

# The Hidden Work of Self-directed Support: A Seldom Heard Reality from the Perspective of Two Disabled Women

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This article is a reflective piece from two disabled women in the UK who use self-directed support. It will encompass the practical difficulties of gaining and maintaining budgets; employing support and managing this, in addition to the resultant emotional labour/work and its impact. We feel the labour undertaken is unrecognised and undervalued in wider social work practice and by society at large. This labour is not seen as equal to other work and the impact is seldom considered when looking at our lives as a whole.

Our understanding of emotional labour moves on from [Hochschild's \(2013\)](#) definition where one has to 'hide or change their feelings in order to manage the emotions of others', but with regard to paid work *only*, to acknowledge that labour and emotional labour of some sort is undertaken by everyone in different forms. We embrace the use of this terminology for the work involved in all relational activity, with special regard to those receiving care, as discussed extensively by [Liddiard \*et al.\* \(2022\)](#).

Both our lived experience as disabled women and our previous research ([Liddiard \*et al.\*, 2022](#)) show that the needs of individual employers are often overlooked. We recognise that for us and many disabled people personal budgets are a tool for liberation, control and promote better well-being. Yet, this comes at a cost to the individual in terms of practical and emotional labour. We want to highlight this hidden work to better inform the support given to disabled people managing personal budgets as we feel that we currently do not have access to the same

resources, respect and recognition nor tools to reach the level of expertise as people in other kinds of social care management roles.

We feel that self-directed support has the right aims in its intention to facilitate our right to self-determination over our lives. The independent living movement liberated many disabled people from institutionalised care and commissioned services which are run by, and entirely at the discretion of, local authorities. Disabled people were instead given budgets and the control to spend the money in ways they felt best met their needs. As part of this, many rejected terms such as care and carer in favour of personal assistants (PAs) to reflect the changing role of being cared *for* to being in control of their support. We agree both our lives have been enhanced through having personal budgets and we would not be the people we are today without this. Yet, we feel the intended benefits often overshadow the hidden realities.

## Realities of using self-directed support

In our previous work, together we have reflected on how we feel words like ‘fight’ and ‘battle’ are associated with the process of both gaining a budget and maintaining our personal budgets at the level of support we need (Liddiard *et al.*, 2022). This often feels like an ‘us vs them’ relationship with professionals who, ultimately, hold the power over our lives, dictating how much money we are allocated and how this can be spent. This has meant we have had to educate ourselves about our rights, associated laws and policies, as well as collect large amounts of evidence of our needs *and* advocate for ourselves. We do all this work whilst being seen as inferior because we do not hold a professional status. This is in addition to managing the disabling conditions we are trying to get support for in the first place and, ironically, sometimes prevent us from working.

Moreover, disabled people are rarely seen as knowledgeable or trusted narrators of their own experiences. To get to the point of being allocated support is all consuming and pushes us to breaking point. This feeling of having to fight for support and of being inferior can leave us feeling abandoned, of no value and ultimately disposable. These feelings are only compounded by the fact that disabled people often have to undertake so many other disability-related assessments that there is little time for anything else but to survive as a disabled person. Yet, we seem to have little choice in undertaking this work. The alternative is receiving commissioned support; losing the choice and control we desire for our lives. Or, to receive no support at all and drop off the grid entirely, thereby endangering ourselves. This is sometimes a tempting alternative when we consider the prospect of sustaining this battle for the rest of our lives.

Once a budget has been allocated, it is necessary to address the practical aspects of getting the support in place, often with little help. PA recruitment involves placing adverts, often containing personal information, and putting it into the public domain to be scrutinised by strangers. Katy experienced sexual harassment online when she was forced to justify her request for female applicants due to personal care requirements. There is the added difficulty of selling a job that is severely underpaid, and although immensely important to us, is undervalued by society. As one care recipient states ‘My heart sinks when people say if you can’t get a job, be a carer’ (Berwick, 2022). Trying to attract potential candidates can feel like we have to make our lives seem more interesting just for someone to consider being paid to support us. Not only does this leave us feeling of little worth, but as Sally states she feels like she has to prostitute herself in some way, often using images and video of her assistance dog at work, just to entice people in.

The next task is to manage the support: The responsibility falls on us to produce staff rotas, record leave, maintain timesheets, seek training, manage and review employees, submit spending proof to the council and many other tasks, taking copious hours per week.

## **The impact on us**

This practical and emotional workload impacts all areas of our life. The time constraints and energy required can limit our ability to do other work. Katy reflects that she has often had to turn down paid work whilst recruiting PAs because there was not time to do both. Whilst she lost out on money and potential future job opportunities, this decision was forced on her due to the necessity of needing to recruit a PA so she could receive the support she needed, as she states; to ensure basic human survival. A fight or flight feeling can dominate our lives especially during the uncertainty of recruitment. Katy feels frustrated that unlike other managerial roles there is no annual leave allowed which creates a permanent state of vigilance; our lives are effectively a 24/7 project manager job. In fact, PAs often accompany us on holidays so there is no break from the role even during conventional breaks. Katy has had to single-handedly run recruitment drives whilst on holiday as well as in the midst of an acute mental health crisis. The relentlessness of this work can and does cause burnout. We have disabled friends who have moved away from self-directed support due to the stress of managing it. This is also echoed in the findings of Arksey and Baxter (2012), which highlighted ‘experiencing a lack of support resulted in people ceasing to use direct payments after relatively short periods of time’.

Managing PAs and working within allocated hours can feel like a huge juggling act, especially when other people don’t understand this and

make or change spontaneous plans. To participate in these and be more involved in society, we then have to attempt to reorganise our PAs, meaning our lives can be hugely restricted by the availability and willingness of our PAs to work. This is an example of how being a recipient of care can be restrictive and not freeing at all. As employers, we then carry the worry that we are impacting our PAs' lives outside of work or impacting their pay if the number of hours we need them for suddenly changes. This concern is another instance (of many) where we carry out emotional labour.

The occurrence of emotional labour in caring relationships is widespread and PA relationships are no different, perhaps even involving a heavier burden. Due to the increasing difficulty of employing PAs, we both live with the fear of our PAs leaving and are very aware of the amount of work we put into maintaining their happiness. This is with the hope that they will stay working with us. The loss of a PA can be terrifying and hugely impact our lives; we have put time and energy into building relationships, gaining trust, sharing private moments and ultimately getting to the point that we feel safe in their care. Moreover, the prospect of having to employ a new PA and the work this entails also reinforces our desire to retain our current PAs for as long as possible, regardless of the emotional labour cost to us, so we can avoid the stress of recruiting and building trust with another stranger.

Sally notes that she goes to significant lengths to maintain her PAs' happiness, sometimes at the expense of her own well-being; depending on each PA and the current working situation at the time, whether she is short-staffed, her care needs are particularly high or morale is low, determines how much work has to be done. Sally is acutely aware of the emotional state of each PA and often feels she has to change her behaviour (e.g. demand less help, be more complimentary, boost self-esteem, lighten the mood) by checking in with each PA and spend time listening to their grievances, personal situations or mental health issues, when she is lacking energy or capacity to do that. This can be exhausting when it goes on for a long period of time and, as care happens in the home, she is carrying out emotional labour even in her most personal times and spaces, such as when she gets up in the morning in her bedroom, still undressed.

It even complicates relationships and invades our personal lives and spaces. The fact that our home or sanctuary is also a workplace, and that there is no break or place to escape from this set up, is another heavy load to carry. The invasion of our space can seem overwhelming with physical space being taken up by Personal Protective Equipment (PPE), paperwork storage and other equipment, as well as a breakroom space for PAs. Those providing funds for self-directed support seem to assume this to be OK or remain oblivious of the impact. Neither is it acknowledged that our homes are considered open to inspection by health and

social care providers who often fail to realise that the judgement of the suitability of the workplace for PAs can seem like a judgement of us and how we live. The home should feel like a safe place to relax and be ourselves but this can feel restricted. The encroachment into our lives and spaces also affects our family members and our relationships with them. Sally comments how when she is away from the home with her PA, her husband relishes the time to be himself in his own home and use it freely without restriction. Sally is currently undergoing home renovations and notes that not only must her own standards be met but also those of support providers, despite the fact that she and her husband are funding it themselves in order to make their home a more comfortable and accessible space. Sally says that when the builders have left, she still won't get her home back.

The nature of self-directed support means that if support from a PA falls through for some reason, then often a relative will be forced to step in, further impacting our personal lives. The delicate balance of managing PAs and their comfort level with trying to have both family and intimate relationships is also difficult to manage and can leave us feeling that we cannot live our lives and express our feelings fully. Project managing building work pales in comparison to managing self-directed support!

## The inequality of this labour

Despite having multiple impacts on us, the undertaking of this work and the knock-on effects to our lives are often not recognised by anyone other than fellow disabled people in our position. One of the ways this is best illustrated is that we cannot be paid for the work we do in fighting for and managing our support whereas someone in a 'professional' managerial role is. We are also not given the same level of training as managers in other roles. When Katy was given a Direct Payment aged twenty years, she had just ten minutes of training. A recognised professional would receive far more training to carry out such tasks and be paid for it! This is even more baffling when one considers that in the standard world of work people are paid more determined by the level of responsibility they hold. It could be argued that this reflects the low value disabled people have in society in that our responsibility to ensure we survive and thrive is ignored. In recent times, it has been well documented that the Covid-19 pandemic brought into question the value society places on disabled people's lives (Martin *et al.*, 2022). Something that has received less attention is the inequality between disabled individual employers' and the larger social care sector when it comes to information and provision of PPE, causing us to feel forgotten and unrecognised for our role as social care employers. Consequently, this marginalisation

within the workforce caused great delays in the provision of guidance and resources for us, which put both us and our employees at great risk, in turn burdening us with more emotional labour.

Managing our budgets is made harder when we are excluded from the knowledge other managers are given as standard. At times we have both had to ‘fight’ to be given access to our care plans and budget break-downs; something anyone with access to the system has at their fingertips and despite the information being about *us* in painfully personal ways. This is also an example of the little overall control we have over our budget and therefore our lives. The ethos of person-centred support is that we are the experts of ourselves and have choice and control over how the budget is spent to meet our identified needs. However, in reality, we have little flexibility or authority in how we spend the money and often have to gain ‘permission’ from someone in a professional role as well as later proving how we used the money. We are given the responsibility of managing a team of people with little support but are not trusted to spend the money correctly.

## Learning

There is great learning to be gained from people in power listening to the experiences of disabled people who self-direct their support. It is disabled people with on the ground experience who are best placed to describe and offer insight into the situation. Lived experience can and should be a valuable asset in the design and monitoring of services. The value we bring to this, alongside the work we do in managing our personal budgets, needs to be seen as work in the same way as those of professionals in the social care sector, with recognition for our role and pay. If there was more awareness of the labour, its impacts and the need for increased support, it may be possible to alleviate the burnout many individual employers experience. Consequently, this could benefit local authorities by reducing crisis situations, hospital admissions and the need to change to more costly commissioned services. [Arksey and Baxter \(2012\)](#) found that a lack of support and the stress involved with managing packages caused some disabled people to abandon self-directed support *in spite* of the increased quality of life a personal budget provided. The avoidance of such situations both saves money overall and leads to better outcomes for disabled people’s quality of life.

We also want to encourage the celebration and recognition of the huge amounts of practical and emotional labour that disabled people carry out in making their personal budgets work for them and their PAs. We have highlighted the many ways disabled people are doing project management 24/7, 365 days a year. Authorities could encourage disabled people to recognise this and highlight that these transferable skills should

be listed on CVs, etc., just as in any other job. In turn, a stronger recognition for the role of individual employers needs to be promoted across the whole social care sector so we feel less invisible and can access the support and resources available to other social care employers.

To conclude, we argue that the voices and experiences of disabled people managing self-directed support are often marginalised, and we strongly believe that disabled people need to be heard in order to inform the approaches of commissioners, social workers, policy makers and other individual employers. There needs to be increased awareness about the practical and emotional labour/work that self-directed support entails and further recognition for disabled people undertaking this work. Person-centred support is rightly celebrated for the choice and control it affords disabled people but managing this should not come at a cost to our health and well-being and more support needs to be in place.

## Biography

Katy Evans is a physically disabled young woman living in the UK. She is a Disability Studies researcher and will soon be starting a Mad Studies MSc, which has been influenced by her difficulty in accessing appropriate support during times of distress. Katy has used a Direct Payment for over ten years to employ a team of personal assistants.

Sally Whitney-Mitchell is a community academic researcher within the Field of disability studies. As a physically disabled woman, she has lived experience of self-directed support as she has had full time support from a team of personal assistants since 2013. She is also supported by her assistance dog Ethan.

## References

- Arksey, H. and Baxter, K. (2012) 'Exploring the temporal aspects of direct payments', *The British Journal of Social Work*, **42**(1), pp. 147–64.
- Berwick, L. (2022) Woman's hour, 'My heart sinks when people say if you can't get a job, be a carer', BBC Radio 4, 6 January, available online at: [https://www.bbc.co.uk/programmes/p0bfpny7?fbclid=IwAR2or3\\_K-Y1PFW3fqkDkRUOnU7xMhIwE4BR1-PFf-T5CGIKhnXuHyWePa0](https://www.bbc.co.uk/programmes/p0bfpny7?fbclid=IwAR2or3_K-Y1PFW3fqkDkRUOnU7xMhIwE4BR1-PFf-T5CGIKhnXuHyWePa0) (accessed August 27, 2022)
- Hochschild, A. (2013) *The Managed Heart*, Berkeley, CA, The University of California Press.
- Liddiard, K., Whitney, S., Watts, L., Evans, K., Vogelmann, E., Spurr, R., Runswick-Cole, K. and Goodley, D. (2022) *Living Life to the Fullest: Disability, Youth and Voice*, Bingley, Emerald.
- Martin, P., de Saille, S., Liddiard, K. and Pearce, W. (2022) *Being Human during COVID-19*, Bristol, Bristol University Press.