

Help in Hand Project

January 2012-December 2014



1. Introduction

Help in Hand was based on pilot projects and research which clearly demonstrated the need for raising awareness and providing support for parents of disabled children in claiming Disability Living Allowance (DLA). Two local pilots had mirrored the results of existing research in evidencing need, showing not just financial outcomes but also the positive impact such support has on health and emotional wellbeing, social inclusion and relationships for the whole family. The project was funded with support from the Lloyds TSB Foundation for England and Wales and the Welfare Benefits Unit who delivered the project.

The brief for the Help in Hand project enabled a very family-centred and holistic approach to the support given during the process of claiming DLA, taking into account the barriers which prevent many parents from claiming.

Demand for the Help in Hand service was high and very early on promotion of the service had to be curtailed to prioritise referrals. Over the three year project there were 327 referrals with a total benefits take up of £2 million. Feedback from parents confirmed that both the extra income, as well as the information, advice and support given during the process of applying for DLA made a big difference to them.

The Help in Hand project was very successful and it is hoped that some of the information and experience gained, and reflected here, might be helpful to others working in this field.

2. The Pilots and existing research prior to Help in Hand

The link between poverty and disability has been well documented and DLA is the main benefit for alleviating the situation for disabled children. DWP administrative data cited in *Out of Reach: benefits for disabled children* (2006) stated that well under half the total population of disabled children in the UK were in receipt of DLA.

In 2006/7 the North Yorkshire & York Welfare Benefits Unit funded a pilot project in the Harrogate & Craven area with the aim of raising awareness around DLA for children. The project ran for 6 months allowing us to try out a model of both signposting and supporting families to claim the benefits and tax credits to which they were entitled.

The pilot ran in partnership with Health Visitors, for identifying and signposting, and advisers at the Carers Resource, who provided the support and advocacy. The pilot saw over £49,000 in new income for families.

A Report by the Take-up Taskforce, Child Poverty Unit HM Government (2009) had acknowledged that many poor families are not taking up all the financial support to which they are entitled and recommended the development of ways to support local services to help parents access benefit and tax credits.

In 2009 the North Yorkshire Advice Service Partnership (NYASP) funded a mini feeder project called *Up DLA for children* and in 2011 the Joseph Rowntree Foundation funded a six-month project to undertake the same preparatory work in the City of York area.

3. The Help in Hand Project

The Help in Hand project brief was simple – to offer one-to-one practical support to families to help them claim DLA for their child and to provide advocacy and support to them throughout. The only targets referred to the number of referrals received and the amount gained in benefits.

(a) Barriers preventing claims

Particularly during the initial contact with parents the barriers to claiming were borne in mind, reassuring parents by talking through the issues known to put them off claiming.

Stigma – advising that DLA is a non-means tested benefit given to help with the well-documented extra costs of caring can help. This may involve talking about what these costs are and acknowledging parents' negative feelings about claiming money for caring for their own children and being labelled a "scrounger"

Accessing information – parents were supported throughout the process by being given all the information they needed at each stage – letters and leaflets would be sent before or after the home visit where necessary. Parents were supported to get the information needed from professionals and were encouraged to ring the Help in Hand

Co-ordinator at any point of the process if they needed further information or advice.

Long complex forms/juggling other demands – many parents told us that they found the DLA form daunting. Finding the time and energy to complete the form is difficult for parents who are often exhausted and stressed by their caring role - juggling work and caring, attending multiple appointments for their child, facing negative public attitudes to their child, sleepless nights and strains on family relationships.

At the beginning of the project all parents were given the information to empower them to take the necessary steps in the DLA process. However, it soon became apparent that problems were being met during the claim process. For example, some parents would forget to send for the form or were not at home when the project worker visited or had not opened the form prior to the visit to look at what information/paperwork they needed. Sometimes parents forgot to keep a copy of the form and the DWP said they had not received it.

As a result Help in Hand would offer to ring for the DLA form to ensure the date of claim was established rather than just take a blank copy. All parents received a letter confirming the date and time of their home visit and telling them what they could do to prepare (for example, keep a diary, get the statement page filled in, gather information and paperwork needed). If the form could not be finished at the home visit the worker would write down what still needed to be done; if the form was completed it could be taken back to the office to photocopy and send off proof of postage.

Depending on the child's disability it can also be very difficult to work out what information is relevant, particularly if the child's needs seem more behavioural than a physical inability to do things.

Most parents experience the form as very negative because it requires them to concentrate on all the activities or tasks that their child cannot do, and the problems they have, with no mention of their positive traits. Talking about this with parents before starting the form can help, pointing out that although it feels very negative at the time, the outcome is likely to be extremely positive and worthwhile, possibly for many years.

A lot of parents said they didn't know there were two components to DLA and that they didn't understand the eligibility criteria for each.

Parents found claiming the mobility component particularly difficult for children who did not have physical disabilities and the criteria wording 'severely mentally impaired' upsetting and confusing because they don't think of, or want their child labelled, in this way. Although their child's behaviour might well be disruptive and dangerous, again, for a lot of parents they don't think of it in these terms, it's their daily 'normal' experience with that child.

Parents expressed appreciation of having someone with the time and knowledge who could explain the terminology in an empathetic and non-judgmental way.

Having no diagnosis/not feeling the condition is 'bad enough' - the word 'disability' in the title of the form can be off-putting, either because parents don't think of their child as disabled, don't want them labelled as disabled, or because the child has a condition, such as asthma, and calling it a disability feels like exaggerating and adds to feelings of guilt.

Many parents whose children don't have a name or diagnosis for their condition/disability believe this means they cannot apply for DLA. By explaining that eligibility criteria are based on their child's care and mobility needs compared to another child of the same age often reassures parents.

Being turned down and facing appeals – if DLA has been refused previously, parents are often put off but having someone to guide them through the form increased their confidence in success. Help in Hand reassured parents by offering ongoing support with mandatory reconsiderations and direct referral on to another service for support with appeals if needed.

Too few advisers with experience of completing DLA forms for children –

Parents and professionals expressed how positive it was to know that there was a named worker available to offer families one-to-one help with completing DLA forms as previously they did not have access for help.

Some parents said they hadn't claimed previously because of a lack of support, others said they tried and failed so didn't bother to apply again. Some organisations helped but had long waiting lists.

David Brewster, Director of Ryedale Special Families said "We frequently come across families who despite having a child with special needs have never heard of Disability Living Allowance and as a result have missed out on claiming it. They have often been in regular contact with statutory services for example health, social services, Department for Work and Pensions or education. Families with children who have mild or moderate needs seem to stumble across Disability Living Allowance very late, if at all. When it comes to making a claim we find parents often need help and guidance".

(b) Home visits.

Offering to visit families at home proved invaluable, not just in terms of completing the form well but in giving the opportunity for more holistic support. Parents are more relaxed in their home and able to 'tell their story' and they have all the necessary paperwork to hand. Many parents of disabled children, particularly in rural locations, spend a lot of time, energy and money attending appointments with their child and they are very appreciative, and feel supported by, a service which offers them a home visit.

The project worker found it much easier to pick up on issues at home regarding equipment, family relationships and finances because it could be physically demonstrated/observed.

Childcare is often much easier for a parent to manage if the visit is at home – the child is in their own environment with toys and equipment, can be put down for a sleep, given something to eat or drink. This would be much more difficult to manage even if the parent was at home and the form was completed over the phone.

(c) Holistic service

The targets were clearly linked to reaching families and focused on DLA claim support. Simple, clear targets and the independence of the project meant that the project worker was able to listen to parents without directing them into areas that were not of direct concern at that point (such as, improving work prospects). This meant that parents could be offered support in the areas that mattered most to them, whatever their situation.

If in the process of completing the form parents identified issues they were offered advice and directed to relevant support. For example, if they talked about how worried they were about their child attacking siblings or dominating the parents' time and attention, Young Carers could be mentioned and/or respite care. Parents interested in returning to work were advised on help to find work or training that would fit in with their caring role and given information about carers' rights at work. Parents struggling to balance work and providing care were advised about the financial impact of reducing their hours and the earnings restriction for Carer's Allowance, or giving up work altogether and the benefits and grants they could claim.

The experience of the Help in Hand project worker, and allowing time for exploration of further issues during the process of completing the form, meant that the advice and information could be tailored to the individual and a natural part of the conversation – responding to the family's needs rather than trying to meet targets and tick boxes for funders.

4. Summary of Help in Hand outcomes

The project had one worker employed for 14 hours a week. The targets were 84 referrals a year with a benefit take up of £174,720. Over the 3 years the outcomes of 327 referrals and £2 million considerably exceeded targets. (See Appendix A-C for further information).

Initial awareness raising with key individuals and organisations was successful, with face-to-face contact and subsequent word of mouth information about the project being significantly more effective than distributing leaflets and mailing out information.

For example, in the early stages of the project the project worker had the opportunity to talk to a consultant paediatrician about Help in Hand whilst attending a conference. As a result the consultant started recommending Help in Hand to parents, advising them to claim DLA, and the project details were included in her assessment reports. This 'endorsement' from the consultant and her team gave parents confidence to ring and ask about DLA; it was also experienced as positive by the team (see Appendix D).

Many parents commented that they had found out about DLA and Help in Hand quite late on in their journey and were frustrated that the professionals they had seen had not mentioned it. There is no doubt that if the promotion of Help in Hand had been continued throughout the project a lot more professionals and parents would have been reached.

5. Evaluation of the project and the impact on children and families

All parents were sent an evaluation form – over a third (119) were returned. A common theme was the appreciation parents felt for the level of support offered by Help in Hand throughout the claim process which they found daunting, often at a time when they were also feeling overwhelmed with the circumstances surrounding their child's disability, diagnosis and care needs.

The feedback received also confirmed that many parents knew about DLA but had not applied before because their child had not had a diagnosis and/or they thought they were not eligible

Information given at home visits was valuable: Carers Centres, parent/family support groups, local and national support organisations, Family Fund, Educational and Health Care Plans, personal payments, respite.

Parents also said they felt more confident applying for DLA knowing that they had a named worker who they could contact at any time during the application process, which would continue through to appeal if needed. They also valued the follow-up offered as they did not always remember what level of care or mobility component was expected and wouldn't have asked for a reconsideration or applied for other benefits to which they were now entitled.

Verbal feedback from parents when they rang to pass on the DLA decision also reveals the positive impact on health and well-being for the children, and often the whole family (see Appendix D). This includes parents saying they have been able to afford play equipment, specialist toys, 1:1 classes for their disabled child as well as leisure activities for the whole family that were not previously financially possible. These activities made them feel more included in the things other families do and improve family relationships.

The families also reported health benefits such as being able to afford specialist foods/diet or healthier foods generally; also reduced levels of stress where a parent had been able to reduce working hours, even give up work or obtain respite care.

As Appendix B shows DLA is often only a small proportion of the total benefits gained – many families are paid extra Child Tax Credit and those gaining the middle rate care component are often also eligible to claim Carer's Allowance.

Feedback from parents (evaluation forms) on form completion support

“Was an incredible help that provided professional, helpful advice at a time when I was feeling overwhelmed. Made a daunting task bearable and more importantly successful. Was guided through the form, simplifying the questions and helping me understand what information was needed. Very kind, honest and professional lady who helped me enormously. Thank you.”

“Invaluable service ... it is so stressful to have to fill these forms in.”

“I found aspects of the DLA form confusing and difficult to interpret. I would not have completed it correctly without the help.”

“Good practical advice given in sympathetic manner”

“I don't think that I probably would have gone ahead and applied as it was so indepth... The DLA rejected my first application...Without this I wouldn't have claimed the DLA for my child.”

“I really don't think we could have adequately described B's situation.”

“Made to feel my issues were “real”. Thank you!”

“I would have included a lot less information and probably wouldn't have got the level of DLA we got.”

“Having a person who was able to help me fill the form in was so useful, dealing with the children is such hard work. I got emotional support and it was quicker with help. I was able to describe situations and discuss how to write them down. Brilliant, valuable service – I hope other families find you.”

“They seem to know what questions to ask to get the correct information required, excellent.”

“Help in Hand was utterly indispensable in helping me to decode the unfathomable DLA form and I cannot praise it enough. Please continue to provide the service, I cannot imagine how I would have coped without it.”

“Could not have sorted this myself.”

“We both felt very supported and comforted by someone who understood.”

Feedback from professionals was very positive.

“We did recommend that families applied for Disability Living Allowance ... most of them were unsuccessful. This wasn’t because their children did not have a high level of need, it was because the parents had got so used to devoting so much time, so much energy and so much effort to supporting their child’s needs, and putting their child’s needs ahead of their own, they lost sight of how much they were doing and considered it to be normal... What they tell us is without [Help in Hand] supporting them in this they really don’t think they could get through the emotional turmoil that filling in these forms causes them... A real support to our service... Getting the correct support to families facing the challenges of meeting the needs of a child with additional needs is so important. It means that the families can cope and carry on in what is sometimes very challenging situations”.

Consultant Community Paediatrician

“Families particularly value that you understand the needs of their children and can help them express this so clearly. They have repeatedly told us how much they value your support to fill in such difficult forms. We spend so much time encouraging families to see the many strengths their children have but to fill in this form they also have to think about the things their children struggle with which is emotionally challenging for most parents... My observation has been that input has made the process more fair as well – in the cases you have been involved in the evidence is presented clearly so the panel has made the right decision. *Autism Diagnostic Service and Specialist Children’s Services*

“we hear good things about you from the parents who have had advice from you, you certainly have been a big help!” *Family support group*

“we have had fabulous results from your intervention with our Family Carers, as a worker it was lovely to have the confidence to refer into a provision where we knew you would do your best for the client.” *Carers Resource*

“I am aware of the immense value your service has brought to many families who we have referred.” *Child Development Centre*

“I have referred several of my customers to you and you have changed their lives with the support you have given them.” *Support Worker, Housing Association*

“it is with sadness that I learn this service is no longer available to our families that we support. I would like to take this opportunity to thank you personally for all the support and advice you have provided to my staff team but most importantly to the many families in Selby.” *Senior Education Social Worker*

“supporting parents to describe their child’s needs honestly but in a way that leads to a successful application, a real skill. However, I think the other aspect is as important, if not more so. It has been very supportive for our families to have someone who understands how hard it can be at times and who is very supportive and absolutely not judgemental.”

6. Conclusion

It is clear that there are still many professionals and families unaware of, or needing support and encouragement to apply for, DLA for disabled children. Any future project might consider building in a clear awareness-raising role as well as the capacity to deal with the work this will bring.

Future projects could also look at how the advice and information offered could be cascaded amongst parents and support groups. Towards the end of the project, Help in Hand ran a workshop for a support group for parents of children with Down's Syndrome. The workshop was designed to teach parents how to complete the form for themselves. Help and advice was given on understanding terminology, eligibility and criteria. This increased parents' confidence in their ability to 'have a go' themselves, or even help each other, in the future. Some parents, whose children were now older, expressed an interest in being trained as 'mentors' to offer help to other parents filling in the form.

Help in Hand's findings and a recent Contact a Family and Family Fund report *Don't Miss Out campaign* (2014) show many similarities. Their report says that 59% of parents given one to one advice via the Contact a Family helpline did not feel the need for face to face support to actually complete the DLA claim pack. Whilst it is likely that some parents, given the right help and support, are able to successfully fill in a claim form themselves, the findings identify that 41% of the parents surveyed did need support. In addition all the families surveyed by Contact a Family had been given details of the project by the Family Fund, had made proactive contact (rather than being referred) and had identified themselves as having a disabled child; this suggests that the number of families needing face to face support with the form is likely to be higher.

Originally, Help in Hand envisaged using volunteers but this proved unrealistic within the project hours and setting. However, it is felt that part of a future project brief could include providing free training along with the opportunity to shadow the project workers on home visits. This could be offered to parents but also to students of law, occupational therapy, physiotherapy or social work wanting to gain experience and enhance their CV in exchange for a commitment to work as a volunteer.

The Help in Hand project was very successful both in terms of benefits gained and the support it offered to families. The project was commended by both parents and professionals and it is hoped that some of the information and experience presented here will help in some way to continue future support for families of disabled children.

Appendix A

Benefit	Cases in Period	Benefits Gained for Clients
DLA - High Mobility	25	£71,996.60
DLA - Low Mobility	123	£135,269.00
DLA - High Care	89	£363,366.80
DLA - Middle Care	132	£366,147.60
DLA - Low Care	15	£16,361.20
Total Benefits Gained		£953,141.20

Appendix B

Benefit	Cases in Period	Benefits Gained for Clients
	10	£0.00
DLA - High Mobility	25	£71,996.60
DLA - Low Mobility	123	£135,269.00
DLA - High Care	89	£363,366.80
DLA - Middle Care	132	£366,147.60
DLA - Low Care	15	£16,361.20
Carers Allowance	145	£439,101.60
Council Tax Benefit	3	£10,385.00
Child Tax Credit	204	£591,031.05
Other	4	£1,450.00
Total Benefits Gained		£1,995,108.85

Appendix C

Region	BenefitsGained
Craven	£13,537.20
Hambleton	£313,222.80
Harrogate	£68,187.20
Other	£19,435.00
Richmondshire	£327,766.20
Ryedale	£172,935.60
Scarborough	£372,958.60
Selby	£183,803.20
York	£523,263.05
Total Benefits Gained	£1,995,108.85

Appendix D

Verbal feedback given by parents at follow-up call to find out DLA decision

We got nearly a thousand pounds in back-payment and were able to buy this amazing **wooden play equipment for the garden** which we would never have dreamt of being able to afford otherwise, **it's made such a difference.**

We have been able to pay for **1:1 music lessons after school.**

He chews and ruins the cuffs on all his **clothes** and is always losing trainers, hats etc. so this money is going to really help with the cost of **replacing** things like this

We are just waiting for a brand new Vauxhall **car** to be delivered which has **the space we need to carry around all the equipment our daughter needs.**

I have **been able to give up the 3 cleaning jobs I was doing.** It was the only work I could find that was flexible enough to fit round all the medical appointments, calls from school asking me to come and pick him up etc. It was such hard work and I was so tired all the time, now I can concentrate on keeping the house clean and tidy, getting the shopping, caring for him and his brother and sister etc. **It's made us all more relaxed.**

I am now able to spend money on **buying the right kind of foods** to help with the healthy diet she needs.

He just **breaks everything all the time** – remote controls, computers, his sister's toys, phones etc. and this money is going to **really help with the cost of replacements.**

We are going to arrange for him to have **private swimming lessons**, he just couldn't cope with the group sessions because of all the noise but he needs the **1:1 attention** as well.

It's great, he's going to go to **judo classes and guitar lessons.**

We've booked **a family holiday.**

We were always stuck at home which made it harder but now the money means we have **been able to get the car back on the road and go out as a family more.**

We often see or hear about **toys or equipment that would help J** and now we are going to be able to order some of them.

I know it sounds ridiculous but I went straight online and order a whole box of his **fidgit toys** for him – he ruins them but gets really upset if they have to be thrown away, now I can just give him another one!

It is so hard as a single parent, I spend hours standing at bus stops and I have to take her younger brother which just doesn't seem fair but she needs to go to her club, it's important for her, now, especially in winter, **we're going to get a taxi sometimes.**