaluation includes a parent feedback questionnaire completed at the end of each workshop, and the results indicate the benefit of attending. Of the 127 attendees, 105 returned the questionnaire and their responses to 4 of the key questions are summarised in the following table:

After attending the workshop parents felt....	Strongly Agree	Agree	Disagree
Better informed	90%	9%	1%
Better equipped	79%	17%	4%
Sense of being included	81%	19%	
More positive going forward	74%	26%	

Data Source: Amaze evaluation materials

Of note, is that some parents who had attended workshops, had found it too hard to do the applications alone and took up the offer of additional follow-on support after the workshops. Follow-on support varies and can include: sending parents examples via 'close-fit' notes; reading, editing and providing feedback on their initial drafts; reminders and help to know how to locate and include copies of supporting evidence; prompts to make a copy and post the forms by special delivery; making further contact 6 weeks later to enquire about the outcome (which is when it can become clear that applications have never been sent off).

Of the 131 survey respondents, 16 had attended a DLA workshop and 12 had attended a PIP workshop. The table summarises the type of help these 28 parents accessed in addition to going to the workshops (respondents were able to tick all services they had used hence the numbers do not tally with the respondent total). It appears from this sample, that a significant number of parents needed more than a workshop to complete a claim. Monitoring and comparing award outcomes in relation to the type of service offered in the future, could help to assess any potential link between award decisions and the type of service received. This is likely to require identifying how many hours are involved in offering each type of service. For example, we heard from the Project Co-ordinator, that depending on how well the forms are completed, it can take between 1-4 hours to read and edit applications that parents email to be checked. While one volunteer explained that even uncomplicated face to face support that does not require chasing supporting evidence can take two full days to complete, there are other examples of face to face casework that involve many home visits or the use of interpreters that have taken hours and hours to finalise. For example, the Project Co-ordinator spends 15% of her time assisting non-English speaking parents to complete applications or challenge decisions made by the Department for Work and Pensions, with parent accounts of the service they received with the aid of interpreters, summarised in the two case studies in Appendix 2.

Workshop Attendees – 28 respondents	DLA	PIP
Workshop PLUS >2hrs face to face support	4	3
Workshop PLUS <2hrs face to face support	4	1
Workshop PLUS arms-length phone support	7	8
Workshop PLUS arms-length email support	6	8

Interestingly, whether parent carers had received either a face to face or an arms-length service, they said the experience had opened their eyes to just how specialised a skill it is to know what and how to communicate their child's extra needs, which was further exacerbated when their DLA claims changed to the new PIP system. For example, albeit a small sample, 11 of the 13 parent carers interviewed, said they would not do it alone next time and would seek Amaze help again, because it is so hard to do alone.

The literature indicates that a major barrier to people applying for benefits, is reduced availability for face-to-face contact to discuss and apply for them (Finn and Goodship 2014). While the workshops go some way towards offering personalised contact, they involve less face-to-face contact than a casework service provides. One of the project volunteers had this to say:

> *"It's much more personal meeting face to face and I get a more complete valuation and it's about forming a liaison really…I can pick up important points when you're face to face. I think they* [parents] *must feel they are getting better support than just on the phone or some other method, there's nothing like communication face to face is there?"*

The capacity to complete applications is dependent on many factors that may not be openly shared or easy for staff and volunteers to detect. For example, parents may not feel able to reveal things like language or literacy difficulties, pressures at home, problems with thinking or organisational skills, deterioration in their child's condition, strained household finances or domestic violence. The general negative impact and disadvantage parents caring for disabled children experience is well documented and widely understood, and all parent carers are under-resourced and managing various levels of risk, which can make it very difficult to know who to offer what to. It may not be possible or a good use of Project time, to strictly manage a threshold for different levels of service.

The Project's assessment of need and the consequent type of support allocated relies greatly on the experience of the Co-ordinator, but there are situations that change quickly or are impossible to predict. The Project could consider identifying those who have already received casework help once, (and hence acquired some application experience), and offer those parents less intensive help via email, phone or workshops next time around. It could also be useful to monitor and evaluate the level of extra help parents seek after attending workshops. However, the move from DLA to PIP, and the frequent, unanticipated changing circumstances for children and their parents suggests the Project will always need to offer casework support flexibly.

Before completing this section, it is important to note, that not all the parents we spoke with in the interviews and focus group, needed very much follow-on support. Some found the workshops enough to get started while others completed the application process without any further Project help at all.

> *"She sent me quite a lot of 'close fit notes' and I just did tiny cuts and pastes which gave me a framework for getting going. I did my claim on the basis of the workshop and she tweaked it."*

And irrespective of how much follow-on help parents needed, they were very appreciative of the chance to meet others in a similar situation and felt the workshops gave them an important link to the rest of the organisation's work.

> *"It's always good when you are a special needs parent to meet others in the same situation, it's quite lonely and I can't get out much."*

> *"It was a great help that we had an interpreter...If we had applied on our own, we would not have stood a chance...**On top of this**, Lizzie applied for Compass Cards* [Concessionary Leisure Pass] *for all 3 children."*

(iii) The significance of including young people in part of the PIP application process

In response to the changing benefits landscape, the DLA Project expanded its service to include advice and support for making PIP claims (becoming the DLA PIP Project). This also involved helping parents to support their 16+ children for the required PIP assessment interview. Since the introduction of PIP, benefit take up has been adversely affected, and the widely criticised changes appear to discourage and make it more difficult for people to access (DWP 2018).

Parent carers we interviewed in this study, said they really struggled to navigate from making DLA claims to applying for PIP. They cite a lack of knowledge or understanding about the eligibility changes and the points system used, concerns about the way in which the process stirs up worries about their children's independence and adult futures, and frustration with having to go through this new process at a time when so many other changes are taking place in their young people's lives.

> *"I was quite concerned because I knew it would be happening, I had to effectively chase each day with the forms and had to put in 'delayed' and had to get Amaze to support me and the timeframe that PIP allowed was tight…he has been on DLA for a long time, it was concerning not to know how things would change and how we would be affected in terms of the support he would receive financially."*

> *"They are all leaving school, there is so much change all in one go, [it's February] and we still don't know where our young people will be going in September, and there might be another battle and a pressure, that while you know where your child needs to be, you can't do anything about it...and to throw PIP in as well."*

Parents also shared significant anxieties about their children being called for face to face assessment interviews. They had a real reluctance to put on paper the things their children could not do which they certainly did not want to talk about or contradict in front of them at the PIP interview. Interestingly, they didn't explicitly mention concerns about the weight attached to the individual interviews. What was striking when we asked parents about the help they had received from the Project, was the strength with which they praised the way the Project Co-ordinator assisted their young people, which is also illustrated in the case study in Appendix 3.

> *"Because Lizzie involved us both in the original application, I knew what to expect more and my son wasn't concerned about it…it was like a practice run and made it less daunting when they called us for the interview….she sent me an information pack and reminded me to try not to let them do yes and no questions - he has cognitive issues, so if you give him provision to give yes or no answers he will just do that or just say the last thing or be led a bit."*

> *"It was very empowering for our son, he was included in the process. She was respectful, told him what she was writing down, asked about his cooking as an example, he understood the procedure better afterwards."*

Amaze conducted a focus group with 7 young people aged between 16 -27 years, who had received help to prepare for the PIP assessment interviews. Their overall feedback about the Project is captured in the following sample of quotes from young people:

What young disabled people said they find helpful about the DLA PIP Project:

Preparation for making a claim

- *"…what I found really helpful was Lizzie saying ok what specifically can you do like how long can you stand peeling vegetables and breaking it down like that was really helpful."*
- *"I didn't understand what most of the form meant, the form itself is really confusing… She like knew what they were asking for, whereas when you read it you don't know."*
- *"She helped me with a few phone calls and got on the phone to the PIP helpline, by my own volition I wouldn't have done it, she was saying you need to get on the phone."*
- *"When I first did my claim, I think I was 14…wouldn't have a clue to break down the questions, she has taught me how to do it, I wouldn't have got any money for sure."*

The individual assessment interviews

- *"Lizzie was very honest, like in a nice way, not like this is going to be so easy… she was like you just have to see how it goes and they might be horrible you just have to do your best."*
- *"I was sent an email with a scanned report and we arranged a meeting. Lizzie asked me more questions and with the assessor's report and how many points you get. She has this table for each section, what needs to be written."*
- *"She gives you a realistic picture of actually what is a really difficult stressful process and if you know it from the beginning then nothing suddenly surprises you and you are made aware of it and I think it's really important."*

The way the help is offered

- *"Helping you not give up is such an important part …feels so easy each time you get ripped down it's so easy to say oh screw this, I'm not doing this. Having Amaze helping you carry the weight of that and helping you continue is massive, I think I would have given up."*
- *"For me it's not the same face telling me the same thing all the time, it will be alright like my mum and dad do. It's someone new who understands it and if you don't get it, you can do this and this will be in place and that will be in place, someone boosting my confidence."*
- *"I would 100% recommend Amaze and would have given up without Lizzie."*

2.3 What difference does a successful DLA or PIP claim make?

Parents told us that DLA and PIP makes a significant difference, not just for their disabled child but for the whole family. For example, they said it helped them to meet the extra costs, improve the quality of their life and the functionality and comfort of their homes, helped to improve their physical and mental health, relieved financial pressures and provided eligibility and access to other benefits and schemes.

> *"Without the DLA we would 100% not make ends meet."*

Most parents responding to the survey reported successful claims. For DLA, 82% were successful, 3% were not, and for PIP, 61% were successful, 8% were not. At the time of completing the survey, close to 15% of DLA and 31% of PIP applications were still waiting a decision, some of which are likely to illustrate the long delays encountered with MRs and appeals.

Additionally, the Project manages to assist parents to make good quality claims that result in high rate awards. Using data collected by Amaze, the table summarises the claim results of almost 40% of the parent carers supported with applications in 2018-19, and clearly demonstrates how only a very small number of the 152 claims resulted in low rate awards.

DLA Awards	
High Rate Care	21
Middle Rate Care	81
Low Rate Care	4
High Rate Mobility	11
Low Rate Mobility	70

PIP Awards	
Enhanced Rate Daily Living	38
Standard Rate Daily Living	8
Enhanced Rate Mobility	25
Standard Rate Mobility	13

Data Source: Amaze evaluation materials

The desk research and data we collected revealed ways in which parent carers use the extra income which is summarised in the following box (Cordon et al 2010).

Ways parent carers use the additional income	
Supplies, equipment, kit to help Treatments, therapies, extra tuition Fares and treats to appointments Different or specialist foods, take-aways Improving the home layout, extra heating Help with general living expenses	Affording to go to work Short breaks, helpers at home, travel buddies Improving outside play spaces, toys Extra shoes, clothes, bed linen, washing Activities, social outings, family trips Extras for non-disabled siblings

> *"This week is a crisis week, so I've had to work less. It helps me not worry so much as it's back up for when I earn less."*

> *"We try to treat her to some nice lunch on those appointment days. I've had to change my hours at work to accommodate all these appointments."*

Parents responding to the online survey were asked to identify what difference being awarded the benefits had made to their family, by selecting all that applied from a range of 7 options. Some of the responses vary, for example, more parents receiving DLA said it helped to afford to buy support for their children while more parents receiving PIP said the benefits had helped to afford to run a car.

Interestingly, a high number of parents in both surveys, said that being awarded the benefits helped them to feel that they and their children were acknowledged and 'less hidden' from others. As in the previous DLA Project study (Walker and Streatfield 2012) and in Amaze's own evaluations, parents talked about the significance of the awards helping to validate their understanding of their child's difficulties. Overall, they said that having help from the Project, meant they felt better informed, better able to support and deal with issues related to their children's needs, emotionally stronger and resilient, more included and connected to other parents, and that their views were considered.

> *"I remembered when I first got the money, I felt sick, it's kind of a validation that my child is disabled… and it isn't just me being a neurotic parent."*

What difference has the award made to your family?	**DLA %**	**PIP %**
Can afford to pay for the basics	33	29
Can afford to buy the support our child needs	49	29
Our child/young person's needs are validated	43	34
We worry less about money	38	26
Can afford to run a car	13	23
We have accessed passported benefits	15	17
We have had a holiday	10	11

> *"It signals to college to help with the Education Health Care Plan, as everyone knows getting PIP means something".*

> *"It's crucial for my son long term as his needs won't improve, he'll need the support and the transition to being an adult it's really important, it's recognised how his condition impacts him, what his needs are."*

Not surprisingly, the things young disabled people said about the way PIP made a difference to their lives was a little different to the views of parents. This may reflect their different roles and responsibilities. For example, most young people at the Amaze focus group said transport was the key benefit, a few said PIP helped them to access fun activities and venues, with one young person saying it had changed their life.

"My family hasn't a lot of money and I can't get about without a car, so the PIP pays for the insurance and the entire car. When the car broke down there was money there, it wasn't like oh I have to stop going to school now, I could keep doing things. I would just be stuck at home and when I didn't have the money, we had to borrow money from grandma's savings."

"I got expelled from school and I couldn't go back and couldn't do my A-levels, I wasn't really well enough to go to school or sixth form. When I started getting PIP, I was able to take my exams separately and buy books and literally it enabled me to do my A-levels at home and then go to university. So, it changed my entire life, like hugely."

Given that disabled young people aged 16-18 were at least twice as likely as their non-disabled peers to not be in education, employment or training (NEET) in the year 2015-16, making successful PIP claims becomes significantly important (EHRC 2017).

3 Conclusions and Recommendations

Our findings conclude that the Amaze DLA PIP Project is effectively supporting parent carers and offering a differentiated service that is successfully meeting the diverse needs of parent carers applying for disability benefits for their children. There is good reason for Amaze to be proud of its DLA PIP Project.

3.1 Parents highly rate the service. Without a single exception, parents praised the quality of the support received. Words used included: ‘knowledgeable’, ‘expert’, ‘integrity’, ‘personalised’, ‘specialist’, ‘professional’, ‘impeccable’. The person-centred way in which the Project delivers its support was greatly appreciated. Parents confirmed the help was instrumental in successfully claiming their children’s entitlement to the non-means tested benefits. The information and help regarding additional passported benefits and schemes, and links to other services and parent support networks was also highly valued.

3.2 Claims are successful and family income is increased. The Project is having a major positive impact on family’s lives. Claims are successful, applications are thorough, and very few low rates are awarded. Parents reported that being awarded the benefits helped them to meet the extra costs of caring for their disabled children, provided relief from financial pressures, improved their physical and mental health and the quality of their family life. While the increased income is key, successful claims contribute to both parents and children feeling recognised or ‘seen’ by the wider world, with parents reporting a sense of acknowledgement for the work they are doing. Parents reported positive improvement on the indirect outcome measures, that is, they felt better informed, better supported, more able to deal with issues, emotionally stronger and resilient, better connected to others and that their voices were heard.

3.3 Positioning the Project locally and in a voluntary organisation maximises the chances of increased take up, successful claims and links to other types of support. Some parents would have given up without assistance from the Project, most were unsure about who other than Amaze could help, and none suggested approaching an alternative local organisation. Both the literature and this study indicate that initiatives taken at a local level by voluntary agencies, is a very effective way to increase benefit take up and successful claims. There are many barriers to claiming DLA and PIP and providing a take-up service that is ‘parent friendly’, trusted and accessible is vital, when making applications is an exhausting, de-skilling and stressful experience that parents avoid or delay doing. Parents were confident the Project helped them to do the best application possible and appreciated being bridged to other types of support. The benefits work provides parents with a ‘face’ and contact that makes it easier for them to link to Amaze’s other services.

3.4 The workshops were highly valued by parents and enabled some but not all to complete applications themselves. The workshops helped many parent carers to complete applications themselves, with the welcomed support of examples via ‘close-fit’ notes emailed afterwards. However, some needed more to get applications completed and sent off. It is unclear if offering workshops is efficiently freeing staff time to help new or less resourced parents as hoped. While the workshops are going some way towards providing a kick-start for parents to make applications themselves, the challenge is to manage those situations when the workshop service inflates into casework. Amaze could evaluate the resource implications of the workshop offer, by collecting data to assess the frequency and level of extra help parents seek after attending a workshop.

3.5 Help with DLA and PIP applications ought to be available to all parent carers. The Project is well placed but not resourced enough, to expand into new areas and offer second tier specialist advice to others. Misunderstandings and the wrong information about who can apply for DLA or PIP stop parent carers claiming or requesting MRs and appealing decisions. It matters that those in touch with parent carers are up to date with benefit eligibility and know who to refer families to for specialist help. The Project could provide services in neighbouring areas and offer second tier specialist advice and training to help other services work with and refer parents. This would require new funding and a workforce commitment to include routinely asking parent carers about their access to disability benefits. However, this seems unlikely when local authorities and voluntary organisations are absorbing major budget cuts and retracting services. None the less, it remains important for Amaze to articulate and frame the way in which the DLA PIP Project facilitates local authority and health targets. Encouraging the local economy to increase investment in benefits advice to tackle family poverty, is likely to be an ongoing task for Amaze.

3.6 Parent carers in East Sussex were delighted to have access to the service. A small proportion of ES parents received help from the Project. Their feedback was the same as others, with all providing consistently positive feedback. One difference noted in the qualitative findings, was that ES parents had low expectations of receiving any help at all. They (like other parents and young people) were generally uncertain about where else to go for help, and some were unconvinced that teachers, social workers or friends and family had enough specialist knowledge to assist. ES parent carers would welcome any type of help with disability benefits claims but the distances involved in servicing a whole county may mean that the small number of workshops running in ES are not reaching those parents with access challenges or additional needs. Demand for help to apply for DLA and PIP ought to be a key priority for the government and local authorities. Broadcasting the impact of generating increased income for parent carers in ES and encouraging the ES local economy to invest in specialist benefits service for parent carers is likely to be a further ongoing task for Amaze. The ES work was made possible by drawing on funding from a chartable grant giving trust, but this funding ceases in December 2020.

3.7 Help to navigate the new PIP system and assist young people with assessment interviews is exemplary. Moving from DLA to PIP applications is stressful and daunting for parents as the eligibility criteria and system for making awards changes dramatically. Parents and young disabled people said the service, staff and volunteers were 'gold star'. Parents of 16+ children were hugely concerned about their children being subject to confusing questioning in PIP assessment interviews and were right to worry that this might influence award decisions. They were unanimously positive about the way the Project Co-ordinator involves and supports their young people in the process. Young disabled people too were very positive about the help they received and could not have managed the PIP assessment interviews without support from their parents or the Project Co-ordinator. Assisting parents to help their children with the interview is having a significant positive impact on both parents and young people alike, but rests on the shoulders of just one worker, the

Project Co-ordinator. Amaze may wish to document and publicise this successful approach to assist them when recruiting and inducting new staff and volunteers and securing future Project funding.

3.8 Deciding who gets what service when all parent carers face disadvantage and warrant support is difficult. There is a plethora of evidence pointing to the negative impact and disadvantage parents caring for disabled children experience, and the evidence indicates that a major barrier to applying for benefits is not having face-to-face contact to discuss and apply for them. Consequently, Amaze could arguably prioritise its resources and only offer a face to face casework service. However, current funding levels impede the expansion of casework help. The service tries to allocate time and resources depending on need however this is complicated when workshop support inflates into time intensive casework. While reasonable to target resources to those who need it most, this is not straightforward when all parents are managing levels of risk and are under-resourced, or when the needs of parents are not apparent or openly shared. Amaze could consider offering a face to face casework service to parents once, providing less intensive help via email, phone or workshops for their future applications, and making this clearer in the service literature. However, the move from DLA to PIP, and the changing circumstances for children and their parents suggests the Project will always need to offer casework support flexibly. To further prioritise the most disadvantaged, it could consider making the baseline criteria for who is offered which level of support more transparent and widely understood, and it could consider capping the service in line with available resources. Amaze may wish to identify, monitor and compare the inputs and outputs of the various types of help offered, to decide how best to allocate its resources to some or all.

3.9 The Project is successful and treasured by parent carers but overstretched. The radical changes to the design and delivery of the disability benefits system over recent years have failed to make applying for DLA or PIP any easier. The changes have met with widespread criticism and the system remains confusing and hard to access and engage with. Unsurprisingly, many parents fail to claim DLA or PIP and some parents report scepticism about whether the government really seeks to increase family income. Without exception, parents have praised the quality of support they received and want more of it, but the Project is already over-run with demand, significantly stretched and over performing. This is unlikely to be sustainable as numbers seeking help increase, more parents move from DLA to making new PIP applications and help for parents to involve young people continues. In the face of these growing demands, Amaze may need to be careful about overtaxing its resources and prioritise ways to urgently expand its staffing or limit the Projects reach and capacity. To further prioritise the most disadvantaged, Amaze could make the baseline criteria for who is offered which level of support more transparent and cap the service in line with available resources.

In conclusion, this parent quote sums up the general parent experience of the Project very succinctly:

> *“If you don’t have an Amaze you just won't be able to fill it in, there are just so many barriers for people who are entitled to these benefits.”*

References

- Amaze Impact Report 2018 https://amazesussex.org.uk/wp-content/uploads/2018/11/7644-Amaze-Impact-Report-2017-18-FINAL.pdf
- Baldwin, S. (2015) *The costs of caring: Families with disabled children*, Routledge: London.
- Bennett, E. (2009) *What makes my family stronger.* Contact A Family: London
- Beresford, B. and Rhodes, D. (2008) *Housing and disabled children* Joseph Rowntree Foundation
- Blackburn, C., Spencer, N. and Read, J. (2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey, *BMC Pediatrics* 10.
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2):77–101.
- Buckner, L. and Yeandle, S. (2017) *Caring More than Most:A profile of UK families caring for disabled children,* Report. Contact: London.
- Butler, K. (2018) Disability Rights UK Response to the Welfare Safety Net Inquiry. Retrieved from https://www.disabilityrightsuk.org/news/2019/february/safetynetenquiryresponse
- Broach, S. and Clements, L. (2020) *Disabled Children: a legal handbook,* 3rd ed LAG: London
- Care Act 2014 (2014) Available at: http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted
- Corden, A., Sainsbury, R., Irvine, A., and Clarke, S. (2010) *The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research*, University of York.
- Contact (2012) *Caring more than most: A profile of UK families caring for disabled children,* Contact with the University of Leeds: London.
- Contact News and Blogs, Busting myths about Disability Living Allowance eligibility July 2016 Retrieved from https://contact.org.uk/news-and-blogs/busting-myths-about-disability-living-allowance-eligibility/
- Daly, D., & Noble, M. (1996). The reach of disability benefits: An examination of the disability living allowance, *Journal of Social Welfare and Family Law*, 18(1), 37–51.
- Davies, M., Porter, L., Lepps, H., Icardi, R. & Bicquelet, A. (2017) *Experiences of Personal Independence Payment (PIP) for People with Sensory Loss,* Research Findings 54, Thomas Pocklington Trust: RNIB.
- DWP (2020) Stat-Xplore: https://stat-xplore.dwp.gov.uk
- DWP (2019) *Family Resources Survey, 2017/18*: www.gov.uk/government/statistics/family-resources-survey-financialyear-201718; Office for National Statistics (2018).
- DWP (2018) *PIP and ESA Assessments*, Seventh Report 2017-2019, London: The Stationery Office Ltd. https://publications.parliament.uk/pa/cm201719/cmselect/cmworpen/829/829.pdf
- DWP (2013) Fulfilling potential. Building a deeper understanding of disability, *UK Today.*
- DWP (2010) *Decision making and appeals in the benefits system*, Second Report of Session 2009-10, London: The Stationery Office Ltd. Retrieved from https://publications.parliament.uk/pa/cm200910/cmselect/cmworpen/313/313.pdf
- DWP (2008) *Valuing and Supporting Carers*, Fourth Report of Session 2007-08, London: The Stationery Office Ltd. https://www.basw.co.uk/system/files/resources/basw_94634-3_0.pdf
- EHRC (2017) *Being Disabled in Britain: A journey less equal*, Equality and Human Rights Commission. Retrieved from: https://www.equalityhumanrights.com/sites/default/files/being-disabled-in-britain.pdf
- Evans, L. (2018) *Nearly £1.3bn of Carer's Allowance is unclaimed,* Turn2us. Retrieved from https://www.turn2us.org.uk/About-Us/Media-Centre/Press-releases-and-comments/Almost-1-3-billion-of-Carer-s-Allowance-unclaimed
- Fazil, Q., Bywaters, P., Ali, Z., Wallace L., and Singh, G. (2002) Disadvantage and Discrimination Compounded: The experience of Pakistani and Bangladeshi parents of disabled children in the UK, Disability & Society, 17:3, 237-253.
- Finn, D. and Goodship, J. (2014) *Take-up of benefits and poverty: an evidence and policy review, Centre for Economic and Social Inclusion*, JRF: York.
- Government School Data Service: https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2019

- Gray, P. (2014) *An independent review of the personal independence payment assessment*. London:HMSO. Retrieved from https://www.gov.uk/government/publications/personal-independencepayment-pip-assessments-first-independent-review
- Joseph Rowntree Foundation (2016) *UK Poverty: Causes, costs and solutions*, (Online), Retrieved from: https://www.jrf.org.uk/report/uk-poverty-causes-costs-and-solutions
- Joseph Rowntree Foundation (2019) *Framing Toolkit: Talking about Poverty*, Frameworks Institute and Joseph Rowntree Foundation. https://www.jrf.org.uk/report/framing-toolkit-talking-about-poverty
- Kagan, C., Leis, S., Heaton, P. (1998) *Caring to Work: Accounts of working parents of disabled children,* Family Policy Studies Centre**.**
- Kasparova, D., Marsh, A. and Wilkinson, D. (2007) *The take-up of Disability Living Allowance and Attendance Allowance: Feasibility Study*, Research Report No 442, Policy Studies Institute:DWP.
- Machin, R. (2017): Made to measure? An analysis of the transition from Disability Living Allowance to Personal Independence Payment, *Journal of Social Welfare and Family Law*.
- Melnychuk, M., Solmi, F., Morris, S. (2018) Using compensating variation to measure the costs of child disability in the UK. *The European Journal of Health Economics*, 2018, 19(3), pp419–433
- McLynchy, J. (2018) *Off Balance: Parents of disabled children and paid work,* Working Families and Unum.
- Mukherjee, S., Sloper, P., Beresford, B., Lund, P., and Greco, V. (2006) A *resource pack: Developing* a key worker *service for families with* a *disabled child.* York: YPS.
- Office of Budget Responsibility (2019) *Welfare trends report*, January 2019.
- Office of National Statistics (2017) *Tribunals and gender recognitions certificates statistics quarterly: January to March 2017.*
- Oliver, M. (1983) *Social work with disabled people*. Basingstoke: Macmillan.
- Papworth Trust (2018) *Facts and Figures 2018: Disability in the United Kingdom*
- Prime Ministers Strategy Unit (2005) *Improving the life chances of disabled children* London: The Stationery Office.
- Resolution Foundation (2018) Available at: https://www.resolutionfoundation.org/comment/boosting-benefit-take-up-is-critical-to-the-success-of-universal-credit-but-we-might-not-be-able-to-measure-whether-its-working/
- Rooney, T. (2009) *Valuing and Supporting Carers*: Fourth Report of Session, 2007-08, Volume 2 The Stationery Office Ltd.
- Roulstone, A. (2015) Personal independence payments, welfare reform and the shrinking disability category. Disability and Society, 30(5), 673-688.
- Royston, S. and Hounsell, D. (2011) *4 in 10: Disabled children living in poverty*, The Children's Society: London.
- Scope (2019) *The Disability Price Tag,* Policy Report, Scope.
- Shaw, J. (2014). *PIP: process, problems and pragmatism,* Child Poverty Action Group. Retrieved from: http://www.cpag.org.uk/content/pip-process-problems-and-pragmatism
- Walker, C. and Streatfield, J. (2012) *The Amaze Disability Living Allowance project…and the experiences of parents with disabled children living in Brighton and Hove*. University of Brighton.

Appendix 1

Case Study

I have 2 children - my daughter is 10 and my little boy is 8, but we keep getting new diagnoses. My hands are full. Both are still in nappies, and my little boy chokes so I buy baby food sachets. We have to pay for physio, occupational therapy, speech and language therapy, it costs a fortune.

It's hideous [applying], *it's the worst, even when I reapplied, I just thought, it's just horrendous. It took me about 2 months to write up,* ***it's the most soul-destroying thing to have to write.*** *It's all about the things your child can't do. Because we've been living with disabled children since I've become a parent, I now know I have to do it* [complete the forms] *in a clinical way to get the award we desperately need. In the early years, I didn't have any friends with disabled children and my children at that time didn't have a diagnosis.* ***I was totally overwhelmed filling it in*** *and it was so massive and lonely. Initially I only got the lower rate because I didn't know, I didn't have time, I didn't have any network with those other parents with children with disabilities.* ***I didn't know about Amaze, and in those days, it was just for parents in Brighton and Hove.***

Because I am determined, and I know they should be getting the higher rate I will always apply, and I won't give up. I am their voice and have to go through this horrible process. I know lots of people who don't do it or have given up. It makes a huge difference to our family.

I've just done the workshops, which were advertised at my children's school. I met 2 friendly people, and it was lovely to meet someone from Amaze. ***The course was brilliant. I learnt lots of interesting stuff.*** *It's such a massive amount of pressure on your shoulders. It's always good when you're a special needs parent to meet others in the same situation, it's quite lonely and I can't get out much. Lizzie is such a presence. What I found most useful is that she has an adult daughter with a disability, and it was good to see a good role model like her, it was really positive and showed me I could get through this. I took some handouts as it's always helpful to use this information. When we did the workshop, Lizzie was so wonderful and said you can email me the details and I'll check them. It's massive, so amazing and a massive piece of work on her part.*
I would say people definitely need help to complete this form as you need the right words.

I get high rate care and high rate mobility. *I remember when I first got the money, I felt sick, it's kind of a validation that my child is disabled. It's a double-edged sword, that my child does need so much help and support...it isn't just me being a neurotic parent. I got Carer's Allowance because they get DLA. We can have 2 Blue Badges but we have never applied for them, that's the final straw for me, I just can't do it and we had an awful experience in a car park so it would have been worse if we were in a disabled bay.*

Appendix 2

Case Studies

Arabic speaking parent carer
انا ام لثلاث اطفال،اكبر اطفالي من ذوي الاحتياجات الخاصة.
جئنا الي المملكة المتحدة في نهاية شهر فبراير .
يشترط ان نقدم بعد ان نكمل اقامة لمدة سنتين فيDWP قدمنا لمعونة ذوي الاحتياجات الخاصة ولكن طلبنا قوبل بالرفض لان
المملكة المتحدة.
مخطئين ، وعاودت وقدمت طلب لمراعاة ظروف واحتياجات ابنتنا DWPولكن ليزي من منظمة أميز قالت ان ال
عند مقابلة ليزي اكتشفت ان اطفالنا الاثنين الاخرين من ذوي الاحتياجات الخاصة ايضاً.
نحن كلاجئين نشعر بالوحدة ولا نتقن اللغة الانجليزية ونعاني من اختلاف نظام الحياة هنا .نشكر ليزي على كل جهودها ودعمها
المستمر لمساعدتنا لكوننا جدد على البلد.
نتمنى ان يجد صوتنا صدى من خلال ليزي.

I am a mother of 3 children. My eldest child has a disability. We came to the UK last February. We applied for the DLA and our application was rejected because the DWP says that we have to be living in the UK for at least 2 years to apply. However, Lizzie from Amaze said the ***DWP has made a mistake****, and she did apply again and sent a request to consider our child's circumstances. When she met us, she discovered that our other 2 children have disabilities as well.* ***As refugees, we have felt extremely homesick, as we are unable to speak the language and the system is very different from back home****. Yet, we are very grateful for the continuous help and support we have received from Lizzie, as newcomers to the country. We hope that our voices will be heard through Lizzie*.

Hungarian speaking parent carer
Nagyon elegedettek voltunk Lizzie-vel es az Amaze-zel. Gyors volt es hatekony es a megbeszelt idopontokban mindig sikerultek a meetingek. Nagy segitseg volt, hogy volt mellette a tolmacs, aki ajanlotta ezt a szervezetet. Igy harman sikerult egy nagyon jo kapcsolatot kialakitani es rengeteg segitseget kaptunk. Ha sajat magunk igenyeltuk volna, semmi eselyunk nem lett volna. Sokmindent nem ertettunk vagy nem tudtunk volna ertelmezni, mert nagyon specifikus kerdesekkel talalkoztunk. Lizzie segitsegevel sikerult rendesen kitolteni a nyomtatvanyt, a hosszu oldalakat, helyesen. Igy nem volt semmi problema, mert 100% volt a kitoltes. Ez igy nem tudtuk volna kitolteni. Az alapjan lett kitoltve, amit mi mondtunk, ami a mi tapasztalatunk a gyerekekkel, szo szerint ugy volt minden leirva, ahogy az nalunk zajlik. Lizzie meg a Compass Card-ot is megigenyelte mindharom gyereknek pluszban. Oszessegeben nagyon faradsagos munkat vegzett, nagy segitseg volt.

We were very happy with Lizzie and Amaze. It was quick and efficient and we always managed to meet at the times we agreed. It was great help that ***we had an interpreter****, who recommended this organisation. Like this, the three of us formed a good relationship and we received a lot of help. If we had applied on our own, we would not have stood a chance.* ***We would not have been able to read or understand the questions****, because they were very specific. With Lizzie's help the long pages of the forms got filled out properly, 100% correctly. We could not have done that. The forms got filled out based on what we said, what our experience is with the children, they depicted our family life word by word.* ***On top of this, Lizzie applied for Compass Cards*** [Leisure Pass] *for all 3 children. All in all, she worked tirelessly and was a huge help.*

Appendix 3

Case Study

My son is 17 now and he used to get DLA as he has a life limiting and degenerative disease.
I wasn't going to apply *[for PIP] as I had heard such terrible stories. Plus, the possibility of him having to attend an interview was off putting and I really didn't want to put him through it – all that focusing on the negative, he would be extremely anxious. So, I considered not applying.*

I rang Amaze and they explained the service and ***I said I would prefer face to face help****. Lizzie came in the door and* ***my shoulders just dropped – it was like sharing the burden.*** *She doesn't come in as the expert but more we will get this down together. We were very happy to have her in our home, she came twice and sent it off for us. There was some to and fro to get the final version that both my son and I were happy with. We filled in the questions and I lifted some bits from the old DLA application. We decided what letters and the new evidence from GUYS Hospital we needed to get. Lizzie included my son in the process, well part of it.* ***She was very respectful****, told him what she was writing down, asked him about his cooking,* ***he then understood the process better.*** *Then the DWP rang me and asked questions about my application. It felt like they were trying to trip me up. I was able to challenge them, as a result of Lizzie briefing me and warning us. For example, they asked if he was out and about and got lost could he call you on the phone? I said, look, you have to understand what we are managing here, they have just found another brain tumour. He would not be able to get lost!*

Eventually we got a letter saying ***the award would be ongoing and we got the high rate****. It means I can pay for taxis to get him to college in the mornings, get some counselling for him, it helps towards some therapies and he has an amount, so it helps him to manage his budget. And on busy weeks or crisis times, I can afford to take time off work, or get a take-away - it can just take the pressure off. It helps me not worry so much, it's back up for when I earn less and it signals to the college and helps with the EHCP, as everyone knows getting PIP means something. I don't know where else I would have gone,* ***I don't know what we would have done without Amaze****.* ***It was so good to hear someone say, 'you deserve this benefit, you have a right to it'***