



# CREaTE

Canterbury Research and Theses Environment

Canterbury Christ Church University's repository of research outputs

<http://create.canterbury.ac.uk>

Please cite this publication as follows:

Hutton, E. and King, A. (2017) Parent/carer views on personal health budgets for disabled children who use rehabilitation therapy services. *Disability & Society*, 33 (2). pp. 254-271. ISSN 0968-7599.

Link to official URL (if available):

<http://dx.doi.org/10.1080/09687599.2017.1398636>

This version is made available in accordance with publishers' policies. All material made available by CReaTE is protected by intellectual property law, including copyright law. Any use made of the contents should comply with the relevant law.

Contact: [create.library@canterbury.ac.uk](mailto:create.library@canterbury.ac.uk)



Parent/carer views on personal health budgets for disabled children who use rehabilitation therapy services.

## Abstract

Personalised budgets are promoted as the person-centred alternative to generically provided services. Nine parents/carers of disabled children (aged 18 years or younger) who accessed at least two rehabilitation therapy services (physiotherapy, occupational therapy, and speech and language therapy) were recruited from one region in England. Focus group / interviews explored their views on the proposed introduction of personalised budgets. Parents and carers viewed a personal health budget with caution and perceived benefits were tempered by their experiences of current provision. Concerns were raised about entitlement and how a personal budget would work in practice.

## **Introduction**

Personalised budgets have been suggested as the person-centred alternative to generically provided services, where families can decide which services to buy for their child and how to arrange care, taking individual circumstances, preferences and needs into account. The intention is not to substitute all services, but provide flexibility to 'purchase' elements of personalised care (NHS England, Patient Participation Team 2014). This paper examines the responses of a small number of parents interviewed about the prospect of using a personalised health budget for their children regarding therapeutic rehabilitation services currently provided through the National Health Service.

A personal health budget is defined in the Children and Families Act (2014) as:

‘...an amount of money identified by the local authority to deliver all or some of the provision set out in an Education Health & Care Plan (EHCP)’.

Personal Health Budgets, available for children who have an Education, Health & Care plan since 2014, are the responsibility of local authorities and clinical commissioning groups in England (CCGs are clinically led, statutory NHS bodies responsible for the planning and commissioning of services in their local area). To date however, relatively few families have opted to have a personal health budget and availability varies across the country (Department for Education and NHS England 2015). A recent Department of Education survey suggested only five percent of eligible families have chosen this option (Department of Education 2017). NHS England, in attempting to increase the availability of personal health budgets has pursued a ‘hearts and minds’ campaign, targeting attitudes, structures and policies that should support personalisation and encourage local authorities and commissioners to embrace change (NHS England Learning Network <http://www.personalhealthbudgets.england.nhs.uk>).

It is difficult to estimate the numbers of disabled children with complex health needs in England due to the paucity of accurate data (Pinney 2017). Current estimates suggest there are upwards of 50,000 children with complex and/or life limiting conditions requiring professional support and involvement from several health, education and social services (Care Quality Commission 2014). The numbers and the degree of complexity of individual need is increasing and a cause of additional concern and responsibility for parents and carers (Fraser et al 2013, Blackburn et al 2010, Children & Young Peoples’ Health Outcome Forum 2012).).

The criteria used by the Department of Health and the Department for Education to categorise children establishes their individual right to statutory resources and support, and is the basis for determining eligibility for a personal health budget. Continuing health care need, is the term used by the Department of Health to describe those whose complex needs require ‘integrated commissioning’ and where specialist and universal provision alone are deemed insufficient (Department of Health 2010, Local Government Association and NHS England 2016).

The Department of Education categorise children with complex needs according to their ‘primary need type’ and distinguish those with an Education Health and Care plan who receive specialist services from those where support is provided by the school (Department for Education and Department of Health 2014). Historic failures across Health, Education and Social care in the United Kingdom to collect data systematically on this group of children has led to an absence of reliable information and lack of consensus about how to categorise their needs (Pinney 2017, Morris 2013). Consequently, children and young people with low incidence conditions or who lack a medical diagnosis are at risk of being overlooked by services (Children and Young People’s Health Outcome Forum 2012).

The impact on parents and carers of caring for a disabled child or young person is well documented and the long-standing failure of health, education and social care to meet their needs, identified a decade ago in the 2007 report ‘Aiming high for disabled children’ where the plans for the reforms under discussion were proposed (HM Treasury and Department for Education and Skills 2007, Care Quality Commission

2014). Families may have one or both parents out of work and experience financial hardship, they are more at risk of family break up, while siblings are at risk of emotional and behavioural problems. There are also psychological and physical consequences for families who are vulnerable to poor psychological health and are known to experience higher levels of stress and anxiety compared to parents of non-disabled children (Contact a Family 2014, Blackburn et al 2010, Wolfson 2004). Despite these needs, families often have limited access to services such as respite care or short breaks, and are frequently expected to shoulder the additional costs associated with caring for a disabled child that may include extra medical attention, equipment, technology, devices and additional therapy (Welch et al 2012, Robinson et al 2000, Bourke-Taylor et al 2014)

The introduction of personal health budgets offered parents and carers a radically new approach to meeting the health care and support needs of their child and parental expectation, following the recent reforms, is consequently at an all-time high (Department of Education, Parent Carer Forum Survey 2015). There are significant concerns as to whether personal health budgets will deliver on the initial promise of allowing parents and carers greater ‘choice and control’ over the support they receive (Slasberg and Beresford 2016).

Children’s therapy services (Speech & Language Therapy, Physiotherapy and Occupational Therapy) provide essential rehabilitation for children with complex and continuing health care needs with the aim of promoting and maintaining a child or young person’s functional skills, in the areas of communication, mobility and self-care (Seal et al 2013). Limited access to these specialist services, coupled with recent cuts to

the numbers of NHS therapists (Chartered Society of Physiotherapy 2011, Royal College of Speech & Language Therapists 2014) may mean that parents/carers choose to exercise greater 'choice and control', by supplementing or replacing existing provision of rehabilitation therapy with purchased care.

Surveys of child health services in the UK have highlighted how families of disabled children are faced with increased waiting times for therapy assessment, raised thresholds to access specialist therapy services and difficulty obtaining specialist equipment (BACD & BACCH 2014, Contact a Family 2014). As an example, hydrotherapy, known to be highly valued by families of children and young people with long term and deteriorating conditions such as muscular dystrophy, is increasingly difficult to access through the NHS (Muscular Dystrophy UK).

Following the publication of the national evaluation of personal health budgets in 2012 (Forder et al 2012), where a personal health budget contributed to a 'significant improvement' in quality of life and psychological wellbeing of recipients, the 'right to have' a personal health budget was technically extended to all adults and children receiving 'continuing care' (Department of Health 2012). This announcement coincided with the publication of the revised Code of Practice that underpins the reform of the Special Education Needs and Disability assessment procedures and the introduction of Education and Health Care Plans for children and young people with special educational needs (Department for Education and Department of Health 2014).

Education Health and Care Plans, identify the educational, health and social needs of a child or young person up to the age of 25 and lists their entitlement to

additional support (Department for Education and Department of Health 2014). Those eligible will be able to combine separate funds from education, health and care services into a single 'health' budget for the benefit of the child or young person (NHS England, National Network of Parent Carer Forum <http://www.nnpf.org.uk>).

In England, children access local health services in their community through a child health multidisciplinary team. Differing eligibility and entitlement criteria apply to these services and access is often cited by parents and carers as a significant cause of additional stress and anxiety - a powerful reason for considering whether a personal health budget could streamline and improve their experience of care. For example, the parents and carers we spoke with accessed items of specialist equipment (daily living equipment, wheelchairs ) from the NHS and other services including bathing equipment and adaptations to their home were provided by the Local Authority.

Little is currently known about what type of support families need or want from rehabilitation therapy or how they may decide to use a personal health budget, as and when this option becomes more widely available. The data reported explores how National Health Service rehabilitation therapy services in one region in the South of England were meeting expectations associated with 'personalized care'. We asked parents and carers their views on personal health budgets. Their responses provide the basis for an analysis that considers their expectations and the challenges of delivering on the promise of a personal health budget when austerity measures are affecting child health services (British Academy of Childhood Disability & British Association for Community Child Health 2014).

## **Research Approach**

We recruited nine parents and primary carers of disabled children (aged 18 years or younger) from one region in the South of England and who accessed at least two paediatric rehabilitation therapy services locally (e.g. physiotherapy, occupational therapy, and speech and language therapy). Participants were recruited via therapy health teams and local parent groups and a research team member attended meetings with these groups to discuss the research. Parents/ carers meeting the study inclusion criteria were provided with an information sheet and expression of interest form together with a postage paid envelope. Twenty-one people returned the expression of interest forms and were contacted by the researcher to discuss the study. They were invited to attend a focus group or one-to-one interview and provided with a range of dates, times and venues. Fifteen people accepted the invitation; of these two attended a focus group, two attended face-to-face interviews and five were interviewed over the telephone. The remaining six people cancelled or did not attend. Participants were not required to give a reason for withdrawing. Informed consent was obtained prior to the focus group/ interviews.

[Insert Table 1]

The sample included parents and foster parents. Participating parents and foster carers were mainly women; one male carer was interviewed alongside the female carer. The age range of their children was between two and sixteen years. They attended either pre-school provision nursery or mainstream primary and secondary schools. Participants accessed a range of services for their children. Ethics approval was obtained prior to the



start of the study from the National Research Ethics Service (13/YH/0374) and R&D approval from a local acute hospital.

A focus group / interview guide was developed to cover the following themes: getting the help you need when you need it (including questions around timely access to services and quality of the support provided); personalised care (which included views on the proposed introduction of personalised budgets and how this might affect care); managing transition (exploring periods of change in support needs and the responsiveness of therapy services). Parent/carer responses to the theme of ‘personalised care’ are explored in this article, details of parent/carer responses to the other themes can be found in a report submitted to the research funder (Hutton et al 2016). All focus groups and one-to-one interviews were recorded and transcribed verbatim. The focus group and face-to-face interviews lasted for around 1 hour, telephone interviews were typically shorter (30-45 minutes). All participants received a summary of the findings at the end of the study.

Interview data was entered into NVIVO and analysed using ‘framework analysis’ (Fern 2005, Bowling 2005, Pope et al 2008). This approach is particularly useful in applied research, in that it allows combining exploring pre-determined themes with more open and emerging categories. It involves five key stages: familiarization; identifying a thematic framework; indexing; charting; mapping and interpretation.

### **Parent and carer views on personal health care budgets**

The questions about personal budgets were for most parents, hypothetical as they had little-to-no experience of personal health care budgets themselves. This is not

surprising based on evidence that suggests there is a lack of information available to parents and carers about the scheme reflected across the country (Slasberg & Beresford 2016). In one case, one of the older teenagers had experience of direct payments for social care. Her mother explained the difference this had made:

“I have this girl come in and she actually baths [name of child] a couple of times a week and once a month she takes her out for the day. In addition, I am in charge of my own transport budget now. They give me £5,000 a year to take [name of child] to and from school and whereas before the local authority were paying me mileage. Now it is up to me to get that taxi.” (Interviewee 01)

While parents could see the potential of a personal budget in this instance, it is unsurprising that there was uncertainty among most respondents, particularly those with younger children, on whether the personal budget applied to them or not, what they could buy with it, and whether it improved their access to services:

“I don’t know if it’s only very profoundly disabled children who are entitled to that budget or quite how that works, and no one’s ever suggested that I would be entitled to a budget.” (Interview 06)

“It doesn’t really apply to us because we don’t get it but I do think it’s a good idea for other people...!” (Interview 07).

Both respondents had children of different ages, but questioned whether personalised budgets would apply to them. For parent seven, the current support

through the local child development centre and a support coordinator made her feel sufficiently supported so that this parent could not imagine that a personalised budget could provide better or more appropriate care.

Parent six already buys in specialist equipment privately to enable her child to go to nursery. While the cost of this was not an issue to her, the lack of support in gaining a nursery place was – something this parent thought could not be addressed through personal budget but required a regulatory change and a requirement to include special educational needs provision into nursery education.

These two examples illustrate that considerations about the personal budgets are above all informed by experiences of the current provisions and systems; and what is articulated as a shared perspective comes from divergent experiences of the care system. Divergent perspectives and experiences is a further dimension that commissioners may need to consider when designing a personal budget framework and marketing it to parents and carers.

The way commissioners choose to promote personal budgets is also likely to influence how parents and carers deem whether the scheme applies to them and as the quotations above illustrate a lack of clarity about entitlement is the first hurdle that needs to be overcome. Government web sites and other information available via the internet about personal health budgets provide contradictory information, which may further muddy the waters, for example, information developed by the national charity ‘In-control’ offers families a largely positive picture of the potential of personal health budgets to improve families lives, using individual case studies to illustrate how budgets

have been used successfully, in some areas of the UK, to purchase specialist equipment (In-Control 2015). This contrasts with information available from NHS England which highlights the exemptions that apply to personal health budgets and the purchase of specialist equipment (NHS England Participation Team 2014, SEND Disability code of practice 2014). Commissioners will need to be able to provide families and carers with clear guidance and entitlement criteria – a challenge where individual needs vary.

Lack of clarity about what a personal health budget might be used for and who is eligible to receive one was a continuing theme in how parents and carers discussed what they wanted from a personal health budget and how they weighed its advantages and disadvantages.

### ***Potential benefits of personal health budgets***

When asked to imagine how personal budgets might work for them, parents highlighted that they might wish to buy in additional services which are not available through the local NHS health services:

‘In some ways is quite useful because it would allow me to pay for some of the private services that I’m already buying’ (Interviewee 09).

‘There could be, as you say, hydrotherapy or it could be some other kind of therapy that he needs that I can’t get [on the NHS] (Interviewee 08).

‘If I had that budget and I was told I had a certain amount to spend and then this is how much this costs, this is how much that costs, I would definitely buy some sensory

integration therapy and I would really value the opportunity to do that.’ (Interviewee 06).

This ‘wish list’ of additional things that their children would benefit from highlights that parents would like to exercise greater ‘choice and control’ over what they could provide for their children, with regard to rehabilitation. The therapies offered within the NHS service provision for disabled children are based on assessment of clinical need, and constrained by service limits; for example, the Royal College of Speech & Language Therapists reports on significant cuts to speech and language therapy services in recent years leading to long waiting times (RCSLT 2014). Provision of child health service more generally are known to vary considerably across the country, dependent on where families live (Parr 2013).

Parents value continuity of care and find waiting times frustrating and unhelpful, particularly when they believe that earlier intervention may help their child’s development. Current research and thinking amongst health practitioners supports this view (Department of Health 2012, Miller et al 2009). Circumventing a system that from a parent’s perspective responds sluggishly to their child’s needs and provides additional choice could offer substantial benefits.

Guidance however suggests that parents will not be allowed to use personal health budgets on services already commissioned and this will likely include rehabilitation therapy and access to specialist rehabilitation services. This is based on the principle of commissioners not paying twice for the same service, even if from a

parental perspective, these services may be inadequate or severely limited in their locality. (SEND 2014, section 5).

Parent and carer personal health budget 'wish list' also reflected gaps in NHS and statutory services, specifically a lack of access to highly specialist therapy services. This includes therapies such as hydro therapy which is only available in very specific circumstances through the NHS, and non-traditional, alternative or complementary therapies, not routinely available on the NHS services. For some parents and carers these constitute potentially important, advanced and innovative therapeutic interventions, which they perceive as enhancing and supporting their children's physical and cognitive development (Bourke-Taylor et al 2015). However, many of these interventions remain untested and are likely to be excluded by commissioners on the basis that they lack 'evidence of their effectiveness' in achieving good outcomes for children (The Communications Trust 2014).

The choice of potential benefits, circumventing the bureaucracy surrounding access and referrals to a wider range of services allows for some reflection about the current lack of responsiveness of child health services. From parent's perspective, delays and bottlenecks in the system are detrimental to the child's development (Contact a Family 2014). The original vision of personalised services could have been a vehicle for addressing these gaps and had the potential to transform services which would potentially be more responsive to parental preferences and choices (Majnemer et al 2013, McCann 2006). It could have led to step changes in service provision, where the landscape of provision would change and adapt to the needs and preferences of the child, with involvement from parents and others involved in their care (National Voices

2015). But current questions about eligibility and exclusion of certain services ( Slasberg and Beresford 2017 ), including those currently commissioned by clinical commissioning groups, would exclude all the options that the parents we spoke with deemed important.

### *Equipment*

Parents and carers also expressed the view that a personal health care budget could be used to facilitate quicker access to services and equipment. For decades, equipment provision for disabled children, including access to wheelchair services have consistently failed the needs of children with complex needs (Centre for Economic and Business Research 2014, Gani 2015, British Health Care Trades Association 2016).

‘You would hope then because you have more control that you would get those bits quicker. I would want to keep what I have but just hopefully like when it comes to equipment then it could be faster (Interviewee 03).

The desire to access equipment more easily and in a timely manner was a common thread throughout the interviews; except for parents with very small children, most parents reported difficulties in ensuring that equipment was received when it was needed. The experience of parents of older children was characterised by a constant cycle of applications for additional pieces of equipment, lengthy waiting times for items being approved through various channels and delays in receiving ordered equipment. This applied to both basic equipment (like hand rails) and bespoke equipment, like wheelchairs adapted to the needs of the child. Unsurprisingly, these were sources of frustration for families.

A personalised budget was perceived as a potential way out of this dilemma, where control over the budget would mean easier access to equipment. The notion that a personal health budget could offer the opportunity for children and their families to have greater choice and control and use their budget to purchase the equipment their child needed is provided in the publication by In-Control ‘Personal Health Budgets and Children’s Equipment’ (2015). However, when considered alongside evidence that statutory provision of children’s equipment is at breaking point – evidenced by the increasing number of applications to charities such as Newlife (2017) to support the purchase of basic items of equipment - it is hard to envisage how such a system could work in practice, when there is no new funding to support personal health budgets (Local Government Association & NHS England 2016).

### ***Potential drawback of personal budgets***

Parents also suggested that personal budgets may also have disadvantages and risks.

#### *Equivalence of services:*

One major consideration for parents was that they did not want to lose out if they opted for a personal health budget. Some parents and carers thought that they would need convincing that the level of funding would be equivalent to what is already available. They were concerned that their children should not receive a personalised budget which would “buy” fewer services than they had before.

‘If I was given the option to choose, I’d want to know on a quantified basis what’s the value of the services that I’m receiving. .... If I had the pot of cash ... to control it myself, my first question would be does my pot of cash allow me to have the exact same service I’ve got now?’ (interviewee 09).



Maybe it depends how much everything costs as well and if you've got enough in your budget to pay for those things that are important.' (interviewee 03).

Behind this was the concern that a system based on a pre-defined budget may not be able to 'buy in' services to an equivalent value of what is now available (Slasberg et al 2012). Work on benchmarking the costs of NHS care are underway, but currently NHS rehabilitation therapy services do not have an identifiable 'price' and parents were concerned that they would find themselves in the dilemma of having to manage the needs of their child with insufficient resources. (National Health Service Benchmarking, Network Programme Report 2015/16). Given the pressures on the NHS as it stands, these concerns are not without merit and parent concerns about potential rationing of services may not be unfounded (Scott-Samuel 2015, Pearson & Ridley 2016 ). Recent guidance from NHS England suggests that personalisation more broadly will provide an 'essential counterbalance' to whole population commissioning, raising concerns that a long-term consequence of personalisation may be the transfer of responsibility from the state to the private sector (Local Government Association & NHS England 2016, Williams & Dickinson 2016)

Some parents highlighted the potential impact of having to make a choice with a personalised budget. They reflected on what the consequences on having a limited personalised care budget were and that they may have to prioritise within the limits of a given budget:

The thing is if you're given a certain amount of money, then I can see that dwindling quite fast with the amount of attention in the areas that she needs.' (interviewee 05).

'Given a choice, if I only had a budget to choose I would have to choose the sort of Down's syndrome specific [one]. I would be very loathed to lose the kind of communication speech and language therapy that we have with the NHS because I think both together in parallel is a very holistic approach to language and they're not contradictory' (interviewee 09).

The prospect of comprehensive personalised budgets highlights the challenge of ensuring that provision would be at least the same as through the current system.

Parents are aware of this as a difficulty; having fought consistently for the level of services of their child, many parents are highly attuned to the value of what they have in terms of services and therapies and hence protective of what they have. While parents in their reflections on potential disadvantages refer to substituting current arrangements, the remarks show that for any new arrangement parents will need to be convinced that it offers a better system of meeting their child's needs than the current, imperfect processes.

#### *Managing the budget:*

Parents expected that a personal budget may well involve taking on additional responsibility of managing such a budget. Some parents questioned whether they either were able to or even wanted take this on, particularly when they are already experiencing the everyday pressures of organising care and services on behalf of their children (Vonneillich et al 2015, Larkin 2015 )

‘You know, I’m busy enough already. If I’ve then got to arrange for her physiotherapy and her occupational therapy and so on, you know, I am...’ (interviewee 01)

Some also questioned whether they would continue existing professional input into care and did want to lose the link to bespoke expertise and the access to valued and in many cases cherished relationships with trusted professionals.

‘You could be sitting with a large pot of cash without really knowing what it is your child is supposed to need. Whereas from my perspective because I had [name of therapist] telling me, “This is what your child is likely to need,” she then made the necessary referrals, we then got the people involved.’ (interviewee 09)

While personal choice was seen to have potential benefits, parents were also aware that the current system provides a degree of certainty and reliability of access to a whole range of services, even if this access is bureaucratic, may involve extensive waiting times, and may be limited. Some parents were concerned that uneven demand for services, through a personalised budget system, may result in uneven provision with high demand for some services leading to shortages in provision and a reduction in those services that were ‘less popular’ – this may be specifically relevant where resources are already scarce, as is the case with rehabilitation therapies.

‘Let’s say for the sake of argument that every single parent wanted physiotherapy and there weren’t enough physiotherapists to do that, and there was no extra money, is that

saying that then budget would be cut like OT or Speech and Language, would it have to be cut, so it doesn't feel very thought through at all' (interviewee 06).

Personal capacity and willingness to add further responsibility to their already high levels of care work, the need for continuous professional support through therapist in care planning, and the value of long-term and expert support, may be the less direct but nevertheless highly pertinent considerations for parents when considering any changes to the current system. Commentators have highlighted that alongside benefits many carers find managing a personal budget stressful (Larkin 2015). Parents and carers understand that their personal circumstances can change rapidly, and they are aware that the broader picture, in terms of the long-term development and changing needs of their children matters. In this, parents might be particularly well placed in participating and contributing to the local design and delivery of any local system.

## **Conclusion**

Parents and carer respondents in this study were asked to consider personal budgets from their current perspectives. None of them had been approached about personal budgets at the time of the interviews, and in this sense the reflections are speculative. Indeed, developing systems to support personal budgets in this region and in many other areas of the UK, are still in the planning stages (Local Government and NHS England 2016).

Parents and carers of disabled children are already experts in managing the care of their children within the current system and hence they have extensive experience about the scope and depths of their children's needs. To that extent their viewpoints are

important indicators of how an offer of personalised budgets may be received, and what parents will consider when weighing the options of using a personal budget. The data provides a contrast to surveys commissioned by the government that have provided a largely positive picture of how the Special Educational Needs and Disability reforms and personal health budgets are being implemented (Slasberg and Beresford 2016, Department for Education 2016).

Personal budgets, for the parents in our study, were not a simplistic choice of having one or not. Parents were aware of the advantages of personal budgets and could see how it might benefit their children by providing more personalised and timely health provision. However, they were also aware of potential pitfalls in the form of under provision due to the costs of services and the additional managerial burden of decision making associated with administering a budget. Interestingly, some parents highlighted the potential impact on the system of provision if therapy services ‘by choice’ were introduced and argue, in some instances for a population based approach to commissioning for specialist services.

What emerges from the interview segments on personal budget is that parents view the programme as assisting improved access to health services, regarding therapy services. This leads parents to consider the trade-off between the current level of services received and the opportunity self-funding may offer in increased flexibility and choice of services that can be bought in. In a system like the UK NHS, where the health services are not monetised but made accessible according to clinical thresholds of need, any new arrangements need to work with implicit and explicit expectations and concerns. As discussed, parental expectations relate to greater flexibilities in relation to

services, concerns relate to not wanting their children to lose out regarding existing provision. NHS England has recently established a 'closed' learning network for commissioners and local authorities to aid the 'roll out of personal health budgets' and address difficulties in how to manage what are likely to be very differing parent expectations.

While none of the parents had actively considered personal budgets, this perception in the 'either - or' categories of personal budget may well be an explanation of why parents have not opted for personal budgets or sought to inform themselves about them and why they may not see a personal budget as a particularly attractive option.

The study has also provided insights into the views of parents and carers about personal health budgets, at a time when personalisation more generally is seen as providing a solution to poor coordination and integration of services for those with long-term care needs (Chaplin 2015). There is some evidence that the introduction of direct payments, a precursor to personal health budgets, for carers of disabled children is a welcome initiative enabling parents and carers 'to take control' and reducing the need for contact with different service providers - regarded as one of the most stressful aspects of caring for a disabled child (Blyth & Gardner 2007).

Reviews of the impact of personal health budgets in other aspects of health care, report mostly positive outcomes, but also identify difficulties with the 'process' and the concept of personalisation has some inherent contradictions in terms of equitable access to health care (Hatton et al. 2013; Williams & Dickinson 2016). Our findings suggest

that in one region there was a general lack of awareness of entitlement amongst parents and carers - only one parent had experience of using direct payments and few had any knowledge or awareness of their entitlement to a personal health budget. There remains concern about how personalisation will work in practice and the impact of personalisation on a wider consensus about equity and entitlement within the NHS (Williams & Dickinson 2016).

### **Summary**

Interviews with a small number of parents of disabled children explored the uptake of personalised health budgets. From the perspective of NHS England the roll out of personal health budgets provides a potential solution to provision of care for those with complex needs, based on an assumption that allowing parents and carers greater ‘choice and control’ may also contribute to more efficient use of limited resources at a time of diminished budgets (Local Government Association and NHS England 2016).

Our interviews highlight that parents and carers view the potential of greater ‘choice and control’ over the provision of a ‘bespoke package of care’ with caution. Any perceived benefits are tempered by experiences of current provision and concerns about how a personal budget would work in practice. Some families may not want the additional responsibility or pressure associated with managing a budget (Hayles et al. 2015, Larkin 2015 ). For Local authorities and commissioners, questions about entitlement and what can and cannot be purchased with a personal health budget are likely to be tested (Department of Education, Parent Carer Survey 2015, Slasberg and Beresford 2017, ).

Based on our interpretation of current guidance and informal discussion with local commissioners, parents may be right to be cautious, as exemptions and limits curtail the original vision of a 'bespoke package of care'. Rather than improving access to and increasing satisfaction with the care they receive, the reforms may contribute to further cuts to the specialist services that parents and carers value as commissioners attempt to balance limited budgets

### **Limitations of the study**

The study is based on a small number of participants. It was conceived to be exploratory and contained, the eventual number of participants was below expectation. Hence the findings do not present a generalizable picture of the viewpoints of parents and carers. In terms of recent experience of research studies, difficulties recruiting parents and carers of disabled children is a common phenomenon. The interview participants in this study were interested in sharing their views and gave their time enthusiastically, and as experts in managing the care of the children within the current system, their views provide a welcome ground level insight into the expectations and concerns about the implementation of personal budgets. To this extent their viewpoints are important indicators of how an offer of personalised budgets may well be received by future recipients and what may inform parental consideration of personalised budget provision.

Word count 5936

References



Alakeson, V. (2013) "The individual as service integrator: Experience from the personal health budget pilot in the English NHS", *Journal of Integrated Care*, 21 (4),188-197, doi: 10.1108/JICA-04-2013-0013

Blackburn, C., Spencer, N. and Read J, M. ( 2010) Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK: secondary analysis of the Family Resources Survey. *BMC Pediatrics*. Available at: 10.1186/1471-2431-10-21. Accessed on 17<sup>th</sup> April 2017.

British Academy of Childhood Disability & British Association for Community Child Health ( 2014). BACCH & BACD Survey: Impact of austerity measures on families with disabled children. November 2014. Available at: Accessed on 17<sup>th</sup> April 2017.  
<https://www.bacdis.org.uk/policy/documents/ImpactofAusterityMeasuresonfamilieswithDisabledChildren16Jan2015.pdf>

British Healthcare Trades Association (2016) *Failing Disabled Children across the UK: Making the Right Decisions*. Available at:  
<http://www.bhta.net/sites/default/files/BHTA%20Equipment%20Provision%20Paper%20-%202016%20Update.pdf>. Accessed on 17<sup>th</sup> April 2017.

Blythe, C. and Gardner, A. (2007) 'We're not asking for anything special': direct payments and the carers of disabled children. *Disability and Society*, 22(3) 235-249. Available at: doi: 10.1080/09687590701259427.

Bourke-Taylor, H., Cotter, C. and Stephan, R, (2015) Complementary, Alternative and Mainstream Service use Among Families with Young Children with Multiple Disabilities: Family Costs to Access Choices. *Physical & Occupational Therapy in Pediatrics*. 35 (3),311-325. doi.org/10.3109/01942638.2014.975312.

Bourke-Taylor, H., Cotter, C. and Stephan, R. (2014). Young children with cerebral palsy: Families self-reported equipment needs and out of pocket expenditure. *Child: Care Health and Development* 40(5):654–662.

Bowling, A. (2005) *Research methods in health: investigating health and health services. 2nd edition*, Buckingham, GB, Open University Press.

Canary, H, E. (2008) Creating Supportive Connections: A Decade of Research on Support for Families of Children with Disabilities, *Health Communication*, 23(5): 413-426, DOI: 10.1080/10410230802342085.

Care Act. 2014. London: The Stationery Office. Available at [http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga\\_20140023\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf). Accessed on 17<sup>th</sup> April 2017.

Care Quality Commission (2014) From the pond into the sea: children's transition to adult health services. Available at: [www.cqc.org.uk/ctas](http://www.cqc.org.uk/ctas). Accessed on 17<sup>th</sup> April 2017.

Centre for Economic & Business Research (2014) The economic benefits of better provision of equipment for disabled and terminally ill children. British Health Care Trades Association. London. Available at: <http://www.bhta.net/sites/default/files/Benefits%20of%20better%20provision%20of%20childrens%27%20equipment%20.pdf>. Accessed on 18<sup>th</sup> April 2017

Chaplin, S. (2015) Putting patients in charge of the purse strings. *Prescriber* 26(7) 21-22.

Children & Families Act 2014. London: The Stationary Office. Available at: [http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga\\_20140006\\_en.pdf](http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga_20140006_en.pdf). Accessed 20<sup>th</sup> February 2017

Children and Young People's Health Outcome Forum (2012) Report of the Children & Young People's Health Outcomes Forum. Available at: [http://www.cpft.nhs.uk/Downloads/Childrens%20Division/Report\\_CYP%20Health%20Outcomes%20Forum%20July%202012.pdf](http://www.cpft.nhs.uk/Downloads/Childrens%20Division/Report_CYP%20Health%20Outcomes%20Forum%20July%202012.pdf) Accessed on 17<sup>th</sup> April 2017.

Chartered Society of Physiotherapy (2011) A survey of NHS physiotherapy waiting times, workforce and caseload 2010-2011. Report by JJ Consulting. Chartered Society of Physiotherapy. London. Available at: Accessed on 17<sup>th</sup> April 2017. [www.csp.org.uk](http://www.csp.org.uk)

Contact a Family (2014) Counting the cost, research into the finances of more than 3,500 families with disabled children across the UK. Available at:

[https://www.cafamily.org.uk/media/805120/counting\\_the\\_costs\\_2014\\_uk\\_report.pdf](https://www.cafamily.org.uk/media/805120/counting_the_costs_2014_uk_report.pdf)

Accessed on 17<sup>th</sup> April 2017.

Department of Health (2010) Getting it right for children and young people: overcoming cultural barriers in the NHS so as to meet their needs. A review by Sir Professor Ian Kennedy. Available at:

<https://www.gov.uk/government/publications/getting-it-right-for-children-and-young-people-overcoming-cultural-barriers-in-the-nhs-so-as-to-meet-their-needs>. Accessed

20<sup>th</sup> April 2017.

Department of Health (2012) News Story. Personal health budgets to be rolled out.

Available at: <https://www.gov.uk/government/news/personal-health-budgets-to-be-rolled-out>

Accessed 17<sup>th</sup> April 2017.

Department of Health (2013) Annual report of the Chief Medical Officer; our children deserve better: prevention pays. London, UK: Department of Health Available at:

<https://www.gov.uk/government/publications/chief-medical-officers-annual-report-2012-our-children-deserve-better-prevention-pays>. Accessed 17<sup>th</sup> April 2017.

Department of Health (2010) National Framework for Children & Young People's Continuing Care. Accessed on 20<sup>th</sup> February 2017.

<http://www.nhs.uk/CarersDirect/guide/practicalsupport/Documents/National-framework-for-continuing-care-england.pdf>

Department for Education and NHS England (2015) Parent Carer Forum Survey 4: Implementation of the SEND reforms. Parent Carer Forum Survey Responses in February 2015. Available at:

[https://www.cafamily.org.uk/media/843593/parent\\_carer\\_forums\\_survey\\_4\\_implementation\\_of\\_the\\_send\\_reforms\\_report.pdf](https://www.cafamily.org.uk/media/843593/parent_carer_forums_survey_4_implementation_of_the_send_reforms_report.pdf). Accessed on 17<sup>th</sup> April 2017.

Department for Education and Department of Health (2014) SEND code of practice: 0-25 years. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>. Accessed 17<sup>th</sup> March 2017

Department for Education (2016) The POET (Personal Outcomes Evaluation Tool) Survey 2015-16. Report commissioned by the Department of Education by In Control and Lancaster University. Available at <http://www.in-control.org.uk/media/239850/national%20ehcp%20poet%20spring%202016.pdf>. Accessed on 17<sup>th</sup> April 2017.

Department for Education (2017) Education, health and care plans: parents and young people survey. Available at: <https://www.gov.uk/government/publications/education-health-and-care-plans-parents-and-young-people-survey>. Accessed on 17<sup>th</sup> April 2015.

ESRC What Works for Children Group (2003) Evidence guide: An introduction to finding, judging and using research findings on what works for children and young people. Available at: <http://www.whatworksforchildren.org.uk/docs/tools/evguide%20June6%20colour.pdf> Accessed on 17<sup>th</sup> April 2017.

Fern, E. (2001) Advanced Focus Group Research. London. Sage.

Forder, F., Jones, K., Glendinning, C., Caiels, J., Welch, E., Baxter, K., Davidson, J., Windle, K., Irvine, A., King, D and Dolan, P. (2012) Evaluation of the personal health budget pilot programme. Commissioned by the Department of Health. Available at: <https://www.phbe.org.uk/index-phbe.php>. Accessed on 17<sup>th</sup> April 2017.

Fraser, I., Miller, M., Aldridge, J., McKinney, P, A, and Parslow, R, C. (2013) Prevalence of life-limiting and life-threatening conditions in young adults in England 2000-2010: Final Report for Together for Short Lives, The University of York. Available at: <http://www.togetherforshortlives.org.uk/assets/0000/6736/TFSLAdultReport2013Final.pdf> Accessed on 17<sup>th</sup> April 2017.

Gani, A. (2015) 'Wheelchair users to launch challenge to improve NHS service'. The Guardian. Monday 20<sup>th</sup> July 2015. Available at <https://www.theguardian.com/society/2015/jul/20/wheelchair-users-to-launch-challenge-to-improve-nhs-service>. Accessed 17th April 2017.

Hatton, C. and Waters, J. (2013) The POET Survey of Personal Health Budgets Holders and Carers. In-Control and Lancaster University. Available at: <http://www.in-control.org.uk/media/138254/poetphbreportfinal.pdf>. Accessed on 17th April 2017.

Hayles, E., Harvey, D., Plummer, D. and Jones, A. (2015) Parents experience of Health Care for Their Child with Cerebral Palsy. *Qualitative Health Research*. 25(8): 1139-1154. Available at: doi:10.1177/1049732315570122.

HM Treasury and Department for Education and Skills (2007) Aiming high for disabled children: better support for families. Available at: <http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/PU213.pdf>. Accessed 17th April 2017.

Hutton, E., King, Annette, Hamilton-West, K. and Hotham, S. (2016) *Understanding the support needs of disabled children and their families in East Kent*. Research Report. (Unpublished). Available at: <https://create.canterbury.ac.uk/id/eprint/15067>

In-Control (2015) Personal Health Budgets and Children's Equipment. Accessed 17<sup>th</sup> April 2017. Available at: <http://www.in-control.org.uk/publications.aspx>. Accessed on 17<sup>th</sup> April 2017.

Larkin, M. (2015) Developing the knowledge base about carers' and personalization: contributions made by an exploration of carers' perspectives on personal budgets and the carer- service user relationship. *Health & Social Care in the Community*. 23(1), pp.33-41

Local Government Association & NHS England (2016) Integrated personal commissioning - an emerging framework. Available at:

<https://www.england.nhs.uk/healthbudgets/wp-content/uploads/sites/26/2016/05/ipc-emerging-framework.pdf>. Accessed on 17<sup>th</sup> March 2017

Majnemer, A., Shikako-Thomas, K., Shevell, M, I., Poulin, C., Lach, L., Schmitz, N., et al. (2013). Pursuit of Complementary and Alternative Medicine Treatments in Adolescents with Cerebral Palsy. *Journal of Child Neurology* 28(11):1443–1447.

McCann, L, J and Newell, S, J. (2006) Survey of paediatric complementary and alternative medicine use in health and chronic illness. *Arch Dis Child*.91:173–174.

Miller, A., Condin, C., McKellin, W., Shaw, N., Klassen, A, F. & Sheps, S, (2009) Continuity of care for children with complex chronic conditions: parents' perspectives. *BMC Health Services research* 9.242 Available at: doi:10.1186/1472-6963-9-242. Accessed on 17<sup>th</sup> April 2017.

Morris, C., Janssens, A., Tomlinson, R., Williams, J and Logan, S, (2013) Towards a definition of neurodisability: a Delphi survey. *Developmental Medicine & Child Neurology*. 55: 1103-1108. Available at: doi: 19.1111/dmcn.12218. Accessed on 17<sup>th</sup> April 2017.

Muscular Dystrophy UK (2017) Hydrotherapy in the UK, The urgent need for increased access. Available at:

<http://www.muscular dystrophyuk.org/app/uploads/2015/12/Access-to-hydrotherapy.pdf>. Accessed 23<sup>rd</sup> April 2017

National Voices (2015). My life, my support, my choice: A narrative for person centred coordinated care and support for children and young people with complex lives.

Available at: <http://www.thinklocalactpersonal.org.uk/Latest/My-life-my-support-my-choice-a-narrative-for-person-centred-coordinated-care-and-support-for-children-and-young-people-with-complex-lives-/>. Accessed on 17<sup>th</sup> April 2017.

Newlife (2017) 25 year impact report. Available at: <http://impact.newlifecharity.co.uk>. Accessed on 17<sup>th</sup> April 2017.

NHS England, Patient Participation Team (2014) Guidance on the 'right to have' a personal health budget in adult continuing health care and children and young people's continuing care. Available at: <https://www.england.nhs.uk/healthbudgets/wp-content/uploads/sites/26/2015/04/right-to-have-phb-guid.pdf>. Accessed 20<sup>th</sup> February 2017

National Health Service Benchmarking Network Work Programme Report ( 2015/16). Available at: <http://www.nhsbenchmarking.nhs.uk/CubeCore/.uploads/Marketing/201617%20Work%20programme/NHSBN201516WorkProgrammeReport.pdf>.

NHS England - Frequently asked questions, personal health budgets. Available at: <https://www.england.nhs.uk/healthbudgets/understanding/faqs/> Accessed on 20<sup>th</sup> February 2017.

National Health Service (2014) Five Year Forward View. Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf> Accessed 17<sup>th</sup> March 2017.

Parr, J, R., Jolleff, N., Gray, L., Gibbs, J., Williams, J. and McConachie, H. (2013) Twenty years of research shows child development team provision still varies widely for children with disability. *Child: Heath, Care, Dev.* Available at: doi:10.1111/cch.12025.

Pearson, C. and Ridley, J. (2016) Is personalization the Right idea at the Wrong time? Re-thinking Cash-for Care in an Age of Austerity. *Social Policy & Administration*. Available at: DOI 10.1111/spol.12216

Pinney, A. (2017) Understanding the Needs of Disabled Children with Complex Needs or Life limiting Conditions – What can we learn from National Data? A report commissioned by The Council for Disabled Children & The True Colours Trust. Available at: <https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Data%20Report.pdf>. Accessed 17<sup>th</sup> April 2017.

Pope, C and Mays, N. (eds) (2006) *Qualitative Research in health care*. (3<sup>rd</sup> edition).  
BMJ Books. London. Blackwell Publishing.

Pope C, Ziebland S, Mays N (2000) Analysing qualitative data. *British Med J*. 320:114–116.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, J, D., Russell, D., Swinton, M., Zhu, B. and Wood, E. (2005) The health and wellbeing of caregivers of children with cerebral palsy . *Pediatrics* 115 ( 6) 626-36. Available at:  
<http://pediatrics.aappublications.org/content/115/6/e626>

Royal College of Speech & Language Therapists (2014) Cuts to speech and language therapy service. Available at:  
[https://www.rcslt.org/speech\\_and\\_language\\_therapy/docs/factsheets/cuts](https://www.rcslt.org/speech_and_language_therapy/docs/factsheets/cuts). Accessed on 17.04.2017

Robinson, C., Jackson, P. and Townsley, R. (2000) Short breaks for families caring for a disabled child with complex health needs. *Child and Family Social Work*. 6: 67-75.

Seal, A., Robinson, G., Kelly, A, M. and Williams, J. (eds) ( 2013) *Children with Neurodevelopmental Disabilities: The Essential Guide to Assessment and Management*. London: Mac Keith Press. Wiley.

Scott-Samuel A (2015) Personal health Budgets in England: Mood Music or Death Knell for the National Health Service? *International Journal of Health Services*. 45 ( 1): 73-86.

Slasberg, C and Beresford, P. (2017) The need to bring an end to the era of eligibility policies for a person centred, financially sustainable future. *Disability & Society* 32: 8 1263-1268. Available at: DOI: 10.1080/09687599.2017.1332560

Slasberg, C. and Beresford, P. (2016) The false narrative about personal budgets in England: smoke and mirrors?, *Disability & Society*, 31:8, 1132-1137, Available at: DOI:10.1080/09687599.2016.1235309



Slasberg, C., Beresford, P. and Schofield, P. (2012) Can personal budgets really deliver better outcome for all at no cost? Reviewing the evidence, costs and quality, *Disability & Society*, 27:7, 1029-1034, Available at: DOI: 10.1080/09687599.2012.736671.

The Communication Trust (2014) Factsheet. What works and the SEND Reforms.

Available at:

[https://www.thecommunicationtrust.org.uk/media/253982/what\\_works\\_and\\_the\\_send\\_reforms\\_final.pdf](https://www.thecommunicationtrust.org.uk/media/253982/what_works_and_the_send_reforms_final.pdf). Accessed 17<sup>th</sup> April 2017.

Vonneilich, N., Ludecke, C. and Kofal, C. (2015) The impact of care on family and health related quality of life of parents with chronically ill and disabled children. *Disability & Rehabilitation* Available at: doi: 10.3109/09638288.2015.1060267

Williams, I. and Dickinson, H. (2016) Going it alone or playing to the crowd? A Critique of Individual Budgets and the Personalisation of Health Care in the English National Health Service. *Australian Journal of Public Administration*. 75 (2 ):149-158. Available at: doi: 10.1111/1467.12155.

Welch, V., Hatton, C., Emerson, E., Collins, M., Robertson, J., Langer, S and Wells, E. (2012). Using direct payments to fund short breaks for families with a disabled child. *Child: care, health and development*. 38(6): 900-909. Available at: doi: 10.1111/j.1365-2214.2011.01339.x. Accessed 17<sup>th</sup> April 2017.

Wolfson, L. (2004) Family well-being and disabled children: A psychosocial model of disability-related child behavior problems. *British Journal of Health Psychology*. 9(1) 1-13. Available at: doi: 10.1348/135910704322778687. Accessed 17<sup>th</sup> April 2017.