



The Amaze Disability Living Allowance project...

... and the experiences of
parents with disabled children
living in Brighton and Hove

An independent evaluation by Carl Walker
and James Streatfield from the School of
Applied Social Science
University of Brighton

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Contents

Key recommendations	3
Executive summary	4
Introduction to the project	7
Findings/discussions 1.	9
Experiences of parenting a child with special needs	
Findings/discussions 2.	19
Amaze and the DLA Project	
Appendices	
A. Acknowledgements to those involved	27
References	28

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Summary Recommendations



Recommendations were as follows:

- The importance and impact of the Amaze DLA Project on multiple facets of people's lives leaves little choice but to fully recommend the **continued funding** of such a crucial service and indeed its expansion geographically.
- If the DLA form is to persist in its current format then there needs to be a greater **commitment to supporting** the families who seek to make claims. Greater funding and support will allow organisations like Amaze to continue to develop to meet the changing needs of parents in a more sustained and holistic fashion. To fail to invest in these forms

of support is to potentially risk a greater public health expenditure through addressing the subsequent needs of the large numbers of parents who find themselves suffering mental ill-health as a result of the financial and social impacts of caring for a child with special needs.

- The DLA Project should be considered by commissioners as a highly **effective mental health intervention** for carers of disabled children as it helps validate their experience and begin to boost and support their resilience and self esteem, in addition to providing obvious financial benefits.
- **Further research** on the relationship between having additional parent carer responsibilities and poor mental health should be considered with a view to identifying what earlier support could be provided to families to build their resilience and reduce periods of depression, anxiety and stress.
- Current provision for the needs of parents whose children have special needs is nowhere near sufficient to address the multiple stresses, barriers and challenges that so powerfully impact on their mental health. Organisations like Amaze provide invaluable assistance but **further attention and resources are desperately needed** for a neglected public health issue. Further work is urgently required to address medical practitioners' understandings of the capabilities and functioning of parents of children with special needs.
- There needs to be a greater commitment on the part of the UK government to work towards **working environments** that are sufficiently **flexible** to allow the parents of children with special needs access to meaningful regular work, affordable childcare and greater home support and respite.

Executive summary

1.

Amaze is a registered charity active in the Brighton and Hove area. Their mission is to inform, support and empower the parents of children with disabilities and special needs. Their Disability Living Allowance (DLA) Project aims to tackle poverty and social exclusion. It aims to maximise the take up of disability-related benefits amongst families with disabled children in Brighton and Hove, by providing a trained volunteer to support parent carers to complete successful DLA applications.

2.

The purpose of this study was to draw upon the multiple stakeholders who use and administer the DLA project in order to

- explore the parenting experiences of the parents with regard to financial, social and psychological impacts
- examine the degree to which the DLA Project contributes to the financial, social and psychological needs of the families who use it
- explore potential improvements that could be made to improve user and volunteer experience

3.

Between February and May 2012, 16 semi-structured interviews were carried out with a range of stakeholders relevant to the project. These included the project coordinator, three volunteer project workers and 12 parents who had recently used the DLA Project. The children of parent participants ranged from age 3 to 15 and included a range of physical, learning and mental health disabilities. Thematic analysis was used to analyse the interviews.

4.

The combination of extra living costs and exclusion from paid work was found to exact a considerable toll on the wellbeing of parents. The presence of a child with a disability in the family appeared to increase the likelihood of severe hardship and financial strain. It was not uncommon for parents to describe their everyday lives as mired by constant anxiety over money and for this anxiety to be directly related to the nature of the costs of bringing up a child with special needs. Moreover several parents were quite explicit in terms of the way in which this had negatively impacted their mental health.

5.

The parents in this study outlined a number of different pathways that contributed to an often painful and debilitating degree of social isolation and loneliness. These included exclusion from the labour market, rejection by other parents and self-isolation due to the shame and embarrassment of their child's challenging behaviour. They included parents being practically isolated due to their incapacity to 'afford' a social network and because of other parents failing to understand the nature of the life of a parent of a child with very challenging and distressing behaviour.

6.

For some parents the sustained burden of vigilant care could be overwhelming. This extra care can include administering complex and continuous medical regimens, coping with challenging behaviour, and prolonged everyday tasks that require a greater time commitment, like toilet use, cooking and transport to and from school and hospitals.

Feelings of desperation, exhaustion, depression, suicidal ideation, anxiety and relationship breakdown were often the eventual outcomes of living a high vigilance life where parents are on 'red alert, day or night'.

7.

All parents noted problems of access to services where delays would last from months up to a year and a half. This contributed to considerable distress from a number of parents for whom an 18 month wait could have grave consequences for their children during key stages in their development. Many parents experienced a problematic relationship with their child's school at some point in their educational history. The pain and impotence of being excluded from the key discussions that concern their child's care could itself be incredibly difficult for parents, many of whom understand themselves as having a great deal of expertise to offer but who are often consigned to a role of passively coping with the after effects of service decision making which they frequently felt to be substandard, inappropriate or sometimes damaging. However this work supported the research that illustrated the essential role of parents in the rehabilitation and treatment of their children.

8.

All parents were receiving or had recently received pharmacological treatment for mental health problems, most commonly depression. Stories were related of breakdowns, of the need for medications to cope with their everyday life and of medication being a worthwhile cost to being able to look after their children.

9.

The parents described the process of completing the DLA form as 'hideous',

'really hard' and 'painful'. The practice of writing down in great detail, depth and length their children's difficulties, what their children couldn't do, where they struggled or failed had a tremendous impact on these parents and had put many off completing the form.

10.

The 41 page form was also a technical challenge and was a daunting prospect for parents who were routinely pushed to the limit in terms of their energy and time. The vast majority of our parents agreed with this and noted that, regardless of qualifications, the form was prohibitively complex.

11.

The help that participants received from the Amaze DLA Project often had a very profound effect on people's lives. Every parent who received help from the Amaze service that were spoken to had received an award. Parents spoke of the importance of having someone else see through their 'rose tinted glasses' to help them provide a more accurate account and the sensitive and professional way in which the Amaze volunteers worked. They also noted the importance of 'just letting respondents 'talk'. In so doing, the DLA volunteers could extract the necessary information without the parent being forced into this 'hideous' information extraction process. There was considerable skill in this approach. Volunteers were also able to help parents to reflect that what was 'normal' for them was not often the typical experience of other parents and in so doing allowed them to complete the form more effectively.

12.

Parents unanimously discussed the way in which the DLA Project, and the resulting

award, had contributed very positively to both their financial and mental health.

100% of parents suggested that their award had led to significant improvements in these areas of their lives and that these had had a knock on effect in terms of the wellbeing of their child and the rest of the family.

13.

The consensus of parents was that the service was extremely useful. Also how friendly, warm, flexible, approachable and sensitive the volunteers were. As such they made a very difficult process much more bearable than it would otherwise have been. Parents talked about the importance of their award in terms of validating their understanding of the child's difficulties, when very often they had felt minimised or pathologised by other agencies. Many parents had lived with long periods of uncertainty with regards to the way that they were parenting their child with special needs. The impact of this validation should not be underestimated.

14.

Amaze contributed to this validation process through the way that they communicated with parents. They listened, empathised and provided a degree of understanding and substantiation themselves as a routine part of their communications.

15.

Through the DLA Project parents were able also to receive information and access on a range of relevant activities, services, support groups and financial offers that had made a significant impact on their lives. The DLA Project was often a 'gateway' where volunteers were able to identify other more holistic needs of the family and signpost parents to other (Amaze) services.

16.

Possibly as a result of resources some parents had been concerned with regard to the time taken sometimes to return their calls. There could be a feeling at times that the service was overwhelmed and that it could take a considerable time to receive the help that they needed, especially if the parents had deadlines. This however was usually framed by a discussion of how important and exceptional the service itself was.

17.

It was certainly the case that the stories of the parents routinely contained experiences of pain, loss, rejection and anxiety. However what was also evidenced were supportive, resilient and loving relationships filled with positivity, love and a great deal of pleasure as a result of a very talented, committed and incredibly resourceful group of people who had been capable of organising rewarding family lives under often extreme duress.

Introduction to the project



Amaze is a registered charity active in the Brighton and Hove area. Their mission is to inform, support and empower parents of children with disabilities and special needs. Central to the ethos of the organisation is a desire for parents' voices to be heard and to build their confidence and resilience so that they can support their children to lead happy and integrated lives that fulfil their potential.

The organisation is parent-led and works with parent carers of children with any special need or disability aged 0-19 years. Amaze runs a number of services and projects, including their Disability Living Allowance (DLA) project.

In 1990 the Disability Living Allowance was formulated in order to address three principal aims: to help meet the extra costs of living with a disability, to widen the scope of former benefits by introducing lower rates of benefit and to allow people with a disability or with a child with a disability to make self-assessments (Banks & Lawrence, 2005).

The Amaze Disability Living Allowance (DLA) Project aims to tackle poverty and social exclusion. It aims to maximise take

up of disability related benefits amongst families with disabled children in Brighton and Hove, by providing a trained volunteer to support parent carers to complete successful DLA applications. This is particularly important since many of the approximately 7,000 children in Brighton and Hove with special needs (3,400 of these have a significant disability) live in the poorest parts of the city and because over 50% of disabled children live on the margins of poverty. In the year 2011/12 the project had 282 new or appeal applications, up from 267 the year before. Of this number only 14 were known to be unsuccessful. A breakdown of the range of needs shows that the DLA project has worked with the parents of children with a range of special needs including challenging behaviour, mobility problems, visual and hearing problems and moderate and severe learning difficulties.

This evaluation was carried out by a member of staff of the School of Applied Social Sciences at the University of Brighton. The purpose of the study was to draw upon the multiple stakeholders who use and administer the DLA Project in order to

- explore the parenting experiences of parents of children with special needs with regard to financial, social and psychological impacts
- examine the degree to which the Amaze DLA Project contributes to the financial, social and psychological needs of the families who use the service
- explore potential improvements that could be made to the user and volunteer experience

In so doing this research will address what

Woodcock and Tregaskis (2008) referred to as a relative absence of perspectives of parents of disabled children on their parenting experiences.

Procedure/participants

Between February and May 2012, 16 semi-structured interviews were carried out with a range of stakeholders relevant to the project. These included the project coordinator, three volunteer project workers and 12 parents who have recently used the DLA Project. Interviews were arranged by the researcher and were carried out in the homes of volunteers and parents. All interviews were tape recorded. The interviews lasted between 30-45 minutes and focussed on a number of key areas relevant to the experiences of the parents and their use of the service. These included the challenges of parenting a child or children with special needs, their experience of interacting with statutory services and their experience of being involved in the Amaze DLA Project.

The children of parent participants ranged from age 3 to 15 and included a range of physical, learning and mental health disabilities. These ranged from physical health complaints like Cardiomyopathy and Type 3 Ehlers-Danlos Syndrome to Autism and Downs' Syndrome. A number of children experienced multiple disabilities. Parents were predominantly female with only one male parent interviewed. The three volunteers interviewed had worked with between 10 and 30 parent service users,

Data Analysis

Thematic analysis was used to analyse the interviews. Thematic analysis is a pragmatically and theoretically flexible analytic paradigm (Braun & Clarke, 2006) that allows researchers to identify, analyse and report patterns within qualitative data. It is ideal for semi-structured interviews where similarities and differences between accounts form key components following which representative themes are developed.

Findings/discussions 1.

Experiences of parenting a child with special needs

“I had to order some all-in-one vests, well you can't get these for four year olds. So you have to go to places like disabledclothing.co.uk, and they were ten pounds each.”

Lucy, parent

The cost of living, paid work and poverty

Recent research suggests that the cost of living is significantly higher for people with disabilities and that these costs include the need for special diets, prescriptions, greater heating costs, clothing and travel, often to and from medical appointments (Banks & Lawrence, 2005). Indeed a severely disabled child has been estimated to cost parents at least three times as much as one who is not disabled (Steyn et al, 2002, Kagan et al 1999). This research resonated with most of the parents who took part in this study.

As a result of challenging behaviour or medical regimens, many parents were not able to leave their children with friends and this had a financial implication.

These extra costs are compounded by the fact that the standard of living for many parents whose children have special needs is low, with 75% depending on benefits as their main or only source of income (Banks & Lawrence, 2005). Due to the need to adopt the role of full-time carer for their child, many families have one or both parents excluded from employment and, as such, find themselves living in relative poverty. This is particularly the case for mothers (Olsson & Hwang, 2006). Families supporting a child with an intellectual disability were shown to be significantly economically disadvantaged compared to those without, had lower rates of employment and delayed entry into the workforce (Emerson & Hatton, 2007) and children with intellectual disabilities are significantly more likely to grow up in poverty than typically developed peers (Emerson et al 2010). Moreover, living in poverty is associated with reduced access to extra familial support through parental support networks and can have a pervasive impact on diet, housing quality and exposure to a range of environmental hazards (Emerson, 2004, 2007). Indeed the capacity to work was presented as the central issue to the financial hardship suffered by many of the parents.

For many parents not being able to work was a source of frustration.

The combination of extra living costs and exclusion from paid work can exact a considerable toll on the wellbeing of parents, many of whom, as we will see throughout the report, have to contend with multiple other sources of difficulty



“They used to feed him at school, obviously I have him all the time now and that has an impact on how much food I've got and then there's washing clothes and things like that because he's been a bit incontinent and he has got better but sometimes he just can't control things like that.”

Beth, parent

However there were also 'hidden costs' associated with having a child with special needs. These may not be immediately obvious in terms of the basic needs such as clothes, washing and heating but were fundamentally important. Some parents talked about the need for special toys and play equipment that they felt were central to their child's development. There was also mention of the increased costs of child care where the informal child care arrangements that many parents typically enjoyed were not possible for them.

“And then your mind, you're always worrying about money and he's really an expensive child, and we keep going, but the cost to our health...”

Penny, parent

“I used to be a real worker, I had three jobs, morning, noon and night. I used to work in a care home for elderly people, I was in the Air Force, and I've done so many jobs. It's hard for me to think I've just got to sit here on me arse.”

Beth, parent

“I came across a parent....and she was living in very, very strained circumstances with a little boy who was severely autistic, and one of the few things he liked eating was Petit Filous fromage frais. She was stealing these from the supermarket in parts of the week when she didn't have any money, until she could go to the Post Office and get some more benefit, this was before she got the DLA. Now, the little lad's dad wasn't around, he was in prison. Imagine how devastating that would have been for him if she'd got caught stealing. But, that was the only thing that he would eat, and in desperation, what do you do? That's a terrible place to be, you know, and it's horrible.”

Lizzie, Project Co-ordinator

and distress. The presence of a child with a disability in the family appears to increase the likelihood of severe hardship and financial strain (Shahtahmasebi et al 2010). There is a growing consensus from medical and mainstream psychological science practitioners that experiences of over-indebtedness and financial strain are conclusively associated with mental health problems, distress and suffering and that the scale of debt and financial strain is approximately proportional to this distress (Jenkins et al 2008, Fitch et al, 2007, Drentea, & Lavrakas, 2000). It was not uncommon for parents to describe their everyday lives as mired by constant anxiety over money and for this anxiety to be directly related to the nature of the costs of bringing up a child with special needs. Moreover several parents were quite explicit in terms of the way in which it had negatively impacted their mental health. This is discussed in more detail later.

Indeed the nature of the needs of some of their children, together with the difficult financial circumstances, had led some desperate parents to engage in humiliating and illegal activities. Faced with a choice of failing to provide for their child's basic needs or stealing, one mother was forced into desperate acts of petty theft

To conclude this section, many of the parents we talked to, previous to their DLA award and sometimes after receiving their award, experienced severe financial strain, isolation from the labour market and difficulty in providing for the increased financial needs of their children. Steyn et al (2002) suggested that for many parents the disability living allowance was very often absorbed into the weekly budget simply to help parents to make ends meet.

Multiple points of isolation and alienation

Swain's (1993) 'disabling barriers' articulates the mechanisms by which people are excluded from full participation in many aspects of civic life. These include aspects related to work, family and leisure. The parents in this study outlined a number of different pathways which contributed to an often painful and debilitating degree of social isolation and loneliness. The first, as described above was exclusion from the labour market. As well as providing a living wage and decreasing the probability of falling victim to the problems associated with poverty, lack of employment can lead to a lack of fulfilment and an isolation both from potential friends and peers. They are also excluded from being able to experience the multiple roles in employment and family life that can have a positive impact on wellbeing and help to buffer some of the stresses that a person may be experiencing in another area of their life (Kagan et al 1999, Jinnah & Stoneman, 2008).

Certainly the degree to which multiple roles is effective depends on employer flexibility and workable child care provision but feeling involved and successful in meaningful work can have a genuinely positive effect on people's wellbeing (Olsson & Hwang, 2006).

The acute social isolation that many parents felt was also driven by a number of other factors related to their experience of having a child with special needs. Often the challenging and atypical behaviours of their children had led to their exclusion from the circles of parent friends that many parents take for granted. For some, theirs is a self-exclusion due to the shame and embarrassment felt when other parents fail to understand the nature of their children's difficulties. For others the

“So I'm kind of nervous and sometimes it's embarrassing, like when he's really upset he will start chewing things, hitting and biting himself, so seeing him do those things in public makes me feel so embarrassed and sometimes people don't understand.”

Jayne, parent

“They see themselves through their child and their child's needs and their child's problems and their child's aspirations, and you put their own needs to one side. How they see themselves in society is really, really wrapped up in their child's special needs.”

Lizzie, Project Co-ordinator

“....so when it came to us dealing with a very ill child who nearly ended up being sectioned, it was incredibly difficult to talk to other people, other parents, because they're actually living completely different lives. [You're] so exhausted, you're isolated because people can't really understand why you can't do coffee, people don't understand why you can't go out and get a pint of milk because you can't leave the house because someone's so sick.”

Karen, parent

exclusion came from the parents of other children who were not prepared to tolerate the challenging behaviour of their child.

This sense of isolation was often painful and debilitating. A potential social network is closed off for parents who may benefit most from such an extended network since social support is a key factor in helping parents to maintain resilience in the face of adversity (Seltzer et al 2004). For many parents their sense of self is fundamentally informed by the performance, aspirations and understanding of themselves as a parent. For most parents this is a key contributing factor to the way that they come to understand themselves but parents of children with special needs, shorn of the multiple roles that can be so useful to buffer against the stress of parenthood and modern living, very often find that their sense of self is entirely wrapped up in their identity as a parent and in their children's special needs. As such, the pain of their child's rejection can be felt particularly acutely by these parents, many of whom hold themselves responsible for the social difficulties faced by their children. For many, their self worth comes not from performance at work, from a hobby or a past-time or from their position in a social network but from their performance as a parent.

Other social practices also contributed to the sense of isolation that they felt. As well as rejection by other parents and self-isolation due to the shame and embarrassment of their child's challenging behaviour, parents were often practically isolated due to their incapacity to 'afford' a social network. It is often necessary to spend money, whether through child care or through the costs of travel and refreshments, when parents meet up with friends. For many who were struggling to

cope with everyday living costs this is simply not possible.

As well as these practical modes of isolation, parents talked of a social and conceptual isolation, that of other parents not only failing to understand the behaviour of their child but failing more broadly to understand the nature of the life of a parent of a child with very challenging and distressing behaviour. An inability to relate to the restrictions imposed on these parents often meant that other parents who had never led such a lifestyle were unable to empathise.

So the 'disabling barriers' that exclude parents of children with special needs from full participation in a normative social life include multiple and overlapping practices of isolation that relate to the behaviour of the child, rejection of the family from networks and childcare, exclusion from paid labour, lack of money and the need to live a life that others struggle to understand.

Vigilance, exhaustion and the relentless nature of the child care

Recent literature on the experiences of children with special needs suggests that the parenting challenges can be persistent and exhausting (Seltzer et al 2004, Moen et al, 2011). However the literature is less detailed in the reasons as to why parenting a child with special needs can be so exhausting or indeed the consequences of this. For many, parenting a child with special needs exerts a particular physical and emotional toll that is related to a number of activities not characteristically experienced by typical parents. One of these involves the sheer duration of the often emotionally demanding care needed for many of the

“And feeding, she feeds for quite a few hours of the day on the machine... she was feeding most of the day, because she was being sick and she was puking her NG tube up, so I'd have to re-pass it which used to stress me out no end, it was pretty much taking up the whole of the day, whereas I'm speeding them up a bit now.”

Lucy, parent

“That struggle is perpetual, for you're constantly, you're always hyper-vigilant.”

Karen, parent

“When you're dealing with a child with additional needs, I think it's the energy levels, resilience, all of that to keep going at a sustained level of caring, and particularly when you sleep, because it's very hard to explain to other parents, because other people, not even professionals understand when you haven't gone through it what it's like to be consistently up at night like you've got a young baby.”

Karen, parent

“The relationship is in tatters, it's shot to pieces. If we didn't have an ill kid we wouldn't have a relationship. I couldn't leave her with him and she couldn't leave me with him.”

Paul, parent

children. For some parents, at particular points in their child's development, this sustained burden of care can be overwhelming. This can include administering complex and continuous medical regimens, coping with challenging behaviour, and prolonged everyday tasks that require a greater time commitment like toilet use, cooking and transport to and from school and hospitals.

Parents spoke not just about the often exhaustive physical and emotional nature of the care but also about the need to be constantly vigilant. For some children a relaxation of this vigilance could have catastrophic consequences. The vigilance of one parent extended to sleeping at the front door to block her suicidal daughter's exit from the house.

The vigilance can refer to a need to closely monitor children in everyday situations such as going for a walk, it can mean monitoring their eating in order that they don't choke and monitoring the potentially catastrophic physical effects of a child becoming upset lest it lead to a need to administer CPR.

For another parent, the nature of her son's almost complete lack of communication meant that she found it a constant source of worry regarding the interpretation of potential serious physical illnesses. This constant worry that the parent had missed a key sign of illness was a source of continued and often profound anxiety.

A number of parents explicitly or implicitly compared the parenting of children with special needs as analogous to the parenting of a small child or baby. This could be the case even when the children were teenagers and it could relate to different types of needs. The parent of a suicidal teenage girl and the parent of a

teenage boy diagnosed with ADHD spoke of their night time regimes as similar to that of caring for a 'young baby' or 'small child'. The continued and prolonged impact of these kinds of lived experiences can be exhausting and ultimately debilitating for parents whose isolation meant that they were often removed from sources of respite and support.

The quotes on the left outline some of the impacts of these kinds of sustained regimes of high vigilance and high maintenance care. Feelings of desperation, exhaustion, depression, suicidal ideation, anxiety, relationship breakdown, and often profound guilt over the rejection of siblings, were the eventual outcomes of living a high vigilance life where parents were on 'red alert, day or night' and living very often in debilitating poverty and with little or no support to alleviate the difficulties. Many of the parents spoke of simply having too little energy to attend to other facets of their lives due to the all-consuming and demanding regime of care for their child. Parents mentioned how this lack of energy made it almost impossible to organise themselves and carry out a variety of important tasks that had been sidelined. This has particular relevance to the discussion of the DLA form later in the report. The impact of this care regime is discussed further in the later section on mental health. Although this was by no means the experience of all parents, it was the experience of a majority of the parents who took part in this research.

It has been suggested that the experience of a sustained and often gruelling caring regime for parent carers can be abated by holistic and practical interventions to support parents. Shu and colleagues (2002) showed that home care services that give parents of children with

“We never actually saw anyone till about a year and a half later.... It had been way too long, so we went from four, a four year old, to this six year old who's now hitting us and had numerous accidents .”

Penny, parent

“Getting speech therapy and we are trying to get help from an OT for him but there does seem to be a very long waiting list for that. So the most help that I got was from the medical professionals, the speech and language therapist, from school, and from Amaze and from the parent group.”

Donna, parent

“She [occupational therapist], was all over the place... I can't explain it, she got very irritated with [child], I could see that, towards the end of the session, which she only gave us an hour, not the hour and a half, she said oh, it's lunch time, and started to rush us off, it was just horrible.”

Penny, parent

“....and the SENCO was very obstructive in it, and was very clear that she didn't want her to be assessed. Then he [psychiatrist] gave us a list of strategies to give to the school, which were basically strategies for ADHD, which I brought in to the SENCO and not one of them was ever put in place for her.”

Danielle, parent

intellectual disabilities the chance to revitalise can have a significant impact on parent mental health up to 9 months after implementation. These care packages included providing direct care to the children, assisting and teaching caregivers to solve daily care problems, guiding caregivers on accessing community resources and seeking community support and providing services by telephone when the needs arose. Mullins et al (2002) noted that 3-7 day respite packages for parents of children with developmental disabilities, led to significantly lower psychological distress at discharge and 6 months and lower parenting stress at discharge, although this had returned to admission levels 6 months later.

Relationships with services: medical, social and school

Parents of children with special needs will inevitably be party to a range of relationships with institutions and services that would not typically be experienced by other parents. Moreover their relationships with organisations that are used by children without special needs, such as schools, is often quite different. In the US, Betz et al (2004) pointed out that the parents of children with developmental disabilities frequently encountered numerous barriers to receiving required medical services and that many children had unmet needs in terms of primary and preventative health and therapy services.

The majority of families who received behavioural services were not satisfied with them and this dissatisfaction related to the problems of a fragmented system where negative provider attitudes, characterised by a lack of accommodation or aggression, were all too frequent. The experience of medical and therapeutic

services for our parents was mixed, with most parents able to isolate examples of both strong and weak medical practitioners. However every parent clearly articulated that their access to, or quality of, services was at some stage deeply problematic and even traumatic.

All parents noted problems of access to services, where delays would last from months to a year and a half. This contributed to considerable distress from a number of parents for whom an 18 month wait was felt to have potentially grave consequences for their children during key stages in their development. When faced with these delays, parents often articulated a debilitating frustration, impotence and lack of control. Moreover there were several concerns about the quality of sessions and the follow-on care received. Kobayashi et al (2011) noted that a failure to provide services can lead to high caregiver distress.

Parents who had used child mental health services noted problems both in the quality and availability of the treatment and the functionality of the tier system.

This resonated with Sin et al's (2010) recent work that suggested that access to Child and Adolescent Mental Health Services (CAMHS) was very uneven with some local services showing no clear care pathways.

Most parents experienced a problematic relationship with their child's school at some point in their child's educational history. Very often this related to the parent's relationship not only with their child's teacher but with the Special Educational Needs Coordinators (SENCOs). Pearson and Ralph (2007) noted that despite publication of national guidance on the role of SENCOs, local

“...he was isolating him from the class, making him sit at the front with his back to everybody, he would single him out, make him sit against a wall, everything, if you wanted to pick what to do to a damaged child, and a child from his background, to make sure he really does sink. Anyway, we had to challenge that.”

Kathy, parent

interpretation of the role led to considerable variations in practice. In their research, consensus about the role of SENCos was elusive, with some questioning the actual ‘do-ability’ of the role. These issues may well have played a role in the difficult experiences reported by a number of our parents where young people with learning or behavioural difficulties were all too often understood as antisocial or naughty as a result of poor awareness (Sin et al 2010). In this study, some SENCos were constructed as ‘useless’ and some as deliberately obstructive, where strategies handed to them from mental health professionals were, in the opinion of the parent, sidelined.

Some communications between SENCos

anxious about struggling children. The quote at the bottom left comes from the parent of a child whose difficulties at school led her to repeatedly inform her parents that she was suicidal. However the response of the SENCo was felt to be unhelpful at what was a deeply traumatic time for the child and parent.

In some cases parents were struggling with what they felt were inappropriate interventions that were being applied to what had been considered the poor behaviour of naughty children rather than effects of children whose special needs had left them unable to function in a normative educational environment without particular practices of support .



“So CAMHS wholly and utterly failed Emma and what they didn’t manage to do was put more pressure on the school, who, because Emma was out of school, very firmly believed that she was just a naughty girl and wasn’t listening in class and wasn’t able to cope.”

Karen, parent

and parents revealed that their children’s needs were sometimes neglected as a result of their child not being the ‘worst’ of the school’s children and because of the SENCos workload. While problems of resourcing the different needs of children in large schools will always impact on the nature of the relations that parents encounter, such explicit reasoning often does little to help parents who are deeply

Where specific services that were designed to meet normative needs take insufficient account of the diverse needs of different groups of people would, according to the social model of disability, be an example of a ‘systemic barrier’ (Woodcock and Tregaskis, 2008). For some of the parents, practices of classroom discipline designed for misbehaving children were mobilised as a technique to ‘bring in to line’ children whose special needs were inappropriately understood through the lens of misbehaviour. The reasons for this may well relate either to a lack of professional awareness, a lack of classroom time and resources, or both.

Constructions of parenthood

Research suggests that parental exclusion from professional discourse is common and that many parents felt that the expectations of their role was to comply with professionals rather than be active participants in a discussion about the needs of their child (Woodcock and Tregaskis, 2008). Moen et al (2011) noted

“Even though I'm a psychotherapist, I've worked in schools, there is an attitude with teachers that parents are the nuisance that get in the way. Like they're idiots, that they don't know anything.”

Danielle, parent

“It shouldn't take somebody like me to go in and write down what the parent is saying, there was nothing she was telling me that she hadn't been telling other people for years.”

Lizzie, Project Co-ordinator

“You become like the identified patient in that sort of a system. And so you become a sick person... I ended up having to challenge the permission, when as a parent you're then seen as you're not co-operating with us...”

Karen, parent

“I would have really have liked to feel we were in a partnership, made welcome. Rather than being made to feel, when you deal with a very clinical model.... you're referred to, child's referred to as a patient and you're the patient's parents. That's hideous.”

Karen, parent

that health professionals and teachers were frequently perceived negatively and that parents felt disempowered and completely at the mercy of professionals and their decisions. They described a frequent ‘tug of war’ between parents and professionals as to who was right and who was wrong and, as such, parents often felt that they were forced into exaggerating their child's difficulties or saying disparaging things about their children. This could be deeply distressing for parents (Moen et al 2011). It was also reported in this work that parents often felt patronised by professionals or excluded through the use of technical language and jargon.

Parents are often considered to lack the kinds of professional expertise that trained teachers and medical practitioners are party too. Urey & Viar (1990) showed that professional beliefs regarding the families of children with disabilities render them deficient, more conflictual or show chronic sorrow and that this has persisted among many health care professionals. Paediatricians rated families as more distressed than the parents themselves. Whereas parents gave highest ratings to problems of social isolation and anxiety, paediatricians gave highest ratings to families as exhibiting poor parent skills, riven with family conflict and marital trouble (Urey & Viar, 1990).

This understanding of these families as problematic, emotional, prone to poor parenting skills will likely impact the ways in which parental forms of expertise are understood and incorporated into treatment plans for their children. However, Guomundsdottir et al (2006) found that the large majority of families with chronically ill children are well adjusted despite being exposed to distressing experiences. dosReis et al

(2010) found that 21% of parents whose children had been diagnosed with ADHD perceived health care professionals and school personnel to be dismissive of their concerns. For the parents in this study, the problem of being unable to ‘be heard’, to be believed and to be understood was recurrent and links to the research above.

Many parents talked about how they felt like a nuisance or an encumbrance for seeking to be actively involved in the care and wellbeing regimen of their child. Such parents were not infrequently ‘talked down to’ or patronised.

The parent themselves can come to be understood as inappropriate or ‘sick’ for seeking to transcend the role of passivity often assigned to them. They can come to be understood as uncooperative and such a process can be further isolating for parents already prone to the multiple points of isolation discussed earlier.

The pain and impotence of being excluded from the key discussions that concern their child's care can itself be incredibly difficult for parents, many of whom understand themselves as having a great deal of expertise to offer but who are consigned to a role of passively coping with the after effects of service decision making that they often felt to be substandard, inappropriate or sometimes damaging.

This work supported the research that illustrated the essential role of parents in the rehabilitation and treatment of their children. Hung et al (2010) noted that parents play an essential role in this rehabilitation. In the vast majority of cases, parents know their children, they know the strategies that they use to teach and manage their children but despite this, several parents report never having

“Parents can wait nearly a year for an appointment at the child development centre, and by the time the parent’s got there, what do you think they’ve been doing in the meantime? They’ve been researching on the internet, haven’t they? So then a parent turns up and they’re almost there saying, “Look, I’m expecting this sort of diagnosis because I’ve looked it up.” In some respects, the parent’s almost two steps ahead of the paediatrician.”

Lizzie, Project Co-ordinator

“When we did get to level three, tier three, her experience was hideous, because we were given eight sessions in CBT which was absolutely the wrong thing, and I ended up having to challenge it... so eventually I’d stop it because it was really traumatizing for her.”

Karen, parent

been asked by providers to assist in problem-solving or the suggestions that they make not followed (Jinnah and Stoneman, 2008). Valentine (2010) suggested that the parents of autistic children have very often become expert not only in their child’s symptoms but also in the research literature and practices of treating autism.

Parents themselves are often the people who notice small changes in developmental progress and, as such, have considerable awareness of how service might be delivered more effectively (Woodcock & Tregaskis, 2008). While this democratisation of expert medical knowledge is essential for parents, it can lead to difficulties in interaction with health professionals where displays of such knowledge can be interpreted as challenging or inappropriate for a parent whose role is largely understood as passive, responsive and benign (Valentine, 2010). That a scepticism and mistrust of medical regimens is often the source of parent activism can further complicate the picture as active parents construct their choices as necessary in the face of ill-equipped and ill-informed schools or doctors (Valentine, 2010).

The new forms of identity formation by many parents that occur in response to shortfalls or perceived shortfalls in resources are no less effective for this initial impulse. Our parents provided multiple examples of where they had to mobilise ad-hoc plans to address the problematic ramifications of the original medical decisions from which they themselves were excluded.

One parent noted that their doctor was dismissive of her views, both in person and through a failure to address her messages of concern. Following a very brief consultation, the doctor suggested a

psychological issue as the root of her daughter’s stomach problems. This parent went along with this procedure during which point her daughter physically deteriorated. It later emerged that her daughter had Type 3 Ehlers-Danlos syndrome, an inherited disorder of the connective tissue.

Participation in rehabilitation, treatment and decision making is central to the desires of most parents. Fiks et al (2011) found that parents are more satisfied if they are able to contribute meaningfully in making clinical decisions and believe that their lived experience yields useful information. They suggested that paediatric medics may well benefit from training in shared decision making. Participation in rehabilitation by parents gives a sense of control, builds confidence and decreases anxiety (Palit et al 2011).

It is worthwhile to reflect on some of the inherent limitations of professional roles in the management of children. Very often professionals are expected to understand the experiences and difficulties of children who have long and complex histories of social and psychological development. Parents accompany their children on these long and sometimes difficult developmental trajectories and have a range of experience and expertise that far outweighs most practitioners who are limited to brief and discreet consultations.

It is perhaps unsurprising that professionals will tend to lean on certain forms of knowledge, that while they can be very useful, can also fail to really address the idiosyncratic nature of the needs of many families. Indeed it has been found that professionals can sometimes seem to be unwilling to focus assessment on specific individual difficulties (Woodcock and Tregaskis, 2008) and hence many parents report

“They (Amaze) totally took, took my point of view as fact. There was no fantasy in it, they took it for what it was and I felt like there was an army on my side. And that's a really profound experience if you feel like you're up against an army, and trying to get through SENCOs and CAMHS is not easy.”

Danielle, parent

“Of course, many of the parents, myself included, have serious depression. I was very depressed when my son was diagnosed and yes, when the school summer holidays and vacations are coming up all our parents from the support group says “OK, it's time to be alone again”. Laughs. So it is a lot of stress, many antidepressants, it is normal to be on antidepressants.”

Donna, parent

unmet needs and dissatisfaction with behavioural interventions (Betz et al 2004).

The reality is that parents are frequently excluded from decision making about their children and often have to engage in prolonged battles to be heard or to have their say. They frequently feel isolated, diminished, embattled and disempowered in processes central to their child's welfare. Indeed a number of parents talked about having to fight and battle against various authorities just to have their voice heard. For most, Amaze had played a key supporting role. Through Amaze, parents felt that they were listened to and supported and this could have a real impact on a parent who is used to being sidelined and their experiences marginalised.

Some schools were thought not to like Amaze because they failed to understand why these parents' voices should be heard, advocated for and supported in organisational decision making. Amaze often made the process of parents interacting with school far more manageable for parents but less so for the schools, where the presence of Amaze could be seen as an encumbrance.

Others discussed the need to adopt certain strategies in order to try to move their children toward the kinds of help that they believed that they urgently needed. Sometimes this would include taking on the role of the naive parent, explicitly publicly disavowing themselves of their knowledge and experience in order to flatter professionals toward the direction that they felt was essential for their child.

Mental health

Several authors have confirmed the problem of mental distress and suffering in many parents whose children have special needs. Emotional distress is high among parents of children with chronic pain, including anxiety and depression (Sieberg et al, 2010, Hung et al 2010). In the US the parents of children with disabilities had more than twice the need for mental health treatment and hospitalisation than those without. The impact on mothers of the children's difficulties resulted in a particularly profound social and psychological impact (Emerson, 2003).

The parents who took part in this research confirmed the broad nature of these findings. All parents were or had recently received pharmacological treatment for mental health problems, most commonly depression. Stories were related of breakdowns, of the need for medications to cope with their everyday life and of medication being a worthwhile cost to being able to look after their children.

The second parent quoted on the left in saying ‘of course’, took for granted the inherent risk of mental health problems and parenting a child with special needs.

The social model of mental health suggests that experiences of suffering that have been understood as symptoms require consideration as complex attempts to maintain survival, dignity and integrity in the face of past and current trauma (Tew, 2005). Mental ill-health can be caused by a range of difficulties including trauma, social dislocation, oppressive personal relationships, isolation and poverty and disadvantage

“....the most difficult bit I hate about panic attacks that I've experienced is when I start feeling like things are crawling from my head to my toes and this makes me more anxious, the more I become anxious, the more, the longer the panic attack is... During the panic attack i was thinking when we move into this place and there isn't any locks, well now there's a lock there, [child] has escaped three times since we came here.”

Jayne, parent

(Tew, 2005).

The work in this section clearly outlines why so many parents who are committed to the care of their child experience these taken-for-granted mental health problems. Such parents are prone to experiences of financial strain and the grind of poverty and debt, forced to be constantly vigilant and frequently exhausted due to lack of sleep and the energy involved in caring for a child with special needs. They can be burdened by guilt regarding the impact of their care regime on siblings and isolated from friends through lack of money, through rejection and through an inability of many to understand the nature of their everyday life as a carer parent. Finally they are frequently exposed to experiences of impotence, frustration and the need to battle to have their beliefs taken into account by schools and medical professionals who often render them unfit or unsuitable to pass comment on the care of their child.

These factors by no means constitute the daily experience of parents of children with special needs but not infrequently parents find themselves struggling under the strain of several of them, all of which individually could be predictive of mental distress. As a result many of these parents find themselves requiring medication as a routine part of their everyday lives.

Findings/discussions 2.

Amaze and the DLA Project



“He was a tough DLA to do because he is so delayed and most of the time you're just trying to be positive about things that he can do and what a personality he has, and the way that he draws people into his life.”

Linda, parent

“With [child], it was emotionally hideous to do, really hideous to document it.”

Karen, parent

The DLA form as an emotional trial

The completion of different kinds of forms can bring different challenges, some of which are rarely acknowledged. The DLA form allows carers access to different gradations of award depending on mobility and care needs. However it also has implications for the amount of money the parent could receive through carer's allowance, child tax credits and income support if indeed families are on income support (Contact a family, 2012). Although there is a lack of official data and formal debate about the effectiveness of the British system of deciding and monitoring DLA claims for children, there is thought to

be significant under-application and specifically from disadvantaged families (Steyn et al 2002). Indeed the authors found 31% under application for eligible children. Banks & Lawrence (2005) found that 42.9% of eligible applicants who did apply were initially turned down. This section considers issues related to the DLA application process and explores the experiences of parents who are required to complete the 41 page form in order to receive their award. Through doing so the intention is to shed some light on a process that has been described as 'degrading, distressing and humiliating' and one that leaves carers frustrated and demoralised.

“So, for many parents, getting the DLA, it is often the first time they get a real acknowledgment that they are doing stuff that’s extra and different and more for their child. And that’s really important when their experience, for years and years, might have been, “You’re an over-anxious parent,” you know, “You’re worrying too much, there’s nothing really the matter, he’ll soon shape up.”

Lizzie, Project Co-ordinator

“So getting the highest level of DLA for her was a massive validation that she was really ill. And so actually getting that money, it was like somebody’s recognising this.”

Karen, parent

“I can’t really, to be honest, remember what it was like, I’ve always remembered living on a shoestring, we always have. And now because of the DLA and all the other stuff I get, I don’t have to stress about, like I do about my phone bill and stuff like that, I still stress about bills, but it’s not as stressful.”

Lucy, parent

The parents described the process as ‘hideous’, ‘really hard’ and ‘painful’. It was generally understood that completing the form was more than just time consuming and technically challenging. The practice of writing down in great detail, depth and length their children’s difficulties, what their children couldn’t do and where they struggled or failed had a tremendous impact on parents and put many off from completing the form. There is no place on the form to think about the positive aspects of their child’s life or their strengths and capacities. The relentless 41 page trudge through their children’s suffering and failings was a hideous process that was distressing because for a number of parents it brought into plain focus just how difficult their child’s life was, and how difficult their life was. For some it brought back feelings of profound distress that they had worked hard not to dwell on. It forced parents who had often worked hard on viewing the positives to rotate this viewpoint and focus solely on the negatives of their child’s development. The emotional impact of this form may not be sufficiently appreciated.

Difficulties of the form - technical

The form is an emotional challenge but it is also a technical challenge which at 41 pages makes it a daunting prospect for parents who are routinely pushed to their limits in terms of the energy and time that they have to devote to issues other than essential everyday survival. A number of parents talked about wanting to get organised but found it difficult to do so due to having so little time and personal energy. A long and technically challenging form is an extreme challenge in these circumstances and the emotional trauma of its completion, in conjunction with the technical difficulty, likely contributes both

to the low number of applications and large number of eligible families who are rejected. There has been criticism of the DLA form due to its complex structure and many people who do claim and who are eligible face inconsistencies in award making with 97.3% of carers finding it ‘difficult to complete’ (Banks & Lawrence, 2005). The vast majority of our parents agreed with this and noted that, regardless of their qualifications, the form was prohibitively complex. The difficulties included misunderstanding the nature of the questions and answering the questions but not in ways that told the full story about the nature of the child’s difficulties.

The essential role of the Amaze DLA Project

To not be able to attempt or effectively complete the form could have considerable impact on the families, many of whom were excluded from paid employment and were challenged by the multiple problems of isolation, poverty and disadvantage discussed earlier. Banks & Lawrence note that the completion of the DLA form entails a process that many people simply couldn’t do by themselves and claimants are more successful if they receive professional or informed help (Banks & Lawrence, 2005). The families who had used the Amaze DLA project overwhelmingly agreed with this sentiment and the work that Amaze undertook with these families had impacts not just in the success of their form completion but in a number of emotional and financial domains. The help that participants received from the Amaze DLA Project did frequently have a very profound effect on people’s lives. All of the parents spoken to received an award.

The second parent quoted on the left

“So [amaze volunteer] was really good. I've got a BA and I've got an MA and I couldn't do it, I just couldn't do it. I'm articulate, I'm educated, I should be able to.”

“So [Amaze volunteer] was holding my hand, she just let me talk, she basically put it on the computer, took it off, redid it all, and she went to the school and asked their views on (child) as well, that was quite difficult because they put a lot of stuff about biting and kicking and stuff like that, but then I suppose I do see him a bit rose-tinted.”

Linda, parent

“And we just went through it and I began to realize he teased it all out. He then gave it language, he was then able to link the things that I couldn't do, he could make links that I just couldn't see.”

Kathy, parent

spoke of the importance of having someone else see through her 'rose tinted glasses' to help her provide a more accurate account and in so doing was very likely to significantly increase the chances of receiving a much needed award. This is a perhaps understandable side effect for parents who have worked very hard over the years to focus on the positive side of their child's disability and to focus on their child's strengths. However to see their child through an overly optimistic perspective when completing the form would mean parent's being incapable of presenting the real nature of the difficulties that they experienced as part of their everyday care regimes.

What was also important was the way in which the Amaze volunteers worked. The parent quoted bottom left and a number of others outlined the way in which the service mitigated the quite profound emotional impact of overwhelmingly focussing on the negative by just letting respondents 'talk'. In so doing parents were able to provide a balanced account of their child that, while providing the necessary information on the difficulties and deficits experienced by the family, also allowed parents to balance these with positive accounts of strength and the joy of parenting their child. The DLA volunteer could extract the necessary information without the parent being forced into this 'hideous' negative information extraction process. There was real skill in this approach and volunteers receive considerable training in order to develop these skills.

There was of course also the fact that having an experienced and sensitive service representative also helped them to overcome many of the technical difficulties that contribute to the low rate of uptake and the relatively low rate of

success for eligible parents.

For many families, deeply challenging and exhausting care regimes simply become part of their normal everyday lives and as such come to be constituted as 'normal' by the parents. This can be a problem when completing the form since such an interpretation of their activities would impact negatively on the likelihood of award. Through carefully 'teasing it out' and helping parents to reflect on the nature of what is and is not considered 'normal', the volunteers were able to help parents to understand that what had become normal for them may not in fact be in any broad sense understood as normal in terms of everyday parenting practices. Volunteers were also able to help provide parents with the language that they needed when they themselves struggled to articulate the nature of their child's difficulties.

The importance of Amaze DLA Project: validation, finance and mental well-being

Amaze had had a significant impact on the parents not only in terms of helping them to complete forms but the parents talked of how their meeting often opened up a range of other crucial benefits. The consensus of parents was not only how useful the service was but also how friendly, warm, flexible, approachable and sensitive the volunteers were. As such, they made a difficult process much more bearable and doable than it would otherwise have been. The volunteers listened with empathy and genuine positive regard and this was a comforting and new experience for many of the parents who had been used to battling against various services and professionals.

“...so even if they are using the money just to live off, it's their kid that is living off the money, not necessarily them, I don't think they go to have their hair cut anywhere nice or anything although I'm sure they really need it. “

Nicola, volunteer

“I think the DLA is obviously a good thing because it takes some of the strain away. I mean this family, the dad had given up work because he thought it was all too much for his wife to cope with. She couldn't cope because she needed two buggies to get out and she just couldn't get out because she needed two people.”

Abby, Volunteer

“So that has given me a bit better awareness and confidence to challenge things.”

Penny, parent

“I'm always getting bits and bobs in the post that says 'oh, we're running a coffee morning for positive parenting' and things like that. “

Lucy, parent

As reported earlier the sheer range and intensity of challenges that face many parents of children with special needs include financial challenges, social isolation, exhaustion and vigilance, mental distress and feeling marginalised socially and sometimes in terms of their interactions with schools and medical professionals. In helping parents to navigate the DLA form, Amaze contributed to the amelioration of a number of these. Parents talked about the importance of their award in terms of validating their understanding of the child's difficulties, when very often they had felt minimised or pathologised by other agencies. For a number of parents, their suffering, trauma and difficulties were understood and validated by their receipt of the award. It validated the sense that their child was ill and it validated their approach as parents in the various conflicts to help their child receive the support that they needed. Moreover, a successful claim acknowledged the extra work they had been doing, often in face of accusations, suggestions and affirmations of overbearing parental concern. A successful award had genuine symbolic significance above and beyond the financial reward. For some, it supported the notion that parents were right to have taken the care approaches that they did. Many parents live with long periods of uncertainty regarding the way that they are parenting their child with special needs. This can be fuelled by the reactions of peers and professionals. With a developmentally typical child, positive feedback on child-rearing practices is available from many other people who have shared similar experience. However these sources are often absent for the parents of children with special needs who often have to contend with their parenting practices being scrutinised through the lens of a normative parenting mind-set that is very rarely appropriate. The impact

of this should not be underestimated. Amaze, in the way that they communicated with parents, listened, empathised, provided a degree of understanding and indeed validation just through initial communications. This was felt to be very important.

Another impact of the DLA Project concerns the financial strain and mental health of parents. Amaze calculates that each year, the families they support, are awarded an average of £8-12,000 per year in DLA benefit—which puts an extra £2m per year in DLA and £1m in other passported benefits into families' accounts (Amaze Annual Report 2011). Very often extra income is used by parents to maintain and replace clothes and furniture and provide diversions and activities for children (Steyn et al 2002). On other occasions it may be used to help with the everyday essentials of living. Parents unanimously discussed the way in which the DLA Project, and the resulting award, had contributed very considerably to both their financial and mental health. Every parent suggested that their award had led to significant improvements in these areas of their lives and that these had had a knock-on effect in terms of the wellbeing of their child and the rest of the family. For some it simply gave them more hope that they would be able to meet the everyday challenges that they faced, others were able to reduce the unbearably long working hours that were necessary to support the family's extra costs and which had put a considerable strain on their relationship. For others it simply removed one of a number of things that they had felt very worried about and so eased the burden. For some, the effect was on allowing parents the finances to reduce the debilitating isolation that they had been used to.

Amaze DLA Project as more

“Something that was very helpful for me was the sense of having somebody on your side, and empowerment at dealing with the SENCO. Because even though I am liked within the school, I felt very disempowered with my voice trying to advocate for my own child.”

Danielle, parent

“I rang in March but it wasn't due to be back until May, but I realized my god, they are really, really overwhelmed. And I did have a bit of a panic thinking oh maybe they're not going to be able to do it.”

Kathy, parent

“It took quite a long time and it was only because I'd rung her up and I said that we were coming towards the end of the point where the forms were due... and I know that she went out of her way to come over in the evening.”

Liz, parent

“Well, she was the first one that came and then the bloke came. I didn't feel so comfortable with him. Maybe because he's a bloke and he's coming into my house and I'm on my own with him and he was a bit austere as well...”

Beth, parent

than DLA advice

Many parents with children with special needs benefit from extra support to cope with their difficulties (Tam & Cheng, 2005) and the strengthening of the personal and social resources of parents can be incredibly important. Through the DLA Project parents were able also to receive information and access on a range of relevant activities, services, support groups and financial offers that made a significant impact on their lives. The DLA Project for some parents was where their contact with Amaze started and finished but for others it opened up a range of opportunities that they had been unaware of. The parent quoted top left used the DLA Project but also received support in the problematic experiences that they had been having with her daughter's school.

For some parents, the extra information and understanding that they had gained had impacted their confidence as a parent of a child with special needs. They now had the confidence to challenge some of the problematic practices that had made their lives so difficult.

For some parents their contact with the DLA Project had helped to open up a range of activities that they and their children could be part of. For parents who had felt excluded, this was extremely beneficial.

Potential improvements

While the Amaze DLA Project was received positively by all parents there were recommendations in terms of improvements. Most parents and volunteers felt that the service should be available beyond the local area so essential did they feel that it had been for them.

Possibly as a result of resources, some parents had been concerned with regard to the time taken sometimes to return

their calls. There could be a feeling that the service was overwhelmed and it could, in the parent's eyes, take a long time to receive the help that they needed, especially if the parents had deadlines.

Although the opinions of the volunteers were very positive there was one occasion when the parent had not 'clicked' with the volunteer and did not feel comfortable with them. The parent felt that by having a certain volunteer they had ended up with a lower chance of receiving an award than they otherwise would have. In practice Amaze quality checks all applications before submission.

Implications for policy/practice

Due to the nature of the information gathered during this research it was clear that the interview process itself could at times mirror the difficulty of the DLA form in focussing on the difficult and negative experiences that the parents had faced. The stories of the parents routinely contained experiences of pain, and loss and rejection and anxiety. However what these narratives also evidenced were supportive, resilient and loving relationships filled with positivity, love and a great deal of pleasure that grew from a very talented, committed and resourceful group of people who had been capable of organising rewarding family lives under often extreme duress. If you ask a group of parents to discuss their experiences of parenting children with special needs it is quite understandable that comparisons with parents of typical children will often tend to emphasise some of the profound hardships that they face. Many of the parents endured great trauma and still felt that they struggled to achieve equilibrium (Woodcock & Tregaskis, 2008) but this should be understood less as a comment on the characteristics, abilities or relations within the families and more as an inevitable consequence of normal,



“She said ‘why don’t you apply for this’, so she told us about that and other places where I can take my son to, like the one who told us about the horse-riding. She gave us all the details. It’s a nice place, it’s affordable, they know all about special needs. So it’s not just about filling in the form and getting the DLA, it’s about telling us other things.”

Donna, parent

everyday people living incredibly challenging lives. It is with this in mind that the following recommendations are tentatively made. Many of the findings and recommendations may not be new but I echo Banks and Lawrence (2005) in their opinion that this is of little importance when the issues faced by these parents continue to receive inadequate attention.

The importance and impact of the Amaze DLA Project on multiple facets of people’s lives leaves little choice but to fully recommend the continued funding of such a crucial service. Moreover geographical expansion would benefit the many families outside Brighton & Hove where the technical and emotionally demanding nature of the DLA process continues to leave them at a significant financial loss. At a time when 97.3% of carers find it ‘difficult to complete’, 31% of eligible children don’t apply and 42.9% of eligible applicants who do apply are initially turned down (Banks & Lawrence, 2005), and with

the manifest benefits associated with successful application, the work of services like Amaze DLA requires expansion and support. If the DLA form is to persist in its current form then there needs to a greater commitment to supporting the families who seek to make claims. Greater funding and support will allow organisations like Amaze to continue to develop to meet the changing needs of parents in a more sustained and holistic fashion. To fail to invest in these forms of support is to risk a greater expenditure on addressing the treatment necessary for the large numbers of parents who find themselves suffering mental ill-health as a result of the financial and social impacts of caring for a child with special needs.

Shu et al (2002) showed the considerable benefits of the importance of home care services that aid with support, educating parents and guidance on accessing community resources. These included the mental health of parents at 9 month follow up. Mullins et al (2002) provided evidence of the benefits of respite care for the parents of children with developmental disabilities in terms of psychological and parenting distress. Current provision for the needs of parents whose children have special needs is nowhere near sufficient to address the multiple stresses, barriers and challenges that so powerfully impact on their mental health. Organisations like Amaze provide invaluable assistance but further attention and resources are desperately needed for what constitutes a significant public health issue. That so many parents of children with special needs experience mental health problems, that every parent in this sample was or had recently been receiving antidepressant medication, and that in the vast majority of cases the mental health difficulties is the effect rather than the cause (Emerson, 2003), represents a lamentable failure of modern

public health. The challenges of parenting children with special needs, experiences of financial strain, poverty, constant vigilance and exhaustion, social isolation, alienation and routine problems of relationships with schools and medical professionals who often regard them unfit or unsuitable to pass comment on their child, can be addressed with attention and resources.

The data suggested a disjunct between the ways in which parents were expected to have the very considerable expertise to complete a technically challenging 41 page assessment form on their own but not have sufficiently valued forms of expertise when liaising with the institutions that govern their children's health. Further work is urgently required to address medical practitioner's understandings of the capabilities and experiences of the parents of children with special needs, the 'doability' and nature of the SENCo role and of the importance of independent parental advocate supporters in assisting parents navigate the various services that their children encounter.

Finally, due to a range of difficulties,

including a lack of opportunities for flexible work and affordable child care, many parents of children with special needs are excluded from the labour market and find themselves experiencing poverty, social isolation and multiple forms of disadvantage. The problems of work environments and cultures are considerable, especially with regard to the degree to which modern organisations are supported to, and have the capacity to, support workers whose family health needs are different (Walker & Fincham, 2011). That said, there needs to be a greater commitment on the part of the UK government to move toward working environments that are sufficiently flexible to allow the parents of children with special needs access to meaningful regular work, affordable childcare and greater home support and respite. Until this is actioned, organisations like Amaze will, for many parents, continue to be the only barrier against multiple forms of suffering and hardship.

Appendix A

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Dr Bob Towler	Kim Tugwell
Anna Waters	Jess White
Farah Woosnam	

Interview Transcribers:

Matilda Cook	Christine Lee
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