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Being a Personal Health Budget Holder: becoming a 'professional parent'

Over the last decade across the UK there has been a push towards integrated personal commissioning and models of co-production to support children with complex medical needs¹. In England this drive has been exemplified by the creation of personal health budgets (PHBs) for children via the Children and Families Act (2014). These budgets are the allocation of pre-existing funds to create bespoke packages of care or to purchase items that can support the child in receipt of continuing care according to their care plan. Their rationale has been to enable eligible children and their parent(s) greater choice and control² and in this regard they have been widely regarded a success³.

As a parent of a child with a PHB in this first-hand account I show that while a PHB has enabled a high degree of control it has come with significant personal cost for me, the budget holder. Being a budget holder has required that I become a 'professional parent'⁴ and, together with my other responsibilities for son, this can threaten to supersede or detract from my parental role of simply being 'Mum'. In sharing this experience, I hope to provide much needed personal insight into the lived experience of self-administering a PHB and make a case for future research into the consequences of PHBs for children that specifically includes the impact on the budget holder.

Being a Personal Health Budget holder

I hold and manage a PHB for my son, who was born with a syndrome that has resulted in complex medical needs including a tracheostomy. We use the PHB predominantly to employ a 1:1 trained personal assistant (PA) to provide respite and undertake practical tasks associated with his needs. My experience of being a budget holder is mixed. On the one hand, the PHB allows my family independence and control over the provision of my son's care. We negotiate hours week-by-week, month-by-month, to ensure that they work for both the PA and for our family. Such flexibility is preferable to accessing care through an agency - as we did in my son's first two years of life - when there was no control over the rota or the carers coming into our home.

Being a budget holder comes with a cost however, and I have yet to see this reflected in the literature on PHBs. I am now an employer, necessitating regular discussions with my employee about tasks and responsibilities, annual leave, training, reviews of workload and so on. I manage a monthly budget, document timesheets, implement HMRC payments and salary, and organise a

significant amount of paperwork for the local authority's annual audit. I liaise with and between the PA and a social enterprise to sort out payroll, tax and pensions.

This is a job that I was unprepared for and for which I have received minimal training, which takes place on top of caring for my medically complex child and holding down employment. Because of my son's needs I am also doing daily medical care, organising and attending medical appointments and therapy sessions, dealing with reviews and paperwork, and coordinating health, social care and special education needs services. Together, I estimate that the bureaucratic requirements are the equivalent of a 0.2 full time equivalent (FTE) job; that is, a day a week. I am doing what Rogers⁶ has called 'professional parenting', whereby I am my son's nurse, project manager, administrator, advocate and chief negotiator all rolled into one. And this is all *in addition* to simply being 'Mum', doing average, everyday parenting – making sure he is clean and well fed, clothed, has a warm bed, ensuring that his life (and that of his older sibling) is fulfilling and stimulating, fostering relationships with extended family, nurturing peer relationships and so on.

Discussion

Concerns expressed by parents about how PHBs work in practice are not unfounded⁶. Being a budget holder and employer means being knowledgeable about care work, the provision of support for the employee, fine-tuned organisational skills, financial literacy and accuracy in all paperwork. Being a professional parent is demanding and there is no preparation for the role. At times, being a professional parent impairs my ability and capacity to just be 'Mum'.

There thus needs to recognition that, while they can be a constructive way to personalise provision for eligible children, PHBs can come with potential cost to the budget holder.

I am not the first to make these points in this journal⁷. Taking them further however, understood in the context of becoming a 'professional parent', as PHBs grow in number there is an urgent need for an evidence base that details the lived experience of managing PHBs for children, and which explicitly recognises the personal impact on the budget holder. This recognition includes examining the role of health and social care services in supporting the budget holder, and how principles of coproduction could be used to help frame that support⁸ so that being a PHB holder does not become a burden to the parent, nor mean that their professional parent role and identity threatens to supersede or detract from their simply being 'Mum' or 'Dad'. To ensure that any future research is representative of the English population this needs to include parents from all socio-economic backgrounds, cutting across income, culture, education, status and so on.

The need for research evidence is pressing given that more children will likely be eligible for a PHB in the next decade⁹. With an ongoing drive for integrated commissioning and personalised provision, framed by laudable coproduction ideals, the evaluation and documentation of the lived experience of having a PHB is critical to ensure that (1) they are the best way to organise provision for eligible children and their families, (2) that the budget-holder is adequately prepared, trained and supported to become the professional parent, and (3) that the professional parent role does not undermine, threaten or impair the budget holders ability or capacity to be a 'normal' parent.

What you need to know

- **Personal health budgets (PHBs) in England are a good way for parents to control healthcare provision for their child(ren).**
- **PHBs come with cost(s) to the budget holder, requiring them to become a 'professional parent'.**
- **Given the growing numbers of PHBs for children, and future growth, there is a need for research into their consequences that includes the experience of being a budget holder. This research needs to be representative of the English population and cut across socio-economic backgrounds.**

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